

NEGOTIATING BARRIERS: AN
INVESTIGATION OF EARLY ACCESS TO
RHEUMATOLOGY SERVICES FOR PATIENTS
WITH INFLAMMATORY ARTHRITIS IN THE
WELLINGTON REGION

Valerie Cavaye Milne

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ABSTRACT

Inflammatory arthritis (IA) is term that encompasses a range of auto-immune joint diseases that can cause severe pain, joint erosion and disability. Although there is no cure for these IAs, early treatment beginning within three months of symptom onset with disease-modifying anti-rheumatic drugs can significantly improve patient outcomes (Combe et al., 2007; Dixon Woods, et al., 2005). The Wellington region in New Zealand is served by public rheumatology services situated at Hutt hospital, and by several private consultants in Wellington and Lower Hutt.

Rheumatologists see many patients with inflammatory arthritis outside the window of opportunity for best outcomes and little is known about why these delays occur. The objective of this study is to investigate why patients may have delayed patient journeys to rheumatology care and situate these causes within the context of the Wellington region and the social and cultural milieu of everyday life. A Collective Lifestyles framework was used to guide the research process (Frohlich, Corin, & Potvin, 2001), and the results are expressed within the concept of Candidacy, which models access as a process that is defined by eligibility for health care that is considered by the individual and the health service (Dixon Woods, Cavers, et al., 2006).

A mixed methods approach was used to conduct the research with an emphasis on qualitative data. Interviews with 22 patients were the main focus of the study, with supporting data derived from rheumatologist referrals data and public rheumatology attendance data. Professionals involved in rheumatology care were interviewed to provide context for the study and nine General Practitioners (GPs) were interviewed to provide perspectives on the access barriers in the patient journey to a first specialist assessment at a rheumatology service.

Patient belief that IA symptoms were an injury or overuse response and cultural beliefs about the management of painful joints prevented early help-seeking at the onset of symptoms. Social and financial resources, working hours and beliefs about the origin of the disease and appropriate treatment all affected the negotiation of barriers to care. Beliefs about the patient and cognitive bias about the cause of

symptoms and knowledge of referrals processes were themes of delayed diagnosis, and GP experience was a significant predictor of early referral to a rheumatology service. Referrals data also showed that patients affected by socio-economic deprivation, Māori and Pacific peoples were at significant risk of non-attendance at a rheumatology service first specialist assessment (FSA). Waiting times to FSA were also a significant risk for non-attendance and these were related to the uneven provision of services across the region. Patients had differing experiences of treatment provided by rheumatologists that affected their treatment concordance. Better information about IA and a greater sensitivity to patient needs could reduce barriers to care, improve the early adoption of treatment protocols and enhance outcomes for patients.

PREFACE

This thesis is submitted in fulfilment of the requirements for a Doctor of Philosophy degree at the University of Otago, and provides a theoretical framework, referencing models and analyses of theorists and researchers. However, I also intend this thesis to be accessible to a layperson, and by reflecting on the personal stories of patients I aim to show how patient access to care is situated within the constraints in which patients, medical practitioners and policymakers act.

The framing of the research objectives, concept and formal approval from the University of Otago Medical School were achieved in 19 July 2007.

Research supervisors were:

- Dr. Andrew Harrison, Associate Professor, Department of Medicine, Wellington School of Medicine, Otago University
- Professor Robin Kearns, Professor of Geography, School of Environment, University of Auckland

In the interest of disclosure, I have an inflammatory arthritis and have benefitted from disease modifying anti-rheumatic drugs (DMARDs) that retard the progress of IA disease. My primary supervisor, Dr Harrison was my rheumatologist when this project was initiated in 2007-2010. My journey as a patient, and as a student of health geography have combined to inspire a curiosity about the experiences of others who require access to rheumatology care.

Ethical approval for this study was received from the Central Region Ethics Committee via an expedited review on 23 January 2008, Reference number CEN/08/02/EXP.

Research from this thesis has been used to submit to:

1. Submission to the Ministry of Health review of some district health boards no longer paying for laboratory tests referred by private specialists cited in the final report as: Milne, V. (2009). Private Specialist Referred Laboratory Testing Cessation of Subsidies: Critique of the Hutt Valley and Capital & Coast DHB Impact Evaluation

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My love and gratitude goes to Nicholas and my family for hanging in there with me when I had trouble seeing the point of it all.

Dedicated to Eden Sarelius

(21-01-1966 to 11-01-2013)

Who did not let the ravages of the inflammatory arthritis that he lived with all his adult life, or his search for relief, define him.

Thank you for reminding me of the purpose of this research.

“The maintenance of health... unquestionably is the first good and the foundation of all other goods of this life”

Descartes

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DEFINITION OF TERMS

ABBREVIATIONS

Abbreviation	Definition
ACR	American College of Rheumatology
APHO	Access PHOs are not-for-profit PHOS that are provided with extra funds from the MoH to provide low cost access to primary health care for targeted groups (Māori, Pacific Peoples, High needs and area of high social deprivation)
BMH	Behavioural Model of Health
CCDHB	Capital & Coast District Health Board
CME	Continuing medical education programme for GPs
DHB	District Health Boards – the major administrative unit of the New Zealand Health system
FSA	First Specialist Assessment. The first specialist appointment after a referral
FTE	Full-time Equivalent working hours
GP	General Practitioner – the equivalent to Primary Care Practitioner, and used throughout to reference the medical practitioner responsible for first medical care
HRQ	Health-related quality of life
HVDHB	Hutt Valley District Health Board
IMG	International Medical Graduate
IPHO	Independent Primary Healthcare Organisation. A PHO that consists partnerships, or single GP, in practices that work for profit
MCNZ	Medical Council of New Zealand
MoH	Ministry of Health the policy and administrative organisation responsible for cost-effective and responsive health service
NHI	National Health Index number. A unique patient identifier used in the NZ health system
NZdep2006	Index created to measure area deprivation. Deciles 9 and 10 are the most deprived areas
OHP	Other health professionals. A referring health practitioner who is not a GP. Usually a consultant in another health speciality
OPD	Outpatients department
PHARMAC	New Zealand's medical drugs buying agency
PHO	Primary Healthcare Organisation. A single or group of GP Practices that work together to administer primary health care for a geographic area or social group
RNZCGP	Royal New Zealand College of General Practitioners
SES	Social Economic Status
WDHB	Wairarapa District Health Board
WRRU	Wellington Regional Rheumatology Unit. Provides rheumatology services for the Wellington Region

GLOSSARY OF RHEUMATOLOGY TERMS

Term	Definition
AS	Ankylosing Spondylitis. Arthritis affecting the spine, hips and other large joints
Corticosteroids / Glucocorticoids	Steroids used in treating RA. They rapidly suppress inflammation and have a minor disease modifying effect. Generally prescribed for short periods due to concerns about side effects
CRP	C-reactive protein. A sensitive indicator of inflammation although not specific about the cause. Measurement obtained from blood tests.
DAS28	DAS-28 A system for scoring disease activity, including an assessment of the number of swollen or tender joints out of a total of 28. Score thresholds include: <2.6 Remission; <3.2 Well controlled; >5.1 Active disease
DMARD	Disease-Modifying Anti-Rheumatic Drug. A range of drugs, not developed for IA, but were found to suppress IA disease activity. The gold standard is methotrexate. These drugs can be used in combination. DMARD usually refer to these synthetic drugs. More modern 'biologics' refer to Anti-TNFs and other drugs of biologic origin that are targeted more directly to IA. DMARDs include methotrexate, sulfasalazine, azathioprine, gold, cyclophosphamide, cyclosporine and anti-malarial drugs
EIA	Early Inflammatory Arthritis. EIA describes arthritis diagnosed early in the course of the disease, before the type of IA can be determined
EnA	Enteropathic Arthritis. Associated with inflammatory bowel disease.
ESR	Erythrocyte Sedimentation Rate. A measure on inflammation
EULAR	European League Against Rheumatism
HBLA-27	A genetic marker associated with SpAs and other inflammatory diseases of the such as Irritable bowel syndromes and inflammatory eye diseases
Hydroxychloroquine (HCQ)	Anti-malarial used as a DMARD
IA / UIA	Inflammatory Arthritis / Undifferentiated Inflammatory Arthritis. An umbrella term to capture autoimmune inflammatory arthritis types, including inflammation that occurs before the type is discernible. These include (but are not limited to) RA, PsA, AS, JIA, and other SpAs
JIA	Juvenile Idiopathic Arthritis – Inflammatory arthritis with onset in childhood
LEF	Leflunomide – a standard DMARD
Methotrexate (mtx)	A standard DMARD and the 'gold standard' in terms of efficacy and cost
MSk	Musculoskeletal
NSAID	non-steroidal anti-inflammatory drug
PsA	Psoriatic Arthritis. Associated with the skin disease psoriasis.
RA	Rheumatoid arthritis. Usually affecting the small joints of the hands and feet at onset.
ReA	Reactive Arthritis. An arthritis that has an onset through an infectious agent. Usually self-limiting, but may persist be reclassified as an SpA
SpA / USpA	Spondyloarthritis Undifferentiated Spondyloarthropies. Umbrella term covering the family of diseases related to arthritis of the spine including (but not limited to) PsA, EnA, ReA
Sulfasalazine (Salazopyrin)	A standard DMARD
TNF	Tumour necrosis factor. A cell-signalling protein involved in systemic inflammation
TNF-Inhibitor (anti-TNF)	Biologic DMARD targeting the Tumor necrosis factor. At present, the most common form of Biologic

Sources: Arthritis Care factsheets (www.arthritiscare.org.uk)

1. INTRODUCTION

A 45-year-old woman has begun to have quite severe pain in both hands over two weeks or so. Although she thinks it may be from working excessive hours at the computer, she visits her family doctor who, on examination, and after discussing the history of the symptoms, suspects rheumatoid arthritis is the cause of her pain. Blood tests are taken to test for inflammatory markers and due to indications of rheumatoid arthritis, the patient is given an urgent referral to the rheumatologist. Because the pain is severe, the patient distressed and the inflammatory markers are positive, steroids are used to control inflammation until the rheumatology appointment in a week's time. When the diagnosis is confirmed Disease Modifying Anti-Rheumatic drug (DMARD) therapy begins immediately.

In another scenario a young man talks to his GP about his unexplained spine and hip joint pain in the previous month. The GP asks the young man about any similar pain in the family and discovers an uncle has Ankylosing Spondylitis (AS). He schedules blood tests for inflammatory markers and the HBLA-27 gene (which is a marker for AS) and at the same time, prescribes anti-inflammatory medication and refers the patient to a rheumatology service where the patient is seen within a month. The diagnosis of AS is confirmed and he begins treatment to reduce pain and delay disability.

These scenarios of treatment paths for inflammatory arthritis (IA) are idealised situations; describing an optimal path from onset of symptoms, through GP referral to a rheumatology service and drug therapy to reduce pain and reduce disability by slowing the progression of the disease (Sandhu et al., 2007).

This thesis explores the perceptions and experiences of people living with an IA and GPs have about IA, its treatment and how these affect early referral to rheumatology services in the Wellington region. The development of the topic was a process undertaken to identify reasons why people with IA may miss out on appropriate care as well as a personal journey. I have an inflammatory arthritis and have benefitted from disease modifying anti-rheumatic drugs (DMARDs) that retard the progress of IA disease. My journey as a patient and as a student of health geography has

combined to inspire a curiosity about the experiences of others who require access to rheumatology care. The geographer's concern with importance of place as more than a setting for health and well-being requires the conceptualisation of place as an integral part of health. Like other social sciences, the conceptualisation of health and illness has moved on from the traditional biomedical and psychosocial models toward more thematic concerns. There is as well, a regard for developing relationships with other social sciences and incorporating good theory, in which place can be shown to play a significant role, rather than paying undue regard to where a relevant theory originated (Robin A Kearns & Moon, 2002).

INFLAMMATORY ARTHRITIS

Inflammatory arthritis (or inflammatory polyarthritis) is an over-arching term used to describe conditions that involve inflammation of the synovial membrane and related structures. (O'Brien & Backman, 2010). The symptoms include pain, swelling and stiffness and, when inadequately controlled, the inflammation can cause joint erosion and physical disability. For the purposes of this project "inflammatory arthritis" includes conditions that primarily affect the joints, leading to joint destruction, and follows the criteria set out in Silman & Hochberg (2001). It includes rheumatoid arthritis (RA), spondyloarthropies (SpA), psoriatic arthritis (PsA), enteropathic arthritis (EnA), ankylosing spondylitis (AS), undifferentiated spondyloarthropathy (USpA) and IA labelled as 'early', or 'undifferentiated' inflammatory arthritis (EIA or UIA) by rheumatologists, where the inflammatory symptoms were clear but not distinct enough to categorise further. For example, PsA when psoriasis was not evident, or IA that is suspected RA, but does not meet the diagnostic criteria for RA at presentation (Symmons, Hazes, & Silman, 2003). Early inflammatory arthritis often presents in an undifferentiated form, which does not meet the established criteria of disease, despite synovial inflammation being present (Quinn, Conaghan, & Emery, 2001; Tavares et al., 2010). Research from one of the longest running longitudinal studies of IA patients, the Norfolk Arthritis Register (NOAR), has revealed, for example, that RA is likely to present as undifferentiated inflammatory arthritis and remain this way for extended periods. The NOAR researchers noted that there are few distinguishing features in what may become RA

from other forms of IA. They illustrated this point when comparing PsA and RA in their analysis of EIA presentation, patients with psoriasis fulfilled the American College of Rheumatology (ACR) classification for RA in 49 percent of cases (Symmons, et al., 2003). NOAR has concluded that too early assignment of a specific label for presentation of an early inflammatory arthritis (EIA) increases the difficulty of identifying potential genetic and environmental risk factors. It also can exclude cases that may later be confirmed as erosive disease from early DMARD treatment (Symmons, et al., 2003).

Self-limiting reactive arthritis (ReA) and juvenile idiopathic arthritis (JIA), are other forms of IA that are less pertinent to this study because post-infection reactive arthritis that does not persist does not usually require treatment with DMARDs, (Papagoras & Drosos, 2012) and JIA affects children, so the parent, not the child, is the decision-maker. JIA children may also have been eligible for advanced treatments earlier in the course of the disease than adults with other forms of IA (Grainger & Harrison, 2005). Although this situation is evolving with new treatments being approved for a greater range of people with the disease as efficacy and safety approvals and economic benefits to the health system meet the requirements of New Zealand's drugs buying agency, Pharmac (Metcalf, Moodie, Grocott, & Wilkinson, 2005).

DISEASE MODIFYING ANTI-RHEUMATIC DRUGS

IA is an incurable disease within the current treatment paradigm. However, DMARDs are a cheap and effective first-line drug therapy which have revolutionised the care of people with IA by reducing the likelihood of joint damage, improving the crippling pain and disability associated with IA thereby improving the potential for full participation in family life and society, and to regain or maintain employment (Rom, Fins, & Mackenzie, 2007b). Synthetic DMARDs in conjunction with the more recent biologic TNF inhibitors¹ mean that inducing remission in IA is a real possibility and is a stated aim of modern treatment protocols (Bykerk & Emery, 2010). The most commonly prescribed DMARDs are methotrexate, which is the 'gold standard'

¹ In New Zealand IA patients who have poor results with standard DMARDs may have access to TNF inhibitors but due to the high cost of this treatment access to these newer drugs is heavily restricted and not used as a first-line treatment for adult patients (Grainger & Harrison, 2005).

treatment preferred for patients with high disease activity, for example RA, and sulfasalazine– prescribed to IA patients with lower risk of erosive disease, often for SpAs such as PsA, and where methotrexate is contra-indicated (Aletaha & Smolen, 2002).

Although IA is treated as a chronic disease, co-morbid conditions increase the likelihood of people with RA dying earlier than a similar non-RA cohort. Ischaemic heart disease is a significant cause of excess mortality and after controlling for confounding factors a person with RA has a three times greater risk of dying from this condition. People with RA are also at increased risk of dying from infections and pulmonary disease (Kelly & Hamilton, 2007). Methotrexate has shown to be effective in reducing mortality in people with RA (HR 0.4 CI 0.2-0.8), with TNF treatments expected to show similar effects (Gabriel & Michaud, 2009). Similarly excess mortality due to cardiovascular events has been observed in AS (Zochling & Braun, 2008), PsA and other spondyloarthropies (Peters, van der Horst-Bruinsma, Dijkmans, & Nurmohamed, 2004).

Treatment strategies are improving to such a degree that there is talk about RA being a reversible disabling condition, rather than a lifelong chronic disease (Ehrmann Feldman et al., 2007) and currently the key to successful intervention is early, aggressive treatment with DMARD therapy, particularly with methotrexate (Lacaille, Anis, Guh, & Esdaile, 2005), ideally initiated within three months of the onset of rheumatoid arthritis symptoms (Emery, Quinn, & Conaghan, 2002a). The improvement in treatment options that reduce inflammation, joint destruction and maximise patient outcomes has meant that understanding the reasons for delays to rheumatology services for people with symptoms of IA has become a major concern for rheumatologists. Barriers to access are also a primary focus of health geographers. Geographers have long been interested in the influences of both the physical and human realms in accessing health care, with medical geography being one of the oldest branches of the discipline. The broadening of medical geography from the purely applied spatial focus to a more flexible health geography reflects geography's role as a 'synthesising social science' (Joseph & Phillips, 1984).

INFLAMMATORY ARTHRITIS IN NEW ZEALAND

Over half of people diagnosed with IA are of working age (15-64) resulting in a very high burden for the individual, their social networks, employment and the national health and disability budgets. Severe rheumatoid arthritis has the second highest disability weight in the New Zealand burden of disease score (0.94), equal with severe dementia and only marginally lower than terminal phase AIDS (0.95) (Access Economics Pty Limited, 2005). Despite evidence of the burden of disease and poor quality of life for people with arthritis, musculoskeletal conditions are not a high priority in New Zealand's health policy statements. The USA prioritised musculoskeletal disorders by naming 2000-2010 the 'bone and joint' decade (Taylor, Smeets, Hall, & McPherson, 2004) and the Australian government made musculoskeletal disorders a national health priority in 2002 (Busija, Hollingsworth, Buchbinder, & Osborne, 2007), however these initiatives have not been universally adopted in New Zealand. A perusal of New Zealand health targets shows that the priorities for health care lie in population health targets that can be modified by social and personal factors and reduced by preventative care for example diabetes, cancer and immunisation (Ministry of Health, 2008a).

EARLY REFERRAL AND DELAYS TO TREATMENT

There is compelling evidence that damage to joints occurs early in the course of erosive IA and early treatment with DMARDS can substantially decrease disability by preventing joint damage and improve long-term health status. Delays of as little as three months in treating RA with DMARDs are associated with poorer outcomes in terms of disease progression and radiologically discernible joint damage (Emery, Quinn, et al., 2002a; Kaushik, Abernethy, Lynch, & Dawson, 2003; Lacaille, et al., 2005; Nell et al., 2004; Suter, Fraenkel, & Holmboe, 2006). DMARDs are effective for SpAs with peripheral inflammation but have not been found effective on the axial symptoms of AS. Unlike RA treatment, for AS non-steroidal anti-inflammatory drugs (NSAIDs) and physiotherapy have been the main treatment options and early referral encouraged for accurate diagnosis, pain relief, monitoring and correct spinal exercises to delay ankylosis (Rudwaleit & Sieper, 2012). Since the advent of TNF therapies that effectively treat AS, and because these therapies have been shown to be more effective if given early in the course of the disease, early diagnosis has in

recent years become more important. The evidence for early treatment of IA, before differentiation, has continued to accumulate and treatment guidelines have consolidated into recommendations for referral in shorter timeframes for patients with characteristics of an inflammatory arthritis. (Aggarwal & Malaviya, 2009; J Braun et al., 2011; Raza, Buckley, Salmon, & Buckley, 2006; Sidiropoulos et al., 2008).

New Zealand Ministry of Health (MoH) guidelines for referral of rheumatology services outpatients recommend that people with inflammatory arthritis are seen within 12 weeks of referral, and people with potentially destructive disease are seen within four weeks of referral (Elective Services, 2001) (Appendix 1). More recently the American College of Rheumatology (ACR) and the European League Against Rheumatism (EULAR) have modified their management of early IA recommendations to take into account the increasing evidence of a 'window of opportunity' (Quinn, et al., 2001) to treat IA before joint destruction begins. The ACR updated classification criteria focuses on attributes of disease that are present early in the course of the disease and are associated with persistent or erosive disease, rather than a defined diagnostic criteria at a later stage (Aletaha et al., 2010), and EULAR advises that people with IA in more than one joint should be referred to and seen by a rheumatologist within six weeks of the onset of symptoms (Combe, et al., 2007). Both organisations stress the importance of referral as early as possible, even if this is before a definite classification of synovial inflammation can be made. Similarly the Australian College of General Practitioners recommends to its GPs that people are referred to rheumatology if symptoms of IA have not resolved within six weeks (March et al., 2009). With advances in pharmacological treatment for IA, the guidelines emphasise that an imperative is to ensure people are referred as soon as possible to rheumatology services. These recommendations have increased the focus on understanding health seeking behaviours by the patient, attitudes toward referral and other barriers to early assessment of IA in rheumatology clinics.

THE CONTEXT OF RHEUMATOLOGY

The New Zealand Health Strategy (2002a) seeks to reduce inequalities in health by using a population health focus, with particular attention to reducing health disparities for Maori and Pacific peoples, and special consideration of barriers to care

for rural populations. The focus on population health and groups with historically poor health and difficulties accessing health services may have implications for resourcing of health services outside of these priority areas. IA, for example, is outside MoH priorities, with population-based studies giving RA a low prevalence rate of up to one percent amongst adults in most countries with large European populations², with incidence and prevalence varying over time (Gabriel & Michaud, 2009), and other forms of IA occurring at similar or lower rates than RA (Picavet & Hazes, 2003). IA prevalence is unlikely to attract interest for reduction strategies, because although non-inflammatory arthritis is sensitive to health promotion measures like a healthy diet and exercise, it is less certain that these strategies will improve prevalence or outcome for IAs, with the possible exception of the inclusion of RA in smoking cessation programmes, because smoking is a confirmed risk factor for the development of RA (Gabriel & Michaud, 2009). Although maintaining a healthy weight and fitness can be important modifiers of pain and promoters of well-being, especially in reducing the increased cardio-vascular risk in established RA (Gabriel, 2008), the evidence is less convincing that it will also reduce the risk of RA onset (Silman & Hochberg, 2001). From the lack of causative factors in IA onset, low health system priorities and the potentially high burden of disease, it is apparent that the single most important thing a person can do to improve the prognosis of an IA condition is to receive early care from a rheumatologist and, from there, have access to a treatment plan which may include DMARDs to retard the course of the disease. In practice, this means a person with IA symptoms must consult with a general practitioner as soon as symptoms develop and seek referral.

NZ primary healthcare services are grouped in primary health organisations (PHOs) and between 90% and 97% of the Wellington region's population is enrolled in PHOs (Ministry of Health, 2009). Individuals who are not enrolled in a PHO are disadvantaged by higher costs of appointments, potential delays in achieving timely appointments and restricted opportunities to build a relationship with a dedicated

² Community-based questions can produce larger self-reported prevalence rates than those derived from registries or physical examination Picavet, H. S. J., & Hazes, J. M. W. (2003). Prevalence of self reported musculoskeletal diseases is high. *Ann. Rheum. Dis.*, 62(7), 644-650. The 2006/07 New Zealand Health Survey produced a prevalence rate of 3.5 percent for RA in the community (Ministry of Health. (2008b). *A portrait of health: Key results of the 2006/07 New Zealand Health Survey*. Wellington: Ministry of Health.

GP (Schoen et al., 2007). Important objectives for PHOs are the reduction of barriers to primary care and improving access to secondary services. Independent practitioner PHOs (IPHO) are individuals or groups that operate on a for-profit basis that are most often organised on a geographic basis, but Access PHOs (APHO) have a focus on not-for-profit services in communities of interest that have poor health outcomes, and are often organised around the needs of low income Māori and Pacific Peoples (Crengle, 1999). In this healthcare setting, medical practitioners expect to engage in a partnership with the patient for the management of health problems (NZMA, 2011).

District Health Boards (DHBs) are the organisations responsible for the public provision of health services for populations in defined geographical areas. “They assess need, fund some services and either provide services or arrange for others to provide them” (Ministry of Health, 2002a). The Wellington Regional Rheumatology Unit (WRRU) located at Hutt Hospital provides a public regional rheumatology service to the three DHBs in the Wellington region; Capital & Coast (CCDHB), Wairarapa (WDHB) and Hutt Valley (HVDHB). The primary clinic based at Hutt Hospital runs outreach clinics at Kenepuru and Wellington hospitals in the CCDHB and at the Greytown Medical Centre in the WDHB. People with suspected IA are generally referred to the clinic nearest their residential address but urgent cases from all areas are likely to be referred to Hutt Hospital. The WRRU is expected to provide an equitable service across the region and the intervention rate across the DHBs provides benchmark data to ensure equity of referral numbers. Financial disadvantages ensue if fewer patients than expected are referred (Wilde, 2010). Private provision of secondary health services is an integral feature of the New Zealand health system and four private rheumatology clinics are situated in Wellington and Lower Hutt.

RESEARCH FRAMEWORK AND DESIGN

This research uses the words of the IA participants to look for barriers and facilitators in the journey from onset of symptoms until the establishment of a suitable treatment regime that halts the progress of the disease. IA participant interviews, the main source of data, are supplemented with referrals data from

rheumatologists in the Wellington region and GP data that may assist in the explanation for barriers the participants describe. Interviews with IA service providers are also used to assist in a fuller understanding of access to rheumatology care.

DEVELOPMENT OF THE STUDY FRAMEWORK

The genesis of this study was that having achieved medical remission from my IA, I could use my Geography and illness experience to investigate why people with symptoms of IA did not receive the treatment they needed to manage IA and achieve the best possible outcomes. It is apparent to rheumatologists there is a widespread unmet need for rheumatology services, and people with IA symptoms who do present at rheumatology, often do not present early enough for maximum benefit from DMARDs. Moreover evidence that patient measures of successful treatment are much broader than the clinical measures of disease activity that are crucial to rheumatologists' treatment strategies (Sanderson & Kirwan, 2009). In light of these points, the framework was developed with two principles in mind:

1. The study would be presented as an examination of the patient journey through the health system
2. The study would focus on patient concerns regarding barriers to healthcare and well-being.

The development of the framework began with acknowledging what was already known about the Wellington regional rheumatology service. The rheumatology service sits within a health system that began with the aim of providing universal coverage (R. A. Kearns & Joseph, 1997), however since its inception through the Social Security Act in 1938 universal provision was not fully realised due to differences between the government and medical profession that has resulted in a level of private provision of health services that has varied over time. Currently people with IA can receive free rheumatology care through the public health system, where the cost of public hospital care, pharmaceuticals and laboratory diagnostic services have been fully funded through tax revenue since 1958, or via private healthcare that is funded through private insurance schemes, subsidised by government. (Quin, 2009).

There is a shortfall in the level of service provision in the Wellington region (Harrison, 2004). The United Kingdom recommendation for rheumatology coverage is one full-time equivalent (FTE) per 85,000 people (Harrison, 2004). Wellington region had 2.3 FTE rheumatologists, equivalent to one FTE rheumatologist per 180,770 people. Despite this limitation, public clinics are distributed throughout the region to enable people to be treated in the areas they live and the number of referrals to the public rheumatology service from each DHB in the region was proportionate to the population size, suggesting equitable access throughout the region.

Researchers have worked to improve access to rheumatology care by highlighting structural barriers, and demographic and socio-economic variables which can then be mitigated (Rom, Fins, & MacKenzie, 2007a). But there are gaps in explaining continuing variations in rheumatology referrals where structural barriers, such as transport and financial barriers, have been reduced; and while access to primary care is widely researched, there is little research on the connections between the perceptions, attitudes and referral behaviours of patients and GPs and the structural barriers that impact on delayed referral or non-referral to rheumatology services (Suter, et al., 2006). Research about access to rheumatology services is scarce within New Zealand. A report for the New Zealand Arthritis Foundation for example, found no funding for public health or management projects focussing on rheumatic disorders from 2001 to 2004 (Access Economics Pty Limited, 2005).

The delay to diagnosis for people with inflammatory arthritis has been conceptualised as having two main components; the time from onset of IA symptoms until consulting in primary care (onset delay) and the time from primary care consultation until being seen by a rheumatologist in secondary care (referral delay).

“... ensuring that persons with rheumatic disease have equitable access to medical care becomes an important ethical issue and a marker of justice in our society.”(Rom, et al., 2007b, p. 1344)

This thesis is premised on a broad concept of access, following the definition of the Institute of Medicine, which defined access as the *“timely use of personal health services to achieve the best possible outcome”* (M. L. Millman, 1993, p. 33). This definition appreciates that an individual must receive healthcare when required, not

simply when that care might be available, and achieve an outcome that is appropriate for that need to realise health care access. (Gulliford et al., 2002). It highlights the appropriateness of and satisfaction with a health service and incorporates health outcomes. This definition is further developed as a more reflexive concept in Chapter Three.

STUDY OBJECTIVES

The aim of this thesis is to improve knowledge about how an individual's perceptions and experiences of IA affect health care utilisation, and the attitudes and beliefs of health providers that affect referrals to rheumatologists and thereby access to optimal treatment plans for people with an IA. Suter (2006) describes the IA referral as a complex process with interdependent stages. "*the parts interact to affect the whole*" (p. 304).

It has been posited that there is a critical pathway to treatment whereby people who wait less than six weeks to see a GP are also likely to wait less than six weeks to see a rheumatologist (Kumar & Raza, 2008). This research seeks to understand why people with IA do not see their GP with the onset of symptoms, and why a referral might not be effected within the ever-narrowing timeframes that research has shown produce the most efficacious treatment outcomes.

The objectives of the study are to:

1. Investigate how people with IA in the Wellington region:
 - interpret IA symptoms and how this interpretation impacts on health choices;
 - understand IA and its treatment;
 - engage with their primary health care providers in ways which facilitate or impede referral to rheumatology services; and
 - perceive and experience rheumatology services and whether these perceptions and experience may preclude appropriate treatment.
2. Document and interpret how access to health care for IA, or lack of access to rheumatologists impacts on the everyday lives of people with IA.
3. Examine the beliefs and attitudes of GPs about:
 - the interpretation of IA symptoms;

- IA treatment and early referral;
 - patients and their reasons for seeking help for IA symptoms;
 - rheumatology services that affect referral rates.
4. Investigate whether characteristics of the GP or the GP practice affect referrals of people with IA to rheumatologists.
 5. Investigate delays in a FSA with a rheumatologist after referral from a GP.
 6. To determine, through using administrative data, whether patient or referral characteristics could predict non-attendance at a public rheumatology service and to identify aspects of the referral process where modifications might improve attendance rates.
 7. Interpret the patient understanding of DMARDs and the expectations of health care after their IA diagnosis, specifically to highlight the perceived gaps in rheumatology care.

Ultimately the research seeks to recognise which people have, or are most at risk of having, rheumatological needs unmet due to insufficient access to services that meet their needs, and the patient, GP and rheumatology services factors that might drive this unmet need. The research seeks to add to the identification of strategies that could improve access to a rheumatologist for people with IA in the Greater Wellington Region by giving an account of both IA and GP participant experiences within the Wellington region, and shows that there is no simple solution to delayed assessment of IA symptoms by a rheumatologist. Patient culture, knowledge and financial resources, GP training, attitudes and behaviours and the provision of services all having over-lapping roles in referral delay.

Rheumatology services FSAs, and the potential to obtain DMARD therapy within three months of the onset of IA symptoms, can be delayed at several points on the treatment journey. These steps have been conceptualised by others as the lag time between symptom onset and medical encounter, and the lag time between presentation to a medical practitioner and diagnosis or referral (Chan, Felson, Yood, & Walker, 1994; Kumar & Raza, 2008; van der Linden et al., 2010). Kumar and colleagues (2007) added the time from referral to being seen in rheumatology services as a third lag time. These three lag times were the foundation for framing of this research and are defined as:

2. Onset delay: the time a person takes to present symptoms to a GP
3. Referral delay: the time between presentation of symptoms to GP and referral to rheumatology services
4. Assessment delay: the time from referral until the rheumatology services FSA.

The research process led to the addition of an evaluation delay to reflect the two distinct tasks of the GP to first, assess an individual's symptoms, and second, to decide whether the person should proceed to rheumatology. Figure 1 conceptualises where the barriers to appropriate care exist, and whether the patient or care provider could provide information to explain the delay³

³ Treatment delay occurs when a diagnosis is not clear, or appropriate treatment does not commence at FSA. Because of the complexity of this topic, a report on the experiences of rheumatology has been included, however this aspect of the IA journey was not included in the main body of the thesis

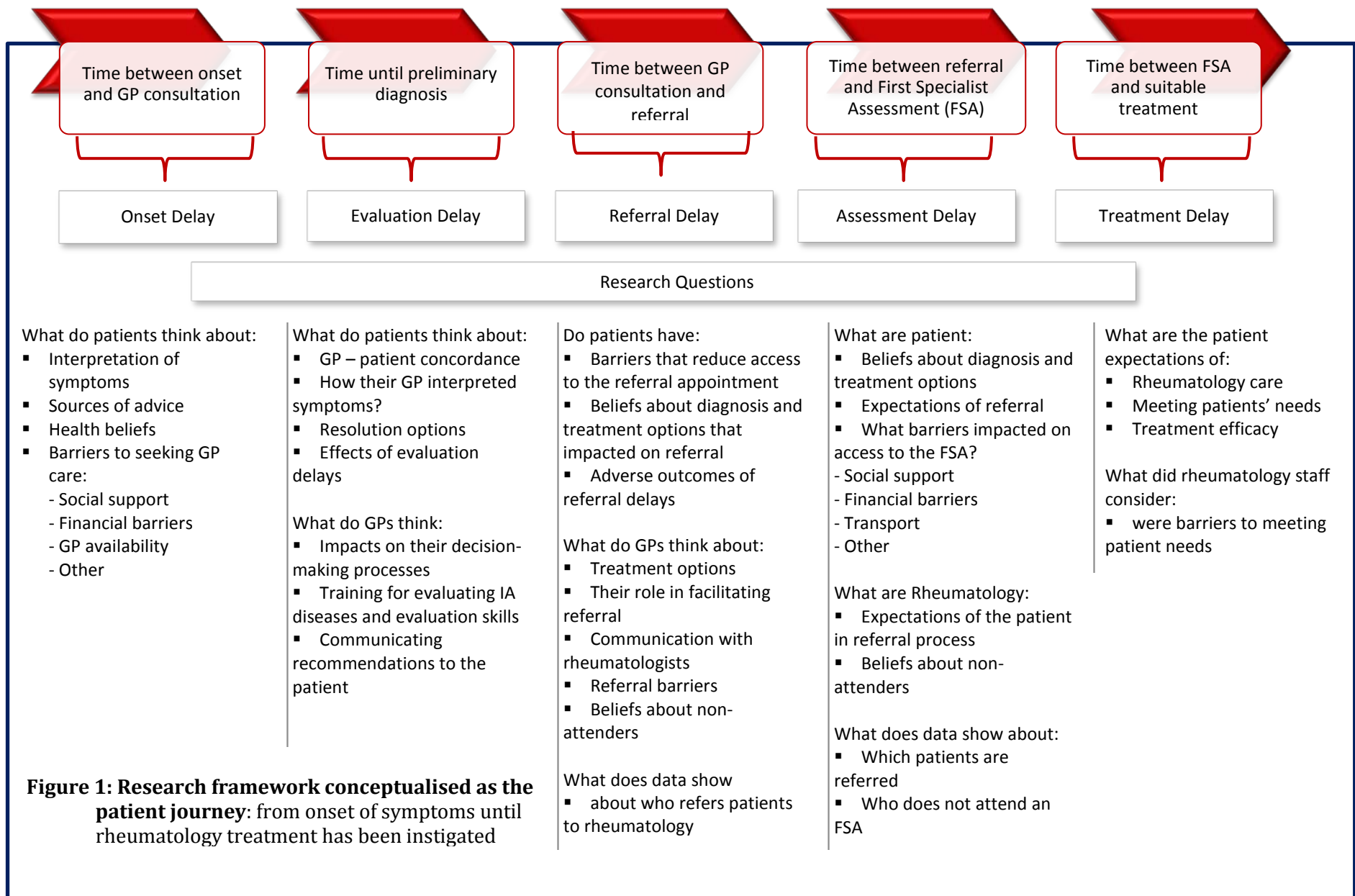


Figure 1: Research framework conceptualised as the patient journey: from onset of symptoms until rheumatology treatment has been instigated

Research on access to rheumatology services tends to be free of a theoretical perspective and the results not transferable to other settings. The proposed conceptual proposition for understanding access to effective health care for individuals with IA is *Candidacy*. The Candidacy model arose from a UK National Health Service investigation into access to health care for vulnerable populations. This model attempts to incorporate the concepts of help-seeking, provision and availability of services, health service organisation and administration, and also to incorporate policy, service developments and interventions to improve access (Dixon Woods, et al., 2005). These concepts tie in a political economy approach that explains the production of health services by looking at the production of health services delivery, within wider societal processes. From competitive and fee-for-service models through to universal and cooperative models, it is argued that decisions about what sort of health system to provide can create inequalities that are reflected in who gets treated, where, and how this can impact on the utilisation and fairness of the health system (Tudor Hart, 2010). Utilisation models, such as the behavioural model of health, search more directly for barriers to care through the patient journey (Aday & Andersen, 1974) and the consumer models suggest a relationship between access and consumer satisfaction (Penchansky & Thomas, 1981). Without ignoring either the production of health services or the consumption models, Candidacy attempts to describe how the patient and health services determine between themselves an agreement on the eligibility a person has for medical attention. Eligibility is subject to influences on the provision of services, people's social context and how people define and redefine what it is that requires health care. In using the concept of candidacy, access to healthcare is recast as a process that is dynamic, constantly subject to negotiation and conditional (Dixon Woods, Cavers, et al., 2006; Dixon Woods, et al., 2005). It draws also on the tension between the structure of the health service and the agency of individuals to negotiate these structures to access the care they require. These approaches are discussed more fully in Chapter Three.

Bridging this structure and agency divide is a challenge that Frohlich and colleagues (2000) have attempted in their Collective Lifestyles framework that has been used to develop the methods applied in this study. This research experiments with the Collective Lifestyles framework with the aim of testing its viability as a means to

study disparities in access to health care. Collective Lifestyles was originally devised to explain variations in the uptake of health promotion messages (Frohlich, 2000). As well as the opportunity to link concepts of access from theories that look at the structures of the health system and those that opted to see healthcare access as a matter of consumer choice (these positions are outlined in chapter 3), the concept of health decision-making within a context that removes the stigma of negative group characteristics was an appealing proposition. It also encouraged the use of a wide range of data collection and analysis methods, which could be linked back to the work of the theorists whose work the framework was built around. The framework (Figure 1) sets out a method for examining access through the Candidacy model and meets the argument of Rom et al (2007b) that an ethical framework is needed to lessen the disparities of rheumatoid disease as there may be hidden and unappreciated inequities in society, and that this framework should be integrated into research and practice so as to move beyond merely acknowledging disparities and toward reforming practice to remove disparities. The argument for an integrated framework outlined by Rom and colleagues led to a search for theoretical frameworks that considered the broad context of people's decision-making when seeking or providing healthcare. French philosopher and sociologist Pierre Bourdieu, whose theory of practice, which has been incorporated into the *Collective Lifestyles* framework (Frohlich, et al., 2001) taught that prior knowledge of the realities of a situation must be incorporated into research in order to understand the beliefs, attitudes and ensuing actions or non-actions of people operating within the organisational structure that is being investigated (Bourdieu, 1999).

In keeping with Bourdieu's sentiments about the importance of understanding the lived-in world of the participants, the incorporation of interdisciplinary approaches and the incorporation of objective and subjective knowledge into his methodologies (Bourdieu, 1999; Fries, 2009), a mixed methods approach has been applied to this research to capture the diversity of participant experiences of IA and GP perceptions of their interaction with both patients and rheumatology services, and I have used a qualitative methodology to tease out the barriers to early referral and early introduction of DMARDs for people with IA. The IA participants in this study were interviewed to gain an understanding of referral pathways, and a purposive sampling

method was used to incorporate as diverse a range of people and experiences as possible. GPs were interviewed and completed questionnaires which allowed agreements and contradictions in accounts of the referrals process to be scrutinised and enabling participants in the referrals process to be heard (Castro, Kellison, Boyd, & Kopak, 2012; Watkins, 2012). To detail the background of the referrals process two years of referrals to Wellington rheumatologists were analysed. The highest and lowest GP referrers were determined and questionnaires and interviews were used to discover differences in practice and GP characteristics, and attitudes and beliefs which may affect referral behaviour.

This thesis fits into a wider body of research concerning access to secondary care and variations in referrals from GPs. Previous research has highlighted variations in referral from primary to secondary care and concurrently emphasised that these variations are not universally applicable. For example, research in Norway and the Netherlands has found women have longer referral times than men (Lard, Huizinga, Hazes, & Vliet Vlieland, 2001; Palm & Purinsky, 2005), but conversely, women were found to be referred earlier in Quebec, Canada (Ehrmann Feldman, et al., 2007). Ehrmann and colleagues also noted higher socio-economic status and greater comorbidities were associated with earlier referral of people with RA. While other researchers have identified GPs' impressions of the referrals process as impacting on GP referral decisions (Thorsen, Hartveit, & Baerheim, 2013). Ethnicity, regional differences, patient demographic characteristics and socio-economic status have also been found to impact on self-reporting of arthritis, but these factors failed to fully explain reporting variations between demographic and socio-economic groups (Cañizares, Power, Perruccio, & Badley, 2008). In a review of referrals studies, over half of the variation in referrals to specialists remain unaccounted for after adjusting for age, sex and other demographic or socioeconomic variables (Sullivan, Omar, Ambler, & Majeed, 2005). The paucity of explanations for referral variations is substantiated in the growing body of literature about attitudes and beliefs of both patients and GPs toward healthcare and referrals which recognises that there is a need for research that takes into account both the GPs' and patients' views about referrals (O'Donnell, 2000). Escalante (2007) provides a thought-provoking paper about the relationship between ethnicity, patient preferences and accurate provision

of information about rheumatic disease. He discusses how bias and discrimination can occur when clinicians and patients may not relate well to each other, and how this may highlight clinical uncertainties and lead to differences in referral pathways. He calls for investigation into the links between the quality of interaction between patients and clinicians, how this may impact on patient preferences and lead to disparities in rheumatic disease outcomes.

THESIS STRUCTURE

Because of the breadth of the topic, this thesis is by necessity an overview of access to rheumatology services with the emphasis on the patient experience. The exploration of delays in treatment followed the patient through the journey from the onset of IA symptoms until establishment of a treatment plan. Through the journey these people come into contact with a variety of healthcare workers, and deal with decisions about their care from onset through to exploration of symptom resolution following referral and the initiation of DMARD therapy. Access to essential care is examined through the analysis of administrative data and examination of the patient and health professional discourse.

The thesis begins with a literature review that explains the importance of establishing DMARD therapy within three months of the onset of IA symptoms and the studies that have looked for reasons why people with symptoms of IA may have delayed paths to a rheumatology service and beginning DMARD therapy. It draws on a mix of quantitative and qualitative studies from rheumatology and other MSk-related disciplines that have shed light on patient attitudes and beliefs that affect consultation with a medical practitioner. Chronic disease studies also have been drawn on to place referrals behaviour in the context of GP and patient relationships.

Chapter Three discusses the frameworks used in this study. A consumerist approach has been taken and the chapter briefly reviews the potential of the Behavioural Model of Health (Aday & Andersen, 1974) and the conceptualisation of 'fit' between the health consumer and service (Penchansky & Thomas, 1981) before establishing the conceptual frameworks of the study; The *Candidacy* model of healthcare access (Dixon Woods, Cavers, et al., 2006), and The *Collective Lifestyles* framework by Frohlich, Corin, & Potvin (2001), which incorporates the work of several theorists

who seek to explain access to, and use of resources within the context of the places people live.

Chapter Four gives an overview of the methodology that explains how the concepts from the Collective Lifestyles framework have informed the methods chosen for the study. A mixed methods approach has incorporated interviews, administrative data and the characteristics of the Wellington region into the context of people's lived experiences in the negotiation of health care for IA symptoms and treatment. Chapter Five locates the research within the Wellington Region and has drawn on secondary health, demographic and social data to capture the nature of the areas that are differentiated in the study.

The findings of the research are presented in the next section as a journey from onset of symptoms to treatment barriers. Chapter six presents the IA participant accounts of the journey from onset of symptoms to consultation with a GP. The findings of qualitative research from the West Midlands is utilised to situate the onset delay and discuss the patient experience of acknowledging the presence of IA symptoms and negotiating the iterative process of recognising the need to consult a GP (Sheppard, Kumar, Buckley, Shaw, & Raza, 2008).

The research uncovered two distinct phases in the referrals delay that are often considered together. These phases have been documented here as the evaluation delay in Chapter Seven and the referral delay in Chapter Eight. Both chapters use IA and GP participant accounts and data to establish how symptom evaluation proceeded and to identify barriers to referral. It has been argued that the shared care paradigm has led to the expectation that patients will use their autonomy and agency to take responsibility for ensuring health needs are met rather than the medical practitioner leading the discussion about care choices (Buetow, 2005). This chapter provides an insight into the expectations patients have of the evaluation and referral processes, and GP decision-making and barriers in the referrals process.

Chapter Nine uses data from staff interviews and WRRU administrative data to assess the utilisation of public rheumatology services. It includes an assessment of individual and area characteristics that may lead to variations in non-attendance at the first specialist assessment (FSA) and equitable provision of services across the

region in terms of waiting times for FSA in each area that may also lead to non-attendance. This assessment is supplemented with IA participant narrative that may explain some of the difficulties in meeting a responsibility to attend an FSA.

The thesis closes with a discussion of access to care throughout the patient journey, conceptualised in the concept of Candidacy, and an interpretation of the barriers to access within the contextual framework of Collective Lifestyles. The chapter closes with recommendations for further research and proposals for reducing barriers to rheumatology services. Definitions of terms used in the thesis, supporting documents and data are found in the Appendices.

5. LITERATURE REVIEW: DELAYS TO RHEUMATOLOGY CARE

INTRODUCTION

Managing patients in primary care and reducing referrals to secondary care is an objective of health administrators in many countries (Carlsen, Aakvik, & Norheim, 2008; Forrest, Nutting, Von Schrader, Rohde, & Starfield, 2006). Treating patients in primary, rather than secondary, care has also been an important objective of the New Zealand health system and this is indicated by boosts in financial and other resources to fund primary care (Barnett & Barnett, 2004; Ministry of Health, 2000). However, early referral of people with IA from primary to specialist care is associated with cost-effective quality of care and improved outcomes in terms of joint damage and disability (Bidaut-Russell et al., 2002; Lacaille, et al., 2005). The importance of rheumatology care for people with IA is outlined in research that shows continuous care by a rheumatologist is strongly associated with regular use of DMARDs and improved outcomes. Those who receive DMARDs in primary care are significantly less likely to continue with this treatment (Lacaille, et al., 2005).

In the early 1990s the delay between onset of symptoms and diagnosis became an important topic in rheumatology care as clinical research began to favour early referral of people with IA for more aggressive treatments to arrest disease progression (Egsmose et al., 1995; Lard et al., 2001; van der Heide et al., 1996). A 1994 report on delays between symptom onset and diagnosis of RA defined two stages of delay: the medical encounter lag time (onset delay) which is the period between onset of symptoms and the first medical encounter with a primary care provider who can make a preliminary diagnosis and referral to a rheumatology service; and the diagnosis lag time (referral delay), which is the period between the first medical encounter and the diagnosis by a rheumatologist (Chan, et al., 1994).

The first aim of this literature review is to develop a case for early referral to a rheumatology service when symptoms of IA are detected and explain why this is crucial for the best possible disease outcome. The main purpose is to critically review

a range of international research about patient delays to rheumatology that has quantified the length of delays and catalogued causes of delays at the onset of symptoms, at GP consultation and at referral to a rheumatology service. These papers have informed and shaped the research presented in this study.

HOW IMPORTANT IS EARLY REFERRAL?

Joint damage from IA varies in onset and severity. Some individuals spend considerable periods of time with intermittent or mild symptoms, while others may have acute onset. Clinical testing for inflammatory markers and rheumatoid factors can help predict more severe outcomes, regardless of the intensity of onset, but these tests are not always definitive. In the early stages of IA the lack of clinical, radiological or biological features can hinder prediction of who will go on to experience erosive disease. The symptom presentation at this early stage is unlikely to meet the classification criteria that a GP may have experience of, and will require the expertise of rheumatologists to diagnose (Fautrel, 2009). Reviews of prognosis and outcome overwhelmingly support the contention that early IA care is optimised when treatment is managed by a rheumatologist, rather than a GP or other consultant (Ehrmann Feldman, et al., 2007; Ehrmann Feldman, Schieir, Montcalm, Bernatsky, & Baron, 2009; Kelly & Hamilton, 2007).

The duration of symptoms is also a predictor of joint damage and disability. Disease of longer duration without early, aggressive treatment with DMARDs is also positively correlated with joint erosions and poor outcomes. Researchers have proven that if initiated before erosive changes have begun, DMARDs delay erosion to such an extent that a person given the same doses later in the course of the disease will never attain similar benefits (Breedveld & Kalden, 2004). The enhanced effect of DMARDs early in IA is thought to be because in the acute, early stages of the disease, although inflammation is very high, it is likely joint and cartilage destruction may not yet have begun. This gap between inflammation and erosion has been called a “therapeutic window of opportunity” (Nell, et al., 2004, p. 907).

Radiographic evidence produces further evidence of the risk of delaying treatment with DMARDs. After a one year delay it can be expected that x-rays will show joint

erosion that may lead to long term functional disability for at least 70 percent of untreated RA patients (Jansen, van der Horst-Bruinsma, van Schaardenburg, Bezemer, & Dijkmans, 2001).

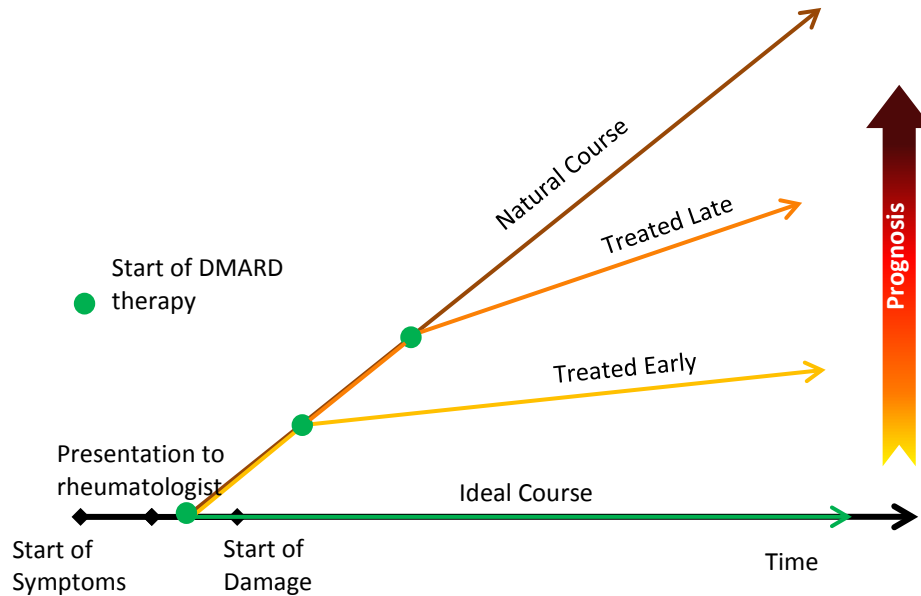


Figure 2: Schematic demonstrating the altered course of IA with early implementation of DMARDs.

Source: (Breedveld & Kalden, 2004, p. 630)

Much of the referrals delay literature considers RA as the confirmed diagnosis of IA symptom presentation, and focuses on the greater risk of joint damage, disability and cost to the health system of RA when compared with spondyloarthropies, which, despite the potential for joint erosion and disability are often considered milder diseases than RA (Silman & Hochberg, 2001). Due to the difficulties differentiating types of IA, many studies now focus on the delay in presentation of early IA symptoms rather than waiting for there to be sufficient information to meet specific diagnoses like RA, PsA and other SpAs. The importance of early treatment is such that some researchers consider IA should be regarded as a medical emergency (Chan, et al., 1994) and early arthritis centres have been established in Europe and the US to facilitate a rapid response for people with IA symptoms (Di Martino & Paget, 2005).

Early referral for people who have symptoms of AS may not at first seem critical to well-being given the long delay between the onset of AS and either the development of debilitating disease or sufficient evidence of the effectiveness of conventional DMARDs. Moreover, with no definitive clinic tests for AS⁴ it can be difficult for GPs to identify individuals with AS before damage begins (Sieper & Rudwaleit, 2005). However, it is known that individuals who are regularly and continuously treated with NSAIDs, rather than taking NSAIDs for irregular symptomatic relief, have less severe disease than those who are not (Sieper & Rudwaleit, 2005). More recently tumour necrosis factor inhibitors (TNF-inhibitors) have become an effective treatment option, and have been shown to reduce disease activity by up to 50 percent in half of people with AS, with younger patients, and those with a shorter disease duration having a better clinical response. Very early treatment is expected to result in a higher rate of remission (Haibel & Sieper, 2010). Incorrect diagnosis results in significantly worse disease activity, functional ability and damage (Aggarwal & Malaviya, 2009).

The symptoms of AS commonly begin in late teens and early adult years and because DMARDs are often of little use, it is possible that GPs have seen little point in referring people with inflammatory back pain – even if they suspect AS. AS commonly has a delayed referral of eight to 11 years from onset of symptoms. However new treatment with anti-TNF agents has improved the likelihood of disease suppression and improved quality of life. As with other forms of IA, treatment options offer significantly better results if provided earlier in the course of the disease (O'Shea, Salonen, & Inman, 2007). Earlier onset of inflammatory back pain is associated with the HLA-B27 gene and a study from The Netherlands found individuals who are tested for this gene have less delay in diagnosis (Chung, Machado, van der Heijde, D'Agostino, & Dougados, 2011; Sieper & Rudwaleit, 2005).

Empirical research has provided support for improved outcomes if DMARD therapy is implemented early in the course of the disease. An example of the likely impact of

⁴ A genetic test for the presence of the HLA-B27 can be used as a screening test for AS, but as a diagnostic tool it would detect one in three cases of AS and patients with back pain, but without AS may also test positive for HLA-B27 Sieper, J., & Rudwaleit, M. (2005). Early referral recommendations for ankylosing spondylitis (including pre-radiographic and radiographic forms) in primary care. *Ann. Rheum. Dis.*, 64, 659-663.

delayed implementation of DMARD therapy comes from a study in Leiden, The Netherlands. At an early inflammatory arthritis clinic, set up to encourage the referral of people with IA before symptoms differentiated to meet specific disease criteria, 598 patients were assessed for associations between delay to treatment, joint destruction and DMARD-free remission. The analysis examined the chance of disease progression over six years if DMARD therapy was delayed beyond the 12-week window of opportunity. The analysis produced a hazard ratio of 1.34 for an increased chance of joint destruction and 1.87 for not reaching remission. The research also found that RA patients with markers associated with poor prognosis (positive Rheumatoid factor or positive Anti-CCP autoantibodies) had significantly longer delays, whereas patients with high c-reactive protein (CRP), used to measure non-specific inflammatory processes and those with symmetrical joint involvement (characteristic of RA) were referred earlier by GPs. Individuals with inflamed small joints of the hands and feet, gradual onset of symptoms or with inflamed joints in the upper body had significantly longer delay to GP consultation than people with IA symptoms in the lower body or larger joints. Females and older patients were at greater risk of delayed presentation to a rheumatologist (van der Linden, et al., 2010).

PREVALENCE OF ARTHRITIS

Prevalence rates have been calculated using either community-based surveys or by assessing musculoskeletal disorders as a proportion of primary health care workloads. It is generally thought that community-based surveys will uncover more arthritis in the community (Access Economics Pty Limited, 2005; Taylor, et al., 2004). In a Dunedin survey 2.0 – 2.9 percent (depending on the criteria used) of the population had RA. This study was based on interviews and examinations of 545 participants (Small, 1984). The Carterton Study and WaiMedCa studies also attempted to establish the prevalence of MSK disorders in local communities (Taylor, et al., 2004) however the prevalence of arthritis in the community has not been clearly established (Taylor, 2005).

Self-reported community prevalence is available from the Ministry of Health's national population-based health surveys (NZHS). Arthritis prevalence was included in the third NZHS survey in 2002/03 (Ministry of Health, 2004) and its inclusion

repeated in the 2006/07 survey. In these surveys respondents were asked if they had ever been told by a doctor they have arthritis, including gout, lupus and psoriatic arthritis and if so, to record the type of arthritis, which joints were affected first, age of diagnosis and current treatment (Ministry of Health, 2008b). The 2002/03 NZHS found almost 16 percent of respondents had been told by their doctor they had arthritis (Ministry of Health, 2004). In the 2006/07 NZHS 14.8 percent of respondents had been told by their doctor they had arthritis. This reflected a small decline in self-reported prevalence of arthritis for both men and women. There was no change in the self-reported prevalence rate for Maori (Ministry of Health, 2008b). Most frequently reported types of arthritis, in the latest survey were osteoarthritis (8.4%), rheumatoid arthritis (RA) (3.5%) and gout (1.3%) (Ministry of Health, 2008b). A full picture of IA prevalence in the community is difficult to ascertain due to the wording of the questions which would lead to the underestimation of, for example AS and PsA (Devlin, M, Pers. Comm, 2009). Self-reported rates of IA are also very high compared with surveys collecting data of clinical measures which consistently measure prevalence of IAs in countries with large European populations at lower rates of disease. For example RA prevalence, the most common IA, in the USA is usually present in approximately one percent of the population (Helmick et al., 2008).

ARTHRITIS AND GP CONSULTATION RATES

Although MSk conditions are frequently seen in primary care, IAs are not seen often. An investigation of consultation rates for a range of rheumatic disorders using the Royal New Zealand College of General Practitioners (RNZGP) database found a consultation rate for MSk disorders of approximately 20 percent of patients over a 12-month period, with RA and SpAs accounting for less than one percent of this total (Taylor, et al., 2004). Taylor et al compared their results of the burden of MSk with the few earlier New Zealand studies (including *The Carterton Study* (Prior, Evans, Morrison, & Rose, 1970) and *A Survey of Rheumatic Diseases in a Dunedin Population* (Small, 1984)). In this comparison Taylor et al consider their study showed slightly higher, but broadly similar rates of MSk conditions seen in primary practice. The National Primary Medical Care Survey (NatMedCa) also provides data about

consultation rates. The final reports provided results for private practice GPs and community-governed/not for profit practices. These reports record 10 percent of GP consultations were for a MSk condition, with 1 in 7 of these visits referred for specialist evaluation, and nearly three percent of these were referred to rheumatologists (Raymont, Lay-Yee, Davis, & Scott, 2004). The consultations and referral rates suggested there were only small differences based on the type of practice and that this required more complex analysis (Raymont, et al., 2004). Higher MSk consultation rates are recorded by rural GPs (10 percent) (Hider, Lay-Yee, & Davis, 2004) and the least recorded by Maori Providers (7 percent) (Crengle, Lay-Yee, Davis, & Pearson, 2004). Unfortunately the numbers (21 of 735 MSk referrals) were too small for further meaningful breakdown to evaluate the proportion of IA referrals (Lay-Yee, pers. Comm, 2008).

DELAYS TO RHEUMATOLOGY SERVICES

A number of studies have attempted to assess the length of delay for people with an IA presenting to a rheumatologist. The allocation of 'responsibility' for delayed presentation at a rheumatology clinic varies with some studies finding the delay in presenting to a GP (onset delay) is the greatest inhibitor of early treatment and others the referral delay is greater than the onset delay. Chan and colleagues (1994), examined medical records for 98 RA patients referred to a health maintenance clinic in central Massachusetts. The median length of delay in this study was 36 weeks, ranging from 4 weeks until more than 10 years. The median onset delay was 4 weeks, with a median referral delay of 18 weeks (Chan, et al., 1994). A 1999 retrospective assessment of changing referral practices in Glasgow, UK found that median delays from onset to rheumatology clinic appointments for RA patients had significantly reduced from 21 months (pre-1986) to four months (1994-97). This reduction was, in keeping with changing recommendations for early institution of DMARDs, however more than half of patients seen in the reduced timeframes still did not receive DMARDs within six months of symptom onset (Irvine, Munro, & Porter, 1999).

Despite the sharp decrease in delays over time in the Glasgow study, further studies working on the three-month recommendation for DMARD therapy found evidence of long delays in treatment for RA patients in a clinical audit in the West Midlands, UK.

More than a third of the 77 patients audited waited more than three months to see a GP after the onset of inflammatory symptoms (range 1 day to 10 years), and four-fifths of patients had delays of more than three months between a GP consultation and referral to a rheumatologist. As a result only five individuals received DMARDs within the recommended three months from symptom onset. The authors highlighted the role and importance of the GP referral letter in delays to FSA, the lack of resources for faster FSA scheduling, and GP and patient education in the identification of IA symptoms (Potter et al., 2002).

The Leiden study, referred to in the previous section, found a median delay of 18.4 weeks from onset of symptoms to presentation at a rheumatology clinic for individuals who would develop RA. The delay for patients with RA, PsA and other SpA was significantly longer than the 13.7 weeks for those who were referred for other non-inflammatory rheumatological conditions. The study showed that only one-third of patients who would go on to be diagnosed with RA were seen at the EIA clinic within the 12-week 'window of opportunity'. The delay from GP consult until referral accounted for almost 12 weeks of the delay between the onset of inflammatory symptoms and diagnosis at the EIA clinic (van der Linden, et al., 2010).

As a result of establishing the occurrence of lengthy delays for people with IA, studies began to be published that attributed the proportion of delays to either the onset or referral phase of the patient journey. Research also began to isolate clinical practice, characteristics of the patient, or GP encounter or provision of services that might explain these delays. For example, aggregated demographic data was evaluated in a study from the Norwegian county of Østfold and gender differences were identified in delays. Women were less likely than men to be referred early, despite similar onset delays, with a referral delay of 10 weeks, compared with referral delay of three weeks for men. The authors reflected on possible gender differences in health-seeking behaviours, socio-demographic variables and subjective assessments of health complaints by the GP as explanations for the gender differences. They considered the most significant barrier was the GP's ability to distinguish inflammatory symptoms in women and attributed this to more women presenting more frequently with non-inflammatory pain and swelling that often mimics early inflammatory disease (Palm & Purinsky, 2005). The attribution of gender difference

in delay to GP referral practices replicates an earlier Belgian finding that despite similar GP encounter times and similar disease activity, women (average referral time 93 days) were referred to a rheumatology service significantly ($p=0.008$) later than men (average referral time 58 days). The authors suggested several possibilities for this difference – that men may consult about MSk conditions more often so GPs were more familiar with male presentation of symptoms, or that they consulted more forcefully due to the immediacy of factors such as time off paid work and the associated employment and financial impacts of delaying symptom resolution (Lard, Huizinga, et al., 2001).

In contrast to the Belgian and Norwegian studies, a UK study group surveyed 169 consecutive RA patients presenting at a Birmingham NHS Trust and found no significant relationship between delay to GP assessment and patient age or sex but identified that individuals who were seropositive for rheumatoid factor were significantly more likely to have delayed presenting at a GP assessment. They found a median onset delay of 12 weeks (range 4-28 weeks), with the referral delay a short two weeks. The authors also analysed the waiting time for an FSA and found a median three week delay, giving a median overall delay of 17 weeks from onset to FSA (Kumar, et al., 2007). These delays were similar to those found by a larger West Midlands audit of care across 11 rheumatology departments, which evaluated questionnaire responses from 1,715 IA patients. The audit found little more than one-third of the respondents sought GP assessments within six weeks of symptom onset, with one in five taking longer than six months to contact a GP. Fewer than half of all people were referred to a rheumatology department within six weeks, with more than one in eight patients having referral delayed for six months or more. Approximately half the patients were seen by a rheumatologist within six weeks⁵ of referral and eight in 10 patients were seen within 12 weeks. Long waiting times, possibly due to the absence of early arthritis clinics and irregular referrals prioritisation were cited as possible structural barriers to early diagnosis. The lack of awareness of IA in the community was thought to delay consultation with a GP. This audit also distinguished the delay in diagnosis and the delay to referral as two

⁵ At the time of this study the Arthritis and Musculoskeletal Alliance (ARMA) standard was for patients with suspected IA to be seen at a rheumatology clinic within 12 weeks of referral, with a developmental standard of six weeks between referral and FSA.

separate constituents of the referral delay that were identified in earlier studies. The researchers concluded there was a predictive patient journey that saw patients who consulted with their GPs early, being referred early and receiving prompt diagnosis and early initiation of DMARD therapy when compared with patients who delayed initial consultation with their GP (Sandhu, et al., 2007).

ONSET DELAYS

Intrigued by the long onset delay, the West Midlands study group began qualitative research to elicit outpatient attitudes and behaviours that may account for their reluctance to seek GP advice for IA symptoms. Interviews with 24 participants revealed four overlapping themes that accounted for delayed presentation in primary care:

1. Symptom experience and how this impacts on physical ability
2. Symptom evaluation including perceptions of the significance of the symptoms and personal explanations for onset
3. Knowledge about RA and its treatment
4. Attitudes towards and experience of GPs and the health system

These four themes suggest that individuals with gradual onset will delay seeking treatment, especially if they have little knowledge of RA and how it may be treated (Sheppard, et al., 2008). These themes were also replicated in an associated British study in which the authors interviewed people of South Asian descent, who had significantly longer delays to rheumatology clinics than people of European descent. In a theme not identified in the main study, some South-Asian participants spoke of spiritual and cultural beliefs that hindered consultation. Management strategies for these participants included prayer and community advice, but not consultation with a GP. None of the ten South-Asian participants in this study mentioned difficulties in accessing GP care (Kumar, Daley, Khattak, Buckley, & Raza, 2010). Participants in both studies often sought advice from family and friends before presenting to a GP and this advice was influential in the decision to access professional medical advice. Almost all participants thought too little information about RA was available to make informed decisions about the importance of symptoms and when and how to seek medical care. Participants were in agreement that if they were aware of RA they

would have consulted earlier. An important conclusion was that individuals with poor expectations of the health system and who found communicating with their GP difficult would delay seeking care even as symptoms progress. (Kumar, et al., 2010; Sheppard, et al., 2008).

Kumar and colleagues considered that the differences in onset and referral delays in the Østfold study which contradicted their own West Midlands studies could be due to differences in socio-cultural effects in Norway that meant people were likely to seek care earlier, thereby reducing the onset delay. On the other hand, the referrals delay might be shorter in the Birmingham study because GPs may have been better informed about RA due to the establishment of EAI clinics and the GP training that was associated with this development (Kumar, et al., 2007). The variations in delay across locations were assessed in a study of onset delays at 10 rheumatology clinics in Europe. The median overall delay from onset to the rheumatology clinic was 24 weeks (range of clinic medians 16-38 weeks). Although there were significant differences between clinics, there was no significant difference in overall delay based on patient characteristics. Comparisons between the individual rheumatology centres found wide differences in make-up and duration of delays, for example centres such as Berlin and Vienna had short onset delays (median two weeks), and longer referral delays (median 10 weeks and eight weeks), while Birmingham (12 week median) had long onset delays and shorter referral delays (median two weeks). This study highlights that effective strategies to reduce delays will need to address the local context and specific causes of referral delays (Raza et al., 2011).

Few studies have attempted to measure the level of undiagnosed IA in the community, but an initiative to collect data on the care received by people with MSk conditions provides some insight. A mobile bus was used to visit towns across Austria during a public health campaign on painful musculoskeletal conditions, providing advice and counselling from rheumatologists and pain specialists at 42 sites. More than four out of 10 visitors had not previously consulted a GP about their pain and only six percent of clients had ever seen a rheumatologist. Thirty-two of the 2,862 clients (more than two percent) were suspected of having undiagnosed IA with one-third of these visitors never having consulted a GP about their pain. People with IA conditions had higher pain scores than people with non-inflammatory conditions.

The self-reported mean duration of MSk pain was 8.5 years. The study authors concluded the level of pain people experienced before consulting a doctor was unacceptably high. There were no significant differences in pain thresholds for consultations between rural and urban visitors, which may complicate theories of social or cultural factors accounting for pain thresholds. However the study does confirm insufficient importance is attached to MSk pain by both patients and physicians, that MSk conditions are relatively neglected in terms of funding and information available to the general public about rheumatic diseases (Machold et al., 2007).

REFERRAL DELAYS

Although delays in referrals from GP practices to rheumatologists have not been published in New Zealand, there is evidence that variations in GP referrals are an important factor in the management of patient care. Enrolment data from the Canterbury PHO (enrolled population 345,254), in 2007 found high rates of practice variation in the uptake of high user health cards and funding for high users with chronic conditions. The study also found variation in hospital admission rates between GP practices. Ethnicity, age and deprivation only partially explain these differences with only 28 percent of the variation in Māori discharge rates from hospitals being explained by patient demographic characteristics (European, 58 percent; All ethnicities, 63 percent) and practice characteristics had a negligible effect. The researchers considered the most likely factor for these differences was GP variability in the assessment and treatment of patients, patient pressure, GP relationships with specialists and diagnostic uncertainty. The possibility of patterns of social exclusion was also raised as a contributory factor (Barnett & Malcolm, 2010a).

For Nell and colleagues, in their study of the greater benefits of DMARDs in very early onset, the most delays in obtaining this treatment were referral delays. They postulated that many physicians prefer to wait a few months before DMARD therapy is instituted (Nell, et al., 2004). Canadian physician reimbursement data supports the view that physicians may delay referral. A review of 10,001 suspected new-onset cases of RA in adults who were diagnosed by non-rheumatologists in Quebec, Canada

concluded that the vast majority with suspected RA did not receive specialist rheumatology care and little more than one in four patients were referred to a rheumatologist within 2.5 – 3.5 years of presenting with RA symptoms. Hazard ratios show those who were referred earlier tended to have co-morbidities, were female, younger or were in higher socio-economic groups. Individuals who had longer onset delays and whose referrer was a woman were also more likely to be referred earlier. The authors surmised women may be referred earlier because GPs were more attuned to their symptoms given the higher prevalence of RA in women. They noted, however, that age was a modifier of gendered referral differences, with older women's referral time extending at a greater rate than older men's referrals (Ehrmann Feldman, et al., 2007).

Studies of referrals from GPs to specialist services have expanded the ideas about access to include such factors as rapport between doctors (Suter, et al., 2006) and doctor-patient relationships (Gardner & Chapple, 1999). Understanding GP attitudes, perspectives and behaviour that affect the referrals process is as important as understanding onset delays in seeking care. In a critical review of the literature on variations in referral rates by O'Donnell (2000) Dowie was identified as a proposer of an early model of referrals behaviour. In 1983 he put forward the idea that GPs may have a unique 'referral threshold'. He considered characteristics which may affect referral behaviour such as training, experience, tolerance of uncertainty, sense of autonomy and personal enthusiasms. This model was supported by Wilkins and Smith in 1987, but with the observation, important in this study, that it was not developed for chronic conditions (O'Donnell, 2000). O'Donnell's review attempted to identify explanatory variables and concluded that practice and GP characteristics explained less than 10 percent of variation in referral rates, with GPs who are intolerant of uncertainty or who perceive serious disease to occur more frequently being more likely to refer (O'Donnell, 2000).

GPs have been known to express low levels of confidence in being able to diagnose and manage musculoskeletal disorders in primary care (Speed & Crisp, 2005). In interviews with 19 GPs in Connecticut, U.S.A a set of broadly defined 'domains' were identified as impacting on timely referral and quality of care (Table 1). Four of these domains directly related to the GP environment: clinical and administrative

leadership in the GP practice; GP confidence and expectations of the referral; the relationship between the GP and patient; and GP and specialist (Suter, et al., 2006). The interaction between these domains is a key point in understanding referral patterns. Previously unappreciated features such as PCP and specialist relationships were found to be critical factors in speedy referrals. Several of the study findings are supported by survey data from 142 primary care physicians and their 83 practices in the U.S. In particular, the confidence of the GP and tolerance for uncertainty and the interaction of clinical, practice, GP and patient factors affected referral patterns. In this study, structural factors such as gate-keeping arrangements, capitated primary care and high numbers of local specialists were additional facilitators of referrals. Referrals were also more likely from larger practices, and managed care practices (Forrest, et al., 2006). Both studies highlight the need to have good systems in place to manage unresolved referrals and to enhance the referrals process (Suter, et al., 2006).

Table 1: Factors that influence GP referral decisions

Domain	Selected Examples
Clinical characteristics of the disease	Signs and symptoms – e.g. ‘classic’ versus atypical presentation. Response to initial treatment – e.g. positive versus lack of response
Patient Preferences	Beliefs about the disease that affect treatment choices, for example that RA is not a serious disease Beliefs about treatment options Previous compliance with treatment
Access Issues	Cost of primary care, geographic accessibility
Clinical and administrative leadership	Institutional prioritisation of IA and MSk expert GPs GP isolation
Physician confidence and expectations of the referral	Diagnostic uncertainty versus diagnostic certainty Perception of specialist competence GP perception of how a specialist views the GP Expectations around the on-going GP role in patient care
Interpersonal relationships	Between primary care practitioner and specialist. Between primary care practitioner and patient.

Source: Suter, Fraenkel, & Holmboe, 2006, p 302

Referrals guidelines have been developed to assist with the uncertainty surrounding the IA diagnostic process. A population-based study in British Columbia tested whether GP decision-making about referrals and DMARD treatment was consistent with referral guidelines. The researchers obtained physician, physiotherapist, hospitalisation and prescription information for all 27,710 RA patients treated in the

province over a four year period from administrative databases of the Canadian Ministry of Health. Only three out of 10 patients had used a DMARD over the last year, increasing to slightly more than four out of 10 patients in the past five years. Referral to a rheumatologist significantly increased the likelihood of using DMARDs with three-quarters of people under a rheumatologist's care having used DMARDs in the past five years, and people prescribed a DMARD by a rheumatologist and under consistent rheumatologist care were, more likely to continue using it than people under intermittent rheumatologist care or referred back to GP care. This study identified women, higher socio-economic and younger people as more likely to be referred for rheumatology care. The researchers concluded the guidance for early aggressive treatment of RA had not filtered through to GPs and further GP education was required, as well as targeting the general population. They also suspected that the relatively low levels of specialist rheumatologist care in this universally-funded health system suggested access barriers and service provision shortages. The gaps in care identified by the study meant that rheumatological treatment was not consistent with recommended guidelines (Lacaille, et al., 2005).

GP-PATIENT RELATIONSHIPS

Whether GPs use the recommendations in guidelines may depend on GP attitudes toward the patient and patient preferences. Escalante (2007), lists four groupings of causes of disparities in rheumatological disease: bias and discrimination; lack of access; patient preferences; and patient-doctor miscommunication. Escalante argues there is mounting evidence of health disparities being driven by patient preference, but few efforts had been made to remodel patient preference by incorporating how inaccurate information impacts on patient beliefs, and thereby preferences, and the primary care practitioners' efforts to correct misinformation.

Patient pressure to refer or the desire to provide reassurance can encourage referral, whereas the desire to avoid the possibility of causing the patient distress by an unwarranted referral can reduce referrals. Patient expectation creates pressure on the GP to take some action rather than none and in these situations the referral or not may depend on whether the individual is a high or low user of medical services, with

high users more often referred and low users treated in primary care (Baker, Lecouturier, & Bond, 2006).

Few rheumatology services studies focus on the GP-patient relationships. A wider search of studies that have considered referral encounters have shown models that emphasise patient involvement in the decision-making process require careful management to ensure appropriate referral. A reluctance to be referred can occur, for example, if patient knowledge of referral is formed by personally witnessed poor outcomes, which is not uncommon for individuals with complex needs or who have consulted social networks about their referrals experiences. Under a patient preference model of health care that considers people's values in the range of possible treatment options, professionals are required to help a patient understand the likelihood of potential outcomes using the best evidence available (Katz, 2001). To ignore this requirement can result in poor referral decisions under the guise of patient preferences. Rather than actual patient preferences being an important factor in the referrals process, it could be that GPs' perceptions of patients' wishes, formed by a poor understanding of the experiences of the patient, is a stronger indicator of whether a referral will be the outcome of a consultation. These perceptions and misunderstanding can impact on the interpersonal relationship and the emotional climate during a consultation, affecting the referral decision (Espeland & Baerheim, 2003). Despite negative attitudes and beliefs affecting consultations and subsequent referrals decisions, an interesting dilemma for early referrals is highlighted by studies that show matching patients' preference for involvement in the decision-making process does not consistently lead to improved outcomes (Fraenkel & McGraw, 2007). In general, fewer referrals are made to secondary care when GPs have a positive attitude to shared decision making (Carlsen, et al., 2008). However, a referral is more likely if the GP has conflicting attitudes toward patient involvement in decision-making or expectations of participatory consultation are not met (Carlsen, et al., 2008).

A frequently raised issue in illness behaviours is the difference between patient and GPs' explanatory models of illness and treatment (Parsons et al., 2007). An important study of referrals for chronic conditions that touches on this point is the qualitative work in a London GP clinic. Gardner and Chapple's (1999) study of cardiologist

referrals in an inner-city primary care practice in London emphasised the importance of cultural gaps in the referrals process. Cultural gaps were often linked to class, language barriers, ethnicity and probably literacy. Doctors' perceptions of patient beliefs and attitudes affected the decision to refer, however these perceptions may be at odds with the actual beliefs and attitudes of the patients. These characteristics were exacerbated by misunderstandings between the patient and GP about the symptoms experience and expectations of the care GPs would provide. The study found that people from deprived areas see themselves as old at a younger age and therefore less worthy of attention and more likely to decline a referral if they perceived an overburdened service. They are also less confident in dealing with doctors than people from more affluent areas and misunderstanding could develop through misinterpretation. For example a doctor may interpret a person's reluctance for further tests or referral as a 'culture of illness' (a desire to be seen as unwell for personal benefit) in the community rather than a fear of hospitals, operations and medical tests. (Gardner & Chapple, 1999).

GP - SPECIALIST RELATIONSHIPS

Communication about referrals to specialists has been highlighted as a particular problem. Barriers to communication focus on importance of clearly communicating a specific question or reason for referral (Stille, Jerant, Bell, Meltzer, & Elmore, 2005). Factors affecting communication and specialists were defined as the method, content and timing of communication, system factors, provider education and interpersonal issues. Rheumatologists rely on the information supplied by the GP to triage patients with suspected IA and prioritise accordingly. The history of symptoms, clinical markers of inflammation, positive RA antibodies and radiological assessments are all important measures of urgency and used by rheumatology services to prioritise and manage waiting lists (Hutt Valley DHB, 2008).

In a Hutt Hospital assessment of referral letters of 128 patients, referral requests often omitted important information that could be considered in the triage process and the most important factors used for prioritisation was the GP request for urgency and the c-reactive protein (CRP) count. GPs relied on CRP (>10) and the presence of swollen joints to indicate urgency. Urgency requests also favoured people of a

younger age, which influenced triage assessment. These findings and the overall time from symptom onset to beginning DMARD therapy of 6.1 months were in keeping with international findings for conventional rheumatology services, without early arthritis clinics (Robinson & Taylor, 2010).

STRUCTURAL FACTORS

The Østfold study in Norway alluded to structural factors in their report by reflecting on the provision of rheumatology services, but by international standards the county is well-served with 5 rheumatologists for a population of 240,000. The authors did, however, call for improved organisation of health care as, given the provision of rheumatologists, the median lag time of 16 weeks does not compare well with other studies (Palm & Purinsky, 2005). In the Birmingham, UK study, their faster referral timeframes were attributed a better GP response to RA symptoms, due to the setting up of a well-promoted rapid access early arthritis clinic and concentrated efforts to improve GP knowledge of IA disease and treatment (Kumar, et al., 2007).

Elsewhere it has also been noted that a perception that rheumatology services are overburdened affects GP views about acceptability of referring (Espeland & Baerheim, 2003). This includes the perception of waiting lists and therefore the availability of perceived best treatment and/or diagnostic path (Baker, et al., 2006). In New Zealand, where waiting lists are used to ration scarce health resources and monitor health system performance, referral to specialist services through managed and prioritised waiting lists may lead GPs to delay referral until a pre-determined threshold is reached for referral, especially because individuals will be referred back to the GP if the referral is deemed inappropriate (Cumming, 2013). As of July 2012 in New Zealand the maximum allowable waiting time for FSA is six months from referral. The main aims of this maximum is to improve the consistency in the selection and prioritisation of patients, and for a greater proportion of patients to be treated in priority order and within prioritisation timeframes (Ministry of Health, 2013).

The use of GPs as gate-keepers to rheumatology services is not universal and the importance of this factor in access and patient satisfaction with care is variable in the few studies whose authors have commented on the matter. In France, before 2006, individuals were able to self-refer to rheumatologists with early arthritis symptoms.

An assessment of access times found that the individuals who did so were significantly more likely to have a shorter wait time than if they were referred by a GP, with 57 percent of self-referred individuals consulting a rheumatologist in less than 6 weeks from symptom onset, compared with less than 45 percent referred by a GP being seen within 6 weeks. This research controlled for medical characteristics of symptoms, family history of IA, age and gender. Individuals with more rapid onset, fever, high swollen joint counts and persistent joint involvement were significantly more likely to consult within the EULAR timeframe of 45 days. Socio-demographic characteristics (age, ethnicity, living arrangements and socio-economic status) were not significantly associated with referral times. Referral delays were also associated with areas of low GP numbers (<150 GPs/100,000 inhabitants) and low rheumatologist density (<15/100,000 inhabitants) (Fautrel et al., 2010). The delays caused by gate-keeping arrangements have been described in terms of the commitment to the public health system with restricted resources and waiting times as a management tool. GPs may be caught between the patient's needs and commitment to the health system as a provider for the wider community's needs (Thorsen, et al., 2013). In the U.S. however, gatekeeping by GPs was found to facilitate referral in a study of referrals from 142 physicians to specialist services (Forrest, et al., 2006). Despite the possibility of longer waiting times in a mixed private/public health system, GP-initiated referrals have been found to confer other benefits. Gatekeeping was found to improve the referrals experience for the consultant, GP and patient in a study of more than 400 referrals from 25 practices to a range of specialists in Marbach, Germany. In this study individuals could be referred via their GP or they could refer themselves. Patients respected GP advice and co-ordination of the referral, and overall were more positive about their referral if the GP was the initiator. GPs were most satisfied with the referral when it was done to reduce diagnostic uncertainty (Rosemann, Wensing, Rueter, & Szecseny, 2006).

DISCUSSION

Research into treatments for IA has concluded that early, aggressive DMARD treatment of erosive IA by a rheumatologist produces the best possible disease outcomes. Because erosive IA is difficult to distinguish from self-limiting or more

benign forms of IA, rheumatology guidelines recommend individuals with inflammatory symptoms consult with their primary healthcare provider and be referred to a rheumatologist for assessment, diagnosis and to begin DMARD therapy within three months of symptoms onset. Delays in treatment beyond this three-month therapeutic window of opportunity lead to worse outcomes for a person with IA in terms of joint erosion and disability and remission. Although beginning DMARD therapy later still results in improved outcomes, the early opportunity for best outcome cannot be recovered.

Although much referrals research in the medical literature focuses on variations which result in over-referral of people to specialists, the Leiden study established quantitatively, the increased chance of joint destruction and poorer outcomes, including increased disability and a lower likelihood of remission, when DMARD therapy was delayed for more than 12 weeks from symptom onset (Bykerk & Emery, 2010). In the case of IA, the real cost to patients, and the health system, of variations in referral rates resides in under-referral (late or non-referral) of people with suspected IA to rheumatologists (Potter, et al., 2002).

An optimal path to treatment where individuals have presented early in primary care, been referred early and treated early has been suggested as a path that might be within the patient's control (Sandhu, et al., 2007), but it seems likely that the severity of disease accounts for this optimal treatment path rather than attitudes or behaviours of patients or GPs that might delay referral (Robinson & Taylor, 2011). It has been established that extended onset delays and referral delays can occur when individuals are unaware they may have an IA, when symptoms progress slowly and when pain is manageable (Suter, et al., 2006). Similar research in cancer delays have also found that considerable associations between delayed consultations and non-recognition of symptoms, with older age, lower education and socio-economic status associated with onset delays. The review of literature carried out by the authors found the GP decision to treat patients symptomatically, or who related symptoms to illness other than cancer, as important associations with referral delays (Macleod, Mitchell, Burgess, Macdonald S, & Ramirez, 2009)

Traditional access concerns like the availability, accessibility and affordability of primary care (Penchansky & Thomas, 1981) were rarely assessed in referral delays studies, with researchers focussing the attitudes and behaviours of the individual towards their IA symptoms. The drivers for seeking GP assessment of IA symptoms were identified as understanding of IA and/or the impact of symptoms on daily life, the severity of onset, the involvement of multiple joints and limitations on usual activities. People often explained that the reason for seeking medical care was not for diagnosis, but for respite from symptoms. Few studies have surveyed men's reasons for delayed referral, while ethnic minorities and locations outside of Europe and North America are over-represented in studies of onset delays (Stack et al., 2012).

Much of the research about onset delays has been conducted in countries where primary health care is provided without fee, or where people can access rheumatology services directly and quickly, under state or private health insurance plans. The European studies gave an indication that the method of rheumatology service delivery may impact on referrals delays, with greater waiting times where early arthritis clinics are not provided, and where waiting lists are used to ration secondary care. In the New Zealand public health system patients usually pay a part charge for their primary care consultations and the GP acts as gatekeeper to free secondary public health services (Cumming, 2013), or the patient can be referred to a private consultant with a fee that may be reimbursed by a private health insurance plan. Because patients and allied or complementary health professionals cannot directly refer to rheumatology services, the importance of consultation with a referring GP is crucial to beginning early rheumatology treatment. The series of qualitative studies from West Birmingham indicate that individuals may consult within their social networks for advice about IA symptoms before consulting their GP. Few studies considered structural access barriers to GP care, concentrating on attitudes toward medical care and behaviours that may delay individuals from accessing that care.

In a Canadian qualitative study of the context of decision-making by GPs, Giddens' structuration model was utilised to explain how GPs have more than a simple gatekeeper role of allowing some individuals to receive further care, and preventing other individuals, for various reasons, from receiving that care. This model is mindful

of the influences on decision makers of the structural constraints imposed by the health system they work within, and the often unacknowledged active, or more subtle, input of patients to the decisions made on their behalf (Geneau, Lehoux, Pineault, & Lamarche, 2008). GP understanding of the rheumatology services that are available, including waiting times and otherwise over-burdened services, and their expectations of the outcome have been shown to affect referrals.

Guidelines have been developed to assist GPs in their referral deliberations, but when clinical test results are inconclusive, or atypical symptoms and comorbidities confuse the diagnostic process either early or late referrals may eventuate, depending on whether the GP is likely to take a 'wait and see' approach or expedite referral to a rheumatologist. This decision can, to a large degree, depend, on the risks and benefits the GP perceives (Baker, et al., 2006; Espeland & Baerheim, 2003; Suter, et al., 2006). Although referrals guidelines can assist GPs, their role in decision-making is unclear. There is an expectation that guidelines will be used, not to replace decision-making, but to inform the decision-making process (Wise, Kumar, & Walker, 2006). However, the attitudes and behaviours of GPs in following these guidelines may be more important than knowledge of current guidelines (Espeland & Baerheim, 2003).

GPs may also lack confidence in diagnosing and planning treatment options for IA. Relationships between referrers and rheumatologists, and experience and training have been highlighted as extremely important factors if reduced referral delays are to be addressed (Kumar, et al., 2007; Palm & Purinsky, 2005). The quality of information the GP forwards to the rheumatologist can impinge on the acceptance of the patient for assessment and the quality of the triage (Robinson & Taylor, 2010).

Practice characteristics may play a part in encouraging referrals, especially if a person with a special interest in rheumatological conditions is available (Suter, et al., 2006). The relationship between doctor and patient, and the ability of the doctor to empathise with the patient are important factors in referrals (Suter, et al., 2006). However GPs and patients having similar attitudes toward care pathways may not lead to referral. There is some evidence that GP attitudes impact on referral rate more than patient attitudes and similarities in beliefs are less likely to lead to referrals in general (Carlsen, 2004). Studies have also identified patient

characteristics such as gender, age and socio-economic status as factors in late referral but some characteristics, for example gender, are not consistent across different health systems.

An individual's eligibility for referral can be considered a product of joint negotiation between the patient and the GP (Dixon-Woods et al., 2006) and a patient preference model of care, if properly managed, assists the negotiation and adjudication between offers of referral and can minimise resistance. These are integral concepts of the Candidacy framework and require clear management and communication, however authors such as Katz (2001) caution that there is a risk of GPs abdicating their responsibility to be an active partner in this process by not ensuring the patient is fully informed about the health outcomes of the decision to accept or reject a referral offer. GPs may, on the other hand, misinterpret or pre-judge a person's response to a recommendation for referral (Gardner & Chapple, 1999).

International research, although a valuable tool for appraisal of referral behaviours, will not consistently represent or be applicable to the situation in New Zealand. Factors can be weighted quite differently in a private system relying on health insurance compared to publicly funded health systems and mixed public/private systems. Health providers and funder may also work under different policies and objectives in the distribution and use of health resources. New Zealand has relatively good access to publicly funded primary care despite patient charges, however access to secondary services is more contested (Cumming, 2013; Schoen & Doty, 2004).

The West Birmingham Study Group research concluded:

"... delay can only be reduced if the reasons that underlie patients' decision making processes when determining whether to seek medical advice are understood...With the development of increasingly more effective therapies for RA this will be an important public health measure" (Kumar, et al., 2007, p. 1440)

This quote pulls in two ideas about how to encourage consultation and referral, and optimise IA treatment. The first is to recognise and incorporate in referrals how individuals make decisions affecting their own care. In understanding the reasons behind the decisions patients make there is an opportunity to move away from the implication of an apparent failure of attitude on behalf of the patient, towards

understanding the context in which seeking medical advice occurs. The second point Kumar et al touch upon is that of IA as a target of health promotion measures. The argument for greater prioritisation of IA in health policy, public health promotion and GP education (of musculoskeletal problems generally, and IA specifically), in order to reduce the risk of long-term disability has been strongly advocated in the referrals literature. Support for this argument continues in the research that is presented in the following chapters.

6. ESTABLISHING A FRAMEWORK

INTRODUCTION

The development of symptoms of an IA condition is a significant life event, albeit one the individual may be unaware of at the time. A diagnosis of chronic disease has been characterised as a biographic disruption, which highlights the resources a person is able to draw on to understand, explain and manage the life changes that chronic disease presents (Bury, 1982). A person's response to these symptoms can be a complicated decision-making process that necessarily incorporates a judgement about the importance of the symptoms, perceptions of the need for, and the availability of, healthcare and the resources a person can call on that enables access to appropriate care.

“Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay” (Ministry of Health, 2000, p. vii) is one of the seven fundamental principles of the New Zealand Health Strategy. However there are a myriad of reasons about why timely and equitable access remains unachieved, but those reasons are difficult to define, despite access being one of the most commonly researched elements in the health care services delivery matrix (Ricketts & Goldsmith, 2009). Some dimensions of access are easily identified and clearly understood, for example an adequate supply of services in the areas they are needed or the effect of the direct cost of a health service to an individual. Many reasons for poor access are more esoteric and this has led to multiple attempts to define both access and the dimensions of access and to develop frameworks to enable these dimensions to be systematically incorporated in explanations of patient barriers to accessing health care services (Gulliford, et al., 2002).

Two of the most frequently referenced models in access to healthcare studies are the Behavioural Model of Health (BMH), the work of Andersen and Aday (1974), and the Penchansky and Thomas (1981) dimensions of access which proposes that a ‘fit’ between the health service and personal need is required. Despite the extensive work to define access and develop theory and tools with which to study the concept, fully understanding the barriers that continue to inhibit access to appropriate health

care remains elusive. In questioning why access remains poorly understood, the sphere of access studies has been extended to envelop the contextual factors of peoples' lives in an attempt to explain variations in their experiences of health care delivery. To examine health inequalities Bolam and colleagues (2004), for example, used the context of class identity, and Mansyur and colleagues (2009) the social context of culture, while Dunn and Cummins (2007) editorialised about the effect on health and health inequalities of collective social organisation and social meanings within the places people live. A critical interpretive review of access studies for Britain's National Health Service resulted in a report that reconceptualised access as a process of candidacy, which defined a dynamic, negotiated and reflexive process of offers and consents to accessing healthcare, and barriers to these processes that may restrict access along the patient journey. It is through these consents, barriers and acceptances that access might be evaluated (Dixon Woods, et al., 2005).

As a geographer, a contextual framework that might evaluate the process of candidacy and which explicitly incorporates dynamic experiences of an influential place (rather than place as simply a contained space, or bounded canvas for a study (Frohlich, 2013)) appealed. Such a tool for understanding access to health care for individuals with IA is appropriate as this disease has variable and often difficult-to-recognise or interpret early symptoms (Chan, et al., 1994; Stack, et al., 2012), as well as being a disease that early access to appropriate treatment is an established reason for clinically significant improved outcomes (Emery et al., 2002; Fautrel, Benhamou, et al., 2010; Nell, et al., 2004). These contextual factors are expressed in Frohlich and colleagues' (2001) paper that proposed a theoretical framework to study the relationship between context and disease.

The aim of this chapter is to provide an overview of the reasons for the conceptual and evaluative frameworks that have been used for studying access to rheumatology services. The chapter revisits the definition of access to healthcare services, and introduces a brief example of the production of health care through a political economy approach to the structure and describes the two most frequently used frameworks for evaluation of access barriers. It then considers the reconceptualization of access as Candidacy and presents Collective Lifestyles as the framework for the evaluation of access in this study.

DEFINING ACCESS

Access is both a policy goal and an important political symbol of competency in managing healthcare services for all. It has been conceptualised as a tool that can be used to examine how healthcare services are organised, funded and delivered to local populations. Despite widespread agreement about the importance of providing equitable access to health services, access has also been described as a “nebulous and obscure” concept that is difficult for policymakers, health practitioners and the general public to ideate (Ricketts & Goldsmith, 2009). Access is a multi-dimensional concept with single measures unable to provide evidence of fair or equitable access (Gulliford, 2002). In reflecting this notion, the Ministry of Health simply defines access as the “ability of people to reach or use health care services”. Despite the broad definition of access the MoH defines barriers to access more concretely as; “(1) a person’s locality, income or knowledge of services available; or (2) by the acceptability or availability of existing services” (Ministry of Health, 2000, p. 48). The MoH definitions draw on the notions of potential access (the ability of people to reach health services) and realised access (the utilisation of health services) that underlie some of reasons for confusion over when access has been found to occur.

Having potential access implies the individual can enter the healthcare system and has the opportunity to obtain health care. In this framing the healthcare system is perceived and experienced as temporally and geographically accessible, and is approachable (Starfield, 2001). This definition allows a number of variables to be studied and compared to ensure access is met for particular persons or groups, for example people in particular neighbourhoods or for people with demographic or socio-economic characteristics that are associated with poor health outcomes.

If realised access is the aim of a health service, the scope for assessment is much broader than relying on the availability, cost and ease of reach to the service that are a function of potential access. Assessing actual, or realised access, must include not only the availability and accessibility of the service, but also less concrete factors such as the attitudes, experiences and beliefs of an individual that inform the need for health care. The scope must also include assessment of the health service that may be implicated in barriers to utilising the service provided (Donabedian, 1976;

Gulliford, et al., 2002; Mechanic, 1995). In other words access can be conceptualised as a *“a matrix of structures and processes that can be manipulated to allow for use (or non-use) of health care and health promoting activities”* (Ricketts, 2009, p. 521). This concept moves beyond definition toward examining the characteristics of people that may affect access, to the context of people’s lives and how that context affects connections with health care services.

MODELS OF ACCESS

The provision of health services, mediated by the ideological and policy decision-making of the State and fund-holders, and the consumption of health services in terms of utilisation and consumer satisfaction are contrasting approaches to access to health care. The production of health care approach stresses the structural barriers people face in their search for appropriate health care, whereas the consumption approaches consider an individual’s movement through the existing health services and their choices about health use. These choices are often considered in terms of barriers such as patient attitudes and behaviours about illness and the health services that are provided and barriers created by the characteristics of the geographic, socio-economic and/or demographic group(s) the patient belongs to.

THE POLITICAL ECONOMY OF HEALTHCARE ACCESS

The production, distribution and delivery of healthcare are targets for tackling the inequalities in health that are prevalent in society (Bambra, Fox, & Scott-Samuel, 2005). A political economy approach to healthcare access focusses on the political and economic determinants of the production of health services and how these impact on an access to appropriate health care for different groups in society. Traditionally class-related, analysis is commonly performed for gender, ethnic, age and area-related inequalities as well (Barnett R & Copeland, 2010). This approach has gained favour as a counter to the personal responsibility approaches that can unfairly blame individuals for poor lifestyle and health choices. The beneficiaries of health policies and the costs of those policies in terms of the determinants of health become the focus of analysis in this approach (Krieger, 2001). Moreover, the

combination of a biomedical definition of health as the absence of disease, rather than a more holistic concept of wellness, and the economic definition of health as a commodity leads to an ideological position that “Health... is an individualized commodity that is produced and delivered by the market or the health service” (Bambra, et al., 2005, p. 189).

This analysis can be demonstrated by changes to the New Zealand health system since reforms in the 1980s when population-based funding and capping of hospital budgets were introduced to contain demand. Between 1983 and 2008, when a new government was elected, the New Zealand health system underwent four reforms. The most significant of these, the 2001 reforms set in place 14 District Health Boards (DHBs) and provided for the implementation of Primary Healthcare Organisations (PHOs). The introduction of the New Zealand Public Health and Disability Act 2000 gave the Ministry of Health responsibility for policy advice funding and monitoring of the health and disability sector (Quin, 2009).

The provision of healthcare services through a public hospital system had been a core value in the New Zealand welfare state. The restructuring of health care services in the 1980s changed the universal provision of care to one that was more targeted to specific populations – those with high health needs and with a limited ability to pay for healthcare. The shifting of the ideological position of universal healthcare to one of targeted provision fitted with a second ideological position of the provision of greater consumer choice in health services. These two factors supported the growth of a private medical network developing alongside the public health service (R. A. Kearns & Joseph, 1997).

The justification for radical changes to the provision of health services included: long waiting times that caused dissatisfaction with public hospital services; the growing use of private health care, which had no waiting lists; and community groups, influenced by societal changes that redefined the public as consumers, and supported by government, pursued an objective of increasing choice and competition in the health sector by providing specialist services. These changes marked the development of health consumerism. Primary care subsidies under the GSM benefits had also failed to keep up with inflation, and increasing inequalities in

access to both primary care services through ability to pay, and hospital services, which were (in)effectively managed through waiting lists were increasingly apparent. The aims of the health reforms over time have been to improve health outcomes, achieve the potentially conflicting objectives of reducing the escalation of expenditure and increasing efficiency and accountability, and also to decentralise health care (Quin, 2009). Two notable failings, in the context of these changes were the inadequate provisions to ensure equitable access between groups with different levels of financial capital, and the associated increase in private provision of secondary care and allied health services; resulting in increasing area differences in levels of provision. Rural areas were particularly badly affected with hospital closures (R. A. Kearns & Joseph, 1997).

ACCESS AS USE: THE BEHAVIOURAL MODEL OF HEALTH

The MoH definitions of access implicitly draw on patient-mediated barriers in their definition of access. The most frequently used approach to inquiring about patient-mediated barriers is the Behavioural Model of Health (BMH) developed in the 1960s (Aday & Andersen, 1974). Another often-used tool to evaluate access to health services is the set of parameters defined by Pechansky and Thomas to measure the fit between a health service and healthcare user and evaluated in terms of customer satisfaction (Pechansky & Thomas, 1981). These approaches are briefly summarised below.

'Access as use' is the concept behind the BMH that was originally conceptualised, in the 1960s (Figure 3), to consider people's use of medical services. It has been one of the most widely used frameworks for investigating the utilisation of health services by specified groups as a measure of access and is used interchangeably as a model and a framework (Aday & Awe, 1997; Gulliford, et al., 2002; Ricketts & Goldsmith, 2009). The model proposed the utilisation of a medical service as a function of the need for health care, the predisposition to use the service, and factors that facilitate or obstruct use. Predisposing characteristics were biologic (affecting medical need) and demographic characteristics, and the status of the individual within the social structure (Andersen, 1995). A recent systemic review of studies using the BMH found that only a small number of variables were commonly used to evaluate access

barriers, and a variety of iterations of the model were adopted to fit different study settings. Predisposing factors were generally defined as age, gender/sex, education, and ethnicity, with enabling variables most often income/financial situation, health insurance, and having a usual source of care/family doctor. These factors did not sit neatly in one category or another, variously interpreted as proxies for predisposing, enabling or need factors (Babitsch, Gohl, & von Lengerke, 2012).

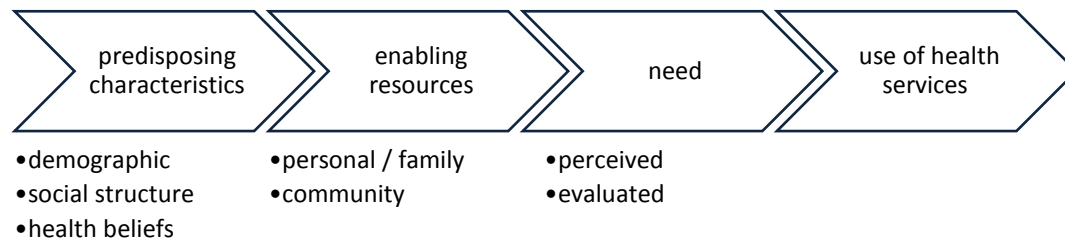


Figure 3: The Behavioural Model of Health (1968)

Source: Adapted from (Aday & Andersen, 1974)

The early BMH focused almost entirely on patient characteristics, although Andersen believed that the more contextual factors which link attitudes and behaviours to the local setting were implied in the social structure component of the model (Andersen, 1995). Later revisions by Andersen and others attempted to address early criticism and explicitly incorporate environmental and provider-related variables that affect the relationship between patient and provider. Although the authors attempted to incorporate an acknowledgement of factors outside an individual's control that might impede the utilisation of health care, an analysis of the use of the model for explaining contextual variables, explicitly defined as *provider-related* and *environmental* factors, found that half of the studies used one of these variables, with only 14 percent interpreted predisposing characteristics as including both of these contextual variables (Aday, Andersen, Morrison, & Phillips, 1998). The revised (Phase 4) model, although acknowledging feedback loops rather than being composed of an entirely linear approach, did not go as far as predicting the health care system will respond to signals from the patient (Figure 4) (Aday, et al., 1998; Ricketts & Goldsmith, 2009).

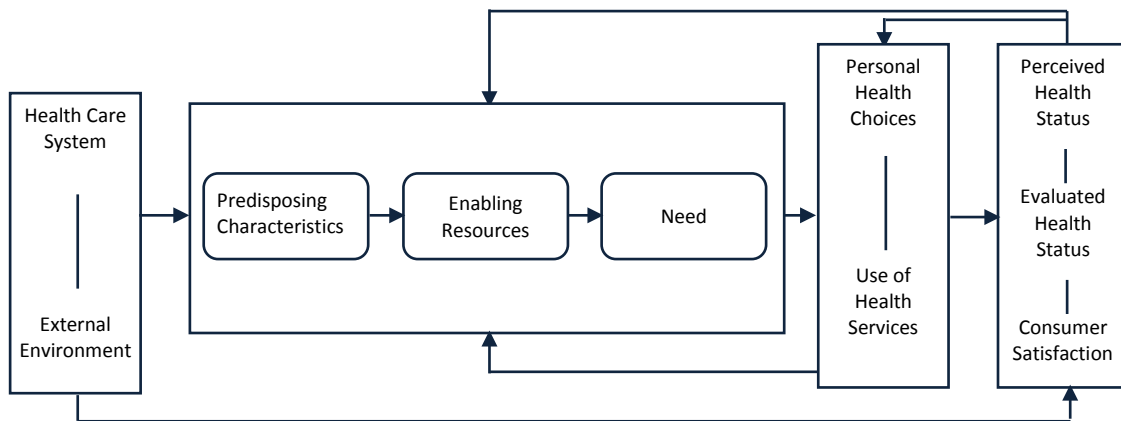


Figure 4: Behavioural Model of health services (Phase 4).

Adapted from Andersen's Behavioural Model (1995)

Source: (Ricketts & Goldsmith, 2009, p275)

Despite the incorporation of more contextual variables, Anderson's work has required adaptation to enable it to be used to model access to services for specific populations, for example a study of access to facilities for the homeless re-interpreted the model to include cultural characteristics (Gelberg, Andersen, & Leake, 2000), one of several important to predisposing or enabling categories (Babitsch, et al., 2012). However, a recent review of studies has shown that the BMH is still most commonly used with only a subset of the variables that may affect access to healthcare services, with these generally being compositional characteristics of the population being studied. The cross-over of variables into multiple factors – need, predisposing and enabling factors is an example of the complexity of access-related barriers and the difficulties in categorising patients by these variables (Babitsch, et al., 2012).

A strength of the BMH is that it explicitly acknowledges perceived or actual need. How a person may perceive their health needs and the response of the actors in the health system, their trust in the medical profession and the assessment of potential benefits of any treatment may define how they will begin their health journey. Knowledge of why a person might use, or delay entry into the healthcare system may provide a greater understanding of the factors identified in access models whereas a focus on the provision of services and satisfaction with care may not (Ricketts & Goldsmith, 2009).

CUSTOMER SATISFACTION

The second consumer-focussed framework considered for this study was the Penchansky and Thomas framework that conceptualised access as a 'fit' between an individual's needs and the health service, with the degree of fit being influenced by the affordability, acceptability and accommodation of the service along with the availability and accessibility of the service (McLaughlin & Wyszewianski, 2002). This taxonomy (Table 2) was derived from measures in previously published studies of access to healthcare. It was then tested for relevance by examining satisfaction with access to physicians for the spouses of employees of a General Motors assembly plant in Rochester, New York. The focus of the study was consumer expectations of, and satisfaction with the health service (Penchansky & Thomas, 1981). Their concept reflects a less specific approach than the BMH but the dimensions are more defined, with less ambiguity about the impact of each dimension in presenting access barriers (Penchansky & Thomas, 1981). Despite the broad concept of access the Penchansky and Thomas taxonomy provides a possibly narrower option for understanding barriers to healthcare. The taxonomy formally recognised the supply of health care and an active role of the provider in the facilitation of access. The authors describe their taxonomy as conceptually similar to Andersen's enabling factors, with the utilisation of services, client satisfaction and provider practice specifically noted as measurable components of access (Penchansky & Thomas, 1981).

Table 2: Dimensions of access

Enabling Variables	Description	Explanation
Availability	The relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs.	Availability refers to the adequacy of the supply of health care providers, facilities and specialised programmes and services.
Accessibility	The relationship between the location of supply and the location of clients.	Accessibility includes access to transportation, distance to the service and the cost of transport.
Accommodation	The relationship between the manner in which the supply resources are organized to accept clients and the clients' ability to accommodate to these factors and the clients' perception of	Accommodation includes administrative functions e.g. appointment systems, hours of operation, walk-in facilities, telephone services.

Enabling Variables	Description	Explanation
	their appropriateness.	
Affordability	The relationship of prices of services to the clients' income, ability to pay, and existing health insurance.	The client perception of the worth of the service relative to total cost; the knowledge of prices, availability of medical insurance, total cost and possible credit arrangements.
Acceptability	The relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients.	Acceptability refers to specific consumer reaction to such provider attributes as age, sex, ethnicity, the type of facility, the neighbourhood of the facility, or the affiliation of facility or provider. It also refers to providers' attitudes about attributes of clients.

Source: (Penchansky & Thomas, 1981)

Meeting the needs of vulnerable groups is extremely important in identifying barriers to rheumatology care, however from the literature review socio-economic disadvantage, age and other characteristics usually associated with population health vulnerabilities are not clearly the main reasons for delays in seeking care for MSk disorders, and patients' perceptions of their symptoms are recognised as equally important to investigate. There is little documented work on who delays consultation for MSk symptoms and who goes on to have problems with treatment and referral delays. The decision to adopt an integrated framework recognised that working solely within a consumer model had limitations by minimising the impact of the structural factors that impact on healthcare decision-making. How an individual perceives and experiences symptoms, and the effect of these personal constructions are an integral part of this study, and suggested very early on in the process an approach that was oriented toward the consumption of health care, without ignoring the structure of the health system and the context of the lived experience.

TOWARDS AN INTEGRATED FRAMEWORK

The present study focuses on the experience of barriers to accessing rheumatology care rather relying on the compositional characteristics of patients as an explanation for access barriers. Where the utilisation of healthcare models begin with a perceived or actual need, this study intended to capture the process that led to the perception of need and to move with the individual to the outcome of their diagnosis

at a rheumatology service. The BMH and Fit models adequately identify barriers for compositional characteristics of groups of people, but are not sufficient to understand the social and cultural resources that led to the perception of need, the complex interactions between patients and health practitioners, or why people with IA symptoms delay their care, experienced access barriers, and what may have occurred to overcome them.

A framework that incorporates health outcomes, rather than focussing on utilisation or customer satisfaction would incorporate the patient journey from symptom onset through barriers such as delayed referrals, waiting times and other organisational or health policy factors that may affect the patient, up to and including the experience of poor clinical outcomes (Gulliford, et al., 2002). Ricketts and Goldsmith (2009) see a need for a “unified field” that the BMH and fit models do not present. The dynamic nature of patient decision-making about the need for healthcare, which providers to use, the provision and integration of health services and social justice are considerations that also need to be incorporated to enable a more comprehensive picture of access barriers to be revealed (Rom, et al., 2007b).

RECONCEPTUALISING ACCESS AS CANDIDACY

The investigators charged with reviewing the substantial body of literature concerning *vulnerable groups and access to healthcare* for the National Coordinating Centre for NHS Service Delivery and Organisation R & D, developed a ‘critical interpretive synthesis’ as a means of identifying groups at risk of poor access to health services (Dixon Woods, et al., 2005). This process led to the reviewers reinterpreting access to healthcare as an issue of *Candidacy*. They described Candidacy as a dynamic process contingent on the negotiation of eligibility for health services between the individual and the health service. Candidacy is constructed and constantly renegotiated through the actions and reactions of the individual and health professionals. Candidacy recognises the social structure of people’s lives, their priorities and competencies, through which they perceive health needs and health services. Candidacy operates in specific local contexts that provide several areas that must be reconciled to ensure an individual can negotiate barriers to their health needs and realise access to appropriate health services.

CANDIDACY

The Candidacy approach is designed to recognise where an individual may be vulnerable in their health care journey (Figure 5) In this alternative approach, access is reconstructed as candidacy; envisaged as an eligibility for health services that is negotiated and renegotiated between an individual and a health service. Access is a representation of the dynamic interplay between the simultaneous, iterative and mutually reinforcing processes arising from people and their social contexts on the one hand, and from macro-level influences on the allocation and configuration of resources on the other. The process to successful candidacy which individuals and their medical practitioners must negotiate (Dixon Woods, Cavers, et al., 2006; Dixon Woods, et al., 2005) is summarised below.

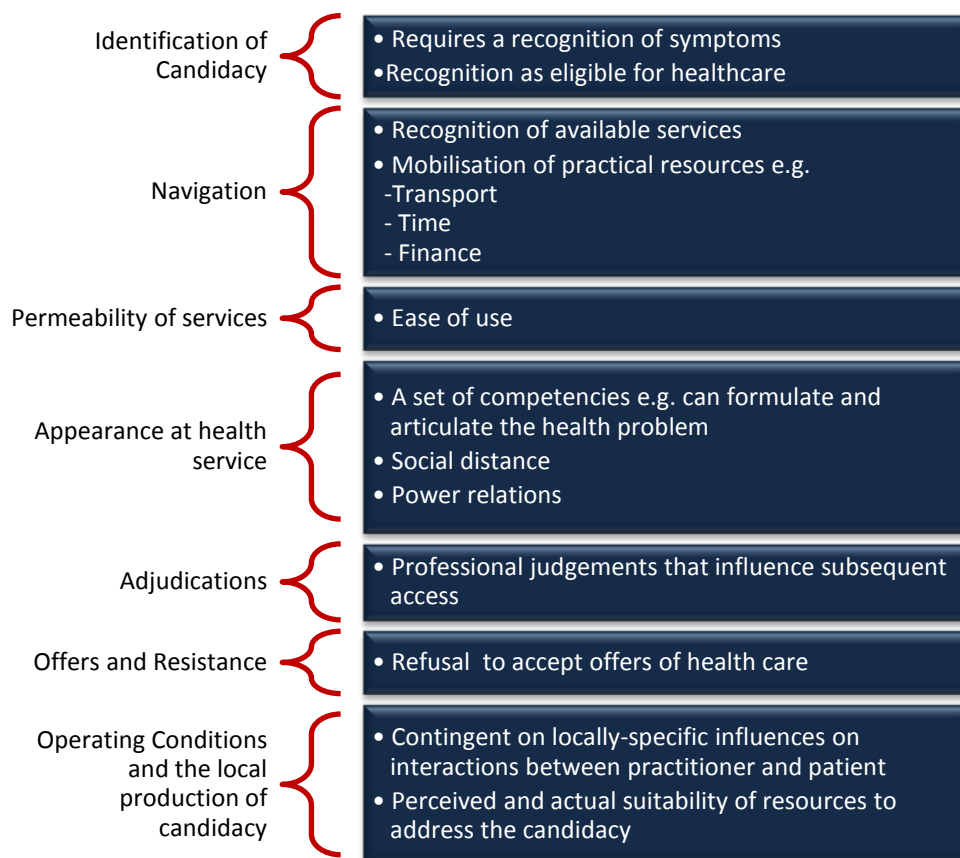


Figure 5: A theoretical conceptualisation of healthcare access: The construct of Candidacy

Derived from (Dixon Woods, Cavers, et al., 2006)

IDENTIFICATION OF CANDIDACY

Individuals must be able to recognise they have a requirement for some kind of medical consultation. How symptoms are interpreted and previous beliefs about how to manage them may impact on the perception of need. Recognition of need enables individuals to begin help-seeking activities that are reliant on the possession of various resources (for example financial resources, social networks) and also recognition that they are eligible for health services. Perceptions of shortages of health system resources and operational priorities may lead some people, for example the elderly, to self-ration and avoid identifying themselves as candidates.

NAVIGATION

Factors that affect navigation are often reflected in missed appointments as well as delays in referral. The individual's opportunity to mobilise resources commonly involves access to public transport and the financial and social resources to make arrangements to attend appointments. An often unrecognised barrier to navigation of services is time. Time requires negotiation with family, social networks and employers to enable appearance at a health service.

PERMEABILITY OF SERVICES

Individuals are often more comfortable with a 'home' GP, where good relationship with medical and administrative staff can encourage use and facilitate a fuller disclosure of symptoms at a more opportune time. Continuity of care under a GP and between specialist appointments reduces the difficulties of access to care in a timely manner, particularly for individuals with complex needs.

PRESENTATION AT HEALTH SERVICES

Individuals are required to formulate their problems in a readily understandable manner. Older people and those with language or cultural differences may struggle to articulate their concerns to a health professional, have a poorer understanding of the advice given to them, be less willing to choose between health options and, associated with this, be more passive making it difficult to build relationship based on shared management of a health problem.

Social distance and power relationships also appear when a person is categorised by social and cultural stereotypes. Stereotypes and expectations of negative behaviours or outcomes can lead to incorrect evaluations of symptoms and differences in treatment and referral options.

ADJUDICATIONS

Recognition that a medical intervention is required must be made before an adjudication about treatment or referral can be processed. Judgements about the conversion of an intervention (from technical candidacy into an offer of an intervention) into a cost-effective health benefit may be compromised by patient characteristics, such as age, or worries about scarce health resources. Health policy or budgetary constraints may be unavoidable for medical practitioners, resulting in rationing of resources based on factors other than clinical need for an intervention to improve well-being.

OFFERS AND RESISTANCE

A decision about the offer of treatment that can improve medical outcome may be balanced against a possible conservative approach that is consistent with expectations of wellness that an individual requiring care has. However, there may be little clarity about whether an offer was given and refused, or if the offer was never given because the medical practitioner had made a decision to withhold an offer based on presumed knowledge of the patient preferences.

OPERATING CONDITIONS

The production of health services can affect the recognition and adjudications of candidacy. An undersupply of services limits capacity and influences the operating conditions in which health professionals work and communicate with patients. The context of the conditions in which decisions are made includes the history of relationships between staff and patients, how medical professionals categorise both disease and people who consult them, the availability of health resources, local conditions and policy imperatives. It is clear that if this reconceptualisation of access is to be tested a framework for studying access requires broader dimensions than the BMH or the Fit Model. In investigating a credible approach I selected the

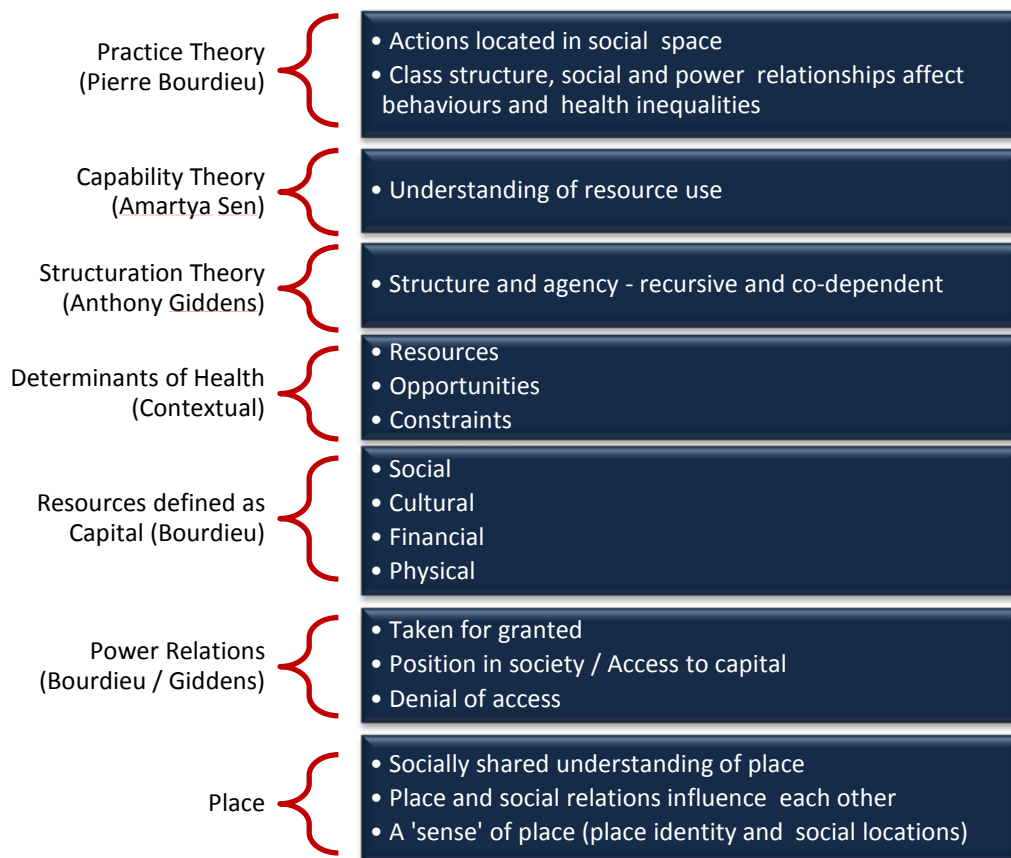
Collective Lifestyles Framework, incorporating Bourdieu's Theory of Practice (Frohlich, et al., 2001) to evaluate the construction of candidacy and interpret access to rheumatology care for people with IA; from their growing perception of a need for medical advice through to the acceptance of a DMARD regimen as the best practice conventional treatment for suppressing their disease.

COLLECTIVE LIFESTYLES

The Collective Lifestyles framework was developed to counter the problem that lifestyle is discussed within the socio-medical discourse as a reference to individual behavioural patterns that affect disease status. These patterns, most often cast as habits or behaviours, are measured discretely and studied independently of the social context. Individual practices are therefore viewed in ways that are devoid of social meaning and systemic influences, with the individual cast as ultimately responsible for negative behaviours (Frohlich, et al., 2001). The Collective Lifestyles approach to studying the relationship between context and health practices aims to provide a dynamic understanding of how context influences the rates and distributions of illness. It argues that inequalities in health outcomes are shaped by context of the decision-making and this must be incorporated in research to comprehend the complex relationships of risk factors in social groups, why these risk factors exist, and how they are interrelated. Moreover, the approach seeks to reconcile 'space' and 'place' within the notion of context because "both the attributes of people and the resources in space will impinge of the social relations and practices found in place" (Frohlich, et al., 2001, p. 783). This framework provides a theoretical position to understand the interactions between individuals and the structure of the system they are attempting to enter to meet their health needs, through incorporating the work of Anthony Giddens and Pierre Bourdieu. Bourdieu has a somewhat objectivist approach to the interaction of structures and individuals and presents these aspects from a consumerist point of view, rather than the more traditional production-centred analysis that typifies Marxist approaches to access and ownership of resources. The Collective Lifestyles approach envisions lifestyles as patterns and ways of living (behaviours), and as interactions with cultural, social and psycho-social factors (Frohlich, et al., 2001). Pierre Bourdieu's (1977) *Theory of*

Practice was utilised to conceptualise the notion of Collective Lifestyles because it “attempts to understand people's actions by locating the point of reference in social practice from which the beliefs or actions emerge”. It formulates practices as emerging from structure, reproducing structure, but also capable of transforming structure (Bourdieu, 1977; Frohlich, et al., 2001, p. 784). The Collective Lifestyles approach has also drawn on *Capability Theory*, the work of Amartya Sen (1997) to emphasise an understanding of resource use before a judgement is made about whether resources are providing the expected outcomes, and Antony Giddens’ (1984) *Structuration Theory* that envisages a relationship between agency and structure where social structures and people’s practices have a recursive relationship, as both mediums and outcomes of social practices. Key concepts are summarised in Figure 6.

Figure 6: Key theorists and constructs of a Collective Lifestyles framework



Derived from: (Dixon Woods, Williams, et al., 2006; Frohlich, et al., 2001; Gatrell, Popay, & Thomas, 2004; Poland et al., 2006; G. H. Williams, 2003)

PRACTICE THEORY

Practice theory envisages people as agents who have the ability, within the bounds of the social structures they live within, to deploy a range of causal powers that can make and transform their world. People's actions (behaviours) are "part and parcel of the routinised, practical logic of daily life" (S. J. Williams, 1995, p. 785). The actions they take are recursive – both a medium as well as an outcome of social practices. In other words, as well as operating within structural constraints, individuals are also constantly re-creating the conditions that make that structure possible. It was Bourdieu's contention that people adapt to their environment rather than consciously interact with it. Although they can engage actively to change social structures they were likely to be constrained by their social positions and access to capital (Frohlich, et al., 2001).

Lifestyle, within a socio-medical discourse, is conceptualised individual behaviours or habits that are the responsibility of the individual, with systemic influences, socio-cultural context or social meaning absent from the discussion. Practice theory considers lifestyle a collective attribute, as actors (re)produce social structure, relative to the power relations they encounter, through their practices. Collective Lifestyles, then becomes "the relationship between people's social conditions and their social practices" rather than "the behaviours people engage in," and infers that there may be similar influences on people in similar contexts (rather than people following the same patterns of behaviour due to similar compositional characteristics, for example age, ethnicity and gender) who express these influences in in similar ways (Frohlich, et al., 2001, p. 785).

CAPITAL

Bourdieu theorised four main categories of capital – economic, cultural (education, social background and cultural tastes from personal and parental educational experiences), social (relationships with others) and symbolic (prestige and status). He also theorised the body as a form of capital, which he at times referred to specifically as physical capital. In this he implied capital and social status are embodied. In other words, an individual's capital and social status are inscribed on an individual's stature, gait and other forms of physical projection (Gatrell, et al., 2004; Veenstra, 2007; S. J. Williams, 1995). In terms of having capital to engage with structural entities, three dimensions were important; the

total volume of capital, the relative composition of economic and cultural capital and changes in these dimensions over time (social trajectory). Bourdieu believed cultural capital and economic capital are the basic principles of distinction and define social space more than other forms of capital (Veenstra, 2007).

POWER

Social engagement and inequalities are operationalised within power relationships. Political, economic and institutional power can affect life chances and influence responses to social problems. Bourdieu called these power relationships that result in negative outcomes *symbolic violence*. In these power relationships people occupy positions in social space with conflicting aims of changing or preserving those positions. The struggle to gain or retain position can threaten those with different capital – whereby people are denied access to resources, without necessarily being aware of the fact, by those with greater capital, while those with more capital may fear risking their status or position of power (Gatrell, et al., 2004).

CAPABILITY THEORY

A Collective Lifestyles framework uses Sen's Capability Theory (Sen, 1997) to model distributive justice in terms of the utility extracted from goods rather than the utility of the goods themselves. The theory focuses on the particular needs and abilities of people and how they can extract resources. The capability of a person is a reflection of their state of being, of how their needs have been met, whether the needs are as fundamental as nutrition or more abstract needs like self-esteem. Capability is a combination of these needs and what a person feels s/he is capable of attaining (Frohlich, et al., 2001).

STRUCTURATION

Only a part of the concept of Giddens' Structuration theory is utilised in the Collective Lifestyles approach. It provides the linkage between the structural constraints people encounter and the individual's agency. Giddens theorised individuals as less constrained by social structures than Bourdieu, and that individuals have the opportunity to change structure in the choices they make and have room to change social behaviour. This relationship between individuals and structures envisages more choice in individual action whereas Bourdieu's Practice

theory considers individuals to be more constrained by life chances. Both theorists, however, accept that agency or structure may be dominant in certain situations (Frohlich, et al., 2001).

DETERMINANTS OF HEALTH

Rather than teasing out the compositional characteristics, or attributes of an individual or space, that may affect health outcomes, the Collective Lifestyles framework aims to determine how these compositional characteristics and the contextual effects of place might be “mutually reinforcing and jointly influence health outcomes.” The determinants of health therefore, include the resources, constraints and opportunities that people encounter in their health journey, rather than these being defined by the socio-economic characteristics of the individual or population (Frohlich, et al., 2001; Frohlich, Ross, & Richmond, 2006).

PLACE

Collective lifestyles envisages practices and social and economic relations that cohere within areas, and people influence places through these social practices, just as place itself influences what people do. As well as there being variable distributions of populations whose individual characteristics influence health (for example Māori are more likely to experience diabetes than Pākehā/Europeans and Māori are more concentrated in Porirua neighbourhoods), people’s health experiences may also be dependent on the attributes of the area within which they live, work and have social or cultural relationships (for example, environmental qualities or the distribution of resources).

People in certain places may also have distinct cultural or social practices that are typical of a place and affect health values. For example countries with a colonial heritage of clearing land for farming may harbour cultural values in remote rural areas, a collective ‘rugged individualism,’ that is an expression of self-reliance, independence and physical strength that affects the perception of need for healthcare and coping strategies when in poor health (Dunahoo, Hobfoll, Monnier, Hulsizer, & Johnson, 1998; Judd et al., 2006). Additionally, there is convincing evidence that place can lead to inequalities in health outcomes through area

deprivation. For example a person of high socio-economic status who lives in a deprived neighbourhood is likely to have worse health outcomes than a person of similar socio-economic status living in a resource-rich neighbourhood (Dixon Woods, Cavers, et al., 2006; Frohlich, et al., 2006).

DISCUSSION

The MoH definition of access is based on accounting for the barriers that potentially restrict a patient from entering the health system and measuring access in terms of the utilisation of health services. A broader definition, and one that reflects the objectives of this study, is “the timely use of personal health services to achieve the best possible outcome” (M. Millman, 1993, p. 4). This phrasing was carefully chosen by the American Institute of Medicine committee on monitoring access to personal health services to reflect both the utilisation of health services and health outcomes in achieving access. Furthermore the committee emphasises a test of equity that determines whether there are systematic differences in society in the utilisation and outcomes from health services and whether these differences result from barriers to care (M. Millman, 1993). It is not so much the study of access that renders the frameworks incomplete, but the assumptions about where barriers lie. Monitoring access does not lead to an understanding about barriers.

These factors are quantifiable and either the BMH or the Penchansky and Thomas framework are clearly suitable for quantifying health system performance in facilitating realised access, spatial and financial accessibility and for identifying patient characteristics which are commonly correlated with low levels of access to health services. For example Penchansky and Thomas’s framework has been considered useful in New Zealand to understand Pacific Peoples and other underserved groups access to health services (Young, 1997); to evaluate programmes to reduce inequalities to health care (CBG Health Research Limited); and inform a study measuring spatial access to primary care (Bagheri, Holt, & Benwell, 2009). The BMH, on the other hand, incorporates perceived and actual health needs, as well as the resources at a patient’s disposal in barriers to health care, but lacks contextual information about how these factors are shaped by, for

example, a person's position in society, the culture of place that may affect health behaviours and practices.

The BMH and Fit models are insufficient tools for assessing the multiple dimensions of access from a patient perspective. Health needs, utilisation and consumer satisfaction are all important measures to provide data about access problems, but they may also mislead, for example, by equating high utilisation with high quality health services, or customer satisfaction with appropriate health care services (Gulliford, et al., 2002). The conceptualisation of the healthcare system as entities that are detached from the people they serve reduces the level of assessment to the attitudes and behaviours of the patient, devoid of context and mutual interaction between the actors in accessing care.

Frameworks that focus on utilisation of health services fall short of fully understanding the problem of non-use or delayed access by not incorporating the system of care (e.g. health policy), the quality of health organisation, the role of gate-keeper processes to control eligibility to services, or how individuals interact with their environment, both before and after the decision to seek care. The utilisation framework ascribes non-use to individual or community characteristics, prompting critics to the inference that barriers to be overcome are community rather than organisational problems (Ricketts, 2009; Ricketts & Goldsmith, 2009). It is also argued that customer satisfaction does not always reflect good quality of health services. A poor quality health service, or a service that provides ineffective but popular treatments, may require the patient to access it more frequently to get the best outcome, whereas a good quality service may produce a more desirable health outcome due to more appropriate care, leading to a lower requirement for access (Dixon Woods, et al., 2005; Gulliford, et al., 2002). Gulliford and colleagues also raise the issue of fairness, or social justice in their appraisal of access to healthcare. Horizontal equity, which requires similar access for groups with equivalent needs, is undetected in utilisation outcomes, but more often noted in studies that focus on service availability and health outcomes.

Vertical equity, where groups with varying needs have services that are available and appropriately differentiated with consideration to their own priorities and

values, remains difficult to characterise and assess regardless of how access is defined and measured (Gulliford, et al., 2002). The validity and reliability of using utilisation of health services as a measure of inequality of access has been raised on the grounds that identifying patients with poor access is difficult because utilisation frameworks make normative assumptions about the reference, or comparative, group that can lead to a failure to identify this group's own access problems. There is also a belief that utilisation studies, in reducing measurements to compositional characteristics of the population and segregating components of access, have created logistical and practical problems in measuring access, especially because receipt of health care is an outcome of a number of complex interactive processes that all need to be acknowledged if the concept of access is to be rightly addressed (Dixon Woods, Cavers, et al., 2006).

Andersen has argued that enabling and predisposing factors of the BMH model are broad enough to incorporate the context of patient decision-making and actions in seeking healthcare (Andersen, 1995), and both he and Penchansky were wary of providing so many variables that access becomes impossible to measure (Penchansky & Thomas, 1981). Advocates of a Collective Lifestyles approach argue that part of the problem is that accepting 'classic' methods of studying health outcomes as characteristics of the individual (or aggregated as attributes of a population) are inappropriate for the study of context. Instead they advocate the study of the situated relationship between agency, social and cultural practice and social structure as a more appropriate framework for studying the relationship between context and health outcomes (Frohlich, et al., 2001).

Researchers of context aim to move away from the individualisation of risk that views health status purely as a result of individual choice and as being dissociated from its social context (Frohlich, et al., 2001). They highlight the role of macro-level variables; the social, material, environmental and political characteristics of the areas in which people live, which influence health behaviours and determine health outcomes (Gatrell, et al., 2004). A strength of the Collective Lifestyles approach is that it can provide a greater understanding of the health and lived experiences of people who have similar social, economic and demographic characteristics, but who are drawn from neighbourhoods that both published research and personal

experience suggest would lead to different outcomes (Gatrell, et al., 2004). This is important for individuals with the onset of symptoms are suggestive of an IA, within a regional health care network where there appears to be few obvious reasons for the variations in the time it takes from symptom onset to the provision of appropriate rheumatological care.

A Collective Lifestyles approach accepts Bourdieu's emphasis on the broader structural determinants and constraints on perceived choice (S. J. Williams, 1995). His model of questioning the relationships between structures and practices of the representations which accompany them is a model for giving voice to the 'other' (Cresswell, 2002). Bourdieu's focus includes the wider social patterns and structures of social life which includes the relationship between structure and agency, beliefs and behaviour, accounts and action, class and lifestyles. In combination, these constructs may help explain the health beliefs and attitudes about health practices (S. J. Williams, 1995). Bourdieu's sensitivity to agency is an important factor in considering his approach for this research. The approach can be adapted and updated to reflect current research trends and methodological approaches without losing the essence of creating a relationship between structure and agency. This is in evidence through a number of health geographers who have used aspects of his approach in their work. Among them are Christina Ergler who uses Bourdieu's *Theory of Practice* to explain children's loss of autonomous play and variations in parental beliefs about unsupervised play across locations and seasons (Ergler, Kearns, & Witten, 2013). Bourdieu's work is also central to Anthony Gatrell and Carol Thomas who, working with sociologist Jennie Popay, attempt to understand health variations in place (Gatrell, et al., 2004) and explore lay understandings of inequalities in health (Popay et al., 2003). Poland and colleagues included Bourdieu in their work to define a culture of place and how this matters in technological and power-focussed health care (Poland, Lehoux, Holmes, & Andrews, 2005).

A broad concept of access in terms of health outcomes instead of potential access, utilisation or satisfaction with health services considers how an individual's resources and constraints can affect acceptance or non-acceptance of the use of a health service. Gathering information about differences in perceptions of symptoms

and referral experiences was the focus of the study, and IA prevalence does not appear to have a strong social or ethnic gradient. For these reasons a model of access was selected that explicitly incorporated the local health structure and policy health settings; the interactions and power relationships between the medical professional and the patient; the perceptions and experiences of the individual; and contextual framing of the patient journey. However the importance of the political setting to the chances people have of accessing appropriate health care is acknowledged. Reconceptualising access as Candidacy allows for a unified field that considers access in terms of a negotiation, both of resources and between an individual and health services. The interaction of people with the place in which they live is an intrinsic part of the Collective Lifestyles approach. The approach aims to recognise common relationships between social conditions and social structures which influence health. The framework enables analysis, from the patients' perspectives, of the complex relationships of risk factors in social groups; why these risk factors exist, and how they are interrelated. It also provides a means to assess the structural positioning within society that leads to asymmetrical power relationships that affect health outcomes. (Frohlich, et al., 2001). These factors are shown in the evaluation of participant narratives in the following chapters to be important precursors to the interpretations of IA symptoms, and the interweaving power relationships that drive the process of access to rheumatology care.

7. METHODOLOGY

INTRODUCTION

The main objective of this study is to understand why patients on their journey to treatment for IA might encounter delays to accessing rheumatology care. There are various methodologies that could increase our knowledge of the barriers patients encounter, but few that would explain these barriers from the patient's point of view. Given the lack of previously published data in New Zealand settings, and the variation in observations detailed in international studies, interviews with key participants in the onset to referral process seemed crucial for the integrity of the study. Findings drawn from the international literature, outlined in the previous chapter, also suggest that the decision-making process for both GPs and patients is not consistent and that the contextual variables affecting access to rheumatology services are not yet well understood. Different social, cultural and health beliefs make the search to explain delays in accessing rheumatology services for individuals with IA difficult to transfer from one healthcare setting to another.

In their *Collective Lifestyles* framework, Frohlich and colleagues (2001) advocated the development of explanations of health behaviours that went beyond identifying behaviours associated with group characteristics like age, ethnicity and income, and which seek to emphasise a range of data for studying the relationship between context and disease. Guidance in methodology was sought in the work of Bourdieu, whose emphasis on a *methodological reflexivity* is thoroughly described by Fries (2009) in the context of health behaviours research. Bourdieu considered that all techniques that were usable, relevant and possible within the limitations of study and data collection should be engaged (Fries, 2009).

Bourdieu readily used qualitative methods in his early ethnographic studies and then moved to more quantitative evaluations, gathering as much information around the subject of the study as he could find. His last work, *Weight of the World* sought to interpret participants' experience of globalisation for the French working class through interviews (Bourdieu, 1999; Cresswell, 2002). An analysis of Bourdieu's work suggests that a firm commitment to his methods would require empirical

analysis which encompasses exploratory statistical data and analysis of narratives offered by the people whose actions are the focus of the study.(Gatrell, et al., 2004).

This study takes a pluralistic approach to data collection and analysis by collecting administrative data about referrals to rheumatology services in the region, and incorporating both qualitative and quantitative methods of data analysis. This situates the patient response to symptoms within the place they live and the structure and administration of rheumatology services in the region. An advantage of using both qualitative and quantitative data sources in the research design is that it broadens the study by combining different methods, data sources and types of data to answer different research questions (Creswell, Plano Clark, Gutmann, & Hanson, 2003; Patton, 2002).

A hermeneutic perspective was incorporated into the methodology for the interpretation of participant data. This perspective takes into account the conditions surrounding the problem that is the focus of the study and poses questions about how to interpret the meaning of the participant's action in terms of this contextual framing (Patton, 2002). In this approach the data is interpreted as fully as possible by examining the text in parts, and then re-interpreting how the text in its entirety signifies the parts. This *Hermeneutic Circle* constructs the reality of the participants, within the framing of the researcher's own background or perspective. The researcher's position in terms of practical knowledge must therefore be made explicit. A practical "everyday participatory" understanding of the topic in question is the starting place of the hermeneutic circle. There the aim of this method is not a definitive answer, but a process whereby discussion is kept open with increasingly sure foundations (Patton, 2002). In this approach each of the participants represents a particular aspect of the patient journey that is complete on its own. The representativeness of patient beliefs, perspectives and social conditions can be used to study experience. Individual characteristics are put to one side in favour of the individual account that can establish an explanation of process, actions and outcome (Bourdieu, 1999; Hamel, 1997).

The purpose of this chapter is to set out the research design and provide a description of the data collection and interview selection process. It ends with an explanation of the statistical and qualitative procedures used to analyse and understand the data.

RESEARCH METHODS

This research makes use of mixed method for data collection and analysis. Mixed methods research developed from the recognition that both quantitative and qualitative methods have strengths that can be integrated to increase the validity of a study (Creswell, et al., 2003; Curtis, Gesler, Smith, & Washburn, 2000). Given the exploratory nature of the research, the focus of the study method is qualitative research. The Candidacy model and Collective Lifestyles framework are based on the context of people's movement through health settings and the context of decision-making. The study would not have fulfilled the objective of examining the contextual setting of the patient experience if descriptive data about the places people lived and the exploration of numerical data from administrative databases were not examined measuring the importance of phenomena that were known to affect access. Numerical data collection and quantitative data analysis allow the strength of an association to be examined and to determine how a phenomenon may impact in different places, or on different demographic groups (Creswell, et al., 2003). A strength of qualitative methods is that data collection, analysis and sampling can be useful in identifying the factors that may explain why a phenomenon occurs and what the impact might be on people in different places or, for example, on demographic groups. The process of data collection and analysis is also adaptable to the input of new information because an iterative process is used. To understand the patient journey it is more important to capture the diversity of the explanations about barriers to accessing appropriate care, rather than to secure a statistically representative sample of participants (Bolam, et al., 2004). This study utilises mixed methods to provide a more thorough explanation of the patient experience (Burke Johnson, Onwuegbuzie, & Turner, 2007). The decision to use multiple data sources and analytical methods fits with the concept of a Collective Lifestyles framework that examines *why* there is variance in patient access rather than relying on which groups are implicated in variance in terms of behaviours at the level of aggregated patient characteristics (Frohlich, 2000).

Quantitative approaches can be used to model and test hypotheses, provide accurate measurements that highlight the significance of a variable, group comparisons and the strength of association between variables. Qualitative approaches can provide detailed accounts of experience that are embedded in the places people live and in the context of their social and cultural worlds (Castro, et al., 2012). Qualitative data was used to capture the diversity of experience and provide detailed accounts of experiences to illuminate issues around perceived behaviours, and to deliver “an in-depth analysis of complex human, family systems, and cultural experiences in a manner that cannot be fully captured with measurement scales and multivariate models” (Castro, et al., 2012, p. 343). Additional statistical data were used to establish referrals patterns and to quantify significant referrals variations. Secondary place-specific data were incorporated to contextualise the patient experience and situate rheumatology services within the variations of the region it serves.

Given the exploratory nature of this research, the emphasis of the study method is qualitative. However the study objective of examining the contextual setting of the patient experience required both descriptive data about the places people lived and exploration of numerical data from administrative databases to investigate the importance of phenomena that are known to affect access. The qualitative and quantitative analyses are set within the Candidacy model and Collective Lifestyles framework as these consider the context of people’s movement through health settings and the background of decision-making, and provide a powerful means of pinpointing and visualising choke points in access (Figure 7) and giving reasons for them.

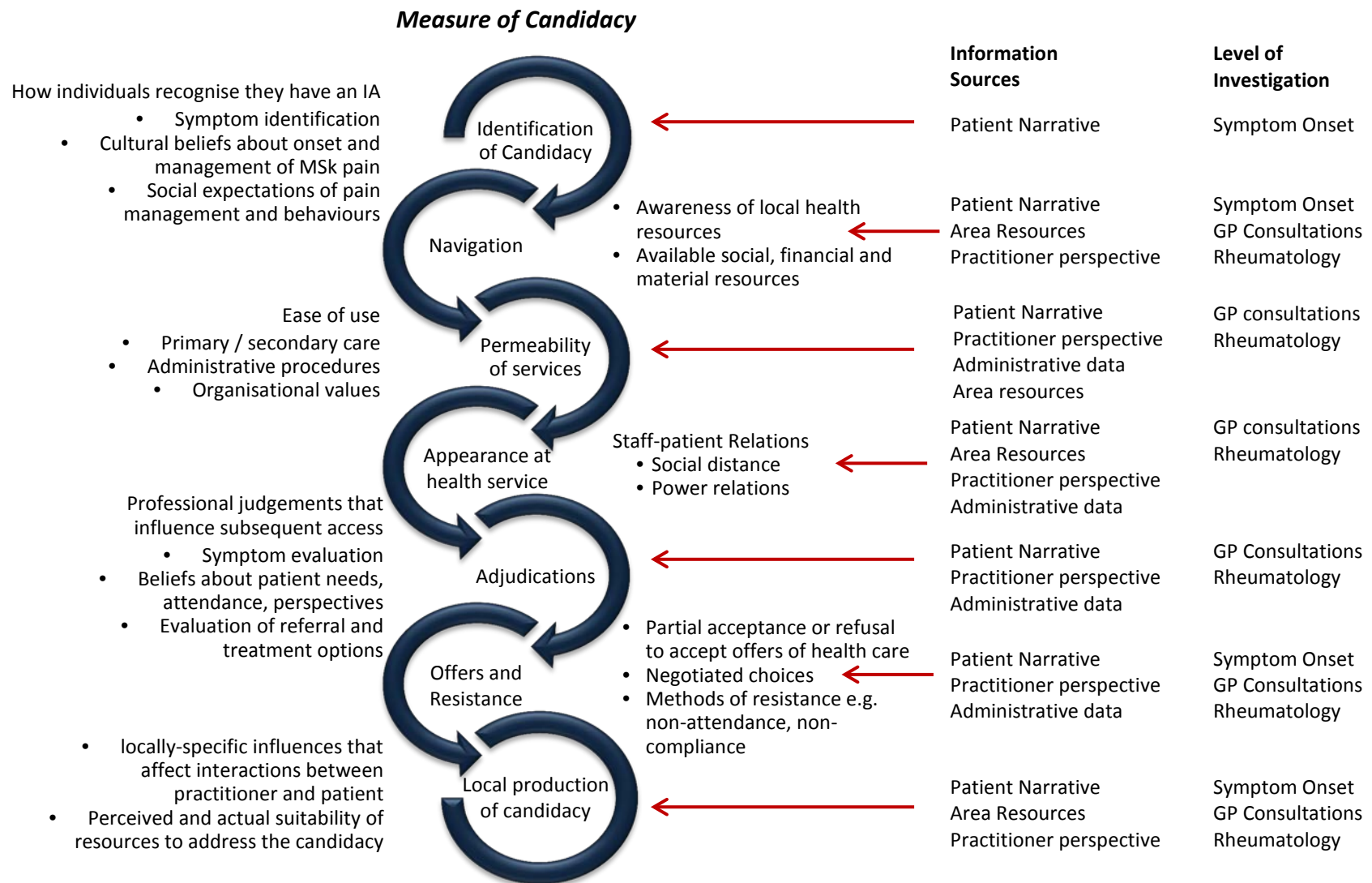


Figure 7: Structure of the research design.

Source: Derived from (Dixon Woods, Cavers, et al., 2006; Dixon Woods et al., 2005)

RESEARCH DESIGN

The focus of this study is explicitly acknowledged at the outset as the patient participant experience of the IA journey, rather than the experience of rheumatology services. The onset and referral delays, which encompass barriers to services, were considered at multiple levels – the individual, the GP and at rheumatology services. The data used in this retrospective study were derived from several sources.

Similar factors may explain health behaviours at multiple stages of the patient journey. For example transport availability constraints on access to primary may be replicated at secondary care. With this in mind, the development of the research design used the Candidacy framework to examine barriers to accessing health services rather than delineating research tasks by each stage of the patient journey.

The location of the study was determined by the catchment area of the three DHBs served by the WRRU rather than the territorial local authority (TLA) boundaries. Originally the study was to focus on patients who had been referred to the WRRU and diagnosed with an IA. However to get an accurate picture of the patterns of referrals the study population also included all referrals to the six private practices that accepted IA patients over the period of data collection. The population of interest was patients who had been referred to a rheumatologist in the Wellington region, with a particular focus on patients referred by a GP practising in the Wellington region and patients diagnosed with a persistent IA. Children and young people under the age of 18 and patients referred to rheumatology services in error were excluded from the study.

Referrals data was limited to a two year period so that any organic changes in practices that may affect GP referrals decisions would only be minimally reflected in the data. Given the comparatively low incidence of inflammatory diseases of approximately 1/1,000⁶ (Sangha, 2000) and the recommended patient lists size of 1400 patients, it was probable that most GPs had the opportunity to refer at least one person with IA symptoms over this two-year period. A decision was made to analyse

⁶ RA, the most frequently occurring IA, has an incidence of approximately 0.5/1,000; AS 0.07/1,000 Sangha, O. (2000). Epidemiology of rheumatic diseases. *Rheumatology*, 39(suppl 2), 3-12.

only GP referrals, rather than include referrals from other consultants because of the role that GPs have as the gateway to secondary public health services, and therefore as the health practitioners who would have the first opportunity to refer a patient with IA symptoms to a rheumatology service.

ETHICS APPROVAL

The research process required personal data that could identify patients who had agreed to participate in the study. Exposure of patient identity is a high consequence ethical risk in qualitative research, particularly when sensitive personal information is disclosed. To guard against this, patient names were changed as interviews were transcribed and these pseudonyms are used for reporting the research findings. The identities of health providers in the participants' journeys were removed. The patient data stored for consent purposes is not linked to patient interviews. Digital data has been kept in password protected files, with hard copies in a locked cabinet away from public spaces. Health providers are schooled in data privacy and provided generalised accounts of process in interviews and discussions rather than information about specific patients. Information about the study was distributed to participants and written consent was signed before the interviews commenced to formalise participation in the study, the conditions of the interviews and the rights of the participant (Appendix 2).

Care was taken to ensure patients are not identifiable from data collected from administrative databases. The referring GP, diagnosis and patient demographic details were required to assess referrals. The patient national health identifier (NHI) was used to establish the integrity of the data, and personal name and address information was not collected. The NHI was not used in data analysis. Ethical approval for this study was received from the Central Region Ethics Committee via an expedited review on 23 January 2008, Reference number CEN/08/02/EXP.

SITUATING THE PATIENT JOURNEY

The quantitative data collected for the study consisted of secondary demographic and area-related information to show the setting in which individuals with IA make decisions about their health care. Rheumatology services administrative data that

identified new referrals, referrers and waiting times was utilised. Referrals letters and FSA letters were accessed for symptom and diagnosis data.

AREA CHARACTERISTICS

The nature of the place where people live and experience healthcare is critical to the choices people have and influences the decisions they make about accessing health care. The first stage of this project was to gather information about the services and areas covered by the three DHBs; Capital and Coast, Hutt Valley and Wairarapa, and the six areas used for analysis; the Territorial Local Authorities (TLAs) of Wellington, Porirua, Kāpiti, Lower Hutt, Upper Hutt and the combined Wairarapa TLAs of South Wairarapa, Masterton and Carterton districts. This secondary data was derived from publicly available local authority databases, Statistics New Zealand census data and journal articles that provided snapshots of access issues to health services.

SPATIAL DATA

Original maps depicting the Wellington region, including DHB and local territorial authorities were drawn in ArcMap 10.2. (ESRI, 2013). Geodata from Statistics New Zealand and the Ministry of Health was retrieved via Koordinates under the Creative Commons Attribution 3.0 New Zealand licence (Koordinates, 2010). The ArcMap GIS was also used to verify GP practice locations and measure distances from GP practices to rheumatology clinics.

ADMINISTRATIVE DATA COLLECTION

The numerical data collected was retrospective administrative information detailing referrals to all rheumatology practices in the Wellington region. The purpose of the quantitative analysis was to provide baseline information (Burke Johnson, et al., 2007) through gathering evidence that referral delays existed, pinpointing where these may occur and identifying significant differences in the patterns of referral and service utilisation across the region. Secondary data were utilised to situate the patient journey in the areas the participants live and work. The purpose of this data was to create a picture of the services available, and the socio-economic factors and

geographic barriers that could impact on patient decision-making about their care options.

Between February and July 2008, all new referrals to the WRRU for the period December 2005 – November 2007 were retrieved from the Concerto patient management system database. The data date range was chosen for two reasons. The first was simply to ensure referrals were available for all categories, in particular for smaller areas like Wairarapa, and smaller groups, especially Māori, Pacific peoples, and older patients. The second was to compare referral and waiting time differences before and after cessation of public funding for private patients' laboratory tests in November, 2006⁷. Retrieved data included the patient identifier (NHI), age, gender and ethnicity of the patients, the referral source (GP or Consultant), referrer name and GP practice, referral priority, clinic allocation, date of referral and date of FSA. The same time period was used to collect administrative data from the six private rheumatologist practices in the region. These rheumatologists agreed to provide data that could be manually copied from their practices' patient letters or databases. The data available varied when compared to that available from the WRRU. Notably NHI numbers were available for only one practice, which precluded immediate checks for double referrals, and ethnicity data was not recorded by private consultants. One practice agreed to provide access to the referrals list but refused access to FSA letters, meaning the initial diagnosis for 21 patients was omitted. A search for multiple referrals of the same patient to different practices was done by cross-checking the GP name with the patient birthdate and gender, where NHI number was unavailable. The raw data showed that of the 3,263 new referrals to a rheumatology clinic in the Wellington region from any referrer, four out of 10 referrals were to a rheumatologist in private practice. A similar proportion of the 801 valid IA referrals were also referred to rheumatologists in private practice.

In the WRRU data, duplication of records occurred for 36 patients and the duplicates were deleted. Where the referral field was blank (128 records) referral information was extracted from initial appointment details or the referral letter. Where the referral record did not have complete GP information (27 records) referral information was extracted from the referral letter. The patient diagnosis was added

⁷ This funding change was reversed by the incoming government in 2008.

to the administrative data from the rheumatologist record of the first specialist assessment (FSA) diagnosis.

Referrals were cross-referenced with patient records to verify final appointment status and, where possible, to complete missing data. Data was also checked against the referral letter and booking input errors (for example mismatched GP and practice information) and for standardisation of GP and GP Practice names. An input error was discovered after discussion with administrative staff and resulted in misattribution of GP referrals to other health professional (OHPs), which was corrected by extracting the correct information from referral and FSA letters. In some cases (less than 10%) area-level data was not able to be verified. These cases were included in the study. FSAs cancelled by the WRRU or the patient were excluded from the analysis as were records in which the patient was referred while an in-patient and treated on the same date, or had died before the appointment date. Referrals excluded from the study were more likely to be for older patients ($p=0.05$) or patients who had longer waiting times from referral to appointment date ($p=0.003$). The sorted and cleaned administrative data produced 1,953 valid referrals of which, 124 appointments were cancelled before FSA, nine patients were deceased and 1,820 proceeded to FSA appointments.

PHO DATA

Because ethnicity data could not be collected for private referrals, a decision was made to analyse the type of PHO the referring GP was associated with as a proxy for socio-economic status. NZ primary healthcare services are grouped in primary health organisations (PHOs) and between 90% and 97% of the Wellington region's population is enrolled in PHOs (Ministry of Health, 2009). Independent practitioner PHOs (IPHO) are most often organised on a geographic basis, but Access PHOs (APHO), which have a focus on not-for-profit services in communities of interest that have poor health outcomes, are often organised around the needs of low income Māori and Pacific Peoples (Crengle, 1999).

The PHO and the area variables were derived from the recorded GP details rather than the patient details as these were easily verifiable and, in the case of private patients, readily available. PHO details were obtained from the Health Information

Service through regular reports to DHBs and matched to GP practices. The reports provided information on the number of patients enrolled, the percentage of high needs patients, Māori and Pacific patients and patients living in NZ deprivation areas 9-10 (the areas of highest socio-economic deprivation in New Zealand) (Crampton, Salmond, & Atkinson, 2007).

REFERRER CHARACTERISTICS

GP and GP practice characteristics were gathered to look for differences in referral rates. The categories reflected those of the NatMedCa survey method, which was designed to collect information on GP consultations and referrals (Raymont, et al., 2004). Names and addresses of GPs in the Wellington region were recorded from local telephone books and checked against patient management system records. Questionnaires were mailed to 105 GP practices representing approximately 480 GPs requesting information about the size and type of practice and information about GP demographics, training and workloads pertinent to assessing differences in referral rates (Appendix 3). GP practices were telephoned up to four times over an eight week period after the mail out to encourage response. However the response rates were low, with practices citing time pressures, privacy and commercial sensitivity as reasons for refusal to participate. Responses were received from 45 practices representing 127 GPs (response rates of 42 percent and 26 percent, respectively). The data was then augmented with readily available data from a variety of sources. Of particular importance was the Medical Council of NZ database from which the year and place of qualification could be retrieved. The NZ College of General Practitioners (through which practices advertise for trainee GP positions), provided information about practice size and full-time (FTE) equivalent GPs. Similar information was found in some PHO annual reports and GP Practice websites. This supplementary data gave 140 referring GPs from 85 practices and 57 practices from a total of 105 referring practices.

DATA ANALYSIS

Administrative data from referrals to all rheumatology clinics in the WRRU region and administrative data from the WRRU were analysed for waiting times and non-attendance differences that could indicate variations in access for particular population groups or local areas. Statistical analyses were generated in SPSS v.19,

(IBM Corp, Released 2010). Variables that were significant for referral differences were included in logistic regression models that produced odds ratios (OR) with 95% confidence intervals (CI). GPs were excluded from the analysis if they were not registered in the NZMC database and/or qualified after 2005 and/or not in their GP practice for the full period of the study. This left 353 referring GPs in the database. All statistical analyses were generated in SPSS v.19, (IBM Corp, Released 2010).

REFERRALS

GPs referred at least one patient to a rheumatologist over the 2-year study period referred from zero to 10 patients who were subsequently diagnosed with an IA on their FSA (mean 1.97. $p \leq 0.01$). Kruskal-Wallis tests were run on the referrals data to determine differences between IA referrals across the categorical variables of the GP and the GP practice that were submitted in the questionnaire. No other GP or GP Practice factor collected in the questionnaires produced a significant relationship with IA referrals. Significant differences were identified in the rate of IA referrals based on the length of time since the GP had graduated ($p=0.03$). Poisson Loglinear models, using an offset of the log of the patient list size were run to obtain the referral ratio of a GP referring relative to the 15-year experience group. Comparative models were run with referral rates of non-IA referrals and Nil referrals.

NON-ATTENDANCE

A considerable problem for the WRRU, and a possible measure of barriers to rheumatology care, is non-attendance at FSAs. To estimate the impact of the social, physical, and demographic characteristics on whether people attended, multivariable modelling was performed using the data collected from the WRRU administrative databases of the 1,953 patients who were given FSAs over the 2-year timeframe.

Appointments that were cancelled by the WRRU or the patient were excluded from the analysis, as were patients who were referred while in-patients and treated on the same date, or those who were deceased before the appointment date. Referrals excluded from the study were more likely to be for older patients ($p=0.05$) or patients who had longer waiting times from referral to appointment date ($p=0.003$). Ultimately 1,821 referrals were included in the non-attendance analysis.

Statistical significance of association with non-attendance was tested using chi-squared tests for the categorical variables and the Mann-Whitney U non-parametric test for the continuous age and waiting time variables. The data were entered in to the models in three stages. First, models were run for each variable. Then models adjusted for demographic variables of the patient (Ethnicity, Age and Gender). Finally a model adjusted for all variables except DHB and Clinic Location (DHB and Clinic Location were not adjusted for Area) was run. The initial Chi-square tests had shown that NZ Māori and Pacific peoples were at significantly more risk of non-attendance than other ethnicities. To focus on these groups the multivariate models were run with three ethnic groups; NZ Māori, Pacific Peoples and All Other ethnicities. The reference category was All Other. Area variables were referenced to Hutt or Lower Hutt. Age and waiting times were modelled as continuous measures on the log odds scale and checked to ensure the linear model assumptions were reasonable. For Age, the OR is reported for 10-year intervals. The continuous fit has an advantage in the multivariable model of only requiring one term. A test for departure from the linear log odds fit is $p=0.42$ and tests of model fit give the linear model as a better fit than categorical variables for age. The primary indicator of potential waiting time is the priority given to the patient when the referral is triaged (Appendix One). These priorities give patients a reasonable expectation of treatment timeframes (Ministry of Health, 2000). The Timeliness variable provides a yes/no categorisation of whether the FSA occurred within the timeframe indicated by the priority ranking. The Timeliness variable has a significant effect on non-attendance ($p=0.01$) compared with Priority ($p=0.42$) so was used in preference to Priority in the third iteration of the multivariable model (Area, Timeliness and PHO type). For Waiting Times there was a significant departure from the linear log odds fit $p=0.035$. When the log of waiting time was modelled the test was not significant $p=0.66$. Tests of model fit give the logged linear as a better fit than waiting time categorical variables.

WAITING TIMES

The waiting time between referral and FSA was a significant factor in non-attendance so these were analysed separately to look for variations in demographic, geographic and administrative variables. The multivariable model to obtain estimates to generate the ratios of waiting time (WR) was run as a log of waiting time. Waiting Times were

modelled in three stages. The first generated unadjusted WR for the variables collected from the administrative data. The second generated WRs for demographic variables of the patient (Ethnicity, Age and Gender). The third iteration was run to include the geographic and administrative variables of Area, PHO type, and Timeliness. A fourth model was also run with Timeliness excluded.

QUALITATIVE DATA

Two groups of participants were recruited for the qualitative section of the study; patients and GP referrers. A purposive sampling strategy was employed to identify representative cases of the phenomena being studied and reduce the prospect of an 'elite' bias in sampling by helping (Burke Johnson, et al., 2007). Purposive sampling is considered a suitable method of participant selection when the research is "informed a priori by an existing body of social theory on which research questions may be based" (Curtis, et al., 2000, p. 1002).

IA PARTICIPANTS

It has been convincingly argued that there is a need to examine the health and lived experiences of people located in similar regions of social space but drawn from different neighbourhoods which might generate different outcomes (Gatrell, et al., 2004), because neighbourhood is an important individual and population characteristic that links to geographic inequalities of health (Bolam, et al., 2004). This opinion was at the forefront of patient participant recruitment. The first selection process was to select patients with similar socio-economic characteristics, but from different areas, looking for an indication that the area of referral might impact on referral pathways through either area characteristics, such as travel to rheumatology services or socio-economic status, or the provision of services. Patients with a history of non-attendance were specifically sought out. However few IA possibilities with that history made contact difficult, and 103 of the 131 non-attenders at FSA had received no diagnosis because they had not returned for a second appointment during the study period. Seventeen of the non-attendees had returned and were diagnosed with an IA. The records showed that of the people with IA diagnosis proportionately more Māori, and younger people did not attend. Anecdotally, young male non-attendance was of concern. Three people with IA and a history of non-attendance, two with an

SpA and one RA, one NZ Māori, and two NZ European (one female and one male), were interviewed. These participants were all from areas of high socio-economic deprivation according to the NZDep2006 index (Crampton, et al., 2007). The next stages were to sort for age, gender and disease characteristics of all other patients. The patient record was examined to search for a range of referral factors that included diagnosis, indication of the length of time between symptom onset and GP referral, the presence of co-morbidities, age and family and employment responsibilities. In total, 17 WRRU patients were selected as possible participants in this study. All possible participants were contacted by letter between March 2009 and May 2009. The letter included an information sheet explaining the purpose and procedures of the study. Pre-paid return-address envelopes were included in the mail-out. Telephone calls were made to patients who had not responded within two weeks. Telephone contact was again attempted one month after the initial letter, if there was no response to previous attempts at contact. Twelve WRRU patients responded positively within this time period. Of the five patients who were unable to be contacted by letter, two were also unable to be contacted by phone after three attempts either because the telephone was not answered, or the patient had moved away from the area. Two patients who had agreed to be interviewed were not interviewed because of difficulties organising a convenient time to do so, a third moved from the area before the interview could take place.

A similar process was performed to select possible participants from a private rheumatologist clinic. Ten patients were contacted by letter and later by telephone if they had not responded after two weeks. Six patients consented to interviews, and four declined. In addition to the interviewees from WRRU and private patient lists, a further four patients were contacted via community sources and consented to interviews. Of these participants, one had never been referred to a rheumatology service, one had been diagnosed with an IA and discharged, and two were current rheumatology patients – one a private patient after being diagnosed with an IA at the WRRU, and the other a WRRU patient. In all 22 IA patients participated in the study; eight private patients, 12 public patients and two who were not receiving rheumatology care.

The sampling criteria resulted in a mix of patients from each of the three DHB areas (Table 3), a variety of ages and relatively even mix of gender and private and public patients (Table 4). The final list included patients with a history of missed appointments or interrupted treatment concordance. They represented a range of social and cultural backgrounds and were referred from high and low referring doctors. The participants had collectively received care from three private clinics and four public rheumatologists.

Table 3: Patient participant residential areas

DHB	Area	Number
WDHB	Wairarapa	3
CCDHB	Wellington (North)	2
	Wellington (Central)	4
	Wellington (South)	3
	Porirua/Kāpiti	3
HVDHB	Lower Hutt	4
	Upper Hutt	3
N		22

Table 4: Patient participants

Study Name	Gender	Age Group	Socio-economic status	Area Deprivation	Time – Onset to Diagnosis	GP Initial Diagnosis	Clinic Type at diagnosis	Diagnosis
Michelle	Female	25-29	3	4	< 6 months	OC	Public	RA
Carol	Female	40-44	2	4	<6 months	RA	Public	RA
May	Female	50-55	5	5	4-5 yrs	RA	Public	RA
Anne	Female	55-59	3	3	12-18 mths	WRI	Private	RA
Catherine	Female	55-59	4	2	>12 months	WRI	Private	RA
Gillian	Female	60-64	5	4	>3 years	OC	Public	RA
John	Male	50-55	2	2	<12 months	SI	Private	RA
Mark	Male	60-64	5	2	>12 years	WRI	Public	RA
Martin	Male	60-64	4	2	>12 months	RA	Public	RA
Lisa	Female	20-24	5	5	<12 months	SpA	Public	SpA
Angela	Female	40-44	3	2	>12 months	SpA	Public	SpA
Louise	Female	44-49	2	1	<6 months	OC	Private	SpA
Carla	Female	45-49	2	2	<3 months	WRI	Private	SpA
Marie	Female	45-49	4	1	>4 years	RA	Public	SpA
Kim	Female	50-54	3	4	>12 months	OA	Private	SpA
Sally	Female	50-54	2	2	>3 years	WRI	Private	SpA

Study Name	Gender	Age Group	Socio-economic status	Area Deprivation	Time – Onset to Diagnosis	GP Initial Diagnosis	at Clinic Type diagnosis	Diagnosis
Zoe	Female	55-59	3	1	>3 years	ND	Private	SpA
Alex	Male	20-24	4	3	<6 months	SpA	Public	SpA
Patrick	Male	30-35	2	2	<3 months	SpA	Public	SpA
Phillip	Male	40-44	4	1	>9 years	SpA	N/A	SpA
Brian	Male	45-49	4	1	>3 years	OC	Public	SpA
Stephen	Male	50-54	3	3	>10 years	ND	Public	SpA

1 = High

5 = Low

OC = Other Condition

ND = No Diagnosis

WRI = Work Injury

SI = Sports Injury

GP PARTICIPANTS

GP participants were purposively selected from the list of GPs who had referred at least one patient who was subsequently diagnosed with an IA at FSA. Recruitment was based on an analysis of high and low referrers of IA patients, with respect to the list size of the referrers. GPs were considered high referrers when they were in the top ten percent of referrers of patients diagnosed with an IA, and also in the lowest percentile of GPs with referrals that resulted in a non-rheumatological diagnosis. GPs' IA referral rates were assessed to create lists of 'high' and 'low' referrers. High referrers were considered those who had IA referrals that were more than one-third of all their referrals, their nil referrals were less than one-third of all referrals and less than half of IA referrals. Low referrers had the opposite results. The results matrix from this process was weighted to take into account the age profile of the enrolled population.

Potential participants were contacted by telephone or email, outlining the purpose of the study and what was expected if they chose to become involved. Nine GPs agreed to be interviewed (Table 5) and a further three GPs agreed to complete a questionnaire about how GP attitudes toward IA, patients, rheumatology services and treatment options affect referrals. Of the nine interview GPs, three were identified as

high referrers, three as low referrers. The remaining three GPs had only referred IA patients (they had no referrals of patients with non-inflammatory rheumatological conditions, and no referrals of patients with non-rheumatological conditions). This questionnaire, based on the findings of the literature review (Appendix 4), was trialled as part of the study but not expanded, in part due to the difficulties in obtaining a suitable response rate in the previous requests for information from GPs. The results of the questionnaire were not analysed, but the information was used to support the qualitative data from the GP interviews.

Table 5: Selected characteristics of participant GPs

Area		Practice Size		Years Qualified	
Wellington	2	2,500-5,000	3	10-14	3
Hutt Valley	2	5-10,000	2	15-19	3
Kāpiti/Porirua	2	10-15,000	3	20-24	2
Wairarapa	1	15,20,000	1	25+	1
N	9		9		9

CONTEXTUAL DISCUSSIONS

In order to complete the setting of the patient journey key providers of services were contacted to take part in interviews. These providers included WRRU staff - two nurses, two rheumatologists and an administrator, and two arthritis educators from Arthritis New Zealand who made themselves available for discussion about the services they provided and how these services were administered.

INTERVIEWS

The driver of the interview method was the principle that the study framework, calling for the interpretation of socially and culturally constructed knowledge, required broad, open-ended questioning that revealed processes of interaction within the everyday context of the individual (Creswell, et al., 2003). The development of the interview method began with the premise that researchers are not neutral observers in the interview process because they bring with them their own preconceptions and understanding of the participants and the problem under investigation (Denzin, 1978).

PATIENT PARTICIPANTS

The aim of the interviews was to understand the perceptions, attitudes and social, cultural and financial barriers that influenced access from the participant's point of view, and the decision was taken to have an unstructured interview process to enable a life history perspective to be narrated. Although the narrative in un-structured interviews is not necessarily comparable with the information obtained in structured or semi-structured interviews, unstructured interviews can open up unexpected lines of inquiry (Grix, 2010). Despite a commitment to non-structured interviews, a checklist was used during the interview to facilitate disclosure, probe statements more thoroughly and maintain a conversational flow, if required, and ensure the aims of the interviews were addressed. Additional information was collected by way of field notes. When these notes indicated uncertainties about the diagnostic journey patient notes were accessed to clarify.

GP PARTICIPANTS

Interviews with GPs were used, alongside patient interviews to examine more subjective barriers to early treatment for IAs. Twelve GPs agreed to answer questions relating to the diagnosis and referral of IA patients and nine of these GPs agreed to be interviewed.

Interviews were requested with a mix of high, average and low referrers, based on weighting from the patient list size. The GPs selected represented a mix of practice sizes and included at least one GP from each area. GP interviews were formulated to cover the decision-making, if to refer and who to refer to, and attitudes and beliefs about care options, and beliefs and expectations of patients and rheumatology services. The GP interviews were semi-structured in respect of GPs' compressed time schedules and their greater knowledge of the topic under discussion. The power relationship in GP interviews is quite different to that in patient interviews. While the patient interviews were designed to reduce the power differential that may have been weighted against the patient participant, the power differential in the GP participant interviews was potentially in favour of the GPs, with their specialised knowledge of health communication with patients and medical decision-making. To reduce the chance of this affecting the interviews a semi-structured interview was used that utilised an interview guideline (Appendix 5).

Participant interviews were arranged in a place to suit the participant, averaged 45 minutes (range: 22minutes – one hour 45 minutes), and were conducted between February 2009 and July 2009. The interviews took place in private homes, local cafés or after appointments at the WRRU, depending on what location suited the patient. All but one GP interview (recorded at the WRRU) took place in GP rooms and usually during a break between consultations. Interviews were conducted between July 2009 and August 2010 and lasted between 30 and 45 minutes. All interviews were recorded and transcribed verbatim. Patient recall was rarely problematic. Participants with a long and complex medical history were more likely to admit they had forgotten dates and the order of medical contacts, however recall was usually prompted by the participant linking information to significant life events. Relevant referral information was verified by records held at rheumatology clinics.

CONTEXTUAL DISCUSSIONS

Prior to the patient interviews in July 2008, discussions with rheumatology nurses and booking clerks and rheumatology patient educators were undertaken in staff workrooms to provide context. These interviews were not recorded. Two rheumatologist interviews were conducted at the conclusion of patient and GP interviews to provide a greater understanding of the patient and GP perspective as well as to confirm details of the rheumatology assessment and treatment processes. These interviews were recorded at rheumatologists' workplaces in October and November 2010.

RESEARCHER RELATIONSHIP

Taking a neutral position in interviews is important to ensure that the information disclosed is accurate (Patton, 2002). However trust and rapport are important factors in the interview relationship, are often built through a mutual understanding of the subject of the investigation, and can help to ensure the participant is open and honest. My immersion in this topic both as a researcher and a patient, makes it implausible to claim impartiality to participant disclosure. As part of the disclosure process I briefly shared with patients my own diagnosis of IA, and that although I delayed consultation, an IA was suspected by my GP and I was referred to a rheumatologist reasonably quickly. Despite seeking to maintain distance between my experience and

the participants' experiences, an affinity was often apparent with some patients, which meant disclosure was probably different in both quality and depth than might have been provided to a more neutral researcher. Using mixed methods provided the opportunity to triangulate the patient narrative with administrative data to validate disclosures (Creswell, Klassen, Plano Clark, & Clegg Smith, 2011).

The Collective Lifestyles framework incorporation of Bourdieu's theory of practice provides the opportunity for Bourdieu's research philosophies to be incorporated into the study design. GP interviews were more structured than patient interviews, and because the nature of their profession means they are confident in managing an interview process, differences in the research process of a hypothetically neutral researcher and me were unlikely. Bourdieu believes it realistic to explore communication by focusing on the "simultaneously practical and theoretical problems" emerging from the interaction of the researcher and study participant but does not consider it useful to turn to "methodological writings" on interview techniques. Bourdieu reasoned that although theoretical and practical problems may result from the interaction between the researcher and the study participant, communication methodologies are more scientific than scientific in an interview setting. The interview and analysis can be managed in a way that mimics the form of a scientific analysis, but lacks the function. The interview is a social relationship and it remains the case that this relationship can have an effect on the results obtained regardless of methodology (Bourdieu, 1999). His view was the interview process is a method that can be used to "attempt to bring to light the respondent's representation of the situation, of the study in general, and of the ends it is pursuing, and to make it explicit the reasons that led to participation in the exchange" (Bourdieu, 1999, p. 609). Accordingly the interviewer has a responsibility to reduce the power that could be exercised, to actively and methodologically listen to the participant – being aware that this is the participant's history - and to reduce as much as possible the social distance between the interviewer and the participant. Social distance can be reduced through the language and signs the interviewer uses and a familiarity with the participant's worldview (Bourdieu, 1999).

Bourdieu does, however, highlight the issues of distortions in the research relationship and these need to be understood as part of a practice of being reflective

and methodical, and rather than positioning the interviewer, reflexivity is about being perceptive and monitoring as the interview is in progress – understanding and controlling for the position of power the researcher holds, active and methodical listening and acceptance of the uniqueness of a particular life history (Bourdieu, 1999).

INTERVIEW ANALYSIS

A strength of qualitative methods is that data collection, analysis and sampling progress in an iterative, rather than linear, manner. From a discursive point of view it is more important to capture the diversity of the discourse on a topic rather than secure a statistically representative sample of participants (Bolam, et al., 2004).

Transcribed data was entered into NVivo 9 (QSR International Pty Ltd., 2010) software that supports qualitative and mixed methods research by assisting the organisation and analysis of interview data. Thematic codes had previously been set up in Nvivo to look for information in three categories for patients; resources, characteristics, social norms and behaviours that affect the options that an individual may encounter in their IA journey and are at the heart of the Collective Lifestyles framework (Frohlich, 2000). The narrative was originally coded in stages of the journey to reflect onset, consultation and referral delays that were identified in the literature concerning rheumatology referrals and delays, but this proved cumbersome and simple headings were used to match the themes with the stages in the patient journey. Recoding the themes into measures of Candidacy allowed the participant's explanations of delay to intersect with multiple stages of the journey to care.

A warning about interpretation of qualitative data was issued by Bourdieu who argued that researchers can too easily and uncritically adopt words and phrases that occur in their own social world as the basis for social research to create a political or social bias. He was also wary of the research tools social scientists use to aid their analysis (for example labels, coding schemes, statistical categories and typologies) as these are themselves, products of the researchers' social relations rather than the patient discourse (Fries, 2009) and with this in mind, coding schemes were kept to a

minimum, with a preference for the patient flow at the forefront of interpretation. GP participant interviews followed a similar process, but with nodes and themes derived from the referrals literature review and interview guidelines. Patient quotes were selected to illustrate the range of experiences, to support the concepts of the study, and allow themes to develop throughout the text. Quotes were also used to highlight thematic interactions that affected delays to care and provide rationalisations for patterns of interactions between patients and health providers. These later quotes have been grouped together in several places and highlighted. Where possible the quotes were selected from the range of participant characteristics to illustrate similarities and differences in responses to the themes under discussion allowing the quotes themselves to signal the interpretation of events (Sandelowski & Barroso, 2003).

The analysis of patient narrative was aided by the access to patient records. Where patients were hesitant about the timing or reasons for events within the referral process patient records could verify the patient account, and lead to further explanation for patient actions.

DISCUSSION

Untangling the details of GP visits over a number of years is difficult as patients' memories of their joint pain history may not be accurate so visits at early stages of IA may not have been mentioned in their interviews. However the use of clinical records adds some credence to their narrative, in at least confirming that the series of events leading to referral were consistently related in interviews and rheumatology FSAs and could help fill in the gaps in topics that participants did not wish to address, but were relevant to the study, such as non-attendance.

Limitations of the methodology of this study include reliance on the accuracy of administrative data. Input errors were found, however cross-checking with patient notes strengthened accuracy of the data. Location details were missing for less than 1% of patients, and timeliness of data was unavailable for approximately one in five patients. Patient characteristics, in particular ethnicity, may not have been entered correctly. (Health Utilisation Research Alliance, 2006; McPherson, Harwood, &

McNaughton, 2003). During the data collection period the WRRU did not derive ethnicity data from PHO databases, a process which has since been shown to be statistically more accurate in identifying Māori than DHB databases (Malcolm & Barnett, 2009), the likely impact being that Māori and Pacific Peoples referrals are underestimated in this study.

The sampling strategies for GP and patient participants were modified as the process moved forward due to an acknowledgement that not all criteria could be covered in a relatively small sampling. Finding a balance between criteria and the practical considerations of the selection and interview process is an important dilemma, in terms of who is being represented in the study, and why (Curtis, et al., 2000). Ultimately organisation of the interview process and availability of the patients impacts on the sampling criteria, especially when there are only small numbers of patients available in some criteria. Only two patients are not New Zealand European and this has an impact on the transfer of findings to referral experiences that may have been a direct result of patient ethnicity. For this reason findings are reported without reference to ethnic differences. Despite this concern the modified iterative approach to sampling has enabled a varied cross-section of patients in the region to emerge and the contextual nature of the referral process to be investigated.

The methodology of this research reflects the position that the disaggregation of contextual and compositional health effects cannot be done on a purely empirical basis (Bernard et al., 2007). Studies that work from a conceptual framework that can draw on a diverse study sample have good potential to add generalisable information to the body of work that seeks to understand health care perceptions and practices (Daly et al., 2007).

The underpinnings of studies that evaluate enumerated and narrative data may be derived from positivist and social constructivist philosophical traditions, which creates a tension requiring careful consideration of positioning the study, yet ultimately the combination of both forms of data in a mixed methods approach can provide new knowledge drawn from a pragmatic appreciation that both forms of inquiry may be required to address the research question (Creswell, et al., 2011). This method is based on the belief that a fuller appreciation of the causes of poor access

can be developed by drawing on an empirical examination of the structure of health services within the region, the operating conditions of rheumatology services and administrative processes that control access, and allying this data with the narrative exploration of the patient perspectives of IA and barriers to rheumatology care. This belief is reflected in the evaluations of the enumerated and narrative data in the following chapters.

8. SITUATING THE IA JOURNEY

INTRODUCTION

Place is not simply a setting for patient action, but is also a receiver of social and economic processes that operate at larger scales than the bounded area in which a patient lives (Poland, et al., 2005). The response to musculoskeletal pain, although set within the local area and the wider Wellington region, is also located within the context of the health services that have been made available in the local area set by national health policies that are interpreted within local DHB budgets.

The type and quantity of resources (for example, social, economic and cultural) an individual needs to access health care depends on the how the structure, administration and distribution of health services is mapped onto a local landscape (Fries, 2009). The local areas served by the three DHBs in the Wellington region are characterised not only by their boundaries, but also by culture, ethnic and social attributes and the economic circumstances of the people living there (compositional factors) as well as the wider social, material, geographical, and political make-up of the areas(contextual factors) (Gatrell, et al., 2004).

The spatial units in this study are defined as the greater Wellington region, which encompasses the DHB regions of Hutt Valley, Capital & Coast and Wairarapa, and eight territorial local authorities (TLAs). The three TLAs in the Wairarapa region have been merged into one area unit for the purposes of this thesis due to the low population of the area. Distinct access issues are apparent on examination of the socio-economic and cultural composition of the constituent TLAs, the geographic variations and the variations in the distribution of health services in the Wellington, Porirua, Kāpiti, Upper and Lower Hutt and Wairarapa areas.

The purpose of this chapter is to describe the Wellington regions and provide information about differences in the local areas that may affect access to health services. Geographical, social and demographic data derived from secondary data sources, are utilised to provide a brief overview of the interplay between the composition of the local areas and service provision that form the backdrop for

understanding an individual's decision-making about accessing medical advice for assessment of IA symptoms, and barriers to referral to a rheumatologist, early diagnosis and treatment. The composition of an area provides context for individuals' connections with health-related services that may have an impact on the individual that are more important than the demographic characteristics of the patient (S. Cummins & Milligan, 2000).

The Wellington region (Figure 8) is an area of over 8,000 hectares, located at the southern tip of North Island, New Zealand (Greater Wellington Regional Council, 2013a). It has diverse geographical features with the Wairarapa plains in the east, rugged hill country in north to south spines, separating Wellington and the western coastal strip from the river valley of the Hutt region. The Wairarapa plains to the east and to the north of the region are separated from the Hutt Valley by the Rimutaka Ranges and terminate in rough hill country on the northern boundary.



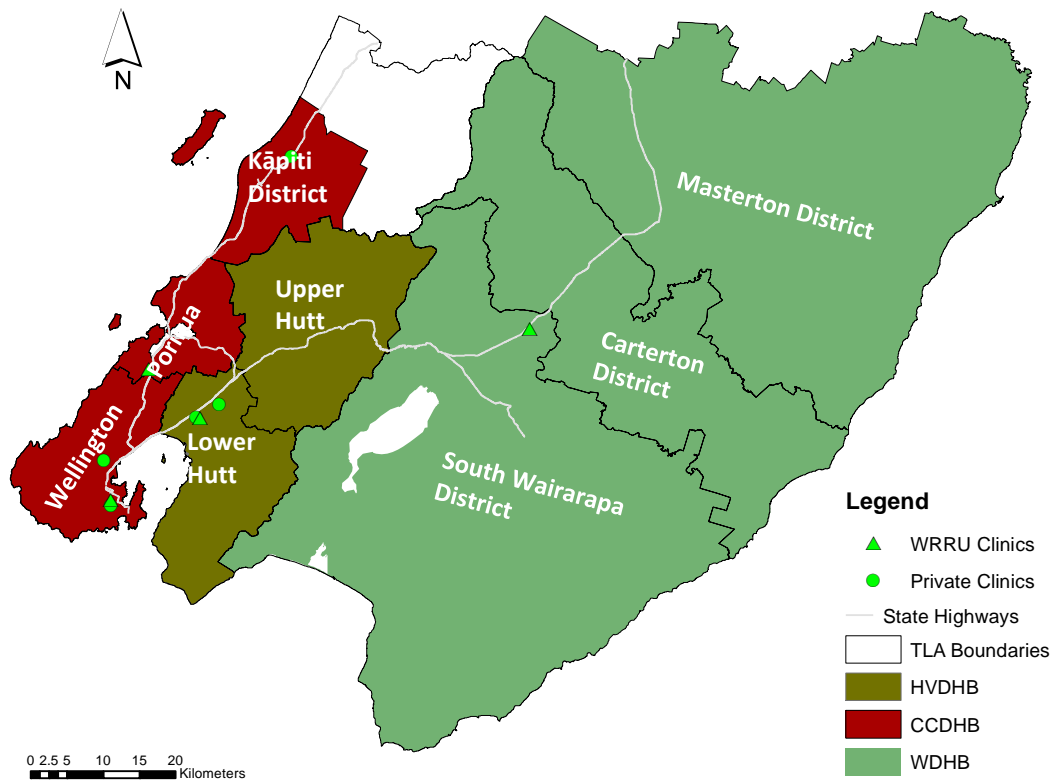
Figure 8: Study location

The CCDHB, with a population of 289,200 in 2006 (Statistics New Zealand, 2008) is the most populous in the region and provides services for three distinct geographic areas – Wellington, Porirua and the Kāpiti Coast. Wellington has, on average, the wealthiest and most educated population in the region with small pockets of relative deprivation. It has good public transport links, lower private vehicle ownership and relatively low ethnic diversity with Māori and Pacific peoples concentrated in Porirua. Nearly a fifth of Porirua residents are of Māori descent and 1 in 4 is of Pacific descent (People of Polynesian, Melanesian, or Micronesian origin). Porirua also has the youngest median age and highest levels of relative deprivation in both the CCDHB and Wellington region. Porirua has a distinctive socio-economic profile with a very high proportion of residents in both the highest and lowest area deprivation quintiles (Statistics New Zealand, 2008). The Kāpiti District has the lowest median income in the CCDHB region and this may reflect the high number of retired people in this coastal area (Capital & Coast DHB., 2011; Statistics New Zealand, 2008). The HVDHB (population 141,500) incorporates Upper Hutt and Lower Hutt cities. One in 6 of Lower Hutt's residents are of Māori descent, while Upper Hutt has 1 in 7 Māori residents. Residents of both cities are on average older than those of Wellington, have fewer post-school qualifications and lower incomes (Statistics New Zealand, 2008). The WDHB (population 39,540) serves a large rural and semi-rural region. The WDHB cites demographic considerations in the provision of health services are its gradually declining and aging depopulation. (Wairarapa District Health Board, 2009). The Wairarapa region has the lowest median income in the Wellington region, low ethnic diversity and the lowest level of post-school qualifications (Statistics New Zealand, 2008).

AREA COMPOSITION

The three DHBs served by the WRRU align with TLA boundaries, except that only the south-western section of the Kāpiti District is included the WRRU catchment (Figure 9). Capital and Coast DHB serves residents of the major population centre of Wellington City, Porirua City and the coastal settlements of the south-west of the Kāpiti District, including the towns of Waikanae, Paraparaumu and Raumati. Hutt Valley DHB encompasses the cities of Lower Hutt and Upper Hutt and their

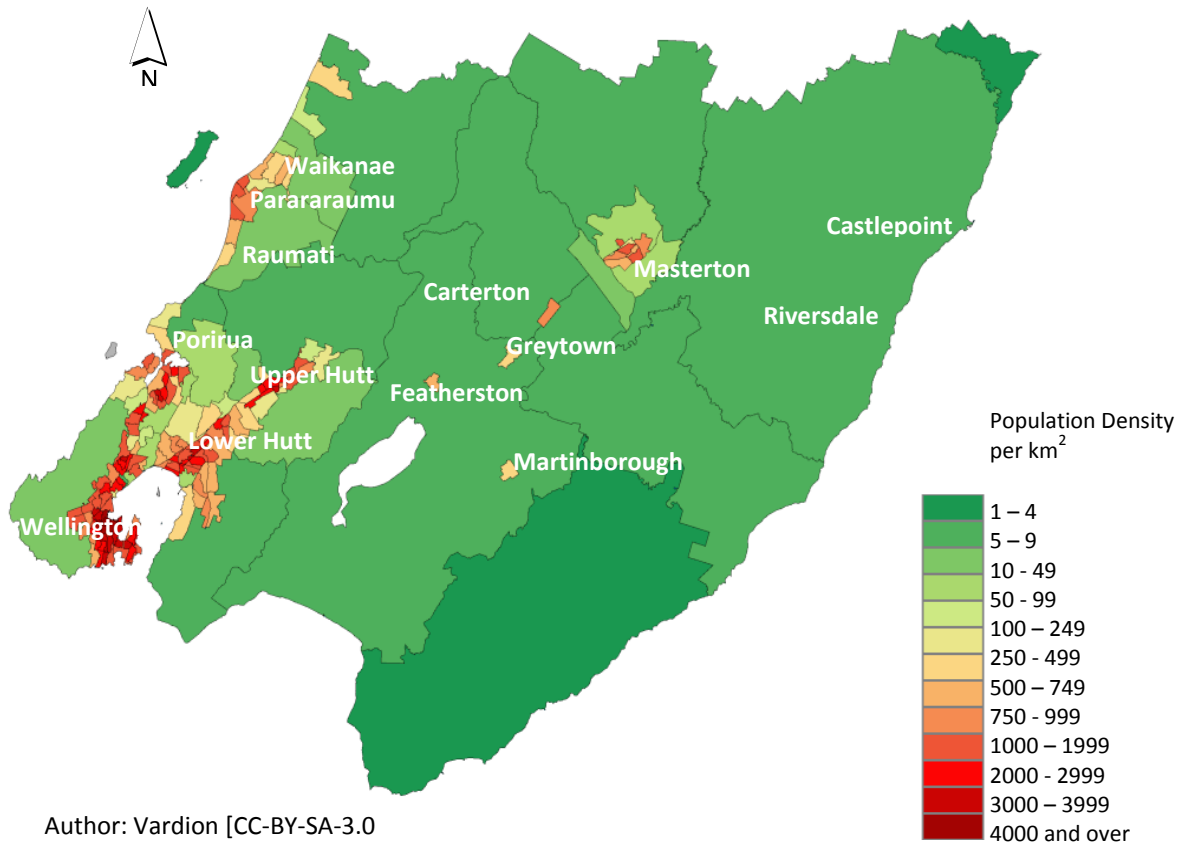
surrounds. The three districts of the rural Wairarapa region – South Wairarapa, Carterton and Masterton – are served by the Wairarapa DHB (Figure 10). Each area has distinct characteristics in economic, social and ethnic composition that affect the provision of health services.



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Figure 9: Wellington regions DHB and TLA boundaries

Data Sources: (Ministry of Health, 2006; New Zealand Transport Agency, 2011; Statistics New Zealand, 2006)



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Figure 10: Wellington Region's Population Density 2006
Data Source: (Statistics New Zealand, 2006)

AGE PROFILE

The age profiles of areas and PHOs focuses health concerns into sectors that are relevant to the local populations. Kāpiti has a significantly higher proportion of over 65 year-olds (25 percent) and this age group defines a significant high needs population compared to other areas, and a smaller working age population. (Kāpiti Primary Health Care Organisation, 2009). Wellington has the highest proportion of young working age populations, a group typically associated with low utilisation of health services (Ministry of Health, 2008b).

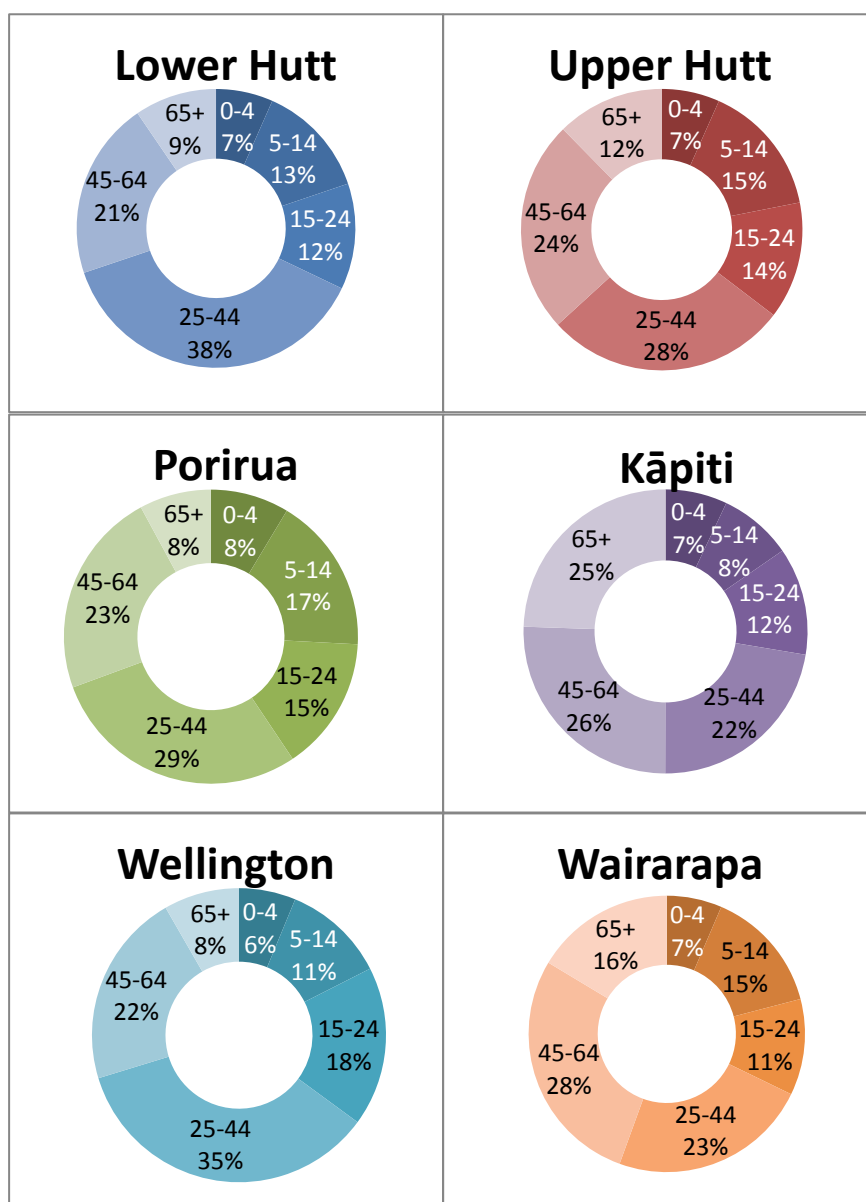


Figure 11: Regional age profile by Area

Data Source: (Statistics New Zealand, 2006)

FACTORING IN THE ECONOMY

As to be expected with the presence of the capital city in the region, public administration is an important contributor to the regional economy, contributing 9.5 percent compared with the national average of 4.5 percent. The largest contributor to the regional economy is the information media and telecommunications industry (9.9 percent), whereas primary industries contribute 0.9 percent. Due to the composition of economic activity, the Wellington region leads the country for employment in highly skilled occupations with approximately 40 percent of employment in this category (Figure 12) (Infometrics Limited, 2011).

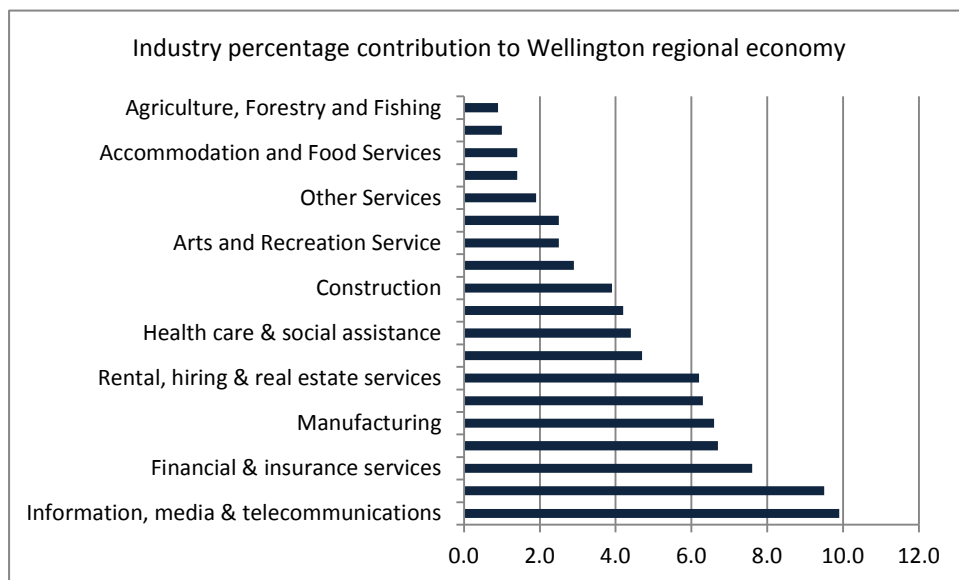


Figure 12: Industry contributions to the Wellington regional economy

Data Source: (Infometrics Limited, 2011)

The concentration of highly skilled industries in Wellington inhibits even distribution of benefits across the regions. Primary industry is the greatest proportion of the Wairarapa economy, Lower Hutt largest in manufacturing, the service sector mainly located in Wellington city, business services in Kāpiti and Porirua, and food and beverage industries in Upper Hutt (Infometrics Limited, 2011). The relative contributions of these industries are intertwined with the distributions of population characteristics. Wellington, for example has the most highly educated population in the region, reflecting its role in government and the greater proportion of highly skilled industries, whereas the Wairarapa population has the highest proportion of

school leavers without an educational qualification (Figure 13). These qualification levels and job skills also correlate to income levels (Statistics New Zealand, 2006).

SOCIO-ECONOMIC DEPRIVATION

The distribution of income levels in the region reflects the pattern of highly skilled employment and educational attainment. Wellington city has the highest incomes in the region (and in the country). The Wairarapa population has one of the lowest median incomes in the region, despite lower levels of government transfers than Porirua and Lower Hutt (Figure 14).

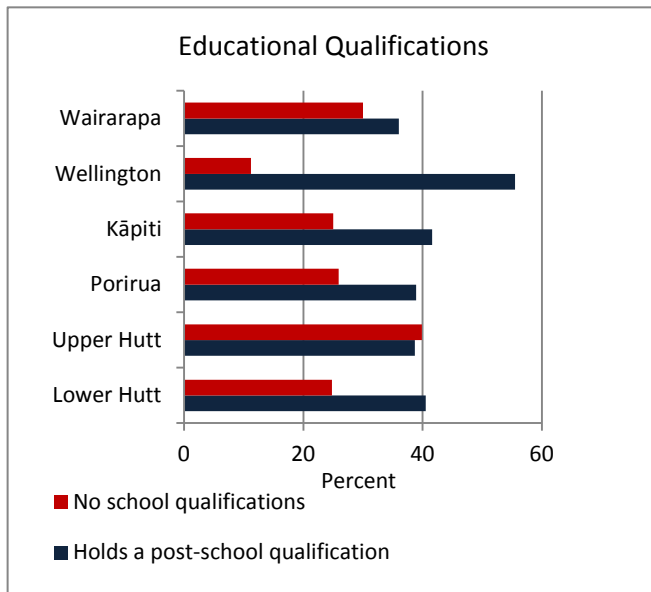


Figure 13: Educational indicators by Area

Data Source: (Statistics New Zealand, 2006)

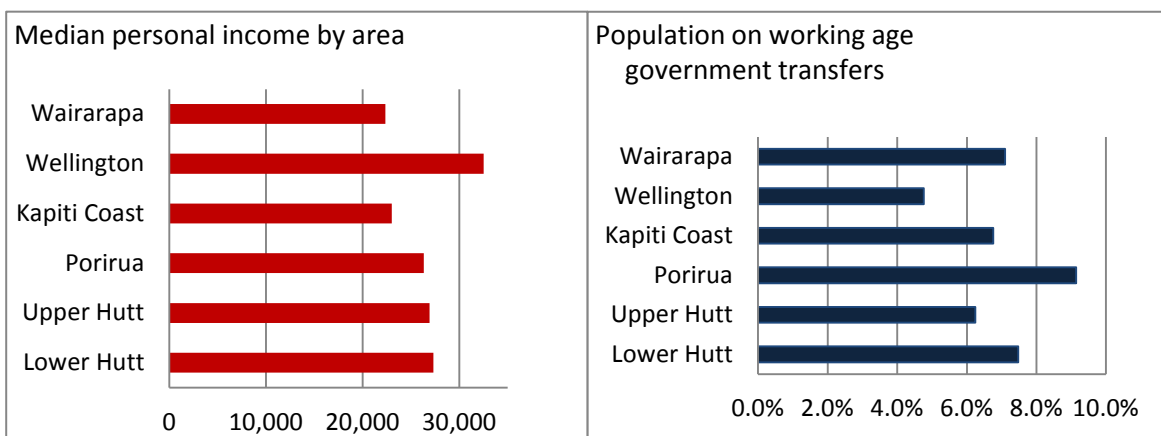


Figure 14: Indicators of relative financial resources by Area

a) Median income and b) The proportion of area population on working age government transfers

Data Source: (Statistics New Zealand, 2006)

Socio-economic deprivation in the Wellington region has an ethnic dimension. Porirua and Lower Hutt, with the highest levels of unemployment also have the highest proportions of Māori and Pacific peoples (Figure 15), who are over-

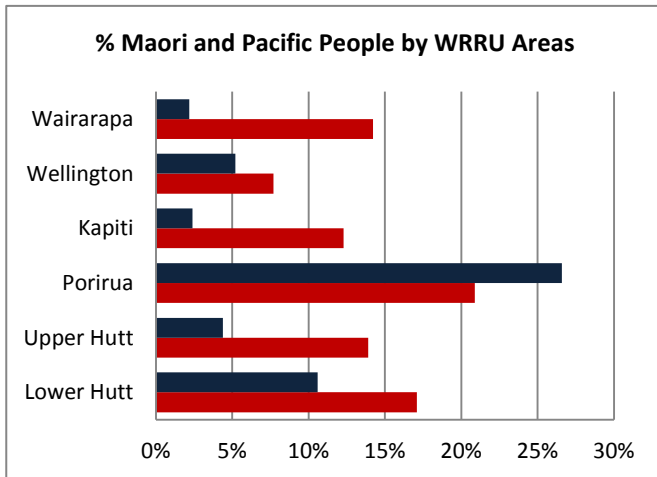


Figure 15: Proportion of Maori and Pacific Peoples by Area

Data Source: (Statistics New Zealand, 2006)

represented in unemployment and low income statistics. These statistics also have an age gradient, with youth unemployment being higher than other age groups. Porirua youth unemployment was highest in the region and lowest in Wellington and Upper Hutt. Kāpiti, despite low income levels also has a low proportion of deprived areas, with the distribution of Māori and NZ

European ethnicities in deprivation statistics proportionate to their populations. The low median income in this area can be explained by the higher proportion of over 65 year-olds (Kāpiti Primary Health Care Organisation, 2009). Lack of access to landlines is a poverty indicator relevant to accessing rheumatology services (appointments are confirmed or cancelled via landlines). Six percent of Wellingtonians do not have access to landline telephones, but this rises to almost one in ten without access to a landline in Wairarapa and Porirua (Statistics New Zealand, 2006).

Access to private transport is more complex. Wellington has the lowest car ownership in the region (15 percent of the households do not own a car) but the city has a compact form and is connected to good public transport (Greater Wellington Regional Council, 2010). The highest car ownership is Kāpiti with 92 percent of the population owning at least one private vehicle (Figure 16). Fewer than 60 percent of Wellington region's population lives within 400 metres of a public transport stop with a timetabled 30 minute service, and the distribution of the population is a significant factor in less access to public transport (Greater Wellington Regional Council, 2010). Variations in services suggest that Kāpiti, Wairarapa and the outer suburbs of areas such as Upper Hutt will have greater need for access to private vehicles to reach a rheumatology clinic. Socio-economic factors have an important association with poor access to health care, although this association is not absolute. The provision of health

services, geographic accessibility, cultural factors and other factors can intersect in area-specific ways to affect access to healthcare (Barnett & Barnett, 2004).

GEOGRAPHIC ACCESSIBILITY

Traditional access studies began with a focus that, to a large degree, analysed distance from services and the availability of transport

to reach those services (Ricketts, 2009). Because transport assistance in the Wellington region is not routinely provided for people with a single health condition, people are reliant on access to private vehicles and efficient public transport to attend appointments. Despite improvements in roading networks and high rates of private vehicle ownership geographic accessibility continues to be a barrier to healthcare (Brabyn & Barnett, 2004). Using a travel distance, travel time and GP to patient ratio algorithm to create a least cost path analysis (LCPA) for accessing GP care, Brabyn and Barnett (2004) found that only the small parts of the Masterton and South Wairarapa TLAs have long travel times using private transport, with between 500 and 2,000 patients having more than 30 minutes travel time to the nearest GP (Brabyn & Barnett, 2004). The population most likely to have extended travel times to the nearest GP are located in small coastal settlements (for example Castlepoint, pop <1,700; and Riversdale pop <1,000) and isolated farms (Statistics New Zealand, 2008). The cost and timing of public transport are as important as the transport routes to meet the needs of local populations. Limited public transport options is frequently identified as a limitation to healthcare services (Jaine, 2008). Access by private transport to the nearest rheumatology clinic is similar across the TLAs. The travel time by private vehicle to the nearest rheumatology clinic is within 40 minutes

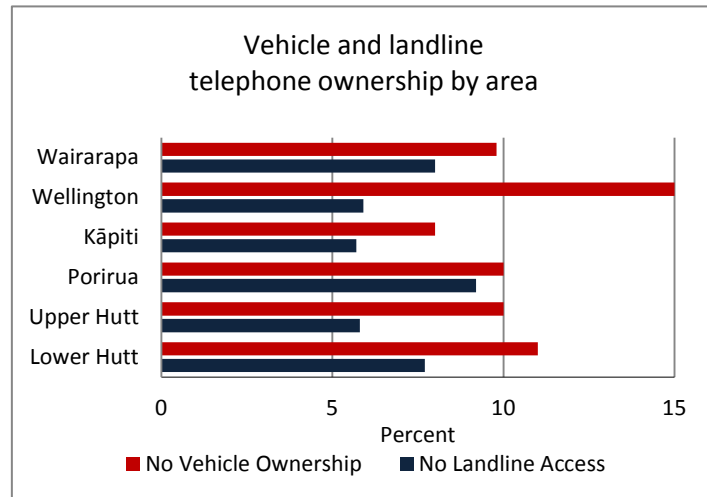


Figure 16: Households without private vehicles or landline telephones by Area

Data Source: (Statistics New Zealand, 2006)

across the region, with the exception of the remote Castlepoint, which is situated more than a one hour drive from Greytown.

Wellington, Lower Hutt and Kenepuru have regular public transport links to local hospitals. A disadvantage for individuals without private vehicles living away from these areas is that public transport links might be less frequent and less convenient. Wellington, Hutt and Kenepuru are well-served by public transport, but links from remote suburbs can result in travel times of more than an hour (Metlink, 2013). Links to Greytown for people relying on public transport are also difficult. Connections to Greytown terminate at the Woodside station, five kilometres from the town centre, with buses connecting the station to the town centre only at peak hours (Greater Wellington Regional Council, 2013b). The bus from the station terminates in the town centre, with a 1.5km journey to the Medical Centre to be completed by some other means.

TRAVEL TIME

Healthcare utilisation has been shown to reduce when travel time to services increases and this reduction is particularly important for the utilisation of secondary care services, preventative healthcare services and when an individual's condition affects mobility (Hiscock, Pearce, Blakely, & Witten, 2010). These factors are all potential barriers to care for individuals with symptoms of IA. The accessibility of local healthcare services has also been shown to have a marked effect on people's satisfaction with healthcare.

The distribution of primary care services may be a smaller factor in accessibility than for secondary services. Hiscock and colleagues (2010) tested whether the accessibility of neighbourhood primary care services affected healthcare utilisation and satisfaction in New Zealand. People in neighbourhoods in urban areas with the longest travel times were not less likely to visit a GP and undergo routine testing (in this instance blood pressure and cholesterol tests) than people in neighbourhoods with the shortest travel times. Travel time was not correlated with satisfaction measures. Further analysis indicated respondents with poor travel time access were less likely to visit a GP if they resided in smaller urban centres, rural centres and sparsely populated rural areas. The authors considered pro-equitable distribution of

services in areas of high socio-economic deprivation may mitigate the effects of longer travel times. Area deprivation is not correlated with longer travel times. This is illustrated by an earlier study of health-related neighbourhood resources by the same investigators, which found travel times to GPs in deprived areas is, on average, only 56 percent of the travel time to a GP in the least deprived areas (Pearce, Witten, Hiscock, & Blakely, 2007).

HEALTH CARE SERVICES

The New Zealand Health Strategy (2002a) includes in its objectives the reduction of health inequalities through a population health focus. Particular attention is paid to reducing health disparities for Māori and Pacific peoples, people with high needs through APHOs and special consideration of barriers to care for rural populations. These policy factors enabled health resources to be diverted to high priority areas and populations. The organisational structure developed to deliver on these objectives allowed for primary health care organisations to provide the interface between primary care and the DHBs that fund health services in the DHB area. People are encouraged to enrol in PHOs through reduced consultation costs for enrolled patients compared to casual patients, because health care access is thought to be facilitated by a primary care provider who knows an individual's medical history, is accessible and can coordinate care (Schoen & Doty, 2004). This strategy has been successful in encouraging enrolment with primary healthcare providers with 93 percent of the Wellington region's population enrolled in 2008 (Ministry of Health, 2008b). Hard to reach groups are, however, more likely to remain casual patients. For example in the CCDHB, despite 96 percent of the population enrolled in a PHO, in the most deprived deciles 9 and 10 enrolment has been achieved for only 80% of the population and almost one in seven young adults aged 18-24 were not enrolled (Capital and Coast DHB, 2009). APHOs cater for more Māori and Pacific peoples – between 10 and 20 percent of enrolled patients, than IPHOs where between three and seven percent are of Māori or Pacific ethnicity (Table 6) (Ministry of Health, 2009).

Table 6: Populations served by IPHOs and APHOs in the Wellington Region

PHOs	High (%)	Needs	Maori/Pacific (%)	Deprivation Decile 9-10 (%)
Independent PHOs	20.2		5.2	9.7
Access PHOs	73.6		16.7	48.7
Total Enrolled	25.5		6.3	13.5

Source: PHO enrolment collection Q3 2007 (Ministry of Health, 2009)

The explicit focus on population health disparities is evident in policies to improve access to primary health services in deprived areas (Ministry of Health, 2002a) and a decline in the unmet need for GP services reported in the New Zealand Health Survey periods (2002/03 – 2006/07) was attributed to this focus (Schoen, et al., 2007). As a result of these primary care changes, including the implementation of the low-cost APHOs, one in eight patients in the Wellington region reported that their last visit to a primary healthcare professional was free. Women and Māori and people from deprived neighbourhoods were most likely to have had a free primary health care visit (Ministry of Health, 2008b).

AREA CHARACTERISTICS

The implementation of the PHO structure has created cheaper access points for target populations, especially in Porirua, followed by Lower Hutt and Wellington, through APHOs, with increased consultation rates across almost all age and ethnic groups and increases in APHO consultations of over 20 percent between 2001 and 2005 (Cumming, Mays, & Gribben, 2008). However, despite an acknowledgement of rural areas also having priority status in the objective of improving access to primary care, Wairarapa did not have a low-cost APHO network in place. Kāpiti and Upper Hutt also did not have APHO structures to support priority populations, although local outreach clinics such as at Te Rangimarie Marae, Masterton serving the marae community on Tikanga Māori⁸ principles have been established by IPHO practices. The introduction of low cost access schemes in 2006 for IPHO practices with high proportions of patients with high needs is a partial solution to this problem, although the criteria for a maximum fee is \$17.00 for practices (compared to the usual \$10.00

⁸ Working within the generally accepted principles and behaviours of Māori life

fee for APHO patients) with 50% of the enrolled patients from high needs, Māori, Pacific or socio-economically deprived areas (Ministry of Health, 2011). The implementation of these low cost provider plans for IPHOs (where APHOs are not available) has led to increased utilisation of primary care by Māori and Pacific peoples, especially for children and adults aged 45+ years (Capital and Coast DHB, 2009), but identifying the high needs patients was difficult to accomplish in areas like Kāpiti (Kāpiti Primary Health Care Organisation, 2009). This is particularly so for Māori. The failure to identify individuals eligible for extra funding also reduces the effectiveness of secondary funds available to ensure people have practical access, like transport and disability services, on referral to secondary health services (Kapiti Primary Health Care Organisation., 2010). Funding to improve access for people with high needs is not generally available for individuals with an IA. The funding criteria specifies two or more chronic diseases as part of the inclusion criteria, despite a severe IA requiring significant health assistance that can exceed that required for a combination of illnesses (Rodenburg, Dryden, & Rodrigo, 2007).

The problem of identifying high needs patients was foreseen with the implementation of the primary health care strategy, with the potential for inequitable access remaining for people in in areas where socio-economic deprivation is spatially dispersed, because area-based funding formulations favour providers in areas that have concentrated socio-economic deprivation (Barnett & Barnett, 2004). The variation in prices across the region highlights the complex issues surrounding the financial resources of an individual and affordability of medical care. Patients enrolled at Porirua GP practices (the most deprived area in the region) are likely to pay the lowest fees regardless of income and PHO type in which they are enrolled. Patients from Upper Hutt and Kāpiti have less opportunity for reduced-fees access if they wish to visit a GP in their local area (Figure 17). This problem is exacerbated by increases in GP fees in IPHOs due to the diversion of funding to APHOs, which has meant that alongside a 20 percent reduction in fees for APHOs, IPHOs had fee increases of 12-16 percent since the implementation of the PHO structure (Cumming, et al., 2008).

The lack of low cost primary care outside of deprived areas (deciles nine and ten of the 2006 index), is of concern because several reports show multiple reasons for

delays other than deprivation, in seeking GP care, and middle income earners are amongst the most likely to delay a GP appointment because of cost. This is particularly the case for women. Māori utilisation of primary care services appears to be high, but whether this is because of poorer health, the improvements in accessible primary care for high needs groups, and/or some other cultural or social factor has not been adequately determined (Jatrana & Crampton, 2009).

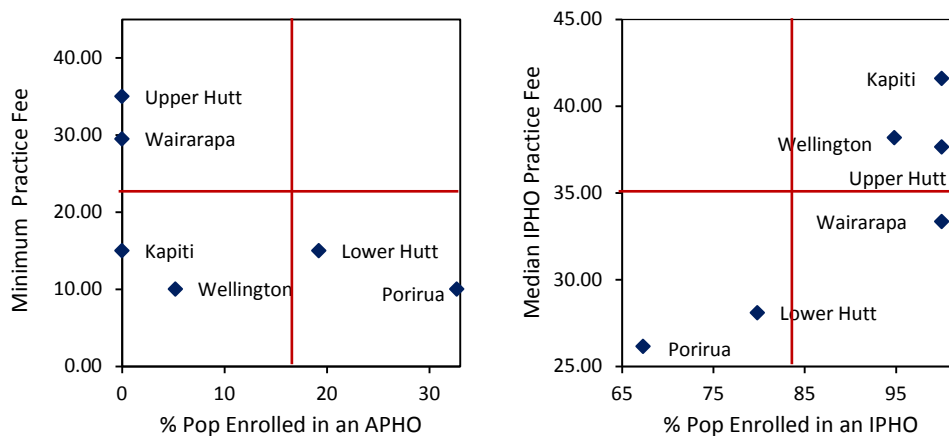


Figure 17: Relative costs of GP consultations by Area

(a): Relative minimum cost of GP consultation by local area for all GP practices stratified by the percentage of population enrolled with an APHO and (b): Relative median cost of PCHP consultation by local area for all GP practices stratified by the percentage of population enrolled with an IPHO.

Data Sources: (Capital and Coast DHB., 2010; Hutt Valley DHB., 2010; Wairarapa Community PHO., 2011)

CAPACITY LIMITATIONS

Of almost equal importance in explaining delayed visits was being unable to get an appointment when required. Women, Māori and deprived neighbourhoods were most likely to report not being able to get an appointment within 24 hours and the NZHS found approximately 1 in 12 Wellington region adults were unable to see a GP when required (Ministry of Health, 2008b). Delays in accessing GP care are likely to be exacerbated by GP shortages that have resulted in list sizes beyond the 1,400 enrolled patients the MoH considers a full-time workload (Medical Council of New

Zealand, 2007). Due to heavy workloads, GP lists may be closed to new patients, leading to greater cost, delayed appointments and inconvenience for local residents. Notable public concern about ‘closed books’ occurred in the Hutt Valley and South Wairarapa towns during the study periods (Appendix 6).

Apart from possible personal preference (for example to see a GP closer to the workplace) at least some of this travel is likely to be a result of GP shortages in these districts over the study period. Wairarapa towns have a GP to population ratio of between 1,500 – 2,343 (Brabyn & Barnett, 2004), and only Wellington City and Kāpiti have average GP to population ratios within Medical Council guidelines (Figure 18). Kāpiti, however, struggles with crowded appointment calendars due to a high proportion of part-time GPs and a large elderly population that requires up to 20 percent more time per consultation (Kāpiti Primary Health Care Organisation, 2009).

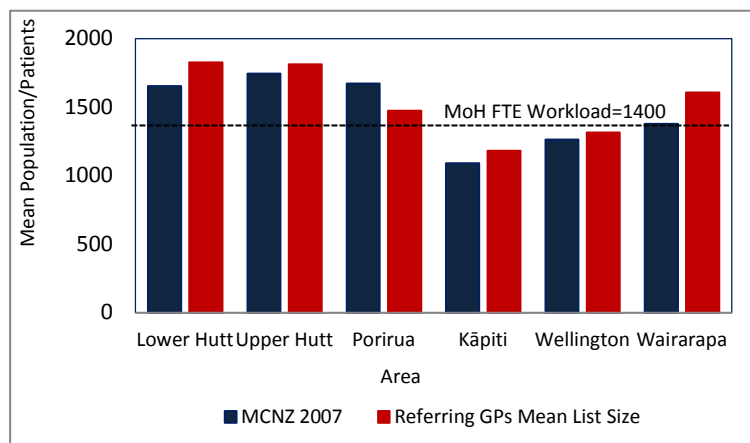


Figure 18: Population per GP by area.

Blue bars = FTE GPs/Area Population. Source: Source: (Medical Council of New Zealand, 2007). Red bars = mean list size of surveyed GPs

CHARACTERISTICS OF THE PRIMARY HEALTHCARE WORKFORCE

More than 60 percent of doctors working in the Wellington region were New Zealand medical graduates. Of the 40 percent who were international medical graduates (IMGs), more than 50 percent of IMGs had left New Zealand within 12 months of their New Zealand registration. This high turnover has obvious implications for continuity of care, and this was especially so for areas of high deprivation which

disproportionately employ IMGs (Medical Council of New Zealand, 2007). New Zealand trained GPs tend to be concentrated in larger, richer areas, with increased ratios of IMGs in areas that have higher proportions of low decile, Pacific Peoples and Māori. IMGs were significantly more likely to be referrers from APHOs ($p \leq 0.001$), with nine out of 10 IPHO referrals from New Zealand-trained GPs (NZMGs) compared with only one in 13 APHO referrals from New Zealand-trained GPs. The importance of cultural connectedness at an institutional level in effective access to health care (Barwick, 2000), is an important principle of the New Zealand Health Strategy and in the implementation of APHOs, which stress the importance of local, and culturally appropriate healthcare solutions for local populations (Cumming, 1999). Rheumatology services administrative data indicate that cultural differences between IMGs and New Zealand populations do not impact on GP referral rates. There were no significant differences in the number of referrals from NZ medical graduates and IMGs ($p=0.53$), or between medical graduates whose first language is English and those whose first language was not English ($p=0.51$). Several factors readily present as speculative reasons for similarities in referral rates of IMGs: the influence of integrated care practices on GPs operating within APHOs; better IMG training in detecting rheumatological conditions in their home countries; some interaction between the higher rates of GP visits for high needs individuals and the possibility that IMGs may refer sooner if they are not clear about how to manage the patient in primary care. The lower cost of care encouraging more frequent GP consultations may also provide an increased opportunity for APHO GPs to detect an IA in populations targeted in the APHO model of care.

Individuals were not always referred to rheumatology from the areas in which they lived. There is no bureaucratic barrier to individuals enrolling in whichever GP practice they wish and GPs are not obliged to enrol patients in their local area, although referred patients generally enrolled with a local GP practice. The greatest discrepancy was the 10 percent of patients referred from Porirua GPs domiciled outside of the Porirua area. Probable reasons for seeing a GP outside the domiciled area may include TLA boundaries not reflecting the local neighbourhood with patients possibly living nearer to a GP practice in the adjoining TLA. This is especially likely in part of the boundary area between Porirua and Wellington, where the

boundary is marked by suburban roads rather than significant geographic features.

Other reasons may be a preference to have a regular GP near the place of employment and this may account for the lower referral rate from the dormitory area of Kāpiti where one-third of the 5,000 plus workers commute to the larger cities for work (Statistics New Zealand, 2006). A more problematic reason is GP shortages in the home area. The practices (Table 7) and GPs (Table 8) included in the study had similar characteristics and practice spatial profiles to the main populations of GPs and practices, but had referred significantly more patients.

Table 7: GP practices comparisons

Variable	All Practices		Study Practices		p-value
N	105		57		
All referrals (mean)	22.7		26.3		.34
IA Referrals (mean)	7.1		8.2		.32
DHB	N	%	N	%	.91
HVDHB	29	27.6	15	26.3	
CCDHB	69	65.7	37	64.9	
WDHB	7	6.7	5	8.8	
PHO Type					.46
IPHO	92	87.6	52	91.2	
APHO	13	12.4	5	8.8	
Area					.99
Lower Hutt	24	22.9	12	21.1	
Upper Hutt	5	4.8	3	5.3	
Porirua	14	13.3	7	12.3	
Kāpiti	9	9.0	6	10.5	
Wellington	46	43.8	24	42.1	
Wairarapa	7	6.7	5	8.8	
Practice Size*	(100)				.96
Small (1-3 GPs)	75	71.4	42	73.7	
Medium (4-6 GPs)	14	14.0	9	15.8	
Large (>6 GPs)	11	10.5	6	10.5	

*(Medical Council of New Zealand, 2008)

Table 8: Comparison between the population of referring GPs (All GPs) and the GPs included in the study sample (Study GPs)

Variable	All GPs		Study GPs		p-value
N	353		140		
Mean IA Referrals	2.0		2.4		.02
Median IA Referrals	2.0		2.0		
Std. Deviation	1.8		2.1		
Range	10		9		
Years Qualified					.98
Mean	23.7		23.5		
Median	23		24		
Std. Deviation	9.4		8.7		
Range	51		51		
	N	%	N	%	
Gender					.65
Male	179	50.7	74	52.9	
Female	174	49.3	66	47.1	
Medical Degree Origin*					.97
New Zealand	238	67.4	96	68.6	
Other English Language Country	68	19.3	28	20.0	
Non-English Country	47	13.3	16	11.4	
GP Location					.15
HVDHB	103	29.2	28	20.0	
CCDHB	227	64.3	100	71.4	
WDHB	23	6.5	12	8.6	
Area					.36
Lower Hutt	76	21.5	19	13.6	
Upper Hutt	27	7.6	9	6.4	
Porirua	48	13.6	19	13.6	
Kāpiti	32	9.1	20	14.3	
Wellington	147	41.6	61	43.6	
Wairarapa	23	6.5	12	8.6	
PHO Type#					.75
Independent	317	89.8	125	89.3	
Access	36	10.2	15	10.7	

*(Medical Council of New Zealand, 2008)

(Ministry of Health, 2009)

PROVISION OF RHEUMATOLOGY SERVICES

The Hutt Valley DHB is the provider of rheumatology services for the Hutt Valley, Capital and Coast and Wairarapa DHBs and it does so via the hub located at Hutt Hospital and outreach clinics located in Wellington Hospital, Kenepuru Hospital (Porirua) and Greytown Medical Centre, a GP practice in the Wairarapa. Rheumatologists based at Hutt travel to these outreach clinics to provide diagnostic and management services for the local populations. The agreement between the three DHBs that provide for the WRRU service, measures the proportion of new referrals per DHB population as an indicator of appropriate service levels (Wilde, 2010). Agreements for regional services are important to maximise the use of scarce skills and resources and to improve access for DHBs with small populations that would otherwise find these skills and resources difficult to provide (Ministry of Health, 2002a). Administrative data indicates that the condition of the agreement for proportionate referrals is broadly equitable ($p=0.20$).

The WRRU rheumatologists' clinic hours are not distributed evenly across the region. The bulk of clinic hours (70 percent) are worked at Hutt, since most urgent and complex cases are seen at the in-patient and day-patient facilities located at the Hutt clinic, as are the rheumatologists' offices. A quarter of rheumatologist hours are divided almost evenly between Kenepuru and Wellington and the remainder are worked at Greytown.

At the time of data collection the WRRU area had one FTE rheumatologist for every 207, 890⁹ people, well below the UK service level recommendation of one FTE rheumatologist for every 85,000 people (Harrison, 2004) . On a population basis, Wellington is the area most poorly served by public rheumatology services, followed by the Wairarapa District (Figure 19). Given the composition of the Porirua populations a high level of service at Kenepuru is an important fit with the New Zealand Health Strategy to ensure accessible services for Māori, Pacific and socio-economically deprived populations.

⁹ Recent unpublished analysis in 2012 showed an improved figure of 188,280.

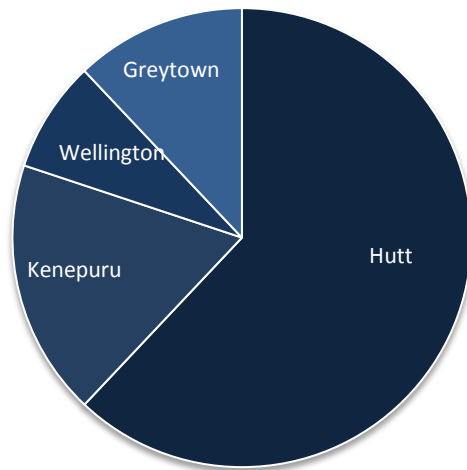


Figure 19: WRRU Clinic hours proportionate to Area population

Over the two-year study period, one in three of the 3,263 patients referred to a rheumatologist in the Wellington region was, at FSA, reported as having symptoms consistent with an IA. GPs in the Wellington region referred 695 of these patients, giving a referral rate per GP of 1.6/1,000 enrolled patients¹⁰ (range=0-10.9; $p \leq 0.001$ ¹¹). Despite referral variations by area, the number of referrals on a population basis from each DHB to the public rheumatology service does not vary significantly ($p=0.11$). This fulfils the criteria for access to the WRRU in the service agreement between the three regional DHBs.

The most extensive not-for-profit primary care networks were located in Porirua, and Lower Hutt, with none existing in the Wairarapa or Kāpiti regions. The referral rates from APHOs did not significantly vary from IPHO referral rates ($p=0.22$). On a population basis new referrals were approximately 90 per 100,000 of population per year. These were relatively evenly distributed by DHB ($p=0.28$) and Area ($p=0.61$) (Figure 20)

¹⁰ The referral rate for All IA referrals from the Wellington region, was 1.7/1000 enrolled patients, or 1.5/1000 of the total regional population, per year.

¹¹ One-sample Kolmogorov-Smirnov Test

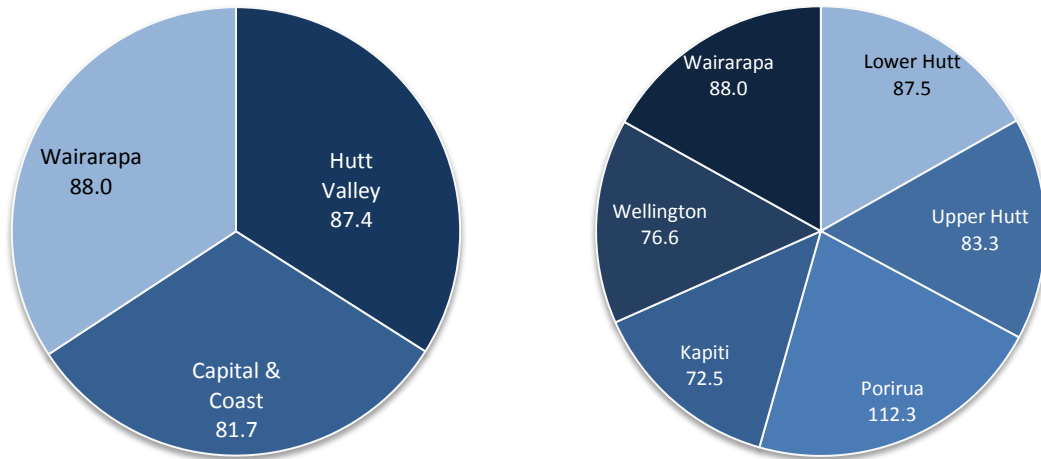


Figure 20: IA referrals per 100,000 population by DHB and Area

PRIVATE HEALTH CARE

It is likely that higher incomes may facilitate greater access to private health insurance and may affect Wellington patients' referral choices. Over half of Wellington City patients are referred to private rheumatology clinics (Figure 21). Approximately 37 percent of people living in Wellington City have private medical insurance compared with a national average of 30 percent and this could account for a greater propensity to seek specialist advice from private rheumatologists (Styles, 2008). Wellington patients were significantly more likely than those from other areas to be referred to a private rheumatologist ($p \leq 0.01$ OR=2.67 CI 95%=1.8-3.94). Possessing private medical insurance is not the sole reason for private rheumatology care – Participants cited the length of waiting time in the public system and choice of specialists as reasons for choosing a referral to private care (Chapter eight, Table 31). Aside from the cost of private care, private patients without insurance paid \$15 per prescription item compared to \$3 per item when prescribed by a GP or a public rheumatologist. Unaffordable private care for non-insured patients led to the transfers from private care to the public system after diagnosis. Patients from Kāpiti, which does not have a local public rheumatology service, but does have a local private outreach clinic, were twice as likely to have been referred to a private specialist as Lower Hutt patients ($p=0.01$ OR=2.19 CI 95%=1.23-3.39) which has local access to both public and private services. Private rheumatologists in the Wellington region are located at two specialist medical centres in Wellington City and two in Lower Hutt, with a smaller visiting service in Kāpiti.

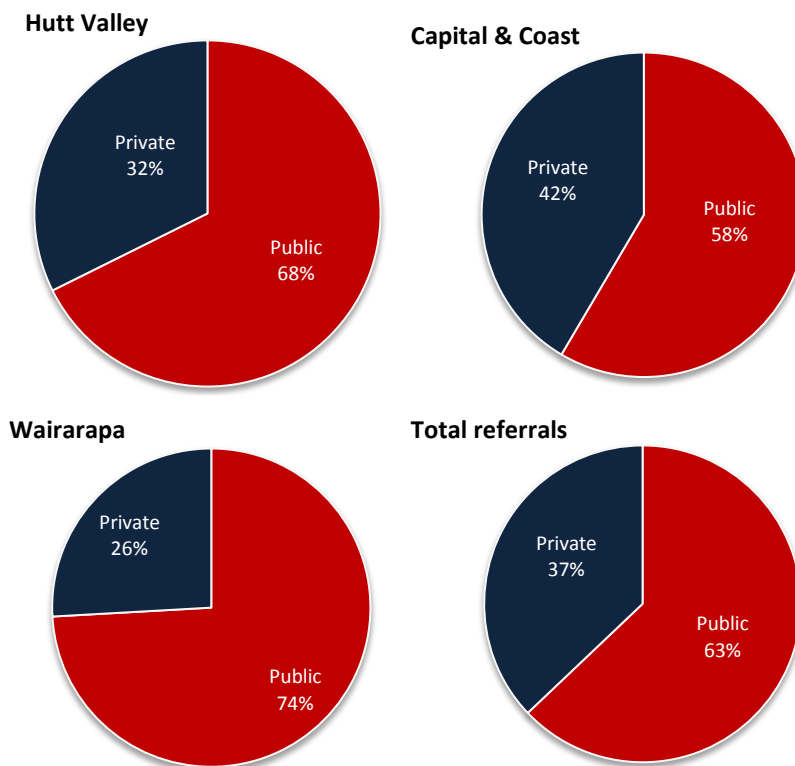


Figure 21: Proportion of Public and Private IA referrals by DHB

DISCUSSION

Conceptualising place in terms of structural constraints, opportunities and resources (Frohlich, et al., 2006) for individuals to access rheumatology services provides a setting for people's actions in accessing rheumatology services in the region. Each area in the Wellington region has unique concerns in the provision of health services for their unique population characteristics (e.g. from concerns about GP shortages in Upper Hutt and Wairarapa, to the cost of care in Wellington and Kāpiti and access for large ethnic minority and socio-economic disadvantaged populations in Lower Hutt and Porirua).

Area characteristics of primary healthcare services illustrate the barriers to early diagnosis given by IA participants, and the availability of GPs and rheumatologists at easily reachable places defines area level constructs. Adequate service level can be measured by, for example, the number of doctors and the proportion of population registered (Gulliford, et al., 2002). GP shortages and the cost of GP services are multi-

faceted issues that differentially impact on the areas of the Wellington region. Area effects depend on the composition of the local population – socio-economic status and the ability of the area to attract GPs. The price of primary care services is an independent factor in the availability of GP services. Variation in the availability of GPs is unlikely to account for delays in accessing rheumatology care due to the rate of IA diagnosis in each area. However GP decisions may account for delays in timing a referral, which cannot be measured using area data. Despite the quite different issues in the provision of GP and rheumatology services there is little variation between DHBs in the proportion of people diagnosed with an IA ($p=0.48$), or between APHOs and IPHOs (IPHOs) ($p=0.64$).

Economic data would suggest that Porirua, Wairarapa and Kāpiti are the areas that are most at risk of poor access due to cost, and Māori and Pacific Peoples are the ethnic groups that would have greater problems accessing rheumatology care. However referrals data indicates referral rates are proportionate to area populations. An important factor in improving access is the implementation of funding to reduce primary care fees. This has led to increased utilisation of primary care by Māori and Pacific peoples, especially for children and adults aged 45+ years (Capital and Coast DHB, 2009).

Poor servicing of secondary health needs in rural areas is an entrenched factor in New Zealand health delivery that has been exacerbated by restructuring of health services in the mid 1980s that led to hospital closures and redistribution of services. The introduction of market disciplines to reduce costs and provide services within fixed budgets supported the rationalisation of health services (R. A. Kearns & Joseph, 1997). The establishment of the Wellington Regional Rheumatology Unit at Hutt Hospital pre-dates the concentration of services in the urban areas and provided an essential service, with the two available rheumatologists in the regions establishing the protocols for service runs into the Wairarapa in 1968. The establishment of the WRRU is underscored by DHB cooperation to provide essential rheumatology services (Tweed, Treadwell, Corkill, & Corkill, 2013). The development of the WRRU provides a number of advantages valued under the health policy approach of providing efficient health services by reducing duplication of resources across the region and by creating tangible and intangible benefits of collegial relationships

between rheumatologists located in the same workspace. One notable disadvantage of a regional service is that the distribution of clinics and specialist time in each DHB does not favour good accessibility or responsive services for people in areas of dispersed population. The compromise between rheumatologists' and patient travel time in the Wairarapa highlights the tensions between service efficiency, which makes the best use of health specialists' time and responsive delivery which maximises patient accessibility (Tudor Hart, 2010), with the WRRU clinic located in the small southern Wairarapa town of Greytown, rather than in the DHB hospital in the more populous centre of Masterton.

The census and NZMA data shows that the rural Wairarapa District, based on total population and the age and socio-economic profile, is underserved by primary health care providers and rheumatology services. Transport links to rheumatology services in Wellington, Lower Hutt and Porirua. Kāpiti, Wairarapa and some areas of Upper Hutt are less well-served and patients are likely to have a high reliance on private transport for efficient travel to rheumatologist appointments. The incorporation of geography, area composition and health services data into the study enables the expression of differences of referral experience between individuals who otherwise might be expected to have similar referral patterns to be explored and provides the canvas for interpreting the IA participants' narratives.

9. ONSET OF SYMPTOMS

INTRODUCTION

Few studies have sought to enquire into why people with symptoms of an IA condition might delay seeking medical advice. Rheumatic conditions associated with the most chronic destructive disease have some of the longest delays to assessment at rheumatology clinics (van der Linden, et al., 2010). In 2008 Sheppard and colleagues reported on a qualitative study they had conducted to discover factors that might explain why people delay presenting with EIA symptoms to a GP in an inner city Birmingham clinic. The results of their study of 24 patients with early rheumatoid arthritis suggest symptom evaluation by the patient was the key factor influencing how quickly medical advice is sought. Symptom evaluation included perceptions of the significance of the symptoms and personal explanations for the onset of symptoms. Other indicators of delayed presentation were knowledge about RA and its treatment, how the symptoms impacted on physical ability and attitudes towards, and experiences of, GPs and the health system (Sheppard, et al., 2008). The Birmingham interviews also suggested help-seeking behaviours might be mediated by cultural factors and this was explored in a study of the South-Asian population, who frequently had long delays between symptom onset and presenting to a GP. The qualitative interviews attempted to tease out some of the reasons for this influence. Cultural beliefs, explained in terms of religious beliefs, and social ties were identified as influential in accessing medical advice. Members of this group would often seek advice from family and friends to evaluate symptoms and establish a course of action to resolve their condition (Kumar, et al., 2010).

The purpose of this chapter is to establish the path participants took from onset of IA symptoms until consultation with a GP. This information is derived from the participants' descriptions of onset of symptoms and the factors they took into consideration when determining a cause, and a course of action. This study is indebted to the work of Sheppard and colleagues (2008) whose work on patient decision-making processes for GP consultation defined the categories of onset experience, IA knowledge, symptom evaluation and response that are reproduced

here, with additional thematic descriptions from participants' narrative of the path to GP consultation.

The enabling conditions and barriers to consulting a GP are complex and considered in three categories that interact to form the responses to symptoms – knowledge of IA, symptom experience and symptom evaluation. Within these categories participants' experiential context is discussed.

The chapter also reports on the response to symptoms by the participants in the study. The availability of financial resources and differences between areas, as outlined in the previous chapter, that can account for differences between participants are discussed. The social identities of the participants are shown to affect the health models and responses to symptoms.

ONSET EXPERIENCE

Participants had little information about IA before symptoms developed. Of the 22 IA participants interviewed only two were aware that they may have had an IA. For the majority of participants IA was not an option that was considered during a self-assessment of symptoms. The reasons for not associating MSK symptoms with an IA condition are summarised by Stephen as no observable knowledge of an IA, a belief that IA was a disease of old age and a lack of publicity about MSK conditions.

“Because arthritis, I associated [it] with an old person's disease... I often wondered why I had [pain] no-one else seemed to have it, complaining of these on-going joint issues. And of course you never saw any, like now you see people on TV talking about joint pain and that sort of thing, you know those sorts of advertisements for voltaren emulgel, so it's more awareness.”

Stephen (onset under 20 years old)

Only one study participant thought, at onset, that an IA might be the cause. Marie was aware she had IA, in part because a work colleague suggested this might be the case:

“I wasn't actually diagnosed but I knew I had it. I started to get sore. That was probably 8 years ago...I didn't know which one it was because I'd never been tested. But I knew that it was arthritis.”

Marie

Stephen talked about the advertising of inflammation relief medications as improving public knowledge of the condition, but as Marie's experience suggests, it is entirely likely that these advertisements could lessen the likelihood of consulting with a GP once IA symptoms have been acknowledged. Moreover participants with recent onset did not indicate that recent increases in advertising of products for relief of inflammation, or any other educational programmes or news helped their awareness of IA or their decision-making.

Participants were all unaware of what treatment options were available for IA so beliefs about the DMARDs appeared not to be a factor in delaying consultation with a GP. However, among this study's participants, the availability of NSAIDs without prescription resulted in delays in consultation in some cases (Table 9). Conversely, an expectation that anti-inflammatories would be prescribed, especially if they were not well-tolerated, could also deter seeking advice from a GP:

Table 9: Effect of availability of NSAIDs on delay

Participant	Comment
Kim	"I had had an anti-inflammatory - my husband was taking some and I took some of his and they were great. "
Marie	"My joints were sore and stuff like that so I would just take voltaren. Self-medicated, as you do, which seemed to do the trick but. And it didn't get really, really bad up until a year ago."
Philip	"Well like I say the conventional medicine said anti-inflammatories. I tried them several times and decided that the cure was worse than the disease because I just felt terrible."

IA KNOWLEDGE

A family history of IA may provide a basis for understanding symptoms and establishing a path to treatment. For participants who had immediate family with currently diagnosed IA, family history was a driver to seek care. Ten participants had a family history of IA but for only one participant was the first GP consultation due to IA in the family. Two participants discovered, after symptom development and unsuccessful GP consultations, that siblings had been diagnosed with an IA and used this knowledge as the basis for a new GP consultation (Table 10).

Table 10: Family History as a driver for GP consultation

Participant	Age at Onset	Comment
Brian	20-24	"My brother, who was an ankle sprain [ASp] sufferer, he kind of saw the warning signs there. Because I'd been to the doctor quite a few times about it and they called it kind of sciatica and stuff like that. So he kind of saw the warning signs and made me go to the doctor and stuff like that, [brother went with him] and explain to him this is what I've got so there is a good chance that he might have it. And sure enough sent me to a specialist and away I went."
Alex	16-20	"It had been going for about 3 or 4 weeks, maybe longer and my mum noticed I'd been limping and bits and pieces so I went off [to GP]... My sister I think was 14-15 when she was diagnosed with it in her elbows...I'm pretty sure my mum has it, and dad has psoriasis."

Brian's comment expresses a keenness to get symptoms diagnosed. Participants did not express denial when members of their social or family network suggested their symptoms might be IA-related. The reverse was often true – they were relieved to have an explanation that might allow them to take positive steps to relieve pain and their emerging disability. There appeared to be little understanding in families of the significance of the symptoms. At best there was simply an observation of IA in others without inquiry of explanation (Table 11).

Table 11: Knowledge of symptoms

Participant	Age at onset	Comment
Louise	40-44	"I remembered people who had had arthritis, older people, but I just expected everything to start gnarling up you know that kind of thing... When the doctor first told me that he thinks I have arthritis has anyone in my family. 'well not that I know of'... So I said to my parents, I said 'did anyone in our family have arthritis?' mum is 'oh no I don't think so' dad is 'no' ... A couple of months later I saw them and mum says 'what are you hobbling around for?' 'I've got arthritis mum'. 'oh your grandmother had that' dad's mum'. And I remember her [grandmother] sitting there, she's not one to moan and groan but there was a time when she would sit on the couch with her legs up and y'know not moving around – she was usually quite active and dad goes 'oh yeah, my grandmother – her mother had it quite bad'. He said her hands were all twisted."
Catherine	55-59	"Yeah, if I'd thought that was what it was [RA] I would have done something earlier, but it just never occurred to me that that's what it was. I think if it had probably come in the other shoulder at the same time, perhaps then. But it was just the one shoulder."
Michelle	20-24	"I didn't realise there was any [IA in the family], and I found out later

Participant	Age at onset	Comment
		on there was... I actually found out that my [great-aunt] was riddled with it so it was somewhere along the line. Because when you say arthritis most people think of the 'wear and tear' one but this erosive one um is a bit more different."

Louise and Michelle's connections to IA were a generation removed and the potential significance was not considered or spoken about in the family. Catherine's mother, who had died before Catherine's own symptoms began, had IA develop in a similar, although not identical pattern, and in common with other participants with a family history of IA pain and other symptoms, the disease was not often discussed and not fully understood:

"All my mother took [for RA] was panadol. Panadol and tiger balm for the headaches. She had severe headaches. And she was on about 12 or 16 panadol a day. She used to have the occasional injections. ... I knew she was in terrible pain, until I had it myself I didn't understand the severity... but I knew how much pain she was in and also the limited mobility she had... and I look back on it now and if she was in the amount of pain I was in I don't know how she survived, she never complained, not really, ... but if she was going through the pain I was going through she was amazing."

Catherine

Other participants' comments support the view that IA is often a hidden condition (Table 12). The poor transfer of family knowledge about IA was explained in terms of stoicism and denial in the earlier generation.

Table 12: Attitude to IA symptoms - family experience

Participant	Age at Onset	Comment
Zoe	20-24	"And my father I'm pretty certain had it... he was a big man and being a farmer you just thought he was carrying the weight of the world, you know? ... He wore a very wide copper bracelet. The old cure."
Stephen	15-19	"My father has it, though he says he doesn't but he does. He was in hospital about a year ago getting plaque scraped off his vertebrae so he could actually move again. He talks about being hospitalised in his teens from a flare-up, they didn't know what was wrong with him... I watch him get out of a chair and he gets out of a chair like I do... he never mentioned [pain]."
John	35-39	"But anyway they were pretty stoic back then, my grandma and my nana would probably lose a leg and carry on. So yeah I think back then if they got sore, they got sore, there was no point moaning about it."

SYMPTOM EVALUATION

Participants who had a perceived rapid onset of debilitating pain rapidly sought medical care. Three participants described an acute onset of symptoms that led to immediate contact with a medical practitioner (Table 13).

Table 13: Descriptions of acute onset of IA symptoms

Participant	Age at onset	Comment
Lisa	20-25	"I woke up one morning and I just fell flat on my face because my legs were just in pain real bad. And then I got down to the doctors."
Martin	30-35	"I just woke up one morning crippled basically. It just hit. Overnight I woke up in the morning and I literally couldn't get out of bed. I couldn't open the door, I couldn't drive a car."
Patrick	25-30	"I woke up one morning and my knees had blown up like softballs and my back was aching, so I went to hospital."

Further discussion with participants revealed that symptoms of IA typically began with an insidious onset. In all of the cases of acute onset the respondents had had at least one previous episode of IA symptoms. These ranged from MSk discomfort that did not trigger a concern that the discomfort should be evaluated by a medical professional to a resolved episode of an IA with the respondents being symptom-free for a number of years.

Participants often framed their symptoms in terms of injury or over-use; as a physical, not a medical problem. Within this paradigm participants' response to symptom onset was in the first instance to wait and see if the symptoms resolved. The length of this initial wait time and the response to persistent symptoms reflects both experience of previous MSk problems and attitudes to pain and disability. Table 14 illustrates how people use their previous experiences of physical stress and injury to explain MSk symptoms. The main concession to pain was to ease off on activities, and a clear pattern emerged where medical help was sought not because of pain itself, but because the participant was no longer able to continue with day-to-day activities.

Mental toughness or stoicism and the ability to be physically strong and active were highly valued and a source of pride. The comments of the men in particular show how important physicality was as an explanation for delays in seeking care for symptoms.

The values associated with mental and physical strength, agility and an ability to withstand pain can be seen as culturally-driven. Stephen and Philip both specifically drew on a New Zealand cultural meme to explain their actions in ignoring IA symptoms, and other participants believed they may have been pushing themselves too hard by continuing with physical activities they thought they should have retired from.

When symptom onset localised respondents were able to rationalise their symptoms in terms of their age, overuse of the affected area or as an injury. These explanations delayed seeking care because experience had taught them that they can recover from injury or overuse by themselves, or that it was no different from previous episodes when they had been referred to physical therapists (for example physiotherapists, podiatrists or osteopaths) by their GP. For these people previous experience reinforced the notion that pain would go away if they cut back on their activities and gave their bodies time to recover:

“You know how you get those little things... anyway I went [on holiday] and um they were pretty sore, both feet then, had swollen a lot and everything and I just couldn’t figure it out so thought oh well. I’ll just take it easy.”

Louise

For participants with a more gradual onset, contacting a GP was only considered after an indeterminate time was spent waiting for the symptoms to resolve. Men frequently spoke of the symptoms that resulted in GP contact in terms of an inability to carry out tasks and women more often highlighted pain. Although men and women equally as often took a wait and see approach before seeing a GP they did so in different ways. The eight men in this study sought advice from a GP first. For six of them this was because their condition prevented the carrying out of valued activities. Women, on the other hand, often chose to seek advice from physical therapists rather than GPs (Table 14).

Table 14: Symptom onset - beliefs and response

Participant	Delay - onset to GP	Beliefs about Symptoms	Initial Response	Symptoms leading to seeking medical care
Martin	More than 2 years	“When I look back on it I probably did notice, like I was doing everything like playing indoor basketball, running cross country, windsurfing, surfing, and I noticed when I was wind surfing I did get sore feet sometimes but I just thought, you know, I put that down to old age. Yeah just overuse basically.”	“Well it wasn't worrying me enough to go to the doctor. As I said I was running cross country at a competitive level, windsurfing, working 24/7 and just doing pretty well.”	“No I just um woke up one morning crippled basically it just hit. Overnight. I woke up in the morning and I literally couldn't get out of bed. I couldn't open the door, I couldn't drive a car. “
Mark	More than 2 years	“Occasionally – ‘oh I haven't been [doing job] for a while ooh. I'm getting a bit of a sore wrist, I'll take some panadol' and it was the same running up and down hills. When I was 32 or something I could beat 19 year olds up a hill. It didn't slow me down. But it might have – Yeah, everything's down to work things.”	“If I did it too much there might have been a little bit of resistance but I never took any notice of it. And ah y'know I just carried on from there.”	“I was having trouble with my fingers. I couldn't spread them anymore.”
Stephen	More than 10 years	“... and I thought 'must have just strained it', because I used to do a lot of running just for keeping fit for rowing and keeping fit for rugby and I used to be an active harrier, I used to belong to a harrier club so you thought, oh probably just pulled something so you didn't worry about it.”	“I could be classed as a bit stoic. And you're bought up where boys don't complain about pain and that sort of thing, get those sort of societal norms, shall we say, and so you just, you know I played rugby and rowed and did all those sorts of sports when I was younger and you learnt to take the knocks. It was part of the macho ethic. You weren't expected to complain.”	“I could see physical evidence of something rather than just the underlying pain in my joint... there was actual swelling. I [also] started to notice it was very difficult to get out of the bed in the morning, back pain and peripheral joint pain.”
John	6 months	“I never thought of any sort of disease it had to be a physical injury because all my life I've never had anything wrong with me only physical stuff, broken things that sort of stuff so it had to be one of those really ... I was still running back then but running was getting slower and harder and worse that's why I thought when my foot started going it must be the running.”	“I didn't worry too much about it and carried on, but in hindsight it all sort of all adds up.”	“A couple of times I'd woken up and just couldn't move in bed, I was in so much pain, I thought it was shockingly bad cramp or something during the nights and one day I woke and both legs were absolutely aching I couldn't do much about it, couldn't get out of bed at all.”

Participant	Delay - onset to GP	Beliefs about Symptoms	Initial Response	Symptoms leading to seeking medical care
Philip	More than 2 years	"But it was a weird one because it was just, um I didn't know I had it but one day I just looked at my finger and I noticed it was bent and odd. And I didn't notice when that had happened."	"I just sort of tough things out... You don't sit and complain about having to do something you just rip in there, the kiwi can do thing, and particularly males that slightly macho - well it's all bullshit - but you end up wanting to project an image of somebody that is strong and capable, so yeah there is a certain wanting to mask it."	"I mean what motivates me to do things is when I get scared. So occasionally if something happens and I think it's really serious then I'll be terrified into action you know. That usually means a visit to the GP."
Marie	6 months	"I really strained my neck one day while doing a bit of gardening. [Later] we went skiing ... I had terribly sore ankles and I thought 'what do you expect taking up skiing at 40 again'. And I used to be in agony the first half hour ... and the young ski instructor used to say to me 'are you all right?' and I said 'oh yeah it's just my ankles they're not very warm' you know – thinking they were warming up because after a while they were fine."	"I had physio and I went to an osteo and even last year actually I hurt my neck again and I got a little bit of physio."	"It was just a flippant comment I made to my doctor one morning and I said not only that [skiing] but when I get out of the bed in the morning."
Catherine	3-6 months	"I was there tidying up the next day and we were putting away [equipment]. And it wasn't long after that when I got problems in the right shoulder and I thought I had done something there... whether I'd pulled a muscle, you know, just done something."	"I went to the physiotherapist for quite a while and ... it was a little bit better."	"Advised by physiotherapist to see GP."

Another complicating factor in evaluating the onset of symptoms as illness was that most participants could recount a situation preceding the onset of symptoms that, for them, was extraordinarily stressful. For these participants formulating an integrated explanation was not achieved. Both the symptoms of stress and the physical discomfort were perceived as separate conditions and steps were taken to deal with them separately (Table 15).

Table 15: Onset and stress

Participant	Comment
Louise	"I'd say probably stress would have done it. Well that year the business we'd been putting in a new machine worth 1.5 million dollars and we had to get all the stuff done – get it driven. There was a lot of stress and stuff like that [and] I went and I did a diet... but 20kg in 8 months was quite quick and in the back of my head I thought that maybe that was it. Too much stress on the body, your body can't keep going if the mind's going too, you've gotta rest one of them."
Carla	"Well I think I know what triggered ... that I was in a very stressful situation and I just think it pushed everything through my body and pushed everything out of whack – because within a week it started. That's my personal view...but anyway that was it and I started to get these mysterious pains we'd been on holiday and I came back and had to do some work very quickly I had some work waiting. So I did that and then it started ."
John	"Admittedly when I got it, I was under huge amounts of stress, the company was in trouble, big trouble. I wasn't sleeping at night it was just really bad times and possibly I got rundown to the point where something just happened. If there's any one thing I can put it down to it would be the massive amounts of stress I was under at the time, but whether that caused it who knows they don't seem to know what causes it."

SYMPTOM RESPONSE

Only two participants went promptly to a GP without an acute onset. For both participants the symptoms in their wrists and hands interfered with job performance. An important prompt for Anne was her attitude to healthcare; despite assuming her symptoms were work-related, she described how from childhood she had been prone to illness and how, because of this she would regularly consult with her GP.

"As a child, when I was born I was covered in eczema from head to toe ... It's all about immune system isn't it? Then I started getting asthma and hayfever always allergic and rubbing my eyes and everyone else would be enjoying the summer...So I don't know if that's related. We used to go and see a doctor in a 3-piece suit and he was on a pedestal. I think

whatever he gave mum, mum would accept it. She would never not accept the doctor's position."

Anne

Anne's comments about GPs' elevated status and unquestioned knowledge were reiterated by four other participants when discussing attitudes to the medical care that they grew up with. Parents of participants were most often described as having great faith in medical practitioners, and were as also likely to wait before consulting for apparently minor conditions and use home remedies instead.

"My mother was a nurse and we were always very healthy and we were given like carrot and honey for breakfast and pumped full of cod liver oil. We never really got sick."

Carla

"I didn't complain about it really, um because if you'd complain and [my parents] couldn't do anything about it because it was totally esoteric and oh sore knees but you look at it and there is no swelling and no redness and you think it's just what the doctor said, growing pains."

Stephen

Participants saw this position as reasonable at the time of onset of symptoms, and their own attitudes and actions mirrored this position, believing if they were sick they would see a GP quickly, but since they did not believe their symptoms fell into the category of 'being sick' (Table 16) they delayed their consultations.

Table 16: Attitudes toward seeking GP Care

Participant	Comment
Mark	"If I'm fit and everything seems to be working fine there's not much point in wasting [the GP's] time."
Stephen	"I've always been like that though 'I'm not dying' so I don't need to go to the doctor."

Only one participant, at onset of symptoms had a world view that might have contributed to an outright rejection of GP care at onset of IA symptoms:

"[the medical profession's beliefs about IA treatment] "So you know it doesn't give me a lot of hope or respect for the whole medical profession basically. And um I have to say I didn't have a lot to start with y'know? [They say] there is no other treatment, or cause, or alternative treatment that will make any difference. And I don't believe that. But

that was his attitude. It doesn't matter what you eat, it doesn't matter what you do."

Kim

Other participants who sought care from physical therapists did so as an apparent practical solution, rather than as a rejection of conventional medicine. Experience had taught them to expect that either the symptoms would resolve by themselves if activities are reduced, or that they would be referred to allied health professionals by their GP:

"You know how you get those little things... anyway I went overseas and um they were pretty sore, both feet then, had swollen a lot and everything and I just couldn't figure it out so thought oh well. I'll just take it easy."

Louise

Interview responses suggested that people experiencing MSK pain can tolerate IA symptoms from several months to several years. Mark (RA) and Philip (PsA) did not seek care for at least 4 to 5 years, until joint erosion and deformity were clearly visible. Philip is still to decide on referral to a rheumatologist, nine years since onset. Both men were adamant their symptoms did not lead to serious pain. Further discussion however, revealed they experienced pain with their symptoms but were reluctant to acknowledge this because beliefs about their physicality precluded admission of pain or lack of physical capacity for work activities (Table 17).

Table 17: Pain and Delayed Presentation

Participant	Initial comments on pain	After further discussion
Mark	"There might have been a little bit [of pain] there that I hadn't noticed. Like if I'd been using a hammer and staples all day my hands sort of got tired of gripping the handle, but there was no twisting [of the hand] and the knuckles ... the thing is it just sort of started to twist over."	"I used to get what I thought was supposed to be tendonitis. In this part of the wrist [inner wrist] and sort of at 3 o'clock in the afternoon I'd feel it coming and I always had panadol with me and I'd get into the panadol. And sometimes in the morning it had gone, other times it would last 2 - 2½ days and that was painful yeah I couldn't put it anywhere to - yeah I slowly got used to it... tendonitis it might happen 3,4,5 times a year sort of thing. That was it. Occasionally it did sort of um get me in other parts but I always just put it down to tendonitis."
Philip	"No pain at all, no. One day I just looked at my finger and I noticed it was bent and odd. And I think I may have noticed that this wrist was	"Because yeah I had pain in my wrists like if I'm working - computer mouse and stuff, or typing I just had periods where it's been quite painful.

Participant	Initial comments on pain	After further discussion
	getting bigger too.... I feel like I've been quite fortunate because I don't get a lot of pain with this."	The only other time it's bad is when I shake people's hand and I don't tell them. It's extraordinarily painful. And the pain goes up the arm."

Being unable to perform physical tasks can also lead to fears of social ostracism. For example Philip was very concerned about how giving into MSK pain would appear at work:

"But certainly you want to appear to be at your best and you want to appear to be successful and all that stuff. It's just probably what everybody does when they go to work. They put on a bit of a work face and put on a little bit of an act. But I think it's more so in [my industry], particularly this sort of gung-ho attitude."

Philip

Women more often sought care from a physical therapist and provided three reasons for doing so. Some women considered cost along with the inconvenience of onward referral:

"I just thought I'd injured myself, I'd done something with my shoulder and I just thought if I go to the doctor he'll probably tell me to go to the physio and I don't think it's anything more than that so I'll just go to the physio - I was just assuming that I knew what it was and I assumed that the next step would be the doctor would send me to the physio so I'll just cut out the middleman and go straight to the physio."

Catherine

Others had previously used these professionals for health maintenance and prevention of problems, for example:

"In November my ankle kept hurting and my toes, and everything swelled. And when I iced it or anything it was more excruciating then helpful so I went to a local podiatrist who I'd seen with my daughter, she used to do a lot of ballet so I just used to make sure her feet were going good, and he ran a few tests I suppose and nothing really came of it."

Louise

A third reason for delaying seeking advice from a GP was a philosophy of care that was more likely to reject conventional medicine and favour holistic wellness. Kim used a variety of alternative therapists and AHPs for much of her health needs and

believes conventional medicine should have a greater focus on wellbeing. Underpinning this non-medical path is the desire to see oneself as healthy, not sick, and therefore not requiring a GP. The “just get on with it” phrase was used by six participants when explaining their attitude to IA symptoms:

“You’re like ok get on with it... probably if I had been a little more aware of it I’d have been getting a bit more adamant about being diagnosed as well.”

Zoe

Men and women spoke quite differently about their responses to IA symptoms. Without exception men chose a GP as for their first professional consultations, the longest delays in seeking care were from men and only one male consulted a GP in less than three months from symptom onset (Figure 22). This graphic also suggests greater financial resources may correlate with an earlier presentation to a GP.

FINANCIAL RESOURCES

Financial barriers to care vary not only by the financial resources of people across the region, but also by the cost of healthcare in the local area. Reducing the cost of health care through APHOs has been a significant achievement in the primary care health strategy (Barnett & Barnett, 2004; Cumming, et al., 2008; Ministry of Health, 2000). However the ability to take advantage of this opportunity is limited by the distribution of APHOs across the region. At the time of this study no low cost APHO practices existed in Upper Hutt, Kāpiti, or the Wairarapa regions. A limited number of IPHO patients were recorded as enrolled in reduced cost outreach clinics based at a local marae in Kāpiti (and later in Wairarapa).

Five of the six women in lower income groups saw a GP as the first healthcare provider and three participants in this study with restricted financial resources confirmed that their use of any primary care was constrained by costs. Lisa’s experience links financial benefits of an APHO with other healthcare considerations. She decided to forgo cheaper doctor’s bills for the certainty of seeing a GP who knew her history to ensure more consistent care for her chronic conditions. For participants on low incomes transport cost and availability impacted on their use of primary healthcare. Gillian rarely visited a GP. She lived in an area without an APHO

and in a suburb with limited public transport options and was without use of a private vehicle (Table 18).

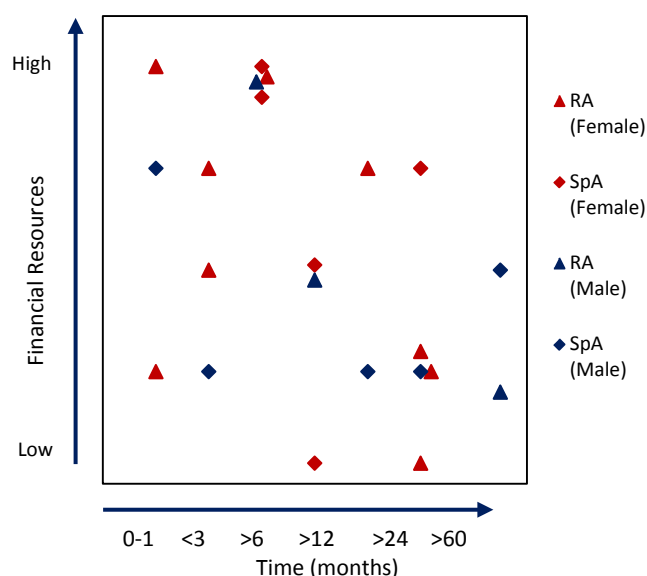


Figure 22: Dot plot of self-reported time to first GP consultation

Stratified for financial resources in men and women with RA and SpA ($p=0.04$). R^2 values for men (0.81) and women (0.27) with RA show a strong inverse relationship between financial resources and time to GP. This effect is less pronounced for participants with SpA (men $R^2 = 0.12$ and women $R^2 = 0.05$)

Table 18: Financial barriers to seeking care

Participant	Comment
Lisa	"I don't go [to GP] if I don't have to... I wait until things get real bad before I go. I went to [a community PHO] because its ten bucks and that's like good for me I could pay off 5 bucks a week and it was done and the whole thing was settled and um then I started getting sick and I needed somebody who was gonna – who knew my history – and somebody who I was always guaranteed the same doctor so I went back to [family doctor]. He's like 27 bucks."
Gillian	"[going to the doctor] used to be a cost issue, because my husband wasn't working and to try and pay bills, that was a mission... The bus used to only come in the morning and at night... You can't just walk from there back home. Sometimes you'll catch a cab... Or you had to walk down [next suburb], you catch it on [the main road] then, to get to the doctor. It was a long thing to do."

AREA VARIATIONS

Once symptoms are considered important enough to warrant consultation with a health professional the decision to seek help is interpreted within the context of local health services. At least some of the delays in GP care are a result of GP shortages that have resulted in oversubscribed patient lists in Upper Hutt and Wairarapa. For example more than 40 percent of referred patients domiciled in the South Wairarapa town of Featherston, and Carterton in the Carterton district, travelled from 15km to more than 35 km to Masterton for their referral visit. These areas have a GP/population ratio of between 1,500 – 2,343 (Brabyn & Barnett, 2004) the worst ratio of GP to population in the WRRU region.

The GP shortage resulted in heavy workloads and reduced the opportunity for timely appointments. In Mark's case, his symptoms did not affect him performing his usual tasks so he did not specify his appointments as requiring urgent attention, accepting delays of several days. By the time of his appointment his symptoms had improved:

"Aw I probably saw the doctor but by the time you make an appointment it's 3 or 4 days and [the inflammation] it's gone. So what are you complaining about?... I'd go and see him and there'd be a slight swelling, but by the time I'd go to the doctor it would be back to normal. And all you can do is say well that's what it was like."

Mark

A further three participants were seen by locums because their usual GP was unavailable. For Louise, a recent history of pain and inflammation was not considered when interpreting symptoms and it is possible the circumscribed access to patient notes led to an incorrect diagnosis:

"I couldn't get in to see mine [GP] so I went to the afterhours. They did a blood test and stuff and then rang me and told me to go straight to hospital and don't pass go. They thought I had [a blood condition]"

Louise

Enrolment in a PHO is an important aspect of reducing health inequalities and improving access to primary health care services. PHO enrolment meets the definition of a medical 'home' whereby enrolled patients have cheaper appointments and GPs have more complete access to patient health records, enabling a greater opportunity to fully assess health problems and coordinate care, including referrals

to secondary care (Schoen & Doty, 2004). Two IA participants who were not enrolled at symptom onset were new to the area:

“After I moved to Wellington I’d just go and see someone - whoever - but I’ve never really had the same person so I guess I’ve never had that relationship with [a GP].”

Michelle

“I remember discussing with [AHP] I don’t have a GP in Wellington and do you know who might I go to? So she suggested a range of people who would be useful.”

Kim

For Michelle and Kim, the lack of a ‘home’ GP delayed consultation. This delay was bound up with Kim’s holistic health beliefs and for Michelle, as a healthy young woman, the notion that she might need a regular GP was foreign to her. The three participants above, who saw a new GP rather than a ‘home’ GP at first contact, were referred by the GP to a specialist other than a rheumatologist. Participants who saw a locum based at their usual GP practice, at other stages in the referral journey did not have a similar outcome (this is discussed in the following chapter).

SOCIAL IDENTITY AND CONSUMER PREFERENCE

Five women consulted with an AHP in the first instance. Aside from an expectation that the GP would refer them to a physiotherapist, these women additionally or alternatively had health beliefs that meant they regularly visited physical therapists, like masseurs, osteopaths, and physiotherapists as a health prevention measure before the assumed onset of IA symptoms. To prevent the build-up of stress and related conditions Kim used massage and related alternative and complementary health practices:

“I always used to go to massage really regularly and I think that might have saved me to a degree [but having moved cities] didn’t really get a lot of massage done that year and the stress was building up... I knew in that in that period of time, in the 4 to 6 months before, I was feeling really wiped, and the really bad symptoms were starting, that I should have been doing something but I wasn’t. So at that time I went to a physiotherapist because my neck was really bad and she gave me the name of a [massage] therapist who was really fantastic and I just sort of built up the relationships with various people in that practice. And so

that's where I thought oh well, maybe an osteopath, maybe I'll be able to get some treatment there."

Kim

Kim's health beliefs were at the more holistic end of the health care spectrum than those of other women in the study, but her explanation for her initial decision to consult an AHP for her pain epitomises a healthcare philosophy expressed by women who chose physical therapists as their first response to IA symptoms - personal responsibility for well-being, expressed in terms preventative, non-medical care.

Men rarely drew on ideas of holistic health philosophies, and more often saw their symptoms as isolated problems and a GP consultation as a pragmatic response to symptoms that interfered with their activities:

"But if I have a bit of a problem then I thought 'y'know perhaps I should go and see a doctor' I'll ring up and go. No good putting anything off, a stitch in time saves nine."

Mark

Mark's view that GP advice would be sought when physical symptoms interfere with work or sport was a common refrain among the men in this study.

DISCUSSION

The qualitative data from the participants in this Wellington study are indicative of long delays from onset of symptoms to GP consultation with a median delay from onset to GP consult of more than six months but less than 12 months (<1 month to more than two years). Only 1 in 7 participants saw a GP within a month of symptom onset, and less than one-third had seen a GP within three months. Seven participants delayed seeking GP advice from two years, to 10 years or more. These self-reported accounts, were also reported in referrals letters. Three participants had visible joint deformities at consultation, adding to the authenticity of their accounts. The West Midlands regional rheumatology survey in which found more than 60 percent of IA patients reported consultation with a GP within three months (Kumar & Raza, 2008; Sandhu, et al., 2007); and the Birmingham study found the mean delay from onset to presentation of RA was 12 weeks, with a maximum delay of 28 weeks (Kumar, et al., 2007). The reported waiting times in the Wellington region contrast markedly with

these UK studies. Further quantitative investigation is required to discover whether the reported waits in this study are indicative of GP consultation delays in the Wellington region.

Early consultation can, to a large degree, be explained by the onset experience. Participants emphasised an inability to do valued activities as the main reason for visiting a GP. Although symptoms were painful, the pain itself was not usually given as the reason for seeking care. Restricted performance of valued activities was more indicative of consultation – because, for as long as activities could continue, pain could be managed. In essence participants contacted a GP because they had:

- an acute episode that resulted in physical incapacity;
- advice from a personal contact who suggested IA was the cause of their symptoms;
- an increasing inability to do time-constrained or valued physical activity;
- been advised to do so by a family member or an AHP.

The opportunity to consult a GP cannot be divorced from the provision of services at an acceptable price - that is the availability, accessibility and affordability (Penchansky & Thomas, 1981) of GP services. These issues are well-covered in literature on accessible primary care, see for example (Barnett & Barnett, 2004; Baxter, 2002; Cumming, et al., 2008; Ministry of Health, 2008b), and fully accepted by the Ministry of Health as areas of concern (Ministry of Health, 2000, 2002a, 2002b). These are relevant issues for people with IA in the Wellington region, which has GP shortages and price barriers that restrict access. Delays in GP appointments reduce the opportunity for diagnosis of being seen during the peak inflammatory phase, if the patient has intermittent symptoms. A failure to recognise inflammatory processes can be pivotal in reinforcing an existing tendency to normalise symptoms.

The experience of periodic spontaneous resolution of symptoms often led to participants waiting until there was large joint or systemic involvement before consulting a GP. This echoes the findings of a Dutch study that examined the characteristic symptoms of 1,674 EIA patients who had long delays in seeking advice

about IA symptoms. The researchers found that respondents with acute onset and inflammation in large joints in the lower-body (typical, for example, of ReA) had shorter delays, but those with gradual onset and symmetrical involvement, characteristic of RA, tended to have longer waiting times, with only one-third of these respondents diagnosed within 12 weeks of onset (van der Linden, et al., 2010).

Although an acute episode is the most common reason for early GP consultations this should not be translated as pain precipitating early consultations. Participants commonly attempted to wait out, or disregard, quite high levels of self-reported pain. This effect has been noted elsewhere. For example, an Austrian programme to promote awareness of MSk conditions used a bus as a mobile consulting room in 42 centres. The authors noted that “the pain threshold above which clients sought medical help seemed to be unacceptably high” and up to 30 percent of the 2,862 clients in the high pain threshold group (at levels where opiates are recommended) were not under the care of a physician. They believed the lack of consultation with physicians (approximately 3 percent of clients had unrecognised IA) and tolerance of very high pain thresholds indicate MSk conditions are not ranked sufficiently highly in terms of dissemination of information to the general public and for health funding (Machold, et al., 2007).

Help-seeking is not a linear progression from onset through various options to GP care. Within the bounds of their symptom experience, participants integrate their knowledge, their evaluation of symptoms and their unsuccessful attempts to find a solution, into a dynamic and evolving strategy that over time narrows, and ultimately leads to visiting a GP.

IA KNOWLEDGE AND EVALUATION

Participants were poorly informed about IA at the onset of symptoms. Arthritis was thought of as a disease associated with older people, or ‘wear and tear’ to which they were not susceptible. Moreover most participants did not have advice from family or other social contacts that led them to suspect an IA was the cause of their symptoms.

Previous research has highlighted the need to improve the general public’s knowledge of IA if delays to treatment are to be reduced. A report of the general

public's knowledge and perceptions of IA in the Netherlands documented low public awareness allied with low mass media interest in IA. Their survey of 569 people found that the general public rarely consults mass media for information about IA and that the less informed people were, the less they saw IA as a serious disease and the more likely they were to believe that they could influence the course of the disease. Even the most educated people were unlikely to be interested in information about IA, and the higher educated were less fearful of IA than people with a lower education and felt less susceptible to it (van Der Wardt, Taal, & Rasker, 2000). These findings can be interpreted as a conflation of IA with degenerative forms of arthritis and are useful to interpret poor uptake of information about IA in this study. No participants cited information from the mass media as informing their decision-making at the onset of their IA journey, but for one participant, the advertising for inflammatory pain relief informed her erroneous decision to treat the symptoms herself.

Participants had minimal knowledge about IA symptoms unless they had family or social contacts with experience of IA and information about that experience was shared, but typically family history of IA was not transferred to younger generations. When immediate family had IA their experiences were not communicated effectively until after the onset of symptoms in the participant. Once the connections were made GP consultations were quickly obtained. Communication with social contacts at symptom onset could be useful, but again due to the low profile of IA in the community, this was an unlikely source of information and advice, unless the contact had immediate experience of IA.

As well as poor knowledge of symptoms, the serious nature of an IA condition, including the levels of pain or disability that occur are not well understood. There was a measure of regret expressed by participants that they were unaware of joint erosions, long-term disability and early DMARD therapy, and that had they known the facts they would have contacted a GP earlier. At best participants suspected NSAIDs would be part of the resolution of their symptoms, and as these could be bought without prescription from a pharmacist their availability was a likely factor in consultation delays. As well, expectation that these would be prescribed acted as a deterrent for people who have an intolerance of NSAIDs, or who have health beliefs

that preclude symptomatic relief of health conditions. The conflation of degenerative and inflammatory joint conditions and the fragmented and incomplete information about treatment provided an ineffective setting for evaluating symptoms.

In lieu of knowledge about IA participants commonly related their symptoms to an episode of injury or overuse, and assumed that any lack of resolution was likely to have been exacerbated by abnormally stressful situations. Explanations were based on personal, subjective examination of previous episodes of MSk pain. Communication with family and social contacts, or health professionals could have resulted in more accurate evaluations of symptoms by establishing awareness that inflammation was not a usual outcome of physical activity, but a reluctance to discuss MSk pain outside of the self-constructed explanation of the injury or overuse was apparent. For some participants this was because of a belief that negative judgements might be made about their character if they were seen to be complaining, were unable to participate in collective activities or complete required tasks. For some participants there was a pragmatic, but erroneous (given the age of onset) acceptance of increasing pain as the body ages. Participants tended to view their condition through a cultural lens that prefers stoicism and self-efficacy above voicing concerns about symptoms and medical intervention for MSk disorders.

SYMPTOM RESPONSE

New Zealand is considered a physically active country and almost half of adults in the Wellington region match the New Zealand average, by engaging in at least 30 minutes of moderate intensity physical activity on at least five days per week, and more than a third are involved in a sport or recreation club (Sport and Recreation New Zealand, 2009). International comparisons in physical activity are difficult due to variations in survey methodologies, but there is a belief among New Zealanders that an active, outdoors culture which values physicality is an important New Zealand characteristic. In an international study of the correlations between perceived and observed cultural traits and national character New Zealand was one of only four countries where there was a positive correlation between international profiles and local perceptions of national character. New Zealanders agreed they meet the internationally perceived national characteristics of extroversion (warmth,

gregariousness, assertiveness, activity and excitement-seeking) and low neuroticism (positive emotions) (Terracciano et al., 2005). Given New Zealanders' belief in the accuracy of the perceived national character; that is physical, active and, in tone somewhat masculine, it is not surprising then, that MSk conditions might be evaluated (especially for men) in terms of physical activity rather than in terms of pain levels, which are hidden, or discounted. This characteristic may also provide a basis for examining why family histories of IA are unspoken.

Delays in GP consultation have elsewhere been associated with cultural traits, in particular the previously cited Birmingham and West Midlands studies observed cultural and ethnic differences in delays in seeking GP care (Kumar, et al., 2007; Sheppard, et al., 2008) and this led to a follow-up qualitative study to understand the differences (Kumar, et al., 2010). These studies have in common the participants' beliefs that their symptoms were not IA-related, the dearth of knowledge about IA and the frequent assumptions that symptoms were associated with physical stresses or injury. Delays in help-seeking despite high pain levels have also been documented elsewhere (Machold, et al., 2007). However, the cultural underpinnings of the evaluation of symptoms at onset vary. Wellington region participants evoked physicality as an explanation for misunderstanding symptoms, did not widely discuss their condition, and were likely to either rest the problematic joints or use over the counter pain relief. By contrast South-Asians in the Birmingham studies spoke of dietary measures, prayer and wide family and community consultation about symptoms before visiting a GP (Kumar, et al., 2010). Wellington participants valued professional advice (either medical, allied health or complimentary practitioners) and only rarely evaluated their symptoms with close social contacts before consulting a health professional.

CULTURAL CAPITAL

The cultural basis of symptom explanation and evaluation was more pronounced when discussing onset with male participants. Galdas (2005) contends existing evidence about men's help-seeking behaviours raises the question of whether help-seeking delays are a result of men's own attitudes, behaviour and values or of societal and cultural attitudes and values. In New Zealand much of the publicity about men's poor help-seeking behaviour portrays men as having a lack of concern – a

stereotypical '*she'll be right*' attitude (all will be well despite the need for fixing the object in question) toward their health (Braun, 2008). This construction of men's attitude to health, although widely used, has been challenged in several quarters (Nelson Bays Primary Health, 2010). An alternative view is that men's demonstrable underutilisation of health resources, rather than being a result of lack of concern, is subject to a dominant masculine identity based on individual strength of character:

"Local ideologies and practices mean that achieving the ideals of conventional masculinity requires an unwillingness to admit weakness or to accept help and a propensity towards risk-taking behaviour. The process of male socialisation and the sociocultural norms that underpin this process result in an adverse risk profile for men and subsequent poor health outcomes" (Jones & McCreanor., 2009, p. 49).

In a paper on *Rugby culture, ethnicity and concussion* the authors illustrate how a 'knock to the head' resulting in concussion but perceived as not serious enough to report is bound with tradition that sees "boys who did not fully participate in vigorous sports were considered weak, unhealthy and emasculated". Further "courage, endurance, assertion, control and self-control" were characteristics that were valued in the sporting arena and these characteristics were transferred to their everyday lives (Hokowhitu, Sullivan, & Tumoana Williams, 2008, p. 3). The expressions of men with IA symptoms fall within this alternative interpretation that masculine identity requires an unwillingness to accept weakness.

The majority of men in this study emphasised that their response of wait and see was based on previous experience of MSK conditions and would have revised their decision to delay if they had more information about the potential of an IA being diagnosed, and this cultural response transcended socio-economic status and the rural-urban divide.

CONSUMER PREFERENCES

Women also referenced typical New Zealand cultural themes in their explanations of delayed help-seeking but not as strongly as men. Women were equally likely to prefer a non-medical explanation for their symptoms, but this manifested as seeking physical therapy rather than GP advice. In the first instance women were more often aware of, and likely to use, alternative sources of professional health advisors, such as

physiotherapists, podiatrists, osteopaths, masseurs than men were. Of the women in this Wellington study one participant expressed distrust in the medical profession, and chose to use at least three physical therapists before seeing a GP, but others who used physical therapists did so because this was part of their regular wellness routine and had found this care helpful in the past. This course of action was justified by an expectation that a GP would refer to a physical therapist anyway.

The definition of healthism as a 'middle-class' concern (Greenhalgh & Wessely, 2004) is also borne out in this study. All the women who referred themselves to an allied or alternative health practitioner were of a higher socio-economic grouping than women who went to a GP in the first instance. Financial considerations were important factors in the decision making in both groups of women, however women from lower socio-economic groups did not mention health advisors outside of GP practices (GPs, nurses and outreach workers). There was no apparent socio-economic gradient in the type of health advisors men believed important. All men saw a GP in the first instance and did not consider any alternative or allied health practitioner instead.

AREA AND ACCESSIBILITY

Physical determinants of access appeared to be area and gender dependent. The availability, affordability and acceptability of GPs led to some delays. Wairarapa, Kāpiti and Upper Hutt appeared to be the areas most affected by GP shortages, and participants who did not consider their condition urgent experienced delays that restricted the opportunity for early diagnosis of joint inflammation. The affordability of primary care was a decision factor in access not only for individuals with restricted financial resources. The high cost of care services in rural and high decile areas and the expected additional cost of AHP services led women in these areas to favour direct contact with physiotherapists, podiatrists and osteopaths and to bypass GP care. Lower income women delayed GP care for as long as possible due to the cost of primary health care, in part because low cost primary care is not spread evenly throughout the region. Low cost providers (APHOs) were not universally acceptable due to the inability to build a trust relationship with a GP. Participants who were new to the region were also slow to enrol in a GP practice, which meant they also did not have an established trusted relationship with a primary health care provider.

Reducing the cost of primary healthcare through APHOs has been successful in deprived areas. Other strategies such as Services to Improve Access (SIA), which can be used to reduce costs for low income people in less deprived areas was not utilised by participants in this study. In part this is due uncertainty about what assistance is available in their area and also because participants were not asked if they needed assistance – this was possibly because PHOs have some flexibility in the implementation of SIA funds, e.g., the Kāpiti PHO uses a large proportion of SIA funding for outreach programmes (Kāpiti Primary Health Care Organisation, 2009), whereas the main provider in Porirua, the Tumai mo te Iwi PHO, incorporates transport initiatives into SIA funding (Tumai mo te Iwi PHO, 2009). The policy for the introduction of SIA funding is also uneven across the region and identification of low income, high needs patients is patchy. These factors reduce the effectiveness of access improvements that might otherwise benefit individuals with inadequate financial resources (Smith, 2009; Wairarapa District Health Board, 2009)

10. SYMPTOM EVALUATION

INTRODUCTION

Inflammatory arthritis can be difficult to detect and in the early stages of the disease can be mistaken for other MSk conditions (Aletaha, et al., 2010). Although postponement in seeking medical opinion has been found to be the main reason for delays in presentation at a rheumatology clinic (Kumar, et al., 2007), other studies suggest delays in referral from primary care is the main reason for late referral to a rheumatologist. This delay is conceptualised as a GP preference to delay referral to wait to see how symptoms develop before considering the institution of DMARD therapy (Nell, et al., 2004). The importance of determining reasons for delays in referral from primary care was highlighted in a Canadian review of physician data in Quebec, where fewer than one in four patients were referred to a rheumatologist within 30 months of presenting in primary care (Ehrmann Feldman, et al., 2007).

Rheumatologists have been shown to be in strong agreement that an early referral to a rheumatology service is the recommended action for individuals with symptoms of and early IA. The European League Against Rheumatism (EULAR) recommends

“Patients presenting with arthritis of more than one joint should be referred to and seen by a rheumatologist, ideally within six weeks after the onset of symptoms” (Combe, et al., 2007, pp. 36-41).

The EULAR guidelines strongly convey the message that if an IA is suspected then the patient should be referred to a rheumatologist even if IA symptoms are mild or undifferentiated. However in practice it is clearly recognised that as well as the type of EIA being difficult to detect, it is also difficult to differentiate from other causes of MSk pain. Patients presenting with a variety of symptoms and at different stages of the disease progression can challenge the evaluation skills of even experienced GPs (Aletaha, et al., 2010).

Although referral is generally perceived as a single process from primary care consultation until a referral is made to secondary care, IA participants in this study articulated two distinct processes. The first is the evaluation process from the first consult until the GP makes a preliminary diagnosis and the second is the decision to

refer and the process of referral. This chapter examines the time from the participant's GP consultation because of MSk discomfort to an IA diagnosis. It details the experience of participants' encounters with GPs, with the objective of highlighting factors that affected early identification of IA symptoms and early referral to a rheumatologist. The chapter utilises information from GPs who agreed to be interviewed for this study, and referrals data from the WRRU to contextualise the patient experience. The expectation at the outset was that GPs have the ability to competently evaluate IA symptoms within a reasonable timeframe and communicate this to the patient. In addition to the interviews with the 22 IA participants nine interviews with GPs were conducted to understand the tools and techniques GPs use to evaluate MSk disorders and identify IA. The GP interviews represent a range of referrers. Three of the highest referrers were interviewed, as were three of the lowest referrers. The GPs represent all areas in the WRRU region and include GPs trained overseas as well as in New Zealand. As well as the nine interviews, these GPs also agreed to answer a range of questions related to issues that the literature has shown to affect referrals. These questions were also answered by a further three GPs who agreed to take part in the study, but refused to be interviewed.

This chapter also examines the role of GP experience in the accurate evaluation of MSk symptoms as IA, and finds this an essential component in identifying IA. An individual's expression of symptoms, their expectations of the GP and perceptions of responsibility for continuing evaluation are crucial to the identification of IA at an early stage. The criteria GPs use to establish a diagnosis and the expectations about the nature of symptoms emerge as drivers that establish the framework for long delays between presentation and initial diagnosis of an IA.

THE PATH TO DIAGNOSIS

The path to diagnosis takes place within the context of the GP's training and experience, the GP's belief about what constitutes a potential IA, and the attitude toward the presentation of symptoms. The delay created by acceptance of the interpretation of events leading up to the consult is neatly encapsulated in one participant's six-month delay to diagnosis:

“The local doctor wasn’t sure what it was ... I had a sore foot, there’s no history of rheumatoid arthritis in the family, and I was a jogger, I mean I had an idea of what it was and probably sold that to him as well.”

John

John’s progressively worse symptoms and deteriorating health led his GP to change his belief that the symptoms were the result of injury over a six-month period, but still did not consider an IA despite referral to a ‘foot specialist’ and despite joint aspiration that indicated an inflammatory condition. Eventual diagnosis was made after the John took advice from social contacts who recommended another medical practitioner who immediately made a preliminary diagnosis of RA:

“It was getting quite a lot worse, and then a friend of a friend said ‘oh go and see this [other] doctor in town’... and she diagnosed it pretty much in about 10 minutes. She said you’ve got rheumatoid arthritis. Just like that. Bang.”

John

Only three of the 11 IA participants who had a path to diagnosis of greater than six months (Figure 23) were diagnosed by the GP they originally consulted. The participants with the longest delays all presented with IA of fewer than three joints. Although GPs did not use criteria this is in keeping with the ACR 1987 criteria for RA. For example five of the seven participants whose symptoms were initially evaluated as work or sports-related injury and who waited between six months and more than 10 years for that evaluation to be updated by the GP (correctly) to suspected RA, presented with inflammation in fewer than three joints.

Of concern is that as symptoms progressed the original evaluation most often was not changed until either referral to a non-rheumatological specialist or non-clinical information was presented to the GP, for example a family member recently diagnosed or social networks leading the participant to suspect an IA (Table 19). For participants with AS information about a close family member being diagnosed with AS, or an osteopath or physiotherapist who suggested AS, were the only way their diagnosis was changed.

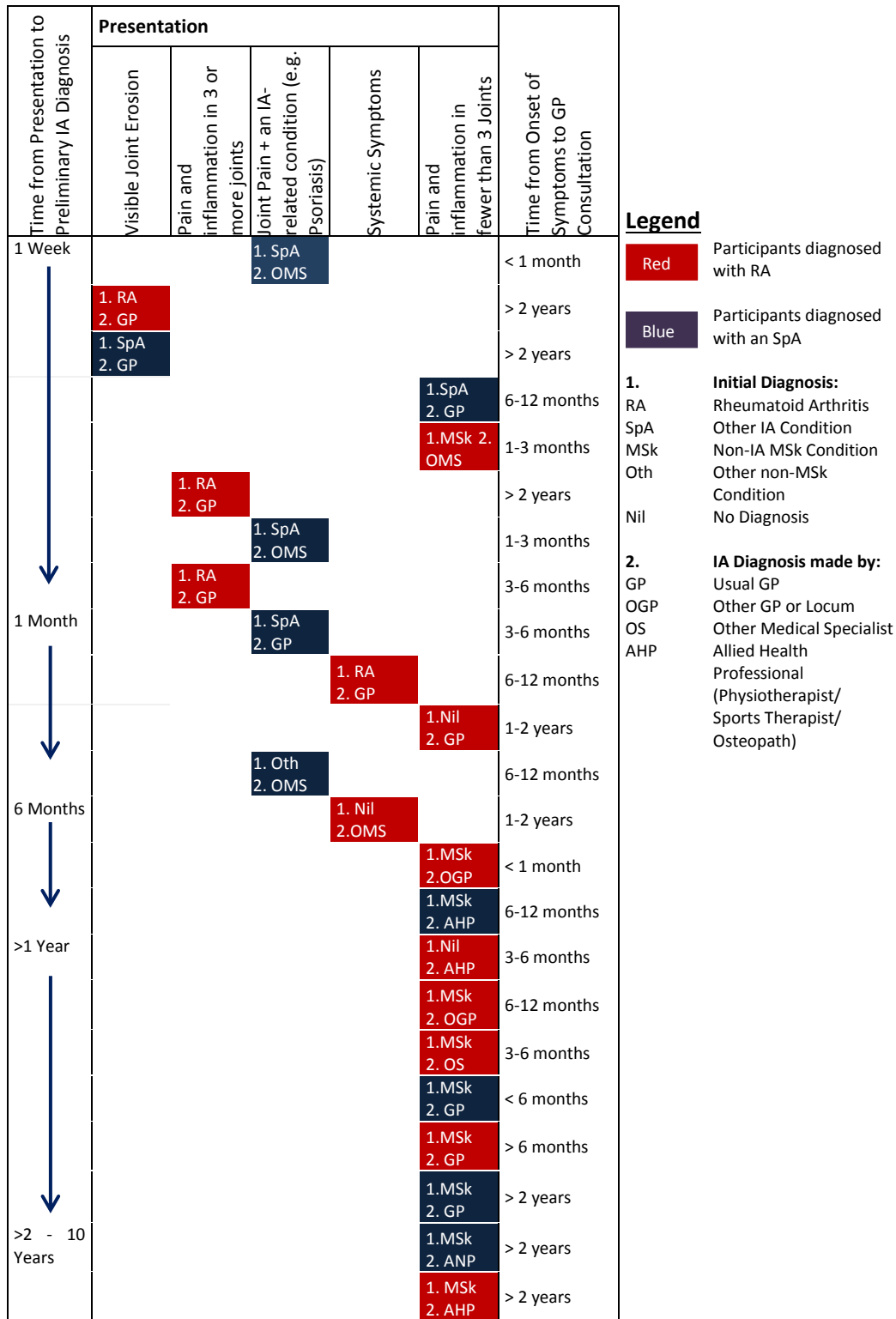


Figure 23: Indicative time to a diagnosis of an IA after presenting to a GP.

Data is organised by symptom presentation and time to rheumatology referral. Participant description of symptom presentation is arranged on the x-axis and the time range to referral on the y-axis. Participant diagnosis is represented in red (RA) and blue (SpA) boxes and labelled with GP evaluation (1) and the health professional who recommended referral to rheumatology (2)

Table 19: Outside influences on evaluation of symptoms by a GP

Intervention	IA participants' explanations of reasons behind GP re-evaluation of symptoms
Social Contact	"I think it was in both hands at that stage – and it was dreadful, just awful – and it went, although I still had quite a lot of pain in my hands, my wrists ... I had a friend that had been diagnosed with RA and it's quite interesting and I was talking to him one day at a social function and he started to talk about what happened to him because he wasn't diagnosed straight away and I knew then I had it. I was almost convinced that that's what I had. So I went back to the doctor and he said 'oh' and sent me off for some blood tests and said I think you need to see a rheumatologist." Carla
Family member diagnosed	"I'd been to the doctor quite a few times about it and they called it kind of sciatica and stuff like that. So [my brother] kind of saw the warning signs and made me go to the doctor and stuff like that, and [he] explained to him 'this is what I've got so there is a good chance that he might have it [AS].' And sure enough [the GP] sent me to a specialist and away I went." Brian
Allied Health Professional	"I kept going back to [GP] and saying there is something wrong with me and he didn't do anything. And in the end it got so bad I didn't care what they found – cancer of the spine, whatever. All I wanted was that I started getting well. We're talking about a 5 or 6 year period that that was going on. [She said] don't think you've got anything that I can correct, I think you've got Ankylosing Spondylitis'...And so she wrote to the GP and the GP was really angry. Very, very angry 'she's not telling me... oh all right I'll prove her wrong. I'll send you off for the blood test'. And so he sent me off for the blood test and there it was, the marker that AS." Zoe
Locum	"I went back to the physiotherapist and she just said to me 'I don't think this is what you think it is' she said 'I think there's something else there, I think you should go to the doctor'... I'd been to the doctor and he'd said no, he didn't think it was, but my mother had had rheumatoid arthritis... I went to see [the duty doctor] the next day and he said to me can you lift your arms and all these sort of things and he said to me I want you to go have a blood test now. And he said 'I think we're talking about rheumatoid arthritis'." Catherine

One conclusion to draw from the experiences of participants reported in Table 19 is that individuals are unable to clearly articulate symptoms and pain levels in a way that resonates with the GP so that the evaluation changes over time. An interconnected explanation is that the GP has not evaluated the symptoms correctly, does not take into account the increasing severity of symptoms and has judged pain on beliefs about the patient rather than the symptoms that have been presented.

COMMUNICATION OF SYMPTOMS

While acknowledging cross-cultural and language difficulties in evaluating symptoms, GPs, when prompted, considered the main communication problems were related to patient expression of how symptoms affected them – a 'vagueness' that made information difficult to interpret. Two GPs associated age, younger or older patients,

with this vagueness. GP and IA participants alike did not consider there were problems with the communication of symptoms because of differences in socio-economic status. High referrers did not offer an opinion about which patients were more likely to have communication problems. Instead they turned the discussion around to the way in which GPs might manage the communication process, empathising with the patient's position and from the outset considering a rheumatological condition in the range of possible conditions associated with the symptoms. Higher referring GPs consider the type of questioning is the key to teasing out information that identifies symptoms as possible IA.

IA participants expressed frustration with GPs not understanding the impact of symptoms on their lives. For women this appeared to be a translation of inconclusive and unsatisfactory consultations into GPs' beliefs about the attitudes of the patient and questioning the legitimacy of symptoms. From Kim's point of view the GP consultation spilled over into hostility due to different interpretations of symptoms, expectations of the consultation and differing health beliefs, including the legitimacy of CAM practitioners. All eight women and four men reported difficulties communicating their symptoms in a way that led to clarity in diagnosis. Kim felt her communication problems were a direct result of her GP being hostile toward the alternative medical model she favours. Although GPs in this study described being open to their patients' use of CAM practitioners, Kim, like Zoe, related how this outside advice was not accepted by her GP. Kim was clear that this led to a hostile relationship with her GP which, in turn, interfered with her diagnosis. On the advice of her osteopath, who thought Kim's symptoms indicated a rheumatological condition, Kim consulted with a GP:


“And I feel that I made a mistake because I said I'm not used to going to a GP I don't normally go to a doctor and that I'd been going to and osteopath and she suggested that I 'get these blood tests, ok?' And I felt that there was an immediate barrier and the GP was absolutely not interested in listening to anybody else's opinion... So I started in on a very bad footing with that GP because she's quite bossy, basically and I didn't feel like she listened to what I said.”

Kim

This example of discordance between the GP and patient, the problem of vagueness in the expression of symptoms and inconclusive symptom evaluation provide reasons why GPs might evaluate the patient's motive or attitudes rather than the patient's symptoms.

GPs' comments in Table 20 tie in with patients' beliefs about behaviour when faced with MSk symptoms, just as the previous chapter describes how cultural expectations led to participants downplaying physical symptoms. So too can GPs make negative judgements on patients if they complained too much. This is probably a factor in the problems with vagueness in expression and understanding of symptoms.

Table 20: GP comments about patient communication of IA symptoms

Referrals	Comments about patient communication
Low  High	"In terms of demographic, they would be younger, whether male or female. In terms of personality, people who are vague about their history, they're more accepting of their symptoms rather than questioning them. They just put up with it." GP8
	"The elderly population. Sometimes it's difficult to take an accurate history or recollection of events when it happens and as long as it's going on for." GP4
	"In early stages of inflammatory diseases can often be a general malaise 'I don't feel right' and you try and focus them down. Some people are good at focusing down and some aren't. You try the direct question after a few opening broad questions and you focus down and they come back with a strange, vague answer. But that's part of our job – to try to tease the story out... other people for the same knee will say 'it's been sore at times but I don't know what's wrong with it'. It's like blood from a stone in terms of getting a story." GP1
	"There are particular cross cultural issues between the minority ethnic groups in the prevailing cultures. So Māori and Pacific, particularly Pacific people tend to have a fatalistic view of things... There are plenty of Pākehā kiwis who think the same way, who have that same kind of attitude – either an element of fatalism." GP7
	"I think the difficulty at times a patient has is being able to make the doctor aware of how much it is troubling them. Often I would perceive they don't feel the doctor is listening to their problem and from my point of view at times it's just trying to um sort of get them on to the right medication in a timely manner." GP5
	"It's easy to relate something to an injury. Patients come in here thinking 'well I need physiotherapy and if I've got an injury then I can get physiotherapy under ACC'. So yes it does happen. It's an easy trap to fall into as a doctor." GP9
	"Any patient coming in complaining of various symptoms, you have to have a sort of open mind and allow them to well - not allow them to talk - just to hear their story but then ask specific questions related to rheumatological disorders and if you don't know about them or you don't have the experience of them it's very difficult to tease it out and know what to test for." GP3

Closely aligned with vague communication of symptoms is the propensity of some patients to incorporate their symptoms as part of a list of complaints or at the end of a consultation for an unrelated condition, as if they are not important enough to be considered as a basis for a consultation.

“The ‘door handle’ consultation we call it. People are about to leave and they put their hand on the door handle and say, ‘by the way, I’ve got this.’”

GP8

GPs’ methods of dealing with this type of introduction of a potentially significant complaint vary (Table 21). Making time to deal with an appointment that may go overtime because of MSk symptoms could be determined by a variety of factors, for example how busy the practice is and the delay to waiting patients. An immediate consultation runs the risk of being hurried, but when symptoms are not evaluated immediately it may be left to the patient to determine the importance of the symptoms in terms of follow-up. An alternative to the patient deciding on the importance of a future consultation is to have a proactive position for enabling continued contact such as setting a further appointment immediately, or requesting blood tests for inflammation, necessitating further contact with the patient. Clearly this technique is only appropriate if the GP has included IA as a possible cause of the MSk symptoms.

Higher referring GPs were aware of cost and convenience barriers, but no GPs indicated that they thought lack of diagnosis would lead to the patient believing that further attention was unwarranted unless the symptoms increased.

Table 21: The 'Door Handle' consultation. MSk as an afterthought

	GP Comments
Low	<p>"I tend to deal with them on the spot so I don't lose that opportunity, even if we run late. People often mention things that really concern them at the end of a consultation; they deal with the more straightforward or introductory topics first. It's a funny human dynamic that you tend to test the water and then launch in with the serious stuff."</p>
	<p>"It depends what it is, it depends what your own level of comfort is... so I'd tell them I want them to come back if it doesn't settle down. If the priority for them is the same as the priority for us...It does your head in sometimes because some things you can't ignore and you might be 20 minutes behind and you've just spent 13.5 minutes covering all of their other issues and then for the last minute they mention this thing that suddenly has alarm bells ringing. And either your technique is to say, 'I think this is more important than you think but we don't have time to sort it today but I want you to make an appointment for this week to talk about it further' and that's a useful technique. If you've got time you might address it there and then. It's a time thing. So it depends on your initial level of concern."</p>
	<p>"If it's something that doesn't have to be dealt with today, then I'll say that's a really important thing you've raised. I can't do that justice in 2 minutes and we're already over time. When can you come back? Let's have a look, how are you placed tomorrow at 10am? 'But will it cost me doctor?' Yes it will. There are some patients I would say, 'no it's not going to cost you'. I think for most people it's not so much the cost of paying for more than one consultation, it's a convenience thing. It's not easy to take time off work and make appointments and things. So they do tend to save it up. Also the little things – it's not worth going to the doctor for that, by the time they do get to the doctor there may be several things and the thing that matters most may be left until last in the consultation."</p>
	<p>"I might tell them I don't have time to deal with it now and they have to make another appointment with me but usually take a quick history and if it's being going on for a while I'll probably give them a blood form and tell them to come back after they've done their bloods and I'll review it."</p>
High	<p>"I think it just depends on the GP and a lot of GPs work to a 15 minute consultation and that's all you've got. There are certain GPs who will take a little bit longer and I know in my health centre there're a few GPs you're only allowed one complaint and that's it, and that's because of time constraints, whereas I'm more keen to say 'oh hang on that might be related' and ask the questions... A lot of people just focus on the injury and 'oh you have to come and see me next week about your elbow'. A lot of people won't like to come back because there is an extra charge and I'm very much aware of that so I'll take a few more minutes."</p>

BELIEFS ABOUT THE PATIENT

Uncertain symptoms and difficulties in evaluation can lead to the GP making subjective decisions about the likelihood of illness that are based on their opinion of the patient. This opinion can be based on perceived attitudes and behaviours:

"You're influenced a lot by how someone sees it as a problem for themselves and that can be related to their personality or what they're like. Some people might say, 'it's a bit sore but it's fine' and really downplay them, but others will completely blow it up and if you know

them you think, 'yeah right' but if you don't [know them], you tend to take it at face value."

GP2

Added to the belief that patients might overplay pain is the suspicion, in difficult evaluations that there may be an ulterior motive in the consultation, for example time off work or accident compensation.

"I take a normal sort of history to try to establish whether there was a convincing connection between the injury and the symptoms, recognising that sometimes, it's often distorted by a wish to get it on ACC, as the patients developed a sore shoulder and consciously or unconsciously it becomes an injury."

GP5

For Anne, a lengthy period for diagnosis, referral and establishing an effective treatment plan was in a large part due to a GP who did not believe her symptom experience. Anne had a long history of feeling unwell and she believes that ultimately this is explained by her IA. Her GP expressed frustration with an inability to understand Anne's illness:

"I was sick for about 5-6 days and I would go over to him [GP] and he said 'you're just trouble, I don't know what's wrong with you' my husband would go in there [with me] and he said 'my god I felt like punching his [the GPs] lights out'. He [husband] said he [the GP] thinks you're imagining it."

Anne

Anne was one of the few participants who sought a second medical opinion. Participants regularly expressed faith in their GPs, returning when symptoms worsened rather than seeking care from elsewhere in the primary care setting. Participants who received an IA diagnosis from a GP other than their own did so serendipitously because their own GP was not available when a further consultation was sought. However a non-diagnosis from a GP tended to encourage three women to look outside the primary care setting, to physiotherapists and osteopaths for relief of what was apparently mechanical pain:

"I've always trusted my doctors. So if my doctor said there was nothing wrong with me then I believed him. And it was only when this osteopath said 'no, no there's something wrong' [that I thought the GP was wrong]. I just sort of thought I've got a sedentary job, and office job, I've

got bad posture, I've caused it type thing – than it's something that I couldn't do too much about."

Zoe

There is some concern that moving outside of the primary care system can lead to delays in diagnosis, but for the four participants who did so after unsuccessful GP consultations, this led to the opportunity for fresh assessment that led to diagnosis:

"Well I wasn't overly impressed [that the GP did not diagnose IA]... yeah, I just don't think, I don't think it was very well done to be honest. I mean it should have been done, when a sports doctor picked it up in 10 minutes of talking to me and going through some simple tests um it wasn't particularly good I don't think... I didn't hold any grudge about not getting diagnosed earlier um but at least I did the right things by carrying on [with other opinions] not sitting on that diagnosis."

John

The alternative scenario for participants who have strong belief in their GP's opinion, and whose GPs appear more concerned with evaluating the patient rather than the symptoms mean the difference between weeks or years of delay until referral. Gillian's trust in her GP's opinion, allied with her own belief that hard, physical work caused her symptoms, meant that her 'rheumatics' were not diagnosed as an IA for 14 years from consultation, after a stay in hospital for an unrelated condition.

"And the doctor there said it was rheumatics, he didn't say it was arthritis. So he told me it was rheumatics at that time that I was getting... . He told me but they didn't ask me to see a specialist or anything."

Gillian

The closure of the consultation on this apparently definite but abstruse definition of her symptoms led Gillian to believe there was nothing more to be done. As a result she lived with her RA, without medical intervention, for many years.

It appears that a convincing explanation by participants of mechanical pain may lead to a cursory assessment by the GP:

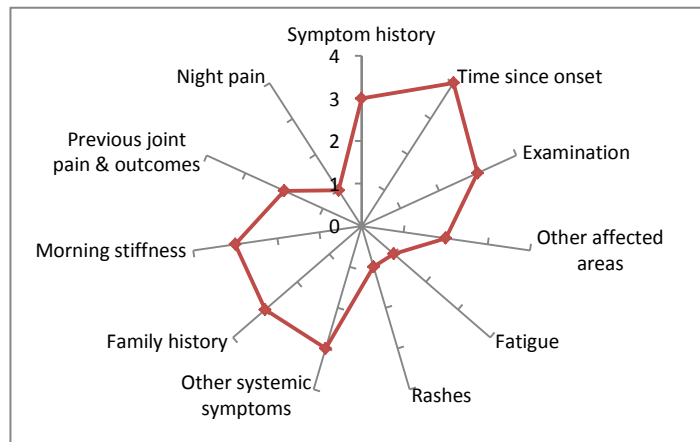


Figure 24: Indicators of IA for GPs

GP responses when questioned about what factors were important when evaluating patient symptoms for an IA. The axis displays the number of GPs who mentioned the response

“If a patient says they’ve done this to their hand or wrist, etc. If that’s the way they present to you, that’s the way you initially have to treat it.”

GP9

In addition to an acceptance of the patient account, two further reasons can explain a less than thorough examination. GPs are time-poor and unless the patient shows concern, rather than inquiry, about symptoms the GP is not likely to spend much time on this. A typical example is the patient who mentions the symptoms as an aside to the main focus of the visit.

A second reason is the patient, who as the manager of his/her own care, visits one or more practitioners to provide health and wellness advice. The individual may make decisions to exclude potentially important information from the GP because it is attended to by other practitioners, for example foot pain that is being treated by a podiatrist, or failing to mention regular visits to pharmacists or CAM therapists for the physical or medicated relief of MSk pain.

SYMPTOM PRESENTATION

In contrast to the GPs' descriptions of how they evaluate patients' symptoms, IA participants describe their symptoms quite differently. For example although stiffness (in the morning for RA patients and after immobility for AS patients) is an essential criterion for determining IA, it was not mentioned as a symptom by IA participants in their accounts of onset (Figure 26). Participants most often described having *pain at night* and/or feeling *sore in the morning* and having difficulty in moving after resting at various times of the day.



Figure 25: Patient communication of IA symptoms

Tag cloud of the words patients used to describe their symptoms while talking about their first GP consultation. Larger words indicate more frequently occurring words

The difference in language infers a difference in the type of pain at different times of the day, but this is not reflected the medical expectations of GPs who are looking for stiffness in the morning as well as pain throughout day, but no specific focus on night pain which, along with the inability to do essential tasks, was the main driver to consultation for seven participants:

“The pain just got more and more and more severe coming right down the left, across the left shoulder and down the left arm. um and it got to the stage where I was sitting up one night and I had had three Panadol and it wasn't making any difference and I was just sitting up in the middle of the night crying with pain.”

Catherine

GPs more experienced in rheumatological conditions widen the evaluation criteria of MSk complaints to include questions about general health and well-being, which was a key factor in establishing an inflammatory process in the shortest possible timeframe. These GPs also use language that is more open-ended:

“I see a lot of patients who have been followed up by GPs for a long time who just don't have that slight lateral thinking - oh this must be a rheumatological disease - and I think that's where your training and exposure counts a lot... you know you have to have a sort of open mind and hear their story, but then ask specific questions related to rheumatological disorders. It's important to find out if there is any other area of the body involved. What's your level of energy like? is there lethargy, has there been skin rashes, what are you like when you first climb out of bed in the morning or is there any itchy feeling or uncomfortable. It's just a different way of thinking.”

GP3

Despite the best efforts of the GP a diagnosis may not be made at first presentation, especially in cases of early symptoms. GPs are clear in the importance of requesting that patients return if the symptoms worsen and experienced GPs can increase the likelihood of a return by communicating more specifically:

“If it's a few days then it could be anything, so you've got to see the progression of the illness and I give them pointers [if symptoms do not improve]... if you notice swelling, if they get hot, if they're too stiff to move in the morning I need to know that.”

GP5

However IA participants were unlikely to return quickly, if at all. A nil diagnosis may mean the symptoms are interpreted as inconsequential.

In instances where evaluation does not provide a way forward, an individual may either not return, if the symptoms are mild, or bypass the GP in order to obtain a more satisfactory explanation. For example Catherine had had various symptoms over a long period and she consulted a GP with pain and swelling in both feet. Despite

recent family history of RA, the GP did not consider Catherine had this condition. After this initial dismissal, when pain arose in her shoulder, which she presumed was a result of physical activity, she bypassed the GP and went straight to a physiotherapist, which she expected would have been the outcome of a GP consultation:

"...And it wasn't long after that when I got problems in the right shoulder and I thought I had done something there...whether I'd pulled a muscle, you know, just done something. That was the first sign and I didn't bother going [back] to my GP I went to a physiotherapist."

Catherine

Although cost is an important factor in not returning for a follow-up visit if symptoms don't resolve, participants' comments suggest it is an acceptance of the GP's opinion that is a greater reason for waiting.

GPs are clear they expect patients to return if symptoms don't resolve. However there is no set timeframe for this resolution and patients often do not return in a timely manner unless symptoms worsen rather than simply fail to resolve.

"That's patient centred care. It's not for us to say, 'Oh you must come back'. Sometimes I will chase them up, you change tack depending on the patient and the condition".

GP1

No GPs indicated they would check on a patient who presented with an MSk if they had asked them to return. This meant the individual, who was often unsure of the seriousness of their symptoms would often refrain from contacting their GP unless they worsened to a level where normal, valued activities were

ESTABLISHING CRITERIA

When GPs were questioned about the process they used for establishing an IA diagnosis they emphasised recent symptoms history, rather than the physical examination of the symptomatic joint. An illustration of how the physical examination is taken is that only one GP mentioned this in an outline of how a typical consultation would proceed. IA participants did not mention it at all. Rather, symptom history and the presence of morning stiffness were used as the criteria to discriminate an inflammatory process from other causes of the symptoms.

Presentation of IA symptoms can vary from insidious; in a single joint to acute with full systemic symptoms of that include fatigue, loss of appetite and flu-like symptoms (Majithia & Geraci, 2007). In addition, non-specific back pain symptoms reported by AS patients are often mistaken for common biomechanical problems that are frequently observed in primary care settings (Aggarwal & Malaviya, 2009). This variation in symptoms had a marked effect on the preliminary diagnosis. Ten of the 13 participants who initially presented with inflammatory symptoms in fewer than three joints did not receive a diagnosis of IA until more than six months (with reports of 10 years and upwards) from first presentation to their GP, regardless of whether the eventual diagnosis was RA or a SpA.

The sense of urgency around the path to treatment conflicts with the GP requirement for time to allow symptoms to develop, to be distinguishable from non-IA causes and to be differentiated as RA or an erosive SpA:

"I think the issue is time. For a patient who has any diagnosis, it's very easy to apply the hind view mirror. ...One of the tools we use in general practice is time. If it's an on-going issue and suddenly you're back and both heels are sore, well that's a bit weird, I think we should do some inflammatory markers and do some tests and see what we come up with. So for GPs to be criticised because we don't make the diagnosis on the first presentation is a complete lack of understanding of using time in the evolution of diagnosis."

GP1


The 1987 classification of RA decision start point is arthritis in three or more joints (Arnett et al., 1988). It is likely that GPs were at least familiar with this model through their basic medical training although, GPs did not use classification or national referrals criteria during their evaluation of patient symptoms, instead basing their evaluation on the presentation of symptoms at consultation (Table 22).

"The classic symmetrical obvious clinical signs would be great! The rheumatology [things] are not necessarily arthritis."

GP2

Without the classical presentation of IA that matches the GP's training the importance of the patient account and GP evaluation becomes critical.

Table 22: Comments on clinical guidelines

Referrer	Comment
Low  High	"I find with any of those guidelines, I don't trawl through them every day and wonder if I should send this patient in or not. I've done what I can with this patient, I don't know what to do next, and it needs the next step up so I send them."
	"I think GPs on the whole are well used to dealing with uncertainty and we're well aware that things don't present classically – not just in rheumatology – there's all kinds of conditions that don't present in the community the same way they do in the hospitals. Also the text books that defined typical presentations were usually written from a specialist's point of view so the specialist themselves don't always have a great feel for how things present in the community."
	"What clinical guidelines? I never look at them. I'm not into cookbook medicine and I don't use clinical guidelines for rheumatology."
	"If there are enough symptoms to suggest it could be rheumatoid arthritis - I use the American classification – more than three, probable; more than eight, definite – I refer. "
	"I think that when people work out in the community people in hospital don't actually realise you've got a 15 minute timespan. I don't have time to look at [guidelines] and I think most GPs will say the same. "

When questioned about factors that might affect assessment and referral GPs agreed RA and other IAs were difficult to detect and they were clear that the absence of inflammatory markers in laboratory tests could not be used to discount the possibility of an IA (Figure 26).

GPs did not necessarily think that the lack of clinical markers of inflammation should rule out IA but at the same time GPs were aware the importance of supportive clinical markers before referring.

"The person's history is far more important than actual positive blood tests. Because a lot of people think oh because your inflammatory markers are minimally raised you can't possibly have this disease which is not correct because we all respond very differently."

GP3

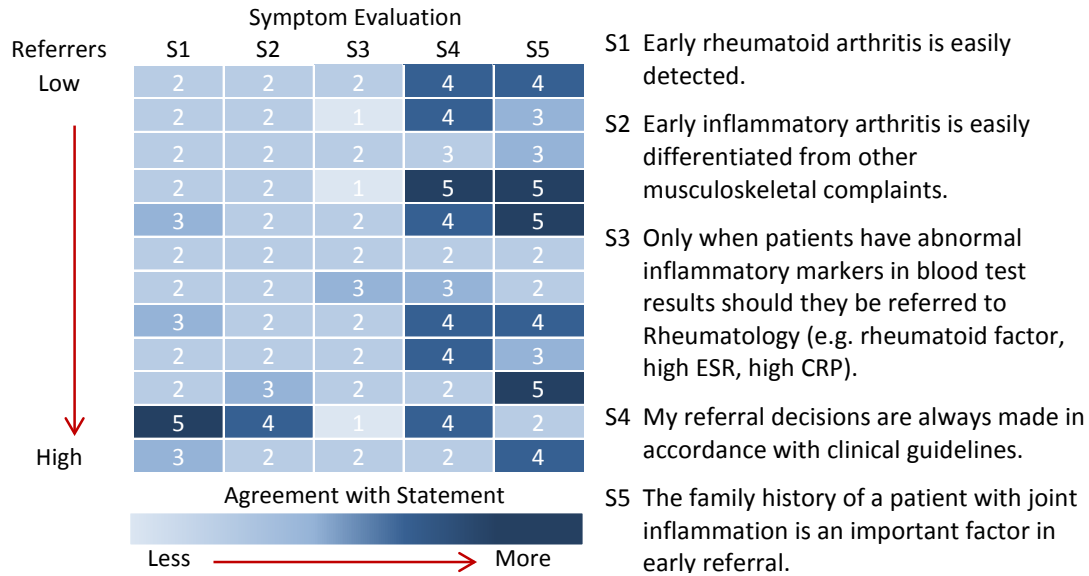


Figure 26: GPs beliefs about IA diagnosis in primary care

GPs can use factors such as family history and clinical markers of inflammation to build a picture of IA, to exclude IA as a diagnosis, or simply ignore them if they do not fit the symptom presentation. Higher referrers tend to place less importance on family history. GPs varied in the emphasis they placed on evaluative factors. These responses suggest a weighting of importance, rather than a process of evaluation. High referrers emphasised the time since onset of symptoms and connections with systemic symptoms, like feelings of general unwellness. High referrers were also more sceptical in their interpretation of the patient story about onset. Family history is treated more as a curiosity rather than a factor affecting evaluation.

All GPs emphasised recent patient history and, if mentioned, the presence of morning stiffness as the criterion to discriminate an inflammatory process from other causes of the symptoms. Little mention was made of an actual physical test for inflammation, such as a compression test, to support a diagnosis.

“[I look for] stiffness in the morning. All the possible information to differentiate between rheumatoid arthritis or inflammatory process or a degenerative process”

GP4

From the patient point of view, the most beneficial path was for GPs to ignore family history and clinical markers in their evaluation if these were not present, and to use them to build a case for an IA diagnosis and referral if they were present. Familial links proved most important for participants with AS. This most probably reflects the difficulty of distinguishing mechanical back pain from inflammatory back pain.

That clinical markers and family history remain a basis for referral for some GPs, rather than examination and patient history is evident in the experiences of two participants who had delayed referral because clinical markers did not indicate an IA but who were both eventually referred based on previously unknown AS in siblings being brought to the attention of their GPs.

“I started to notice it was very difficult to get out of bed in the morning, back pain and peripheral joint pain and I'd get episodes where I'd get swelling. The knees and knuckles and that sort of thing which sort of classic arthritis rheumatoid arthritis type things, so I had blood tests for that, and of course there is no rheumatoid factor...”

Stephen


GPs varied in the emphasis they placed on evaluative factors. These responses suggest a weighting of a subjective ranking, rather than a process of evaluation of clinical presentation. High referrers emphasised the time since onset of symptoms and connections with systemic symptoms, like feelings of general unwellness. High referrers were also more sceptical in their interpretation of the patient story about onset. Family history is treated more as a curiosity rather than a factor affecting evaluation (Table 23).

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“[I look for] stiffness in the morning. All the possible information to differentiate between rheumatoid arthritis or inflammatory process or a degenerative process”

GP4

Table 23: GPs' emphasis on family history in the evaluation process

Referrals	Comment
Low  High	"It's significant emphasis. I'm certainly not generalising by thinking the family history must mean that is what's going to happen or where the pain is coming from. I also explain to the patient that it is not necessarily a connection or a definite diagnosis but it rings a bell and open up a possibility if there is a family history. Maybe rather than delay we get a possible blood test ... it is better to go for an investigation straight away to see if it is clear. A diagnosis of exclusion or possible inclusion."
	"I always ask [about family history] but it does make things a little more complicated and can delay their diagnosis [if there is no family history]."
	"Not a great deal on the whole. I'm not sure how much I should. The reason is that once they have an established disease, they'll probably mention at that stage a family history."
	"Well it tends to steer you down pathways more rapidly."
	"It's not one of the criteria... we are not documenting family history [but] if they come to me with suspicions of rheumatoid arthritis I will ask about their family history."

GP EXPERIENCE

Over the two year data collection period 695 individuals with IA were referred to the rheumatologists in the Wellington region by 353 referring GPs, ranging from 0-10 diagnosed IA patients with a mean of 2 per GP or 1.6/1,000 enrolled patients (this excluded GPs who had been qualified for less than two years). At the outset of this study it was unclear whether difficulties in identifying the cause of MSk symptoms might prompt inexperienced GPs to over-refer in comparison with more experienced GPs, or whether diagnostic uncertainty would mean inexperienced GPs would be less likely to refer. It was also hypothesised that older GPs might refer fewer patients if they were not up to date with changes in treatment protocols. The mean length of time since qualification was 23.7 years (SD 9.4; Range 2-53 years) and GPs who had completed their medical degree between 15-30 years ago were more than three times as likely to refer a patient diagnosed with an IA than GPs who had graduated less than 15 years ago (RR=3.48, CI=1.5-8.06) and almost three times as likely as a GP who graduated more than 30 years ago (RR=2.81, CI=1.02-7.87) (Figure 27). Adjusting the model to include the age structure of the GP practice did not improve the referral rate differences between the three groups ($p=0.002$, RR 3.6 CI 1.60-8.22) and ($p=0.41$, RR=2.84-7.73).

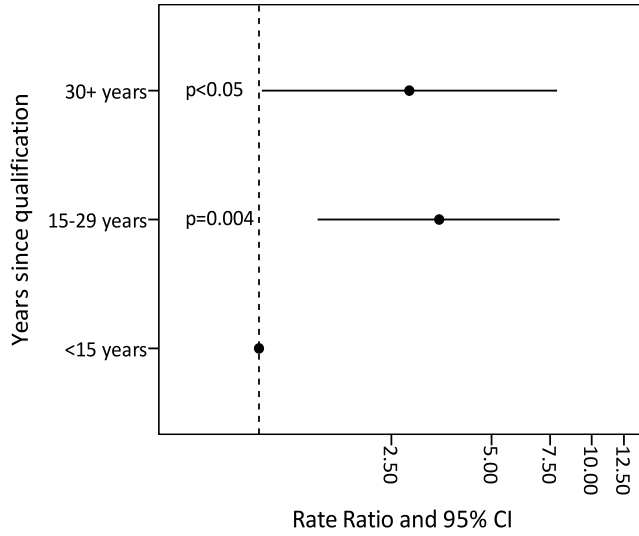


Figure 27: GP experience and the rate ratio of referrals with an IA diagnosis.

Referrals that resulted in an IA diagnosis at FSA Offset by the log of the GP list size (n=140)

Similar significant differences in referrals rates were not seen in the referral of patients who were not diagnosed with an IA condition (RR=2.50, CI 0.55=11.30) and (RR=1.79, CI=2.80-11.26) (Figure 28).

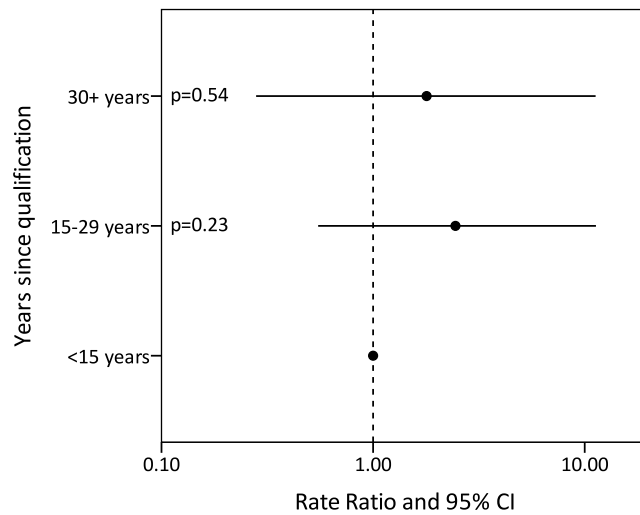


Figure 28: GP experience and the rate ratio of referrals with no IA diagnosis.

Referrals without an IA diagnosis at FSA. Offset by the log of the GP list size (n=140)

This observation suggests that IA conditions are more difficult to diagnose than other rheumatological conditions.

High referral rates do not necessarily equate with accurate referral, and can signal healthcare costs through poor use of secondary care, as much as low referral can increase costs due to later intervention (Coulter, 1998). The higher referring 15-20 year experience group (IA referrals) was not more likely than the other experience groups to have referrals that resulted in a non-diagnosis of a rheumatological condition. Higher referring GPs speculated that a large part of the reason for accurate referrals performance was due to growing familiarity with IA symptoms and the WRRU over the years they had been in general practice. The high referrer GPs, believed that because of the relative rarity of patients presenting with these conditions in general practice and because they believed that general medical training provided only brief coverage of inflammatory conditions that experience was a major factor in detecting IA conditions (Table 24).


These comments indicate a widespread (albeit not unanimous) acknowledgement that training in rheumatological conditions does not meet the level required to adequately detect IA conditions in general practice. GPs consider there is probably no real solution to the lack of time and training for the wide range of conditions seen in primary care:

“There’s never adequate of anything [for example training, time and staff] for independent practice because you can’t fit it all in, no matter which sub-specialty you look at. It’s always going to be inadequate. There’s always going to be a lot of learning on the job so it’s always going to depend a lot on the capacity for self-reflection and the willingness to take steps to update somebody who thinks that he hasn’t got anything that he needs to learn won’t learn anything.”

GP5

The experiences of the IA participants occur within this context of sometimes inadequate training and experience, and variable abilities, of GPs to diagnose IA conditions.

Table 24: GP participants training and experience

GP Referrer	Comment	Training
Low  High	"I think there should be more training because it is such a complicated area."	(less than 15 years since qualification)
	"I have to admit there are several areas in my job that I'm a bit vague about and rheumatology would be one of them. [And after attending a CME] we were still as confused as ever. It seems to be more of an art than a science. Then they seem to change the diagnosis as they go along!"	CME (less than 15 years since qualification)
	"In the broad scheme of what I have to cover - rheumatology, gynaecology, paediatrics, neurology, psychology and sports medicine, orthopaedics, dermatology, gastroenterology and every other ology, so yes it is. I find it adequate. I'm no expert in rheumatology; I don't have a particular interest in it beyond my interest in medicine."	(less than 15 years since qualification)
	"[Training is] probably not adequate before they get to be practising independently, but there is reasonable opportunity for good CME and updating as they go along."	CME (more than 15 years since qualification)
	"I think I was a fairly confident younger doctor. The advantage of experience means you're better placed to be able to assist patients because of the extra knowledge you have about how things work. That I think is always very useful...you learn as you go."	CME Interest in MSk Disorders (more than 15 years since qualification)
	"I think there is too little [training], because just from my experience at the health centre where I work at a lot of [other GPs] often come and ask me questions because they are not sure., or I see a lot of patients who have been followed up by GPs for a long time and just don't have that slight lateral thinking - oh this must be a rheumatological disease... I think that's where your training and exposure counts a lot."	Rheumatology experience (more than 15 years since qualification)

DISCUSSION

Identification of IA at an earliest possible stage of the disease is important so a treatment path can be established before joint damage occurs. For RA there are "no clinical, biological, or radiological characteristics specific to RA diagnosis" (Fautrel, 2009, p. 2375) and because early IA symptoms are often undifferentiated it has been persuasively argued that in general practice a classification criteria for early IA (EIA) is more important than criteria for the range of IA diseases so that individuals with potential, rather than actual, erosive disease can be referred to a rheumatology

service and effective treatment can be started before the window of opportunity is lost. (Combe, et al., 2007; Kiely et al., 2009; Symmons, et al., 2003).

The premise of a 'critical treatment path' where patients who waited less than six weeks to consult with a GP, were also likely to wait for less than six weeks from consultation to referral (Kumar & Raza, 2008) does not appear to be borne out in this study. The main indicators of early diagnosis for study participants were visible damage to joints, an associated condition (e.g. psoriasis, colitis) and/or pain and inflammation in more than three joints. Delayed diagnosis was associated with pain and inflammation in fewer than three joints and early presentation to the GP. It is likely that only seven participants (four with RA) were diagnosed within six weeks of the onset of symptoms. Eight of the 22 IA participants (including four with RA) were not referred to a rheumatology service for at least 12 months ranging up to 10 years, after their first GP consultation.

There is an expectation that classical presentation of RA assists a speedy diagnosis and research has indicated delays are often caused by unfamiliarity with atypical presentations (Suter, et al., 2006). For the Wellington participants typical and atypical presentation was not a clearly differentiated factor in long diagnosis delays. This contention is exemplified by the narratives of four women¹² with symmetrical IA symptoms in the wrists; GPs and patients had coincidental belief in injury narratives (in these instances a repetitive strain injury). This preference to accept an existing narrative channelled the evaluative process, resulting in premature closure and delaying the next consultation until symptoms had significantly progressed. Three of the four women did not manage to persuade their GPs to reconsider the initial diagnosis, initiate laboratory tests and facilitate rheumatology referrals without an external catalyst.

The consultation process described by GPs is characterised by abbreviated evaluation, i.e. at the first consult the GP does not consider all the information presented and the range of diagnostic aids that are available to confirm a diagnosis. This situation calls into question whether the methodology used by GPs for symptom evaluation is appropriate for uncovering EIA symptoms. High referring GPs

¹² A fifth woman with wrist pain was misdiagnosed with an inherited condition.

emphasised that because of their experience they are able to keep the possibility of an IA in mind at the earliest stages of an evaluation of a MSk complaint, but for less frequent referrers a selective search for evidence tends to prevail. Both GPs and IA participants described accepting the patient's reasoning for the symptoms, although GPs may also work through possible causes beginning with those most commonly encountered in general practice and settle on one that fits the symptoms as presented, truncating further investigation. Only after common causes were ruled out and the patient returned for further evaluation would alternative causes and diagnostic procedures sometimes be considered. This means that a participant who consulted a GP with little background in IA, commonly did not have diagnostic tests and was not referred to a rheumatologist at the first GP consultation. GPs reasoned that the most likely scenario is most often the correct one, and patients, if advised to, would return within a reasonable timeframe if this reasoning appeared incorrect. However, IA participants described how they accepted the GP's conclusion about cause and took 'wait and see' approaches, sometimes not returning to the GP unless seriously incapacitated or the pain had become unbearable.

Important contributions to understanding diagnostic errors attributed to the GP, like delays in successfully evaluating IA symptoms, have been attributed to cognitive bias of the GP (Graber, 2005), knowledge deficits (Norman & Eva, 2010) and attitude toward the patient, including attitudes that created barriers to effective GP-patient interaction (Gardner & Chapple, 1999; May et al., 2004).

COMMUNICATION OF SYMPTOMS

An agreement between the patient and the GP about the conceptualisation of cause of symptoms, based on patient narrative giving a presumed symptom history can delay correct evaluation and referral. Besides a preference for an injury explanation, evaluation is compromised by the difference in description of symptoms. IA participants did not describe their condition in terms that might trigger thoughts of IA for the GP. The more experienced, higher referring GPs tended to talk of more open-ended and wider questioning to overcome this barrier.

Congruence in the presumed cause of symptoms can originate from differing medical models. Beliefs of the patient about GP knowledge translates into trust in the decision

reached during the first consultation and a reluctance to abandon the GP opinion. IA participants with a strong belief in the GP as an expert elevated GP opinion above the actual experience of symptoms, delaying further consultation or seeking symptomatic relief from physical therapists, for example physiotherapists, osteopaths and masseurs. The GP on the other hand has an expectation that the patient would be more sceptical, or understand the inconclusiveness of the evaluation and quickly consult again if symptoms do not improve. Despite the patient's beliefs that they have had an expert opinion, GPs were in agreement that IA and RA can be difficult to diagnose and few described themselves as confident in detecting an IA. In conjunction with these beliefs and expectations are the resources the patient has (time, money and convenience) that remain unacknowledged.

GPs admit they follow-up with patients who have been asked to return only in cases they have assessed as potentially serious, but will not follow-up on a MSk condition that does not meet this criteria, even when IA is suspected, unless the patient has been referred for laboratory test that have produced a positive IA result. Ironically perhaps, three participants who embodied the cultural tendency to play down physical pain and who lacked good financial resources were less affected by extended diagnosis delays because their initial symptoms delay was so extended that joint damage or incapacitation was undeniably an IA so a positive evaluation and diagnosis was readily made.

COGNITIVE BIAS

Graber analysed the possible attribution of system-related and cognitive factors to the diagnostic errors for 100 patients and found 74 percent of the patients had encountered diagnostic errors with an average of 5.9 cognitive errors per case. The study concluded that the most common cognitive errors were faulty synthesis and premature closure and diagnostic error. A diagnostic error was defined as closure, faulty context generation and misjudging the importance of findings.

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"a diagnosis that was unintentionally delayed (sufficient information was available earlier), wrong (another diagnosis was made before the

correct one), or missed (no diagnosis was ever made), as judged from the eventual appreciation of more definitive information.” (Graber, Franklin, & Gordon, 2005, p. 1493).

Faulty perceptions and the use of heuristics also resulted in diagnostic error. This list of errors raises important points that conflict with usual evaluative processes. GPs use a heuristic process (making judgements about probability of a condition) to inform the diagnosis of the overwhelming majority of patient problems and facilitate faster, correct diagnoses (Norman & Eva, 2010).

Graber and colleagues found little evidence of faulty knowledge (insufficient knowledge of condition and insufficient diagnostic skills) in their analysis of diagnostic errors; instead favouring processing bias (Table 25), faulty data gathering, information processing and verification as cognitive causes of diagnostic error. This conclusion does not mesh with Wellington GP experience and IA referrals data, which was used as a proxy for GP diagnosis rates. This data shows that GPs with less experience are significantly less likely to have an IA diagnosis made for a patient they referred, despite the likelihood of diagnosis rates for rheumatology referrals for non-IA conditions being similar. For IA patients the lack of GP knowledge is an added factor in delayed diagnosis.

Table 25: Cognitive Bias and diagnostic error processing biases

Processing Errors	Descriptions
Availability	A tendency to preference a diagnosis that is more easily retrievable from memory.
Base rate neglect	A tendency to ignore the true rate of disease and pursue rare but more exotic diagnoses.
Representativeness	A tendency to be guided by classical features of disease and miss non-classical presentations.
Confirmation bias	A tendency to seek data to confirm, not refute, the hypothesis.
Premature closure	A tendency to stop the diagnostic process too soon leading to ignoring the availability of useful tests or persist with further information gathering.

Source: Norman and Eva, 2010

THE KNOWLEDGE DEFICIT

In a review of the Graber study it was suggested premature closure of the diagnosis, the most common cognitive processing error, is likely to result from knowledge deficits due to either the condition being unknown to the practitioner or the presentation being unusual (Norman & Eva, 2010). The Wellington GPs acknowledged IA might be difficult to diagnose with vague presentation of symptoms. Their descriptions of the patient evaluation suggested they were slightly surer of diagnosing RA, however they were aware that unusual presentations might be problematic. Despite the greater confidence in diagnosing classically presented RA, IA participants who classically presented RA symptoms (symmetrical presentation of inflammation in small joints) were missed for extended time periods.

Overconfidence, attributed to insufficient knowledge about a disease, is also cited by Berner and Graber (2008) as cause of diagnostic error. This belief in diagnostic abilities also goes some way towards explaining a lack of discussion about problematic IA cases with colleagues. In GP practice peer-review processes, GPs did not believe there would be any consultations with colleagues on MSk symptoms, believing that the low likelihood of a perceived catastrophic outcome if the diagnosis was incorrect, and the patient's decision not to make a return consultation, were sufficient reasons to avoid losing valuable time in re-assessing the outcome of the consultation.

For six participants who waited from two to more than 12 months from the first GP consultation for an accurate evaluation, a catalyst was required to trigger a change from a diagnosis of injury toward preferring a suspected IA diagnosis. Until an outside opinion was sought by the patient, the GP did not deviate from the initial interpretation of symptoms. This catalyst could be the recognition of the same illness in a family member (notably two instances of participants with AS each with a diagnosed sibling), a social contact or an AHP contact who introduced IA as an explanation for symptoms that would not improve.

To highlight diagnostic difficulties for the GP a French study has shown that even in rheumatologist clinics diagnostic uncertainty has led to delays in instituting DMARD therapies. Thirty-four percent did not receive DMARDS within six months of referral

due to the difficulty rheumatologists had in reliably ascertaining the condition was RA (Benhamou et al., 2009). The Norfolk Arthritis (NOAR) project identified only 38 percent of patients met classification criteria for RA at FSA, but 66 percent of the patient cohort had been diagnosed with RA five years after symptom onset (Symmons, et al., 2003). These studies highlight the importance of GPs identifying and referring patients with IA symptoms rather than waiting to confirm a diagnosis of a particular type of IA.

In the context of the complicated diagnosis of IAs that rheumatologists must negotiate, to expect GPs to diagnose an IA without specific training seems unrealistic. Diagnostic criteria might aid the GP but 11 of the 12 GPs questioned were reluctant to use these criteria in their decision-making process. The most frequent reason given for this reluctance was the impact on consultation time. The local operating conditions outlined in Chapter Five, of acute GP shortages in some areas and long patient lists undoubtedly have an impact on the length of appointment time and the tendency of patients to 'save up' several complaints for consultation, which exacerbates the problem of time-poor consultations. In 2007 the average consultation time in a GP practice was 12 minutes, with the median appointment length of 15 minutes reported by 73 percent - down from 86% reporting a median of 15 minutes in 1998 (RNZCGP, 2008b), indicating greater pressure on the GP and patient to get through the consultation quickly. Several GPs were also unaware that criteria and guidelines were available, with mixed opinion on their use if they were available. Two GPs also questioned the suitability of IA guidelines in primary care. It is clear from IA participant interviews though that the use of guidelines was an irrelevant consideration simply because IA was not considered in the evaluation process. However, the issue of the efficacy of IA guidelines in primary care is worth exploring. One high referrer diagnosed and referred on the criteria set out in the 1987 ACR criteria of RA. The GP did so within the context of good contact with WRRU consultants and a strong interest in rheumatic diseases. Despite a near-universal rejection of using IA criteria in primary care, GPs in their evaluations, appear to inadvertently adhere to the ACR 1987 RA classification (Appendix 7) , which has a start point of inflammation in three or more joints, despite symmetrical joint involvement being a characteristic of RA. IA participants presenting in this way were

among those with the longest waits to diagnosis. The suitability of EIA guidelines in primary care settings is a concern of organisations like the ACR and EULAR (Sieper & Rudwaleit, 2005; Smolen et al., 2010) and this concern takes on a more urgent character if GPs have a mind-set that rules out IA if inflammation is present in fewer than three joints. Adaptations of the updated criteria produced by the ACR and EULAR working group should be distributed, which in lieu of general practice guidelines may help to encourage evaluation that points toward an IA diagnosis at an earlier stage.

Despite a clear requirement for aids to detect IA at an early stage, rejecting criteria is a reasonable position to hold given that rheumatologists also express difficulty with established criteria. For example, the sensitivity and specificity of ACR 1987 criteria is lower than that of expert opinion, and this reflects a role as a classification tool, rather than a diagnostic tool (Banal, Dougados, Combescure, & Gossec, 2009). This situation is, however, changing, with new classifications that more readily lend themselves for GP use and earlier referral as do both ACR and EULAR. Unfortunately for many IA participants in this study, the ACR and EULAR criteria, which advise that testing should begin in any patient with synovial inflammation in at least one joint that is not better explained by another condition, is a complete reversal of the evaluation criteria that GPs without familiarity with IA described.

TRAINING AND EXPERIENCE

Quantitative measurement of GP and practice characteristics uncovered, after adjusting for the patient list size, that the length of time since qualification was the only significant GP characteristic in likelihood of referring patients, with GPs who were qualified for more than 15 years significantly more likely to refer more patients diagnosed with an IA. The length of time since the GP qualified was a significant factor ($p=0.03$) in variations in IA referrals. GP practice (the type and size of practice, and the age profile of the enrolled population— older, average and younger), and GP characteristics other than the length of time since qualification were not significant factors in referrals patterns. GP Practice characteristics did not appear as significant factors in referral rates. The lack of correlation between GP and practice characteristics and referral rates is a similar finding to Barnett and Malcolm's

(2010a) study of GP practice hospitalisation rates and the NatMedCa studies that found only small, unexplained differences between the referral practices of GP from different practice types (Independent, not-for-profit, rural and Māori/Pacific peoples providers) (Raymont, et al., 2004).

That a similar difference in referrals for conditions other than IA was not seen, is indicative of the difficulty in interpreting patient stories of onset and incorporating these into the observation of physical indications of disease (or dis-ease). These results suggest that differences in referral rates can, in part, be explained by low levels of primary care specialist expertise in rheumatological conditions, the low likelihood of encountering new cases of IA and the wide variety of presentation scenarios. At the time of this study, unlike comparable countries (e.g. Australia, Canada, United Kingdom), New Zealand GP registration did not require on-going vocational training. This situation is of concern to the RNZCGP which believes that on-going specialist vocational training should be a requirement for working as a registered GP (RNZCGP, 2008a). New Zealand-trained GPs understood their undergraduate training in IA conditions was not comprehensive enough to deal with the range of presentations they might encounter in primary care. Five of the six NZ-trained GPs agreed they would have benefitted from more training at the undergraduate level. The dissenting GP thought that, given the low volume of IA patients in general practice, further training would be disproportionate to the GP workload; and that any knowledge shortfall could be improved with CMEs. IMGs described their undergraduate rheumatological training as being more extensive than they perceived their New Zealand colleagues received. With no significant difference in the length of time since qualification between NZ and IMG medical graduates, an unanswered question in this section of the research is why the extra training of IMGs is not reflected in greater IA referral rates. Perhaps there is an interaction between language, unfamiliarity with the health system or other factors influencing referral rates by IMGs that this dataset has not uncovered.

EVALUATION SKILLS

Patients' conceptualisation of their symptoms can be quite different from what is described in criteria for referral. The clearest indication of this situation is that none

of the 22 IA participants in this study used the term “stiffness” to describe their symptoms, whereas this term is of clinical importance for detecting IAs; early morning stiffness is characteristic of RA and SpAs like PsA (Combe, et al., 2007; Emery, Quinn, & Conaghan, 2002b; Tavares, et al., 2010); and stiffness that improves with exercise is characteristic of AS (Sieper & Rudwaleit, 2005) even after diagnosis ‘stiffness’ remained a word only once used by IA participants to describe symptom experience.

It is clear that for IA participants the description of symptoms before treatment concentrated on the ability to perform tasks ahead of pain, except if the pain was debilitating. They would describe their early morning experience as soreness when attempting a task for example, getting out of bed or walking downstairs. Experienced GPs understood this descriptive preference and the task-oriented focus and used more open phrasing to elicit information. A focus on the inability to perform tasks can also lead IA participants to under-report symptoms elsewhere in the body that did not interfere with day-to-day performance.

Without finding a medical cause for painful symptoms, GPs may also begin to focus on the patients’ attitudes and possible non-medical reasons for presenting with MSK complaints rather than extending the evaluation to include IA conditions. IA participants rarely suggested their own GPs did other than evaluate symptoms, but GP comments, in both interviews and in patient referral letters, confirm this scenario is an important issue.

FRAMING BIAS

Changes in diagnosis, referral and treatment guidelines might not be conveyed to primary care settings because GPs rarely use them. GPs in this study relied more on the experience in their primary care setting for improving diagnostic skills with some input from CMEs. Medical decision-making can be affected by non-clinical characteristics that are irrelevant to the evaluation of symptoms (Burgess, 2010) and listening sceptically to the patient’s story appeared to be a key factor in the early diagnosis of IA. This is not the same as being sceptical about the patient’s symptoms, which tends to delay diagnosis but encourages the GP to look at the possible attitudes of the patient that led to the consultation. The combination of unquestioning

acceptance of the patient's story and questioning the patient's symptoms leads to a framing bias that results in incorrect evaluation, delayed diagnosis and delayed referral (Figure 29).

The effect of the framing bias means that the patient has to produce enough evidence to convince the GP that a thorough clinical examination and laboratory tests for markers of inflammation are warranted, but the injury narrative combined with vague or incomplete descriptions and history from the patient; short appointment timeframes (especially if symptoms were presented as additional to the main reason for the appointment); and experiential and intellectual differences in defining symptoms suggest this is unlikely on first consult unless the patient consults a GP with interest and experience in identifying IA conditions.

The GP's decision to make time to deal with an appointment that may go overtime because of MSk symptoms could be determined by a variety of factors, for example how busy the practice is and the delay to waiting patients. An immediate consultation runs the risk of being hurried, but when symptoms are not evaluated immediately it may be left to the patient to determine the importance of the symptoms in terms of follow-up. An alternative to the patient deciding on the importance of a future consultation is to have a proactive position for enabling continued contact such as setting a further appointment immediately, or requesting blood tests for inflammation, necessitating further contact with the patient. Clearly this technique is only appropriate if the GP has included an IA as a possible cause of the MSk symptoms.

Experienced GPs were aware the cost and convenience of further appointments created barriers to returning for further, timely consults and that these barriers added to the importance of an accurate initial diagnosis. No GPs considered the scenario that if the GP had determined that the condition didn't require immediate attention a patient may delay a return because they believed further attention was unwarranted unless the symptoms increased, rather than failed to resolve.

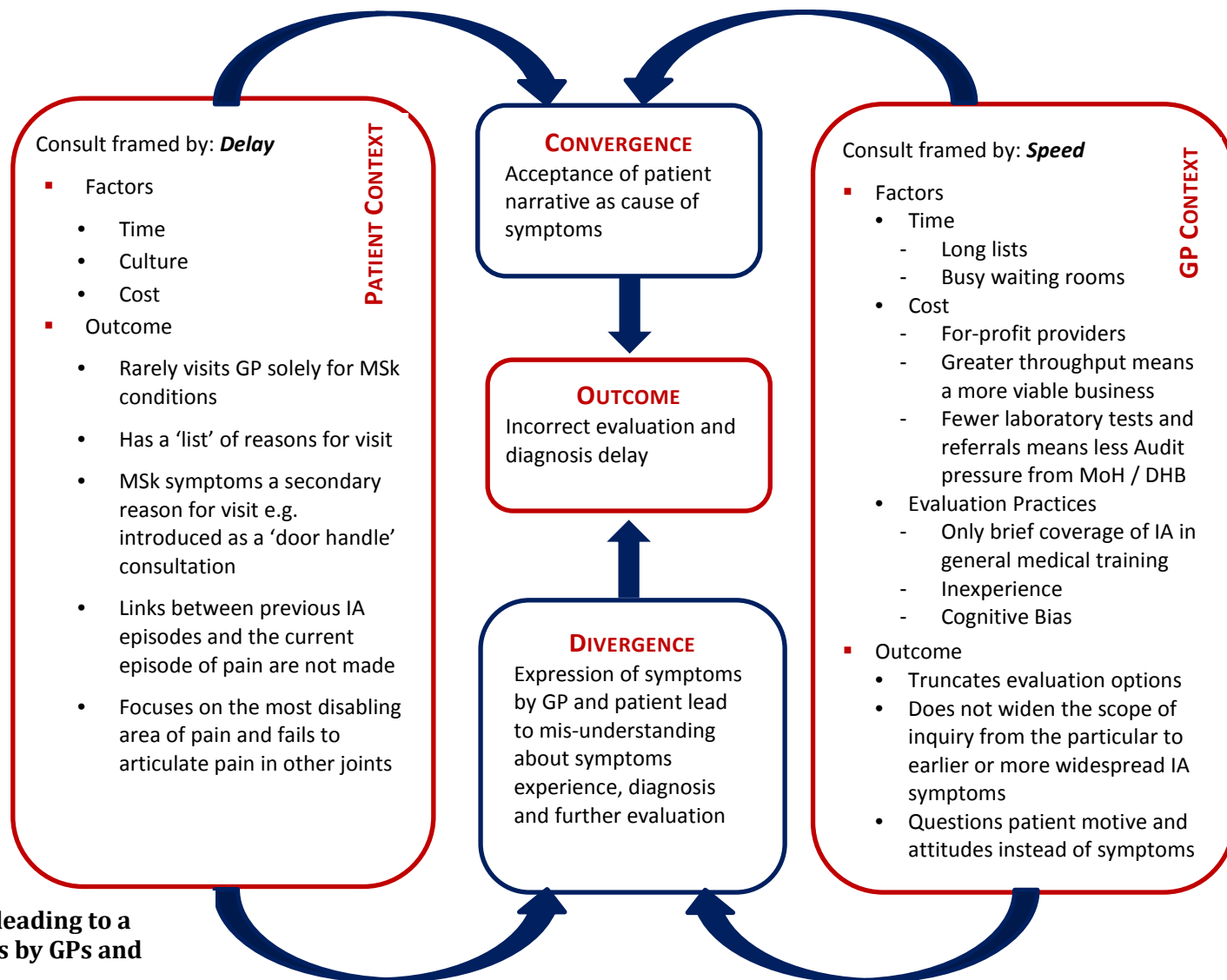


Figure 29: Factors leading to a framing bias by GPs and patients.

Assumptions by the GP about the patient's knowledge of the probable cause of the symptoms and poor communication about symptoms are barriers to early diagnosis. Patients and GPs also have expectations of the other that are not transparent. The GP has an expectation the patient will return within a reasonable timeframe if symptoms get worse whereas the patient may simply see this expectation as an unlikely indicator that a further consult may improve the diagnosis. Central to the GP-patient relationship is the expectation the GP has the skills to diagnose the problem, with the patient unaware that diagnosis of an IA is difficult, and GPs may have preconceived notions of how symptoms would present, both physically and in patient descriptions.

Participants who accepted that the initial opinion of the GP was correct might bypass the GP when symptoms did not abate, especially if the symptoms were manageable. In this study participants' reasons for bypassing the GP varied; initially the lack of resolution at a GP consultation drives the decision; the GP response can confirm a suspicion that the symptoms result from injury and the patient can save costs by directly consulting an AHP; or the patient may have speedier service - especially rural areas - by direct consultation with an AHP.

Participants presented with a range of symptoms and durations from as little as a week to as long as 10 years. The main focus for participants was on pain in only one or two joints (13 participants). As shown in the previous chapter, patients are likely to blame a physical trauma for this type of joint pain and study participants carried this explanation through to their first GP consultation. Other participants had obvious joint damage, conditions related to an IA, for example psoriasis or wide-spread illness with flu-like symptoms (two participants). These variations in symptom presentations can make diagnosis of an IA condition extraordinarily difficult for GPs. Patients often did not present with symmetrical arthritis, but in part, this is a miscommunication due to the patient focus on the joint causing physical incapacity. For example an office worker may notice a right hand is more of a problem in day-to-day work, than the left and the focus of the consultation becomes the noticeable inflammation that is preventing work being done with the right hand, with the patient omitting reference to any other joint pain or discomfort. Patients presenting with symptoms in fewer than three joints, or with systemic symptoms, had the greatest chance of an incomplete evaluation. The patients' vague or incomplete

communication of IA symptoms can be seen in the context of playing down pain, and focussing on activity in keeping with the narrative of physicality.

In summary, the patient understanding is that GPs are in control of the evaluation process, whereas GPs may expect the patient to be proactive in the care process, especially in terms of decision-making about referral. GP and patient agreement about the cause of symptoms, without adequate evaluation, reinforces unsubstantiated conclusions by the patient and/or the GP about the cause of symptoms, and probably adds to the delay in making a decision to return when symptoms do not subside. For the patient the chance of a correct evaluation early in the disease process lies in the knowledge of the GP about the symptoms as they are presented, and the GP beliefs about the accuracy of patient portrayal of symptoms and assumed motive for presenting.

11. GP REFERRALS

INTRODUCTION

Once a GP has decided a patient has a suspected IA, the recommended treatment path is referral to a rheumatologist in the shortest possible timeframe, preferably within six weeks of the onset of symptoms (Combe, et al., 2007; Emery, Breedveld, et al., 2002), because the early initiation of recommended treatment protocols is the key to limiting joint erosion (J. Braun et al., 2011; Emery, Quinn, et al., 2002a). The previous chapter details the one significant GP or GP practice characteristic of those collected – GP experience - that significantly impacted on the number of referrals to Wellington rheumatology services. Rheumatologists' administrative referrals data cannot provide quantitative data about how long referrals from GP practices may have been delayed, however qualitative information from interviews with GPs and IA participants proved to be a rich source of information that could be used to investigate the reasons why a referral to the rheumatology service might be delayed for people with suspected IA.

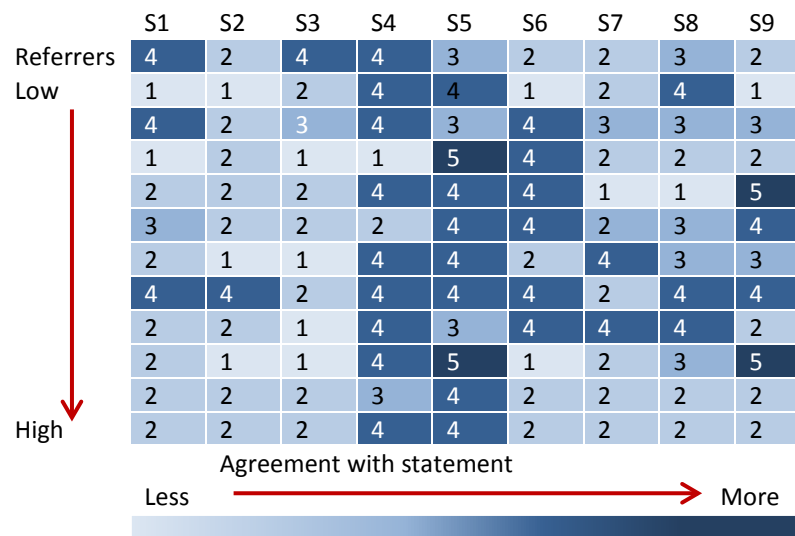
The interaction between patient and GP is multi-faceted and the psycho-social and psychological interactions are beyond the scope of this research. What this research does provide is narrative that details what patients understood about the referral process, and what GPs believe are important factors in the referral decision. This detail includes beliefs about the disease and treatment options; the respective responsibilities of the GP and patient, and about the adequacy of public rheumatology resources. The IA participant interviews have shown people are unprepared for decision-making when presented with a probable IA diagnosis. This theme of decision-making was carried forward from the IA to the GP participant interviews with the aim of understanding what efforts GPs might make to ensure a patient is fully informed of their options, and that the patient resources that affect the outcome of a referral are reflected in the decision-making process. . Inter-woven into this discussion are narratives from IA participants that illustrate their perceptions and explanations of how delays have occurred and the effects of these delays on personal well-being.

These deliberations need to take into account patient perceptions and experiences that have led to the formation of a narrative for the symptomatic individual that can be difficult to counter, even if the GP was aware of it. This chapter references the complex narratives of Gillian, Holly and Philip that illustrate the underlying context of decision-making about treatment and referral.

The chapter examines reasons why GPs delay the referral of patients who have been evaluated as having a probable IA. It covers how the facilitation or delay of referral is mediated by the GPs' understanding of the importance of early referral, and their perceptions of treatment options, rheumatology resources and of patient need. The topic of pain relief between the referral and FSA is also discussed. Pain relief during this period arose as an important factor in patient well-being, and GPs were divided on the appropriateness of prescribing before FSA.

REFERRAL FACTORS

When asked about factors that have been identified in international research as having a bearing on delays to rheumatology referral, GP responses indicated that there is no one factor that delays the decision to refer a patient with a suspected IA (Figure 30). Collectively, GPs indicated referral delays would be a combination of several factors involving beliefs about disease progression and treatment, expectations of and about the patient, and interaction with rheumatology services. Throughout this chapter the responses ranked in order of referrers who had had fewer than three referrals in the study period, to referrers who had up to ten referrals in the study period, with a low proportion of patients who were not diagnosed with an rheumatological condition.



Statements

- S1 It is better to wait and determine the progress of inflammatory arthritis before beginning DMARD therapy.
- S2 It makes no difference when DMARD therapy is started as it will be just as effective if given when IA is more established.
- S3 The possible side-effects of DMARDs such as methotrexate outweigh the benefits in most cases of inflammatory arthritis.
- S4 Patient preferences about treatment influence my decision to refer.
- S5 If a patient is reluctant to be referred to a rheumatologist I would work hard to change his/her mind.
- S6 Long waiting lists affect my recommendations about referring to public rheumatology services.
- S7 I am less likely to refer people who I think are unlikely to attend specialist appointments.
- S8 I am more comfortable referring cases I am not sure about when I have a good relationship with the rheumatologist.
- S9 I am more likely to refer a patient who can afford to pay for private rheumatologist care.

Figure 30: GP beliefs about factors that may affect early referral

DISEASE PROGRESSION

A GP's assessment of the progression of an IA disease is an important reason for delayed referrals. Eleven out of 12 GPs agreed that starting DMARDs early in the course of the disease was more effective than beginning them later, but this agreement is qualified by the perceived level of disease activity the patient is experiencing (Table 26).

GPs' reluctance to refer for DMARD treatment included both a belief that the side effects might outweigh the benefits in apparently mild cases of IA, and also that the rheumatology resources required to implement and monitor DMARD therapy is an inefficient use of scarce rheumatology resources in cases where disease progression is intermittent or the symptoms mild.

NEGATIVE BELIEFS ABOUT TREATMENT

High and low referrers were equally as likely to talk about encouraging patients to accept a referral and patience with patients who needed time to accept referral as the most appropriate course of action. GP comments would suggest that patient aversion to DMARD therapy was not often strongly countered. However, a reluctance of GPs to participate in the patient decision-making process regarding referral is supported by the commentary of two of the three IA participants who delayed the implementation of DMARD therapy due to their belief that it was unnecessarily 'strong' or because the side effects were unacceptable. These participants agreed to referral because treatment options in primary care failed to control their symptoms. The third participant, Philip, was reluctant to be referred for several reasons that included the stigma if his condition became widely known, of having a chronic condition that might be perceived to affect his strength and agility, and the effect side effects methotrexate might have and the potential for this DMARD to impede his ability to network socially, which was an important aspect in building client and colleague relationships (Figure 31).

DECISION-MAKING AND INTER-WEAVING SOCIAL, CULTURAL BARRIERS WITH BELIEFS ABOUT TREATMENT: PHILIP'S STORY

"[Having IA] that's going to put people off whether you like it or not. People sort of discriminate against people with disadvantages, they'd rather have a fit person... So you end up wanting to project an image of somebody that is strong and capable, so yeah there is a certain wanting to mask it, and so I don't want anyone to know about this".

Philip was also very concerned about taking methotrexate due to the possibility of side effects of methotrexate and the consequences, in the context of his employment and professional networks. His perception about effect of medication is one of the main reasons for non-referral:

"One reason why I avoided all this medication is because I can't stand feeling even the slightest side effect feeling nauseous or anything because my job I really have to feel I think possibly more than other jobs I have to feel really good and focussed, sharp, enthusiastic and so if there is anything taking that edge off then I'm not a happy chap at all..

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...Yeah I like a bit of red wine I remember with methotrexate I'm sure they just said - I mean liver damage is a possibility with all these drugs if you - you know they all seem to affect the liver if they are going to affect anything".

It is clear Philip believed his treatment options and the outcomes of delay were not effectively communicated to him over the nine years of his disease activity. He was originally prescribed an anti-inflammatory and was under the impression that this has remained the first-line treatment for erosive inflammatory disease:

"[The GP] he prescribed something called brufen retard and from what I can recall that was the only treatment. You know anti-inflammatory medication, only conventional medicine...and I asked him again at some stage more recently, well not in the last couple of years - earlier on, because I got the impression that that was basically the only conventional medical answer."

More recently, through social contacts, Philip has been made aware methotrexate can be prescribed for his IA. But previously he had experienced side effects when it was prescribed many years ago for a related inflammatory condition. Despite being in contact with his GP as his condition has worsened, he was not aware of advances in DMARD therapy that reduce side-effects since this initial unsuccessful trial of methotrexate, or that alternative DMARDs might be available:

"Every time I go and see him he looks at this [enlarged wrist with clear erosive changes] and goes 'ohh we should probably do something about that, you know'.... I think probably where the conversation ends up is 'well, anti-inflammatories disagree with me', where he just sort of goes 'oh well'. But as I said the impression I was left with was that the only conventional medication was anti-inflammatories and they don't agree with me so I'm on my own."

At the time of writing Philip had still not been referred to a rheumatologist to have his options explained to him. He also feels he has a good relationship with his GP and that any blame for his non-referral lies with his own attitudes rather than the GP's management.

"My attitude through this has been a kind of 'give up' attitude. So it wouldn't surprise me if [referral] ever came up that I might have said 'oh no I don't need it, there's no point.'"

Aside from his negative beliefs about treatment he is also constrained by his employment status – as a contracted employee he is reluctant to take time off work to explore his options – and by his beliefs about how he should respond to physical impairment.

Figure 31: Patient context informing negative beliefs about referral

It is important for GPs to be able to speak positively and knowledgably about DMARDs to promote the potential benefits and communicate a realistic risk of side effects. However, it can be difficult for GPs and patients to achieve a positive referral outcome with patients who are reluctant to consider this treatment. Three GPs recounted examples where patients with severe disease had refused to consider DMARD therapy. In GP2's example the patient had already considered and rejected the options of DMARDs:

“I had a very tricky lady who had very bad arthritis and who had been to see the rheumatologist and did not want disease modifying drugs but she would come in every couple of weeks saying to me that she wanted me to do something to help. She was really bad and I finally convinced her to go back and she finally went back on methotrexate and she did really well. I would spend a lot of time discussing the usefulness of some of those supposedly nasty drugs – if you don’t have them, this is what’s going to happen.”

GP2

PAIN RELIEF BEFORE FSA

A seemingly misunderstood aspect in the path to treatment, and one that was of great importance to the IA participants, was symptomatic pain relief between the referral and the FSA. GPs had a range of views on prescribing steroids such as prednisone while patients were waiting for their FSAs (Table 28). Views ranged from agreement with prescribing glucocorticoid steroids (GCs) before the FSA through to concerns about side-effects and patient reliance on symptomatic relief and concerns about masking inflammatory symptoms, making the task of an IA diagnosis more difficult.

Table 28: Prescribing GCs before FSA

GP	Examples of GP views on prescribing steroids before FSA
GP2	“I have an interim plan and will do that with any referral as they won’t be seen tomorrow. I just about always put something in that will hold them until their appointment. It depends how confident I am about what I’m treating. Obviously I have to keep a close eye on them and see them within the week to see how things are going. On the other hand if you make them too well before they go and see the rheumatologist, they’ll say, “what are you sending me this person for?” [but] Ideally they would be able to see the rheumatologist within the week rather than within the year.”
GP3	“I wouldn't go as far as steroids. Steroids are definitely indicated but once you put a person on steroids with a rheumatological disease on steroids you have to be cautious. You have to know exactly where you're going and often it's a cloudy picture so I think sometimes giving steroids too early can actually make it even murkier and you can run into some more problems with that. If I'm going to put somebody on steroids I'd rather discuss it with a rheumatologist and say look 'this is what I've got this is what my findings are these are the blood results, can you see him within the next week while we make him comfortable' you know?”
GP6	“Yes, I use steroids quite frequently for a variety of conditions but I need to know confidently what I'm treating rather than thinking I am. I wouldn't give out a steroid unless I had a confident diagnosis, and sometimes I'll use a steroid whereby I think it's this condition and if it is they should respond well. But steroids are a pretty blunderbuss drug. It works for a lot of things and patients often want more. Some patients are very aware of the side effects of steroids and are reluctant to take them others have no idea [but] if I feel they are in strife, I put them on steroids while they are waiting.”
GP7	“I will certainly use high dose prednisone in the short term while someone’s waiting to be seen. I just don’t like to get myself in the position where the patient thinks that the prednisone is the answer to their problems. I will give them 40mg a day without compunction if I think that they need something to settle them down acutely and keep them functioning.”

GP	Examples of GP views on prescribing steroids before FSA
GP8	"If we don't get anywhere with getting an appointment then I'll ring the registrar and have a chat to them. It is a problem when you've got an acutely inflamed joint and it might need some steroid injection into it and we don't do that here, well not those specialised injections. It's a big problem."

Several IA participants, on the other hand, exhibited visceral recollections of the pain and uncertainty in the period between referral and FSA, but only two were aware their pain could have been better controlled during this time (Table 29). All participants were prescribed NSAIDs for pain relief before referral, but when this did not provide relief discrepancies in prescribing steroidal treatment left several participants in poor condition to deal with the challenges of their daily lives while awaiting the FSA.

Table 29: Symptom management before FSA

Participant	Comments on symptom management before FSA
Carla	"I thought 'oh god my life's over'. But I was really annoyed because the nurse from that practice phoned up from the doctor I had been seeing and said [the GP is] away. Now I had a CRP of 58 or something at that stage, which is quite high. Bitch, is all I can say. I'd like her to have a CRP of 58 and wait four days instead of referring me to another doctor. I was furious. Absolutely furious. I'll never go back to her and I wouldn't take my child to her either. I was absolutely outraged that I could be left with that. Christ that was the thing that really annoyed me."
Catherine	"I went to see my own doctor [after diagnosis by a locum] and he didn't want to give me the prednisone [that the Locum had earlier prescribed], and I said 'you've got to give me something' because the pain is just horrific. The doctor said 'I'm not happy [to do that]' and explained the reasons why and I said to him 'well you know you can't just leave me'... and he said 'when's your appointment' so I told him and he said 'well, I'll give it to you until you see the specialist and as I say I think that was about 6 weeks. I got the prednisone on the Friday. Saturday morning I felt like a new woman. It was absolutely amazing."
Kim	"I couldn't move my arm higher, even one foot out from my body, I couldn't move it backwards at all and I could move it slightly forwards and I could barely [bend to] wash my hair. And terrible pain, just crying at night and I had to lie on my back all the time. I spent six months lying flat on my back in bed I couldn't do any other way of lying. And quite a few times I couldn't go to work because I just couldn't get down those stairs, I couldn't get from the first step to the doorway and I had to sit on the chair and basically think I need to go to the toilet soon and plan how I'm getting up and get over to the toilet in time then back to the chair. I had quite a few days like that."

Prescribing GCs was a lesser issue for GPs experienced in communicating with the WRRU, because these GPs could advocate more easily for earlier FSAs for patients. GPs that either did not accept that pain levels were severe, did not feel they could

influence the referral priority and were reluctant to prescribe prednisone risked leaving their patients in severe distress.

PERCEPTIONS OF PATIENT ATTITUDES

The GPs' perceptions of patient behaviours and reasons for consultation have been shown in the previous chapter to affect symptom evaluation. These perceptions also affect referral. For some GPs, despite an ethos that preferences referrals ahead of treatment in primary care, administrative procedures can still impact on patient access about which the GP may not be aware:

"Patients have the right to be referred and it's up to [the WRRU] whether they've been seen or not, and if my patient did not attend then it's usually they were not advised, or it's gone to the wrong address. There are multiple causes that's half the problem."

GP5

A GP's decision to not refer can also be based on the perceptions of the likelihood of a patient following a recommended treatment path falls anywhere within the continuum of GP5's belief (above) that all patients have the right to be referred if their condition warrants referral, to GP4's belief (below) that the GP should assess the patient's attitude before confirming a referral decision, this is particularly so when patients had apparently mild symptoms.

"There have been situations when I've referred the patients to the hospital and the patient hasn't turned up because they didn't feel it was necessary or a problem so first of all I want to make sure it's not a waste of an appointment".

GP4

Two reasons that GPs used as examples of patients' attitudes that impeded referral were the negative beliefs about treatment and the social, cultural or financial barriers to attending an FSA. These examples were mirrored in IA participant discourse and the experiences of Philip and Gillian (below) illustrate the impact on late referral of these factors.

PATIENT PRESSURE

Patient preferences in terms of pressuring for referral is an acknowledge problem in GP referral practices. In this study only one IA participant described placing pressure on a GP for referral. No GPs described patient pressure for a referral as being a problem for rheumatology referrals for IA. Brian was referred to the WRRU after his brother, previously diagnosed with a SpA, advocated for referral at a GP consultation:

"I'd been suffering for a little while, just the odd, it started off once a year just with a pain in the rump, which was the hip of course, and then it would go away. And then it kind of came on a little more regularly and then all of a sudden it was two or three times a year it was happening and then it would stick around for a couple of days sort of thing. I'd been to the doctor quite a few times about it and they called it kind of sciatica and stuff like that. [My brother] saw the warning signs and made me go to the doctor and stuff like that, [brother went with him] and explain to him this is what I've got so there is a good chance that he might have it... [The GP] looked up his journal and said yes it was hereditary and that's when I got my first referral to the hospital. And sure enough sent me to a specialist and away I went."

Brian

The clinical record shows the GP felt pressured to refer because Brian had tried his brother's NSAID, which effectively controlled the pain and also from the brother's intervention at the consultation. He was however reluctant to refer and believed a SpA was not the cause of the symptoms because laboratory tests did not indicate inflammation over a threshold the GP would expect.

PATIENT RESOURCES

A GP from an ethnically diverse and low income suburb introduced the twin barriers of culture and social class into the discourse of referral delays and poor adherence to medication (Figure 32). Everyday cultural, employment and financial issues interfere with utilisation of medical resources and adherence to treatment regimens that involve a variety of medications and monitoring

These factors can lead a GP to delay referral and manage the condition in primary care for as long as symptomatic control can be maintained. The GP, with an already established doctor-patient relationship, may do this because of an awareness that the patient's options may be limited by the context of their illness beliefs, combined with financial, social, cultural, family or employment factors that can limit the likelihood of treatment adherence that is critical for the safe and effective implementation of drug therapies such as methotrexate. These decisions usually come at some considerable cost to the GP practice in staff time and unless the practice or patient is eligible for SIA or CarePlus funding these costs will not be reimbursed. Using the example of a patient with a chronic condition who required more intensive care indicates the cost and benefits involved:

AN INTERPRETATION OF HEALTH AND ILLNESS – GP7

"I think there are the people who view health and illness and disability in different ways. Sometimes there's a poor fit between a medical model and the way a patient actually thinks... [I can tell them the medication] may make you feel sick they may have these side effects but you'll be glad you did in the long term. It takes a bit of persuading.

[Sometimes] it's a just a cross cultural issue [but] there are plenty of Pakeha kiwis who think the same way, who have that same kind of attitude; either an element of fatalism or an element of I am fine don't tell me otherwise; who see doctors as a necessary evil.

I simply try to be aware that each person brings their own particular set of values and their own ideas about health and illness.

I'll add that people with significant social deprivation or significant mental illness or home stuff often have got so much else going on in their lives that taking regular medication be it for their asthma or for their blood pressure or their diabetes or their rheumatoid arthritis is just too much. They'll only take something if it actually makes them feel better on a day to day basis. But to expect them in their over-wrought lives to look after their health, they've got too much else on their plate. Their long term health is the least of their concerns. They're just trying to get through today."

Figure 32: Referral and treatment concordance
A GP's view of social and cultural barriers

"We just despaired of ever effectively managing his [conditions] ... we now have a system in place where the nurse sees him free of charge once a month, says how are you doing. If he forgets to come we ring him up. We gently encourage him to come down and if he can't come today we'll fit him in tomorrow. We provide all his care free of charge and she just tries to keep encouraging him to take his medication. That's all she focuses on... It's costly in terms of hours mainly... It needs a big commitment of time on the part of nurses. Half of it is time on the phone trying to encourage him to come in. But at the moment it seems to be working for him, he seems to be taking his medication where somebody's taking that kind of interest."

GP7

GP7's interpretation of health and illness attitudes is an echo of the experience of Gillian (Figure 33) who was diagnosed with 'rheumatics' by her local GP, but not referred to a rheumatologist.

CULTURAL, SOCIAL AND ECONOMIC BARRIERS TO REFERRAL: GILLIAN
<p>Gillian is in the over 60 age group and lives in a mid-decile suburban environment. She belongs to one of the most deprived ethnic groups in New Zealand. Her suburb lacks a good public transport infrastructure and has poor access to medical services. Gillian was, for many years, the sole income earner for her partner and children and worked in low-paid, low-skilled, physically demanding jobs. Low pay, no private transport, and poor access restricted her use of medical services and after being diagnosed with 'rheumatics' she lived with the diagnosis for many years.</p>
<p>With no treatment and acute pain in her hands and wrists she accepted redundancy from her full-time job. This led to her employment as a casual worker as a cleaner. Lack of job security and uncertain hours reduced further her options to meet her medical needs. Her condition at times meant her children assisted her in her work.</p>
<p>Gillian was correctly diagnosed after spending time in hospital for an unrelated condition, but the nature of her work, her strong work ethic ("I don't want to you know get money if I wasn't doing anything."), financial insecurity and distance from the WRRU meant she often did not attend appointments. She maintained some therapy by filling prescriptions from her GP, but was often without medication. The DMARDs she was prescribed did not maintain their efficacy. ("Last year was a bad year for me, I was in and out of the doctors, and the year before. I was in and out of the doctors").</p>
<p>It was not until after the death of her partner, her subsequent disengagement from paid employment due to her health, and access to regular benefit payments that her financial situation improved and private vehicle use obtained. These life changes have enabled her to maintain regular appointments at the WRRU and obtain suitable combination DMARD therapy to control her IA.</p>

Figure 33: Path to treatment - Gillian

It is not known why her GP did not set out a treatment path or referral for her, but the message that there was nothing to be done was accepted with a stoic, albeit fatalistic, attitude that she would have to live with the condition her GP diagnosed. Gillian exhibits a sense of powerlessness to change her diagnostic status and this had led to significant negative changes in her life and those of her family. This is another situation where a participant's GP practice was not eligible for additional SIA funding. This was not because of her complex health needs, but because she lived in outside an area with significant APHO services. It is likely that her stoicism did not provide an indication to the GP practice that she was a vulnerable patient. This is even more likely when later in the interview she spoke about having to repeat her health history to a variety of GPs before managing to secure the services of a regular GP.

The vignettes above show that intensive intervention can be vital to fill in the gaps when patients and GPs have difficulties communicating requirements of, and barriers to, treatment. For one participant, May, this intensive care pathway through funded management of her healthcare needs in an APHO practice, led to her to her referral to the WRRU after long delays. May has similar socio-economic circumstances to Gillian - with two exceptions - good family support, and access to extra health care services that are available to patients with high needs living in low-decile areas. This access to more intensive primary care services was available to May, not because of her IA, but because she had several chronic health conditions (Rodenburg, et al., 2007). Although there are several reasons why an individual may not be referred immediately to rheumatology once IA has been identified (for example mild symptoms, worries about the impact on possible comorbidities or the time it takes for GPs and patients to formulate a treatment path), four participants with insufficient financial resources to seek second opinions or private care, and/or had other vulnerabilities, had extended delays from the time their GPs told them they had a rheumatic condition until a valid referral was made to a rheumatology service (Figure 34).

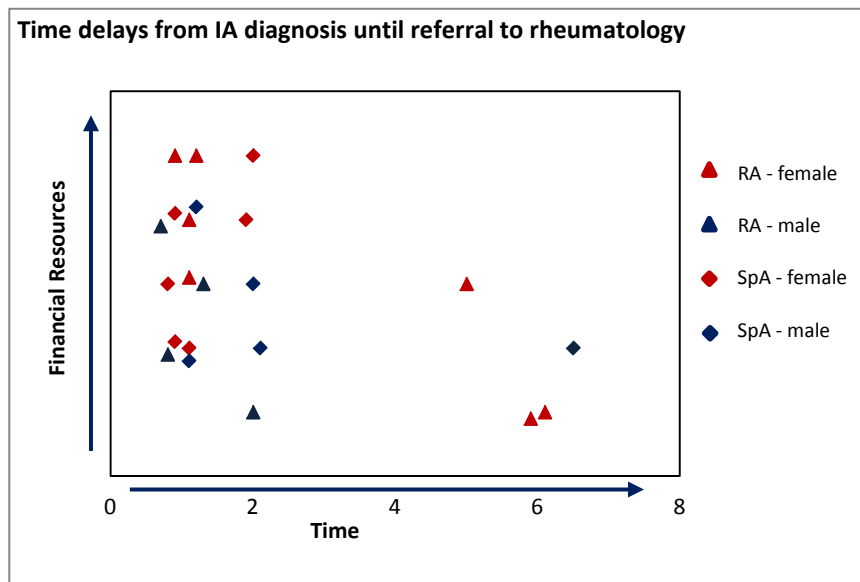


Figure 34: Dot plot of self-reported time from GP consultation to referral
Stratified for financial resources in men and women with RA and SpA.

SYSTEM FACTORS

Concern about the shortage of rheumatology resources at the WRRU were expressed by both GP (Table 30) and IA participants (Table 31). The outcome of these concerns

was a GP preference for referral to private rheumatologists based on the belief that patients would be seen faster in private care and would be able to choose a rheumatologist whose model of care was likely to be more compatible with the patient's health beliefs. Half of the GPs agreed that long waiting lists affected their decision to refer to public rheumatology services, but the accessibility based on the travel time from the GP practice to the nearest WRRU clinic of the WRRU was not significant in referrals patterns of IA patients ($p=0.39$). A third also agreed they would be more likely to refer a patient if that person could afford private care.

"... She said 'you'll have to go private' I said 'that's fine'. I would have sold my first born just to get in. So I went to [a private rheumatologist] for an assessment and he asked me if I had insurance and I said no I haven't. So I got into the public system."

Anne

GPs expressed doubt that the practice of a private referral for FSA with a later transfer to public rheumatology services was widespread. However the administrative data shows one in 12 patients was referred to the WRRU by a private rheumatologist. These transfers from private to public care could be for a variety of reasons – personal, financial and distance to care, for example, but it is a reasonable assumption, based on patient letters, that at least some of these transfers were due to an inability to pay for private care after the initial assessment with a private rheumatologist, and that this initial private assessment was chosen because of long waiting times for FSA at the WRRU.

Concern about waiting times also arose with GPs who were less confident about communicating with rheumatologists, either because they were not fully conversant with procedure or from miscommunication (Table 32). None of nine interviewed GPs were familiar with the published guidelines for rheumatology referral, and contact with the rheumatology service to speed up an FSA was driven by the patient's condition, not by an expectation that a patient would be seen within a particular timeframe. However, despite instances of poor communication with the WRRU, GPs were generally appreciative of the methods of communication channels that were available to them but not all GPs were aware of the communication channels they could use.

Table 30: GP perceptions of public rheumatology resource constraints

GP	GP perceptions of rheumatology resource constraints
GP5	"The difficulty they have is the numbers of people being referred and in private generally it's not too long to be seen. I do try to refer a bit according to patient request and trying to match the patient with the individual personality because they are quite different and we can do that in private [referrals]."
GP7	"[Due to waiting times] I offer them private and if the private option is out of their budget range, I gently encourage the [WRRU]. It's kind of easier here because I can say to them, "here in the Hutt valley we have the rheumatology centre for the whole of the wellington area and it's convenient and its local and its really good and they look after you well."
GP9	"We phone [the WRRU] but they quite often say they're so booked they can't see anyone for several weeks. That happens quite a lot."

Table 31: IA participant perceptions of public rheumatology resource constraints

Participant	Perceptions of rheumatology resource constraints
Louise	"I went private. I thought I hurt so much I need to get it sorted out. My main thought was to get in and get it sorted. Because I couldn't walk and I have 2 flights of stairs in my house just to get to bed and I was sleeping on the couch downstairs... [and] I've got 3 kids and stuff and I can't just sit around."
Sally	"I tried to go through the public system but it took so long. I went private – it was only 2 weeks faster, but I thought I needed to get this done, and I could afford it."
Catherine	"I thought I knew what was ahead of me and so did my husband and my family because they've lived through it with my mother [who had RA], but when I went to see Dr Becker who was the GP who diagnosed me, not my own GP, the one that diagnosed, and he said he could write to someone in Wellington, or he could wait for the public system, but the wait, I'm sure he said it was about 6 months for an appointment... The Pain was just so bad I thought I'm not waiting 6 months, and [the Locum wrote to a private rheumatologist] and organised an appointment for me which I think was about 6 weeks after I was initially diagnosed."
Carla	"I thought I'd go private straight away so I'd have a choice of who I'd see. I went straight to [a private rheumatologist]. I don't know how long I would have waited in the public system. I thought I'd be better to go straight to someone who had been recommended rather than taking pot luck at the hospital."
Patrick	"Actually yeah I got an appointment, 6 months is an exaggeration, but it was several months [before] I got to see someone at Hutt Hospital."

Table 32: GP assessment of problems that may occur on referral to the WRRU

Referrers	Problems occurring when referring to the WRRU
Low	"I don't know what's in place at this stage but I think the only other thing that would speed things up would be to have phone advice. If there was an on call consultant where you could leave a detailed message or speak to someone. That would smooth the process and reduce the number of referrals. "
	"I'm satisfied personally [that] if I have any concerns with my patients, I can speak with their rheumatology registrar or their consultant and as far as I'm aware, they are very helpful. That is enough for me to justify the waiting time for a referral. If I ask one of my colleagues to assess a patient as soon as possible, I will be heard, and my patient concern will be heard."
	"It's easy as anything to refer although waiting times are a pain. I've had a few letters back from new rheumatology registrars that are bit condescending. They haven't been particularly helpful."
	"I like the email system that we have in terms of getting advice and from some of those times I've sent emails to rheumatology at Hutt DHB, the response has been to get this person in, because sometimes you're not sure whether to refer, so that works well... In a service like rheumatology where there is a high unmet need, the role of the consultant implies consulting, so if I've sent a referral -I'm very happy to be phoned or emailed by that person. The consulting email line they've got is very valuable."
	"If I have someone in severe distress, then I'll often phone and the difficulty there is that we're talking to a junior doctor who has little experience and they vary quite considerably as to how they manage the enquiry. The enquiry is generally is there something I can do for this person or are you able to see them in a short period of time to assess their situation or a combination of both. Sometimes they are very helpful, other times they are very unhelpful, so it varies a lot."
High	"If I'm a bit stuck I just phone and say 'hey I've got this problem and I think it really needs to be seen pronto rather than waiting in line.' I often find [WRRU staff] are helpful."

The effects of these delays on the patient may go un-noticed by the GP (Figure 35).

ADMINISTRATIVE DELAYS TO FSA AND SOCIAL SANCTIONS : MAY'S STORY

Although communication with the WRRU and an understanding of referral guidelines may seem like minor issues, this combination of factors resulted in one of the longest delays between referral and FSA

"I remember I reported to him 1999 or 1996. I report about my arthritis and he did put it on his computer in 2002 that he wanted specialist to look at my arthritis. I have to keep on asking him, asking him, about me. If he can do anything quicker for me... and he showed me on his computer that he already put me through to the hospital for an appointment but nothing happened from the hospital."

Despite repeated visits to the GP, increasing pain and deformity no progress was made on the referral for four to five years. The reason for this lack of action appeared to be an administration error or mislaid referral. The WRRU booking clerk is aware the referrals can be mislaid, in particular paper-based referral requests (WRRU Administrator, Pers. Comm.). (Continued on next page)

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The analysis of FSA notes from the two years of administrative data uncovered only three instances of delayed appointments due to lost referrals. The effect on May's life was extraordinarily harsh. She felt ostracised by members of her local community due to her deformity, and the inability to perform her usual daily activities, with only over-the-counter anti-inflammatories and paracetamol to relieve symptoms, was extremely upsetting.

"Because knowing my own people they can giggle or mock or talk behind your back. So I don't want to tell my own people what I'm going through... Sometimes my people they look at me, I know a few women – because I just wear more short sleeves – they notice a difference in my arms. They ask me what happened to me. And I just 'why do you want to know' 'oh because your arm is different'. Then I told them and they nod and they move back and turn around. The worst time at night time I felt the pain. And in the afternoon. And on a hot day it was so painful I couldn't do anything. I used to sew, weaving, crochet, I couldn't do any of these things, even garden."

May's distress during her wait for FSA was apparent during the interview. The effect of pain, the inability to do her usual activities, her inability to perform family tasks; *"my daughters did the cooking and cleaning for me, or my husband did the cooking"*, and the lack of a way forward led to serious negative emotions that were not addressed in any of her medical consultations:

"Sometimes some stupid ideas come to my mind. Like hiding myself behind closed doors, and something like that. And sometimes I cry for, you know..., and most of the time I said if I'm going to be this way it's better for me to die. You know, that how I feel. But my husband was encourage me. He always with me, encouraging me, supporting me, helping me what I'm going through."

After more than four years since onset, May's GP eventually referred her to the local health programme for patients with high medical needs (This was possible due to other chronic health conditions). Through this programme the referral was facilitated very quickly:

"After a while he told us that he put me to the Wellness programme and that's how it [the rheumatology referral] started about 2006 or 2007. It's a very long time."

Although May's referral, after a straight-forward diagnosis, was exceptionally long, she was not alone in expressing physical and emotional distress between referral and FSA. Pain, disability and lack of effective symptomatic relief between referral and FSA permeated the patient narrative. An extended referral process strained the trust in conventional medicine, the participants' well-being and employment future. The patient participants' options at this stage were tightly bound with GP beliefs about the patient's condition, the benefits of encouraging early treatment and waiting times to FSA.

Figure 35: Effects of delayed referral on the well-being of a participant

DISCUSSION

GPs views about the timeliness and efficacy of treatment do not completely explain why they might delay a referral. Drug side-effects, belief that treatment options in New Zealand, do not adequately control IA, and the benefit of a timely referral qualified by the perceived seriousness of the IA all affect GP and patient decision-making. The beliefs GPs have about DMARDs and how these relate to referral were

difficult to tease out of the narratives. All GPs who were asked, agreed that early treatment was important for individuals with IA, but this view appears tempered by a subjective assessment of the seriousness of the person's condition, belief in efficacy of DMARDs, assessment of possible side-effects and the level of disease the patient experienced.

The perception of insufficient rheumatology resources and administrative processes are system factors that weigh heavily on GP decision-making and in some instances were described as influencing the chance of a patient gaining an early referral. These system factors affect GPs' decisions to refer patients who they consider have only mild IA symptoms and therefore an apparent good prognosis with minimal erosive changes likely. The treatment of mild IA with DMARDs and beliefs about patient preferences that might affect treatment decisions may also delay the referral decision. Finally, the GP may take into account beliefs about the patient – the likelihood of attendance at an FSA and the perceived willingness of the patient to follow treatment protocols – when making the decision to refer. The emergent reasons for timely referrals by GPs of patients with a suspected IA can be categorised within five themes (Figure 36) that are used as the basis for the discussion of GP referral decisions.

SYSTEM FACTORS

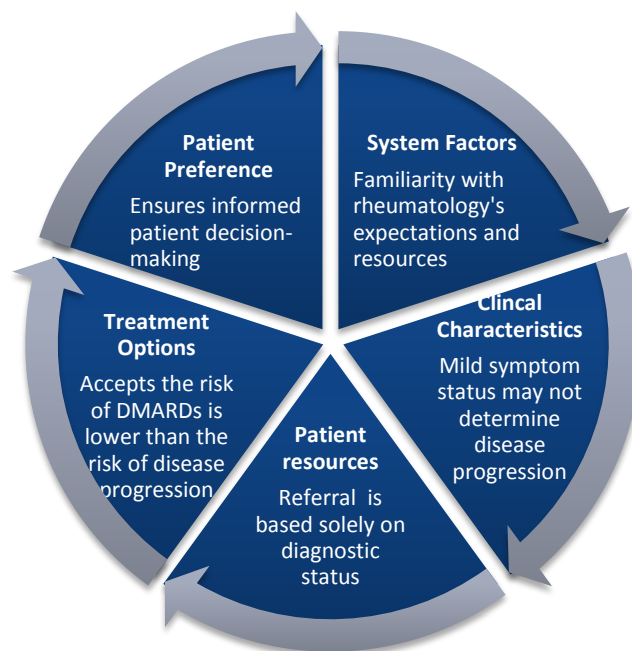


Figure 36: GP referral processes and timely referral

Features of the that impact on the opportunity for patients to receive a timely referral

The gate-keeping role of GPs in the interface between primary and public care and its use to manage excessive demand for specialist services treatment is well established (Coulter, 1998). It is also acknowledged here that GPs are under pressure to reduce the use of secondary health services by treating patients in primary and avoid unnecessary referral. Strategies to reduce unnecessary referrals and waiting times in public hospitals, has led to prioritisation procedures to give patients certainty that they will be treated within specified timeframes. Patients are to be referred back to primary care assessment if secondary care cannot be treated within six months of referral (Ministry of Health, 2000). Mindfulness of the impact of unnecessary referrals on under-resourced rheumatology services, patients and attempting to control appropriate and efficient use of health resources can influence decisions to refer patients for rheumatological assessment. The belief that public rheumatology services cannot treat rheumatology patients in a timely manner has led to two strategies for managing patients with symptoms of IA. A majority of GPs recommend private care for faster referral. Concern about the overloading of public rheumatology resources can also lead to deferment an early referral for people who have symptoms that are uncertain or relatively mild, and who cannot afford private care. Several GPs expressed a preference to treat apparently mild cases symptomatically in primary care. Another reason for treating patients in private care is the belief that the benefits from referral of patients with mild symptoms were outweighed by the possible side-effects of DMARDs. There are indications that this decision is more likely for older patients. The justification for these strategies is that rheumatologists' time is freed up to spend on patients with severe, and urgent, disease. GPs' experience of monitoring patients with low levels of disease activity following the discharge of patients after FSA after a confirmed IA diagnosis for monitoring in primary care provided justification for this course of action.

The success of any referrals system lies in the appropriateness of the referral rather than the number of patients referred (O'Donnell, 2000). Guidelines are thought to improve referrals behaviour when there is general agreement with the practitioners who must implement them (Coulter, 1998) but rheumatology referral guidelines were not referenced by GPs that were interviewed, with none knowing what the referral or local clinical guidelines were. This suggests that GPs are not clear about

which patients should be referred, when. Nor what the expected wait for an appointment at the WRRU would be. This research has shown that unless GPs have clarity on these matters they will under-refer and delay inquiring about the status of referrals.

Attempts by GPs to reduce the numbers of patients referred to the WRRU by delaying the referral of patients with established IA, albeit mild symptoms, is counter-productive because the medical consensus, outlined in both the ACR (Aletaha, et al., 2010) and EULAR (Combe, et al., 2007) recommendations, is that it is difficult to predict which patients will progress to erosive disease. Due to the uncertainty of the prognosis in early IA the recommended treatment path is that healthcare professionals should refer patients to a specialist rheumatology clinic when they first suspect RA or an undifferentiated inflammatory polyarthritis (Kiely, et al., 2009).

A factor exacerbating delays between diagnosis and FSA is the lack of clarity in the administrative procedures. This administrative uncertainty seemed to result from an expectation by the GP that once the referral was made it was the WRRU that drove the referral process. The administrative referrals procedures led to an extended delay for one participant, with the referral being 'lost' with no apparent procedure for correcting the missing referral. The narrative described clear evidence of referral, and of the GP waiting for a rheumatology service response. Interviewed GPs also described communication issues with the WRRU that made it clear they are not familiar with the conventions around contact with the WRRU or the factors that enter into the appointment prioritisation. The highest referrers were familiar with the bureaucratic process of referral. They were aware of the priority rankings for referral and were confident in requesting urgent referrals. High referrers also expressed ease in communicating with the rheumatology services and maintained good contact with rheumatologists throughout the referrals process. An electronic referrals system has the potential to improve referral prioritisation, procedures and administrative coordination, improving patient outcomes (National Health Committee, 2007). Only one of the participant GPs was regularly using the partially implemented WRRU e-referral system at the time of the interviews, with several expressing a lack of surety about the receipt of the referral and dislike of a system that might constrain referrals by introducing arbitrary referrals boundaries:

“At least with a fax you know where it’s going to go.”

GP1

“The electronic referral system is user unfriendly. It’s easier to just do a referral from my computer using our own template, than to use the hospital one that wants boxes filled. We can very simply attach the blood test results and the x-rays in our own system.”

GP7

The combination of ability to pay for private care and an expressed propensity of GPs to refer patients if they can afford private care, creates the potential for inequitable referral decisions. This can result in patients with suspected IA who can afford to pay for rheumatology care being referred privately with mild symptoms, while patients with similar symptoms who cannot pay for private care remain in the care of a GP, without a referral to public rheumatology services being offered until the symptoms progress. This situation may have area differentials with a negative impact on patients in Porirua, Upper Hutt and other areas with low private health insurance coverage, while speeding up the referrals process in Wellington where private health insurance is greater. Chapter Five shows Wellington patients are significantly more likely to be referred privately and Wairarapa DHB patients are among the most reliant on the provision of public rheumatology services, with three out of four patients referred publicly. Individuals with RA and low SES have elsewhere been identified as low users of health services at the beginning of their RA journey (Jacobi et al., 2003) and are likely to present at FSA with less functional ability (Eras Study Group, 2000).

The expectation that private referral waiting times would be shorter than those at the WRRU was the main reason for patients requesting referral to private care. The belief that private rheumatologists would provide better care was mentioned by two participants as an additional reason for preference for private referral, however most participants were aware that a rheumatologist they saw privately also consulted in the public sector¹³. GPs at times advised patients they could consult with a rheumatologist who was more aligned with their interest in private care. However this was not a strong influence on patient decision-making in the first instance. None

¹³ There were two exceptions -in the study period a retired rheumatologist saw several patients and another rheumatologist, consulting in sports medicine, also saw several IA patients. Two of these patients were participants in this study.

of the IA participants referred privately noted lengthy referral delays, although one patient, referred over a holiday period waited for more than two months to see a private rheumatologist. All other private IA participants indicated a waiting time of approximately four to six weeks.

CLINICAL CHARACTERISTICS

Referral delay, due to a the belief that public rheumatology services are under pressure and fewer referrals will result in more timely care for patients with serious symptoms needs to be considered in conjunction with a belief that it is possible for GPs to determine which patients with IA are likely to progress to erosive disease. Joint destruction can begin early in the course of IA, therefore delayed referral can lead to an increased risk of erosive disease (Lacaille, et al., 2005; Quinn, et al., 2001).

GPs universally agreed that early treatment of IA was important, but interviews established that this agreement was often qualified by subjective assessment of the severity of the condition. Symptoms assessed as mild, combined with the GP's perception of the likelihood of the patient experiencing erosive disease is an important factor in delaying referral. However, it is uncertain that a GP could accurately predict which patients might experience a mild disease with few serious outcomes or one that may lead to disabling joint loss, serious disability and increased mortality (Harrison, 1999). Research shows for example, that up to 55 percent of EIA patients go on to develop classic RA, but who these patients will be is impossible to predict from the initial presentation at a rheumatology clinic (Kiely, et al., 2009).

PATIENT PREFERENCE

Only one IA participant refused to be referred to a rheumatologist after a preliminary IA diagnosis. Twenty-one of the 22 patients, in lieu of a comprehensive understanding of their symptoms and treatment options (even those reluctant to begin DMARD therapy), and often in severe discomfort, were keen to be referred if only to confirm diagnosis and begin a treatment plan for symptomatic relief. But almost all GPs could recount stories of patients with IA, RA in particular, who refused referral based on a reluctance to start DMARD therapy. GPs were evenly split about the responsibility for encouraging referral if patients had ambivalent views about their diagnosis and if

referral was opposed. IA participants' fears about referral were centred on the appropriateness of DMARDs (for example why a chemotherapy drug is a suitable treatment for joint pain) and the perception of risk. Individuals with a very physical lifestyle (either in work or fitness activities) and cultural beliefs that precluded early consultation with a GP, were keen to attend a rheumatology appointment to get their symptoms under control so they could resume their activities. There was one exception to this generality. A combination of fear of DMARDs, fear of exposure in social and work life as someone who was physically incapacitated, and apparently painless symptoms despite obvious joint deformity, led to a rejection of the opportunity to be referred to a rheumatologist. The description of meetings where referral was discussed gave a picture of benign disconnect between the patient and the GP. The relationship described as 'good' by the participant, seemed to lack direction and decision-making appeared to be based on the patient's ability to remain physically functional rather than the clinical evidence of synovitis and joint changes.

The disconnectedness in the doctor-patient relationship that inhibits appropriate referral has been described as a difference in conceptual terrain during a consultation that is the root cause for a lack of momentum in chronic disease resolution. The failure of a GP and patient to work within the same medical model can lead to collusion with the patient to embed illness behaviour (in this instance, the dismissal of glaringly obvious symptoms) and reduce the motivation for positive steps toward resolution. In such circumstances GPs can be very aware that with no resolution an individual's (dis)ease can become chronic. The GP can also be frustrated with the inability to solve the patient's problem but be concomitantly trapped by the patient preference for inaction (May, et al., 2004).

GPs have an essential task in promoting informed patient decision-making with regard to treatment and prognosis if there are delays in referral. GPs could either actively promote referral or let the patient come to the decision on their own. Abdicating the educative and encouragement role is only a proper position if the patient is fully informed about treatment options, the actual risk of DMARD side-effects and comparisons with the role and side effects of NSAIDs and steroids that they may need in lieu of DMARDs to keep pain and inflammation at bay. Patients may find it difficult to establish the risk of disease progression and weigh up the risk of

side effects from the different classes of medicine without professional medical input, especially with ready access to non-verifiable and unfiltered information readily available via health-related websites (Crooks, 2006). GPs may also find themselves in the position of advising on the relative benefits without knowing the likelihood of disease progression. For this reason alone it is essential that GPs do what they can to persuade patients to take the next step to referral as early as possible.

TREATMENT OPTIONS

IA participants showed caution about DMARDs and rheumatological expertise is required to enable patients to make decisions on the level of physical deterioration they're willing to accept, care pathways and the probability of side-effects from the different classes of NSAIDs, steroids and DMARDs. GPs were aware that patients fear DMARDs and overstate the risk of side-effects, and have a lesser understanding of the serious side-effects of NSAIDs and steroids. They may also have an inadequate understanding of the effects of each class of drug on the eventual outcome of their IA. Patients are likely to need more support and education than GPs can probably provide given the specialist nature of the anti-rheumatic drugs, the time constraints of a busy primary care practice and lack of specialist support services. Unfamiliarity can also be a reflection of the relative rarity of encountering IA in general practice, comparatively little time being spent on familiarisation with recent rheumatology research or on continuing medical education.

An expectation that patients will come to their own decision about the need for referral to rheumatology services in a timely manner must be tempered by actively ensuring patients are fully aware of the most recent treatment regimens and that there are a variety of options that may suit their particular needs. This encouragement and information may instil confidence in the patient that they can manage the referrals process and decisions about treatment. Communication of risk is thought to be better transferred to the patient by using a shared decision-making model (Godolphin, 2003) with caution that shared decision-making can spill over into a consumerist model where the focus is simply on whether a patient consumes the healthcare product (Holman & Lorig, 2000) with patient options and understanding

of risk and benefits of treatment often omitted from discussions about care pathways (Godolphin, 2003).

PAIN RELIEF BEFORE FSA

The importance of substantial pain relief between referral and FSA was not strongly considered by the majority of interviewed GPs, but this loomed as an issue of critical importance for patients. GPs may be reluctant to use steroids to control pain in this period, either because they lack confidence to prescribe in suspected IA cases, are concerned about the potential for patient reliance on steroids as a suitable alternative to DMARDs, or are cautious about masking IA symptoms before assessment by a rheumatologist. An experienced GP, who preferred not to prescribe steroidal pain relief, ensured timely FSAs were available for patients due to a willingness to frequently advocate for patients, the apparent respect the WRRU had for the experience of the GP, and the GP's perceived ease in communicating with consultants (rather than administration staff or registrars) at the WRRU. The GP more often achieved timely FSAs for patients because of referring, or following up referrals with essential information such as a complete description of symptoms, history, clinical and social reasons for prioritising the FSA, and laboratory results. In this instance a mutual respect between the WRRU and GP was well-established.

PATIENT RESOURCES

Experienced GPs most often spoke of referring patients on clinical need rather than perceptions of need (for example prioritising the needs of employed workers over the unpaid), or attitudes and behaviours that appeared likely to compromise attendance or the care pathway. Evaluative judgements about the patient can lead a GP to mistake fatalism about health outcomes with ambivalence about referral (May, et al., 2004) and an inclination to not attend an FSA because a patient may appear to lack concern about health – their own health and the health resources that are available to them. The context of people's lives; social, employment or financial constraints, are not well catered for in referral decisions and administrative procedures, with no clear responsibility between the GP practice and rheumatology services to ensure the patient has the resources to appear at FSA, and these factors may preclude referral in some instances. Removing the context of an individual's everyday life from the

referral process suggests that, in addition to delayed referral due to an inability to afford private care, people from lower socio-economic groups may have a greater risk of having a referral deferred if the GP bases the referral decision even partly on beliefs about the patient's attitudes and behaviours rather than only on the clinical evaluation of patient need. Evidence from research in a culturally-diverse lower socio-economic neighbourhood show cultural values that precluded further medical care, financial problems and low expectations about treatment were often hidden from GPs and compromised access to specialist care (Gardner & Chapple, 1999). In a 15-minute consultation window, GPs do not have the resources to delve into the reasons why a patient behaviour may result in non-attendance at a referral FSA or the resources to manage the contextual fields, such as transport requirements and other assistance that might increase a patient's reliability in managing their own health care.

Services to Improve Access programmes, which could provide more intensive support for low income and high needs individuals, including monitoring health status monitoring treatment and ensuring transport is available and costs met, are available for people with multiple chronic health needs (Ministry of Health, 2007b; Tumai mo te Iwi PHO, 2009). Individuals of low socio-economic status who are not enrolled in an Access PHO, and ineligible for SIA funding are constrained in their health-related decision-making because they costs of accessing care can be insurmountable.

A commonly cited problem in referrals behaviour is patient pressure on a GP to refer. However this was comparatively unproblematic in the rheumatology referrals participants in Wellington. In the single instance described by an IA participant the reason for patient pressure to refer was the result of inconclusive evaluation processes that failed to take into account non-classical presentations of RA and SpA and/or relied heavily on clinical markers of inflammation rather than the symptoms of disease and, the participant was correct to press for a referral.

Patient factors need to be considered by GPs to improve referral delays. Of crucial importance in the GP's assessment of pain and disability is the cultural ethos that prevents patients from articulating the seriousness of their symptoms. Patients may

also have fears about the social impact of being labelled with a physical disability disease, fears about side-effects of DMARDs and beliefs about intervention with conventional medicines without taking into account the holistic effect on the body. These themes reflecting the patients' cultural imperatives occur at each stage of the referral process. However, the stoicism and denial of physical impairment that delayed help-seeking with the onset of IA symptoms also encourage a pragmatic attitude that aided referral decisions. Despite being a barrier to consultation with a GP when symptoms begin, these participants were matter of fact about their diagnosis and referral to a rheumatologist, accepting that this referral and the start of a DMARDs regime would improve their physical symptoms and reduce the likelihood of disability.

12. NON-ATTENDANCE AT THE WRRU

INTRODUCTION

The rheumatology first specialist assessment (FSA) is where the suspicion of an IA is confirmed, prognosis factors analysed and initial treatment plans implemented. Non-attendance at a rheumatology clinic FSA is of particular concern for rheumatology departments because it results in a lost opportunity for early diagnosis and treatment of rheumatological conditions and is detrimental to the efficient and cost-effective delivery of rheumatology services. Each patient who does not attend an appointment adds to misallocation of clinic resources increasing costs and waiting times for other patients (Leung, Castan-Cameo, McGhee, Wong, & Johnston, 2003; Murdock, Rodgers, Lindsay, & Tham, 2002).

There is a lack of published data on risk factors for non-attendance, defined as failure to attend an appointment without prior notification, in rheumatology clinics. In other services, multiple factors influence non-attendance (Paterson, Charlton, & Richard, 2010). Factors identified in previous studies include age - either younger (Corfield, Schizas, Williams, & Noorani, 2008; Gill & Owens, 1998) or older patients (Johnson, Weinert, & Richardson, 1998) - and ethnicity (Renshaw, Jack, Dixon, Moller, & Davies, 2010). Gender has not featured strongly as a predictor of non-attendance (Paterson, et al., 2010). Associations of non-attendance with area-level variables like urban and rural differences have also been highlighted in several studies (Goldbart, Dreiherr, Vardy, Alkrinawi, & Cohen, 2009; Johnson, et al., 1998). The structure of the service under investigation may also exacerbate non-attendance with long waiting times (Bowman, Bennett, Houston, Aitchison, & Dutton, 1996; Goldbart, et al., 2009; Leung, et al., 2003) and the quality of clinic administrative procedures (Koppens, Dai, & Mora, 2005) identified as impeding attendance.

This chapter uses WRRU administrative data to identify variables that lead to non-attendance for rheumatology patients in the Wellington region. Administrative data is limited in building an understanding of the causes of non-attendance but can identify groups that are over-represented in poor attendance statistics and may provide insight as to how resources might be distributed to improve attendance rates. The

data in this chapter includes all referrals to the WRRU, rather than being restricted to IA diagnoses. This is because before FSA the eventual diagnosis is unknown and because unless the patient returned within the two-years of the study timeframe, a diagnosis would not be verified. Staff interviews provided insights into administrative procedures, as well as perceptions of causes and responses to non-attendance. The patient perspective rounds out the chapter with personal experiences that have impacted on poor attendance at rheumatology appointments.

NON-ATTENDANCE

Patient forgetfulness can account for up to half of non-attendance (Murdock, et al., 2002; Ritchie, Jenkins, & Cameron, 2008; van Baar et al., 2006). To improve attendance rates the WRRU follows-up written notification of appointments with telephone calls one to three days before the appointment, and if unconfirmed either during the call or after a voice mail message has been left the appointment is cancelled (Staff 3). Telephone reminders have been found in several studies of non-attendance to be a cost effective method to remind patients of their appointment and reduce non-attendance (Lee & McCormack, 2003; Ritchie, et al., 2008). However these reminders may be less effective in reducing non-attendance for some groups of patients, for example young men (Corfield, et al., 2008). Although cancellations may rise with reminders these are less of a problem for clinic administration because resources can be reallocated (Jayaram, Rattahalli, & Kader, 2008). Of the 57 cancellations during reminder telephone calls the most common reasons were opting for private care (51 percent), and changed address without forwarding new address details (16 percent) (Figure 37).

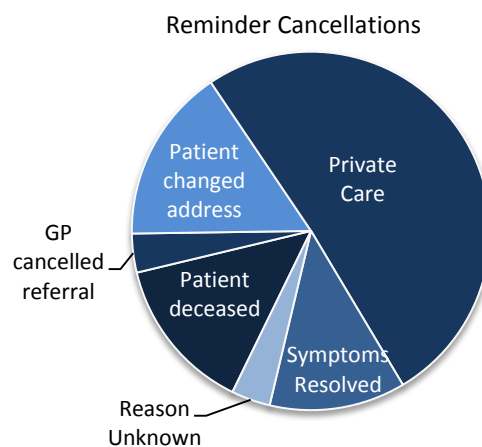


Figure 37: Reasons for FSA cancellations

Source: WRRU Administrative data

The WRRU FSA non-attendance rate, excluding cancellations, was 7.1%. This rate compares favourably with the mean non-attendance rates in the Wellington region. The HVDHB recorded 13.5%, non-attendance, CCDHB 9.5% and WDHB 9.8%. The WRRU non-attendance rate is similar to the mean national rheumatology outpatient department (OPD) non-attendance rate of 7.3% (range=3.0 – 15.7%) (Ministry of Health, 2007a).

DEMOGRAPHIC VARIABLES

Patient characteristics that were significantly associated with FSA non-attendance (Table 33) were patient age ($p \leq 0.001$) and ethnicity ($p = 0.002$). PHO enrolment was significantly associated with non-attendance and patients referred from APHOs were more than twice as likely as patients referred from IPHOs to miss their FSAs ($p \leq 0.001$). The mean age for a non-attender was 44.2 years (SD 17.4) compared with 51.6 years (SD 17.0) for an attended FSA.

Table 33: Demographic, Geographic and Administrative variables

Included in non-attendance and waiting time analysis for all WRRU referrals

Variable	N	% of total	% non-attendance (7.1%)	Mean wait (69.4 days)	Geometric Mean Wait (47.0 days)
Gender	1821	100.0	(p=0.11)	(p<0.01)	
Male	590	32.4	8.3	64.9	43.2
Female	1224	67.6	6.6	71.5	49.0
Ethnicity	1821		(p=0.001)	p=0.15	
NZ European	1111	61.0	6.9	69.9	46.9
NZ Māori	166	9.1	12.0	64.6	43.1
Pacific Peoples	156	8.6	12.2	59.0	41.7
Other European	204	11.3	3.9	71.3	52.0
Other Ethnicities	184	10.0	3.8	76.5	51.5
Age Group	1814	100.0	p<0.001	p=0.20	
Under 20	43	2.4	4.7	57.0	37.8
20-29	175	9.8	17.1	71.4	48.5
30-39	263	14.5	9.9	69.7	47.9
40-49	389	21.3	5.9	73.6	49.5
50-59	354	19.6	6.8	70.3	49.9
60-69	306	16.9	4.2	68.2	45.8
Over 70	284	15.5	4.2	64.3	42.1
DHB	1808		p=0.67	p<0.001	
Hutt Valley	716	37.6	6.4	50.4	55.7
Capital & Coast	928	53.2	7.5	78.7	77.8

Variable	N	% of total	% non-attendance (7.1%)	Mean wait (69.4 days)	Geometric Mean Wait (47.0 days)
Wairarapa	164	9.2	6.7	98.6	47.1
Area	1807	99.6	p=0.51	p≤0.001	
Lower Hutt	531	28.2	6.2	50.2	33.2
Upper Hutt	183	9.9	6.0	48.8	34.2
Porirua	263	15.1	7.2	69.1	50.6
Kāpiti	155	8.9	5.2	76.7	56.8
Wellington	509	28.6	8.8	84.6	58.4
Wairarapa	166	9.3	6.6	99.7	78.1
Clinic Location	1819	99.9	p=0.47	p≤0.001	
Hutt	1023	52.6	6.5	51.1	34.6
Kenepuru	343	17.4	8.2	75.3	58.0
Wellington	338	17.4	8.6	100.5	75.4
Greytown	115	6.0	6.1	119.1	104.7
PHO Type	1755	96.5	p≤0.001	p≤0.001	p=0.13
Independent	1525	86.7	5.8	70.6	48.2
Access	230	13.3	13.0	63.0	44.2
Priority Timeliness	1453	79.9	p=0.008	69.0	
On-time	1118	77.9	6.7	47.7	
Late	335	22.1	11.0	144.3	

Patients aged 20-29 were nearly three times as likely to miss a FSA as 50-59 year-olds ($p \leq 0.001$). The odds of non-attendance based on age remained unchanged after adjusting for ethnicity, gender, geographic and administrative variables, suggesting that age is an independent factor in non-attendance with younger age groups having a significantly greater risk of missing an FSA. The age stratified chance of attending an FSA reduced by up to 20 percent for every 10 years reduction in age (OR=0.77, CI 95%=0.69–0.86) (Table 34).

Māori and Pacific Peoples were twice as likely as NZ Europeans to default on a FSA. This difference is partially explained by age (Figure 38) with a 10.8 percent reduction in the odds of non-attendance for Pacific Peoples and 6.2 percent reduction for Māori, after adjusting for age and gender. Adjusting for the PHO-type reduced Pacific Peoples' chance of non-attendance from almost twice that of NZ Europeans to less than 1.3 times the NZ European non-attendance ($p=0.52$), and for Māori the odds of non-attendance for PHO-type reduced from 1.9 times to 1.6 times the NZ European rate ($p=0.19$). The multivariate analysis shows location and administrative variables

account for a further 21.4 percent reduction in the OR for Māori and 29.2 percent for Pacific Peoples leaving the differences in attendance between Māori, Pacific Peoples and all other ethnicities non-significant. .

Table 34: Demographic Variables and their association with non-attendance
Data is for all WRRU patients

Demographic Characteristics	Unadjusted		Adjusted for Ethnicity, Age and Gender		Adjusted for All except DHB and Clinic Location	
	OR & 95% CI	p-value	OR & 95% CI	p-value	OR & 95% CI	p-value
Ethnicity		0.001		0.005		0.24
Other	1.00		1.00		1.00	
NZ Maori	2.10 (1.25–3.50)	0.005	1.97 (1.17–3.31)	0.01	1.65 (0.86–3.18)	0.13
Pasifika	2.12 (1.26–3.58)	0.005	1.89 (1.12–3.22)	0.02	1.5 (0.76–2.97)	0.25
Age (per 10 years)	0.77 (0.69–0.86)	≤0.0001	0.77 (0.69–0.86)	≤0.0001	0.77 (0.67–0.88)	≤0.0001
Gender						
Female	1.00		1.00		1.00	
Male	1.27 (0.88–1.83)	0.20	1.20 (0.83–1.75)	0.33	1.09 (0.70–1.70)	0.70

*DHB and clinic location not adjusted for each other or area

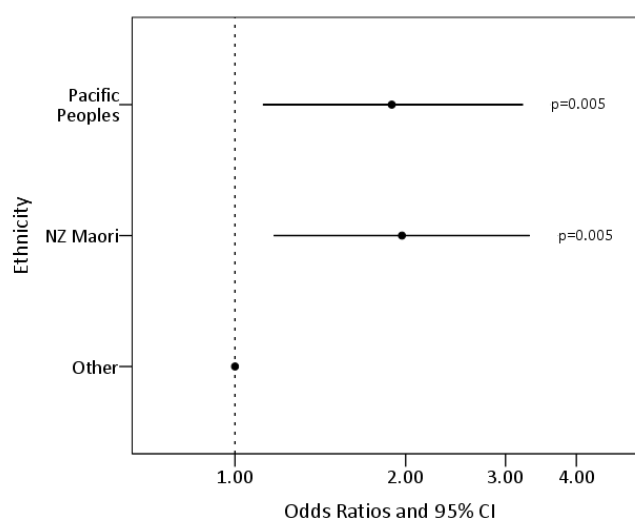


Figure 38: FSA Non-attendance by Ethnicity
adjusted for Gender and Age Group

GEOGRAPHIC VARIABLES

Geographic variables of the DHB the referral was from, the area the patient resided NZDep2006 index (Crampton, et al., 2007), or the clinic attended produced no significant effect on non-attendance (Table 35). Even when adjusted for demographic variables, which are shown to be significant.

Table 35: Geographic variables and their association with non-attendance
For all WRRU patients

Geographical Characteristics	Unadjusted		Adjusted for Ethnicity, Age and Gender		Adjusted for All except DHB and Clinic Location	
	OR & 95% CI	p-value	OR & 95% CI	p-value	OR & 95% CI	p-value
DHB		0.81		0.92		0.48
Hutt Valley	1.00		1.00		1.00	
Capital Coast	1.01 (0.69–1.48)	0.94	0.99 (0.67–1.45)	0.96	0.76 (0.47–1.21)	0.24
Wairarapa	0.81 (0.40–1.63)	0.55	0.87 (0.43–1.76)	0.69	0.74 (0.34–1.61)	0.45
Area (Patient)		0.64		0.93		0.63
Lower Hutt	1.00		1.00		1.00	
Upper Hutt	0.76 (0.39–1.50)	0.43	0.88 (0.45–1.75)	0.72	1.18 (0.56–2.52)	0.66
Porirua	1.09 (0.62–1.92)	0.76	0.91 (0.51–1.63)	0.76	0.86 (0.44–1.68)	0.67
Kapiti	0.61 (0.28–1.34)	0.22	0.8 (0.36–1.77)	0.58	0.41 (0.14–1.24)	0.12
Wellington	1.08 (0.68–1.72)	0.74	1.13 (0.70–1.81)	0.62	0.83 (0.46–1.48)	0.52
Wairarapa	0.79 (0.38–1.62)	0.51	0.89 (0.43–1.86)	0.76	0.78 (0.35–1.75)	0.55
Clinic Location		0.40		0.53		0.96
Hutt	1.00		1.00		1.00	
Kenepuru	1.29 (0.81–2.04)	0.28	1.26 (0.79–2.01)	0.34	1.05 (0.60–1.82)	0.88
Wellington	1.41 (0.90–2.22)	0.13	1.37 (0.87–2.17)	0.17	1.02 (0.56–1.85)	0.96
Greytown	0.94 (0.42–2.10)	0.88	1.08 (0.48–2.43)	0.85	0.82 (0.34–1.99)	0.67

ADMINISTRATIVE VARIABLES

Administrative factors appeared as significantly increasing the odds of non-attendance (Table 36); the type of PHO the patient attended and the length of wait between referral and FSA. Patients from IPHOs are more than twice as likely to attend a FSA compared with patients from APHOs. After adjusting for ethnicity, the odds of

patients from an IPHO attending remain twice that of patients from APHOs (Figure 39). This effect was reduced by 22 percent after adjusting for patient age, gender and ethnicity and a further 18 percent after adjustment for timeliness of the FSA, clinic location and waiting time. Surprisingly, given the role of priority rankings in setting waiting times, priority did not have a significant effect on non-attendance, therefore the timeliness of the appointment was tested. Whether the FSA was within the referral criteria timeframe or not was a significant factor in non-attendance with patients whose appointments are outside the priority timeframe being 1.7 less likely to attend ($p=0.01$ OR 1.73 95% CI 1.14-2.61). The odds ratio of a person not attending due to late appointments was reduced by 41.6 percent when adjusted for all other variables, with other administrative and geographic variables combining to smooth the effects of timeliness on attendance.

Table 36: Administrative variables and their association with non-attendance
For all WRRU patients

Administrative Variables	Unadjusted		Adjusted for Ethnicity, Age and Gender		Adjusted for All except DHB and Clinic Location*	
	OR & 95% CI		OR & 95% CI	p-value	OR & 95% CI	p-value
PHO Type						
Independent	1.00		1.00		1.00	
Community	2.39 (1.54–3.71)	≤0.0001	1.85 (1.13–3.02)	0.014	1.51 (0.85–2.65)	0.16
Wait time (doubling time)	1.34 (1.16–1.56)	≤0.0001	1.37 (1.18–1.59)	≤0.0001	1.41 (1.14–1.74)	0.002
Priority						
Priority 1	1.00		1.00		1.00	
Priority 2	1.03 (0.97-1.09)	0.42	1.02 (0.96-1.08)	0.54	0.99 (0.93-1.06)	0.75
Priority 3	1.03 (0.96-1.10)	0.39	1.03 (0.96-2.00)	0.44	0.99 (0.92-1.06)	0.74
Timeliness						
On-Time	1.00		1.00		1.00	
Late	1.73 (1.14–2.61)	0.01	1.70 (1.11–2.58)	0.014	1.01 (0.58–1.77)	0.96

*DHB and clinic location not adjusted for each other or area

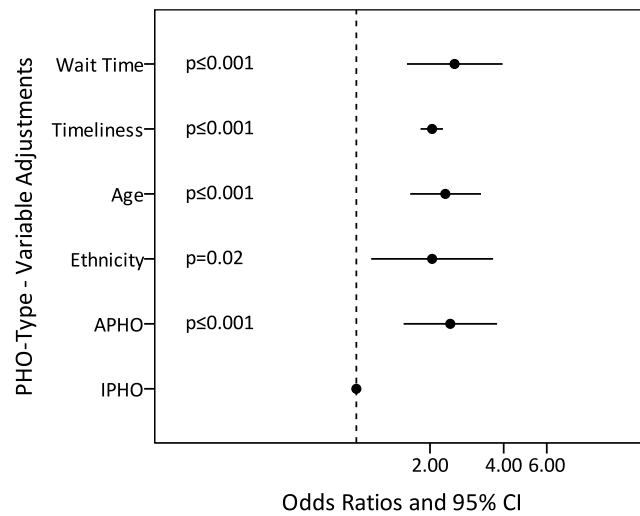


Figure 39: FSA non-attendance comparisons between APHO and IPHO referrals.

Showing unadjusted APHO non-attendance, and adjustments for Ethnicity, Age, Timeliness of the appointment, and Waiting Time

WAITING TIMES

The previous chapter described how the perception of long waiting times can affect the decision of a GP to refer and, arguably, the greatest concern for patients was the waiting time from referral to the first specialist assessment (FSA). Concern about long waiting times was the predominant reason for choosing private health care, at least for the FSA, for those who could afford to do so.

To understand the causes of long waiting times WRRU referrals data was analysed for patterns of referral that might lead to long delays to treatment waiting times. Waiting times are normally derived from the priority assigned to the presenting symptoms. Priority rankings are set in a triage meeting between rheumatologists and take into account the clinical markers of disease as well as the GP assessment of patient need, for example the impact of the symptoms on paid work (Staff 5). These triage checks do not mean that patients are routinely given an appropriate priority, with approximately one in eight patients diagnosed with an IA at a WRRU FSA having been previously prioritised as routine (P3) status, normally an indication of a non-IA

condition with a waiting time of up to six months, assuming the recommended waiting times are met. WRRU Rheumatology Referral Criteria recommends Priority 1 (P1) patients be seen within 4 weeks, P2 within 12 weeks and P3 24 weeks (Hutt Valley DHB, 2008). Priority ranking varied only marginally between ethnic groups and age groups and these variations did not disadvantage Māori, Pacific peoples or younger age groups with high non-attendance rates.

The length of the waiting time from referral to FSA was significantly correlated with non-attendance ($p=0.003$). Attending patients had a median wait of 51 days (mean = 67.9, SD = 57.2) compared with a median wait of 75 days (mean = 84.6, SD = 57.1) for non-attenders¹⁴. Although the majority of IA referrals should not be affected by this correlation given the recommended three month referral guideline, 28 percent of patients diagnosed with an IA at the first FSA were seen outside this recommended timeframe, which would suggest the information provided with the referral letter did not match the criteria for an IA diagnosis, or the clinic resources that were required to assess the patient within the required timeframe were not available.

After adjusting for priority ranking waiting times were not significantly associated with either patient age or ethnicity. Minor gender differences in FSA waiting times were noted; the raw median wait time for women was 17 percent longer than men (female median wait = 55 days, male median wait = 47 days), however when gender was adjusted for priority it was no longer significant at the .05 level. Women were as likely as men to be seen within the expected priority timeframe ($p=0.27$) but there were almost 40% more P3 FSAs for women ($p\leq 0.001$) as for men.

Individuals who did not attend may have a variety of reasons but these are not recorded in the administrative data. Interviews with the three patients in this study indicate struggles to organise transport, childcare and time off work, as well as forgetfulness and dissatisfaction with communications with medical practitioners over assessments of the patient's illness and treatment recommendations. Work by Coffin and colleagues (2003) for the South Auckland Health produced similar reasons for Māori non-attendance at outpatient clinics, and also found that administrative problems such as not receiving notifications and reminders were important reasons

¹⁴ Because IA cannot be diagnosed in a non-attending patient, the data for all referrals was used to analyse non-attendance.

given for not attending. Factors associated with the individual's motivation to attend were also an explanation for non-attendance. There was no indication in the South Auckland research that the individual did not attend because their condition improved, however this reason is a distinct possibility in a rheumatology clinic with MSk conditions that periodically flare and subside or resolve over time. Militating against this in the WRRU is the appointment reminder within three days of the appointment. The administrative database shows the bookings administrator records 'feeling better' as a cancellation, so this is unlikely to be a reason for non-attendance.

Waiting times were significantly associated with the geographic attributes of the referral; DHB ($p \leq 0.001$), Area ($p \leq 0.001$), PHO ($p \leq 0.001$) and Clinic ($p \leq 0.001$). Patients referred to the Lower Hutt clinic were significantly more likely to be seen within the expected priority timeframe compared with patients referred to the Wellington clinic. Wellington patients were likely to wait twice as long as Lower Hutt clinic patients for an FSA (WR=2.17, 95% CI=1.95-2.43) and Greytown clinic patients could expect a wait three times as long as Hutt patients (WR=3.03, 95% CI=2.55-3.59). The Lower Hutt clinic also saw 20% more patients within the expected timeframe than Kenepuru ($p \leq 0.001$) (Figure 41).

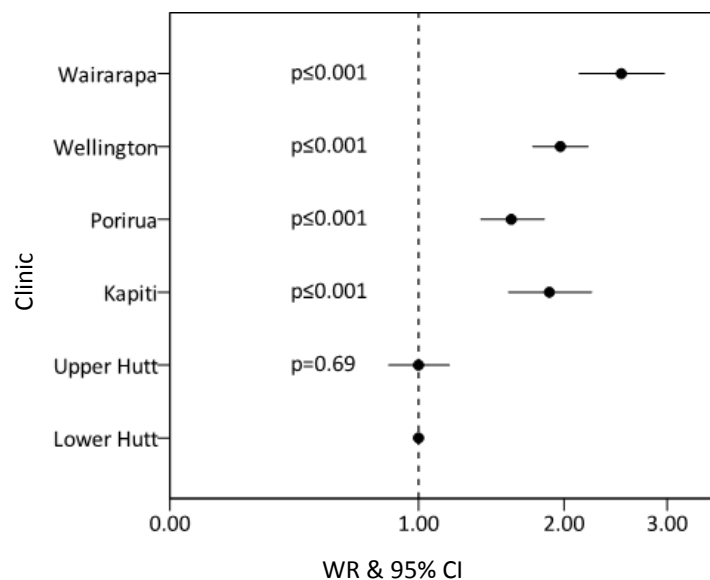


Figure 40: Wait times to FSA for patients diagnosed with an IA by Area.

Adjusted for referral priority: WR and 95% Confidence intervals

For Māori and Pacific Peoples, adjusting for waiting time only increases the odds of non-attendance by 3 to 6% ($p=0.02$). These two groups of patients in Porirua and Lower Hutt have shorter waiting times and this may have a suppressive effect on the unadjusted non-attendance rate.

While patients referred from Lower Hutt and Upper Hutt GPs were significantly more likely to have a shorter wait to FSA, waiting times between DHBs and between clinics (Figure 41) also varied considerably. Patients referred from Capital & Coast DHB and Wairarapa DHB waited significantly longer for FSAs than Hutt Valley DHB patients ($p\leq 0.001$). This result reflects the very long waiting times at Wellington (mean wait=100 days) and Greytown clinics (mean wait=119 days).

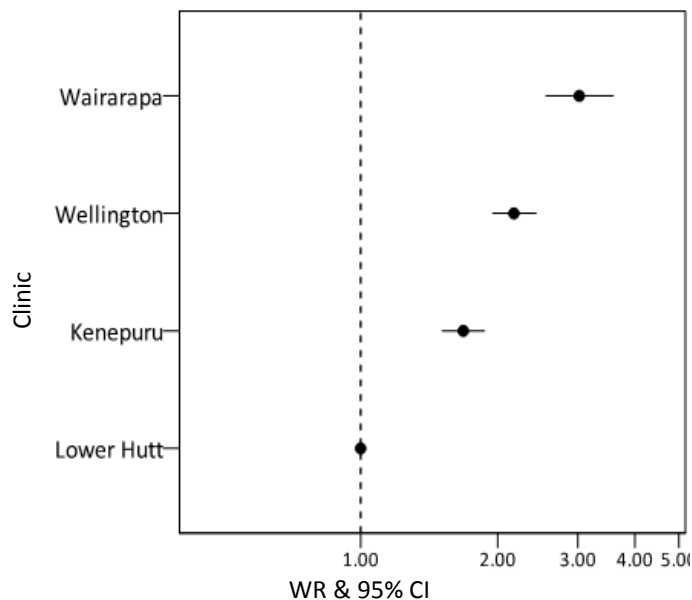


Figure 41: Plot of analysis of variance for Clinic Wait times to FSA (IA patients)

Adjusted for referral priority: WR and 95% Confidence intervals

These geographical distributions have two connected explanations: Administrative staff allocate patients to the clinic nearest their home address unless there is an overriding request, for example if a patient requires an urgent consultation and a local clinic appointment is not available or the patient requires facilities available only at the Hutt clinic¹⁵ (Staff1); and the number of clinics is not allocated on an area population basis (Figure 42)

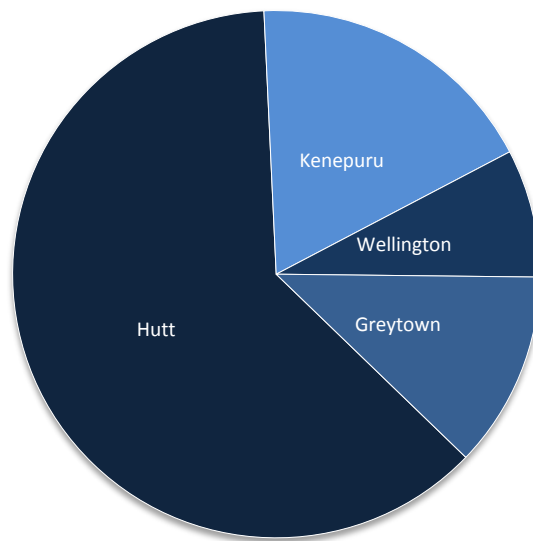


Figure 42: Allocation of WRRU Clinic Hours proportionate to Area

Despite Hutt taking the most urgent cases, separating the urgent from non-urgent referrals shows that longer waiting times for both types of referral remain significant ($p \leq 0.001$) for patients referred from areas outside of the HVDHB catchment (Figure 43).

The relationship between waiting times and location traces the ease of access for rheumatologists moving between the WRRU hub in Lower Hutt to the outlying clinics (Figure 44). This figure also shows that the areas with the greatest proportion of people from within the most socio-economically deprived populations (high needs,

¹⁵ This most often affects referrals from the Wairarapa because of the extended time between clinics. Rheumatologists attend Wellington and Kenepuru clinics on 2 days each week, and Greytown clinic once a fortnight. Rheumatologists are available at Hutt 5 days per week.

Māori and Pacific) and the highest proportion of APHO clinics are also the areas relatively well-served by the WRRU.

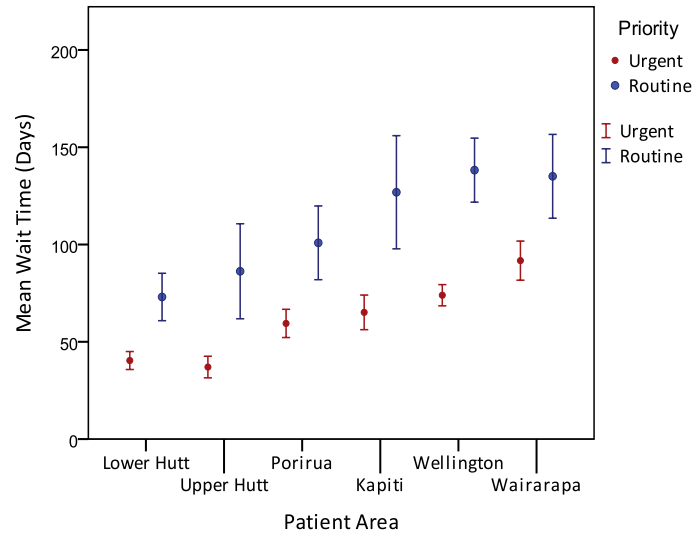
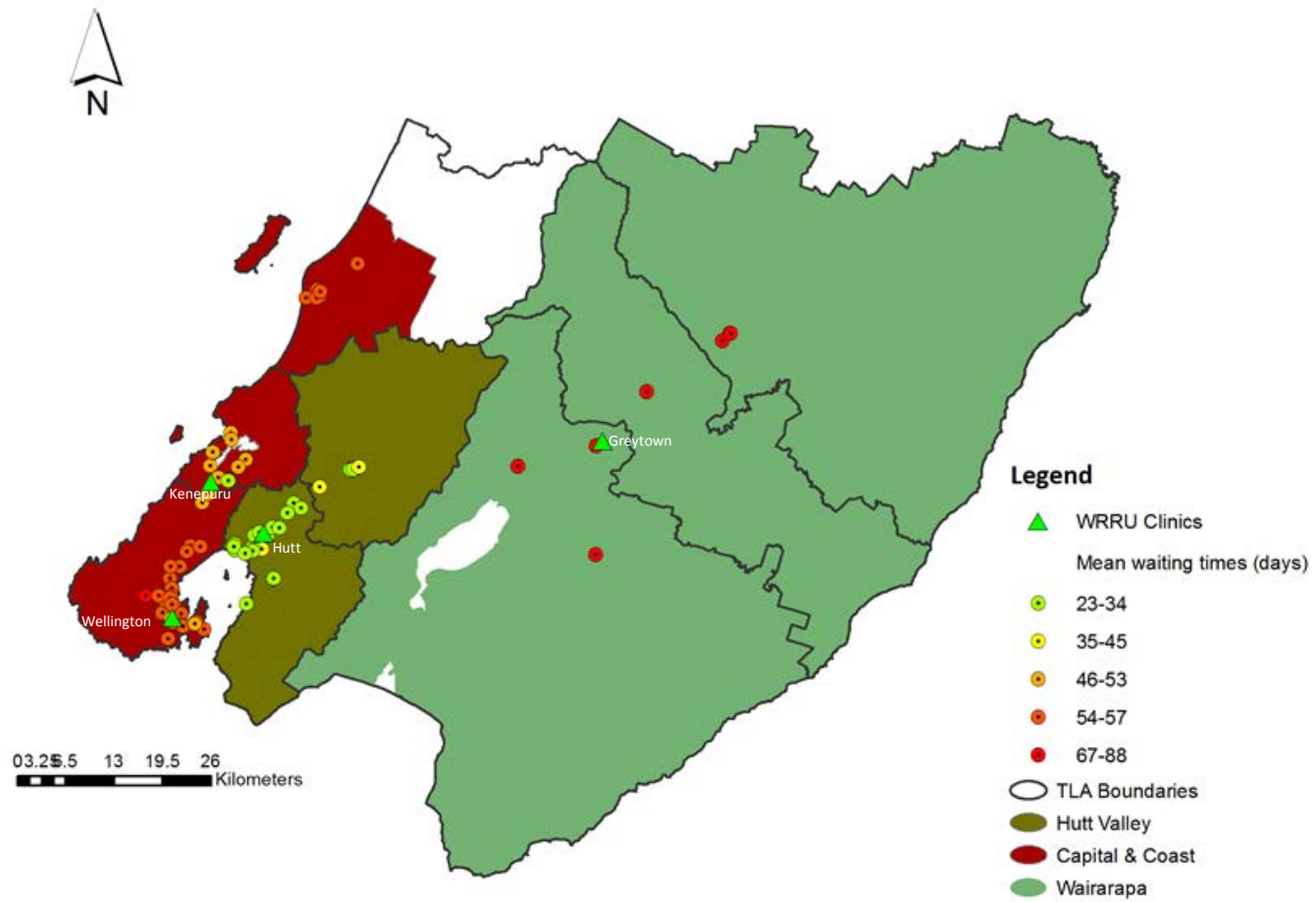


Figure 43: Mean waiting times to FSA by Area

Separated by urgent (P1 and P2) and routine (P3) priority ranking: Geometric means and standard deviations



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 Link: <https://koordinates.com/license/attribution-3-0-new-zealand/>

Figure 44: The mean waiting times to WRRU FSA for all referrals of patients with IA grouped by the referring GP practice

NON-ATTENDANCE IN CONTEXT

In addition to non-attendance factors outside the control of the WRRU (transport, social support and financial barriers) patients described administrative and communication problems that hindered attendance at rheumatology appointments, for example:

“The bus used to only come in the morning and at night, like it didn't come right into [our suburb] , over the years while we were living there, we have to catch the bus, just to support it so they'd put buses into [our suburb] so they could go right through the day. You had to walk right from around [the next suburb] to back to home. Sometimes you'll catch a cab... It was a long thing to do”

Gillian

The journey from her home to the WRRU, the nearest clinic, takes almost an hour by bus¹⁶ or costs a minimum of \$60¹⁷ for a taxi fare. These options were beyond Gillian's means, given her low income, lack of private transport options and precarious employment situation. One other participant relied on public transport and found timetabling difficult to coordinate with appointment times.

Lisa is part of the considerable number of young people and people with financial constraints who do not attend rheumatology appointments (Figure 45). Her story encapsulates the difficulties that patients with co-morbidities, children and poor social support and low financial resources can face in order to coordinate their healthcare. Lisa also epitomises a sense of disengagement in her own health care that frustrates care providers and that can lead to a cancellation of rheumatology appointments.

An administrative response to missed appointments is the refusal to offer another. This refusal is usually justified because the appointment time is better utilised by shortening the waiting time for another patient, and by the conviction that it is up to the patient to make arrangements that facilitate attendance.

“Well, patients have to take some responsibility for their own health needs” Staff 4

¹⁶ <http://www.metlink.org.nz/journeyplanner>

¹⁷ <http://www.numbeo.com/taxi-fare/>

A COMPLICATED HISTORY OF NON-ATTENDANCE

Lisa is a young mother of one child and lives apart from the child's father, although he takes care of the child on occasions. She is not in paid employment. Her family has moved to Australia so relies on friends for support.

"My mum... she's moved to Australia like the whole family is over there so... and like [child's] dad he was pretty [unsupportive] at the start – but he's a lot better now – but at the start when he had to take time off work, sometimes he'd go half a day and then he'd have to take time off. We're not together and he's like I can't take time off work. So, he just doesn't understand."

As well as IA she has two other chronic conditions that have led to emergency hospital visits and overnight admissions.

"It's funny because everything was just happening at once it was like god I'd have one thing and then I'd have another thing and it was just so all building up."

As a result of inadequate social support for child-minding, financial difficulties that affect her transport options and her health conditions that require appointments with a variety of consultants. She has missed several rheumatology out-patient appointments.

"But I haven't seen [rheumatology] for ages because I missed the last appointment and I think I missed the appointment before that too. They sent me out another letter and they said 'Well here's another appointment. Make sure you ring if you can't come.' But then when I was sick the night before [in hospital] I didn't end up ringing I forgot about it ... I've told [ex-partner] before 'ring up and tell them I can't come in and what not' but he's running around after [our child]."

The response of the WRRU to the missed appointments was to discharge Lisa back to her GP. But while her other illnesses appear under control, her IA is not.

"The only problem I really have now is the joint pain. Sometimes it's all right and sometimes it isn't. 'Cause like my back - stress contributes to it real bad. I've been stressed out like the last 2 weeks and my back, my neck was stiff as and everything so... [child] she's always on my back and she's like 'is your back sore' and I've trained her to rub my back. And then I just haven't heard anything. So I don't know, it just feels like I should see someone."

Lisa understands her arthritis medication requires regular monitoring, but does not regularly comply with the requirements of the regime.

"I'm supposed to have blood tests once a month but I don't go until maybe the second month or I don't go until I get a letter saying you should have blood tests. I don't like blood tests... I haven't been since I was in emergency not that long ago. I got like a big huge bump... I had this big ugly bruise so I haven't been for a blood test since. ...They just say 'your bloods look fine'. So I can't understand if, like, I look at it and I can't tell what it means. Like markers and what not, so I just have to rely on them they say 'yeah bloods look fine'. [So], yeah, [it's] not much use to me. I don't even know what my arthritis was called. I asked the doctor and he told me and I'm like there is no way I'm going to remember that."

Lisa needs to re-engage with the WRRU, but the process to do so is unclear to her. She struggles to afford her GP bills so delays as often as she can – or goes to the Emergency Department when her situation becomes too serious for her to manage. The unaffordability of GP prescriptions compared with hospital prescriptions and the deterioration of her IA were incentives

Figure 45: A narrative of non-attendance - Lisa's story.

Brian also had IA onset at a young age and spoke of an inability to understand his illness and become engaged in his own healthcare. Brian attended his FSA with a sense of urgency after his delayed referral, but was soon in conflict with his rheumatologist and missing appointments.

“[The rheumatology appointment], it was only once a year and it seemed like I only had five minutes with the guy and I had all these questions we just didn’t have enough time together you know? I was kind of in there, I’d sit there, I’d talk to him, I’d tell him about what was going on and he’d tick little boxes sort of thing and after about five minutes [and] ‘yeah righteo’ he’d put his pen down and that was it. It was really, really frustrating ay mate y’know?”

Brian

As a previously healthy young man Brian, unsure of protocols around specialist consultations, did not know he had the right to request another rheumatologist when their relationship became ineffective. He soon found himself disconnected and in conflict with WRRU staff. It was not until a change of rheumatologist that Brian began to understand WRRU requirements and treatment protocols.

“I never knew any better ay mate, I was probably me own worst enemy, I should have done a little research myself, but I didn’t. I had questions for them but I can’t get over I never really walked out of there satisfied if you know what I mean. [It was just luck] I got another rheumatologist. I’ve learnt over the years that if you don’t ask you’re not going to get it. It’s as simple as that. Because they can’t read your mind, they don’t know what you’ve got to get from them. So as long as you tell them, and you play the game, you take your pills and do what they ask you to do... So yeah I do my best to try to keep [my rheumatologist] happy, to make the job a bit easier... And I can imagine how frustrating it would be if they are asking you to do things and you never did. I mean why would they want to continue helping you, y’know? So I appreciate that, I really do.”

Brian

Nevertheless the observation was made that it seems harder now for patients to leave work to attend appointments than staff had noted previously. Patients from higher socio-economic groups tend to phone and cancel, whereas patients from lower socio-economic groups, elderly patients and participants, like Lisa, who are often dealing with other health issues and social isolation, as well as newly referred patients are more likely to fail to attend appointments with no notice (Staff1; Staff2).

DISCUSSION

Primary analysis of administrative data identified patient age, ethnicity, PHO and waiting time as the main factors associated with non-attendance. Māori, Pacific and younger patients were less likely to attend than other ethnic or age groups but, did not have longer waiting times, moreover the areas and clinics with the longest waiting times did not have significantly higher likelihood of non-attendance. Age and waiting time independently influenced non-attendance, while PHO type smoothed the ethnic variations in non-attendance.

The factors behind Māori and Pacific Peoples' non-attendance may differ. A reduction in the strength of association between Māori and Pacific Peoples non-attendance is apparent after adjusting for age. The effect of age on non-attendance for Pacific Peoples, who have a higher proportion of 20–29 year-olds is greater than for Māori. When adjusted for area variables, the risk of Māori and Pacific Peoples non-attendance remained significant.

Significant differences in area non-attendance rates were not observed, despite significant differences in area waiting times. Administrative variables provide similar adjustments that indicate administrative processes may affect non-attendance rates for these groups. This lack of significance could be associated with the small numbers of Māori and Pacific peoples residing in areas outside of Porirua and Lower Hutt (areas with shortest time to FSA) and variations in the attendance rates of the much larger European populations across the regions. Although area differences are not significant, Wellington, with long waiting lists, has higher non-attendance rates for NZ Europeans than in all other areas, and Porirua non-attendance for NZ Europeans is also relatively high. The non-attendance odds ratio for APHOs reduces by almost a quarter after adjusting for demographic variables and Māori and Pacific Peoples chance of non-attendance is no longer significant after adjusting for PHO type suggests a socio-economic gradient in Porirua non-attendance where approximately one-third of enrolled patients reside in the most deprived DEP2006 areas, and where 90 percent of referrals are from APHOs. Chapter Five provides data that shows people from Porirua and Lower Hutt (areas with shorter waiting times) are likely to have fewer material (private transport, telephones) and financial (for example, higher

unemployment) resources than in other areas, so may face greater obstacles in meeting FSA requirements. NZ European non-attendance rates are also higher in these areas.

Administrative data does not usually provide information about the contextual background of patient groups and a focus on the recorded patient characteristics is insufficient to explain why negative healthcare responses might arise (Frohlich, et al., 2001). However, the distinction between APHOs and IPHOs allows some comparisons to be made in terms of population groupings and area-level deprivation because PHOs reflect the socio-economic characteristics of the population groups they serve. The funding formula for APHOs encourages location of health services in deprived areas (Cumming & Mays, 2002), and up to two-thirds of patients enrolled in Wellington region APHOs were from high needs communities (Māori, Pacific Peoples and/or living in the most deprived areas), compared to a quarter of IPHO patients (Ministry of Health, 2009). This stratification between IPHO and APHOs provides a basis for investigating whether rheumatology services are effectively reaching high needs patients, and area deprivation should be a focus of further research about Māori and Pacific Peoples' non-attendance. Although there appears to be a connection between high needs and non-attendance, alternative explanations for these groups having greater non-attendance rates are that language barriers make the notification and reminder process more likely to fail, particularly for Pacific Peoples, or that customs, religious beliefs and cultural expectations (Barnett & Barnett, 2004) influence non-attendance. These issues have been recognised in primary care programmes designed to improve access to healthcare within the Wellington Region (Tumai mo te Iwi PHO, 2009). The argument against language barriers is that patients of 'other ethnicity', who are non-European, non-Māori and non-Pacific peoples, and who may reasonably be expected to experience language barriers, have the second highest rate of attendance.

The timeliness of FSAs has a noticeable association with Māori non-attendance and is a factor in young people's non-attendance. A possible explanation is patients' beliefs about the reasons for longer than expected waiting times. Perceptions of institutional racism that include cultural barriers or perceptions of discrimination have elsewhere been cited as a reason for low engagement of Māori patients in the health system and

Māori are ten times more likely to self-report experiences of discrimination than European healthcare users (Harris et al., 2006). A study of hospitalisation rates in Christchurch found that while European rates were strongly related to deprivation, hospitalisation rates for Māori patients living in areas of high deprivation were similar to those for Māori patients living in less deprived areas (Barnett & Malcolm, 2010b). A study of young rheumatology patients transferring to adult services has shown that young people regard long waiting times as a lack of respect and that attendance is affected by perceived discrimination (McDonagh, 2008). Understanding the beliefs about, and effects of, appointment timeliness for groups at risk of non-attendance could be a productive line of inquiry. Beliefs and expectations around symptoms (Sheppard, et al., 2008), having an episodic illness that subsides with time, or the availability of primary care treatment that suppresses symptoms may also account for non-attendance in these groups. For example there is a recognised tendency for Māori and Pacific Peoples to use pain relievers in preference to appropriately prescribed preventative medications (BPAC NZ, 2007).

The association between non-attendance and waiting times is not an unexpected finding and has previously been cited as independently influencing non-attendance (Leung, et al., 2003). This study shows that the WRRU service structure is the predominant cause of long waiting times. Longer waiting times for FSAs reflects the longer travelling times for rheumatologists from the WRRU base at Hutt Hospital to outlying clinics. This finding is in keeping with previously published data on rheumatology service volumes (Harrison, 2004), and reinforces a conclusion that waiting times result from an unequal distribution of rheumatologists' time. The WRRU base at Hutt Hospital has the greatest share of service volumes with more than twice the clinic hours per head of population than the combined hours of all other clinics, mainly due to the location of rheumatologists' offices, more capacity for acute cases and availability of ancillary resources at Hutt such as allied health professionals. The data suggests Māori and Pacific Peoples' non-attendance rates are suppressed by shorter waiting times because a large proportion of these populations live in proximity to clinics with the most adequate resources (Hutt and Kenepuru). A similar suppressive effect for younger patients occurs, with half of all patients aged 20-29 seen at Hutt and only 3% seen at Greytown where waiting times were longer, This

observation suggests that any adjustment to improve waiting times by reducing variations in clinic resources needs to account for probable increases in non-attendance of Māori, Pacific Peoples and other high non-attenders unless mitigating measures are taken.

Strategies to ameliorate deprivation effects that reduce access could improve non-attendance rates for Māori and Pacific Peoples as well as high needs patients. A study of Māori non-attendance at OPDs in Auckland found almost half of respondents were unable to get to the clinic due to factors associated with deprivation, for example access to transport (Coffin, et al., 2003). The study concluded that:

“There were no significant cultural safety issues detected in this study that caused Maori to not attend clinic appointments. This is interesting in that it suggests that any of the reasons given by the patients in this study for not attending appointments could be equally as applicable for patients of other ethnic backgrounds. This implies that any solutions to decrease non-attendance rates should be focussed on individuals regardless of ethnicity.” (Coffin, et al., 2003, p. 18)

Gender differences in waiting times can be explained by areas with longer waiting times having more enrolled female patients and disproportionately more female referrals. For example Kāpiti, with an average wait time of more than 76 days has an enrolled female population of 54.5 percent and 70.5 percent of its referrals are women. Upper Hutt on the other-hand, with an average wait of 47 days, has approximately 51 percent female enrolled patients, with 64 percent of its referrals being women. The area differences in gender referrals could also explain the almost 40 percent more women than men prioritised as ‘routine’ ($p < 0.05$) with patients from areas with an older age profile (Kāpiti and Wairarapa) referring greater numbers of patients with degenerative, rather than inflammatory arthritis, but further investigation could clarify the reasons for more P3 female patients.

The differences in IPHO and APHO non-attendance suggest a socio-economic gradient in non-attendance. The Manukau survey found that socio-economic deprivation was a significant impediment to attendance with 37 percent of the respondents citing lack of financial resources for transport or medical costs, or that they could not afford the time off work, and a further seven percent stated their illness had deteriorated to a

level that their ability to travel was restricted (Coffin, et al., 2003). Participants failing to attend WRRU appointments provided examples of how poor financial and social resources interact with appointment preconditions to prevent attendance at rheumatology appointments by narrating how pain and disability may preclude driving or use of public transport, and how childcare issues affect their chances of meeting appointment obligations. It is assumed by the GP or WRRU that the patients have the assistance they require to attend rheumatology appointments and patients are not asked if they can physically travel to the clinic. It is likely that there is an unmet need for assistance in attending the appointment. At present there are only limited options of transport help through the WRRU, and administrative staff are reluctant to suggest help with transport because the WRRU may become inundated with requests (Staff 1).

Patient narrative also suggests some frustrations with the administration and conduct of the consultation that can lead to erratic attendance. The relationship with the rheumatologist, and impatience about an unknown health and medical future were inferred frustrations that could lead to the relationship with the WRRU breaking down. Some clinic staff also suggested delayed and rescheduled appointments could affect the patient attitude toward attendance. These points echo the findings of a qualitative study of asthma patients' reasons for attendance at a West London outpatient clinic. The study found that for patients who thought that the structure of the service was discouraging, poor health and forgetfulness were important reasons for non-attendance, whereas a wish for control over the asthma and having a relationship with the consultant that the patient did not want to jeopardise were the main reasons for wishing to attend appointments (van Baar, et al., 2006).

Eliciting information about patient resources gives insight about cancellations and non-attendance of IA patients at DHB appointments. Despite there being many personal circumstances which could affect the likelihood of a patient not attending an appointment, there are several strategies that could improve the chances of IA patients receiving timely care and access to suitable treatment plans. These include ensuring transport needs are met, keeping waiting times within an expected timeframe and ensuring administrative processes are responsive to the level of pain and immobility a patient is experiencing.

13. CONCLUSION

INTRODUCTION

This thesis began with an examination of the reasons why there are delays between the onset of symptoms of inflammatory arthritis and the first specialist assessment at a rheumatology clinic in the Wellington region. The empirical chapters finished with an examination of patient ideas about what constitutes care pathways that will enable outcomes that both patients and rheumatologists would like to see.

The aim of treatment for IA should be therapeutic or complete remission (Breedveld & Kalden, 2004; Raza, et al., 2006; Smolen, et al., 2010), yet delays to treatment can severely reduce the chances of this outcome. A Collective Lifestyles approach frames access to rheumatology care within the places people live, social practices, and social and cultural expectations about appropriate responses to health needs and practices (Frohlich, et al., 2001). These considerations have been drawn on to investigate the patient journey to treatment for an IA condition, and to situate it within the construct of Candidacy (Dixon Woods, Cavers, et al., 2006) as a concept to explain barriers to accessing healthcare for IA patients.

The chapter considers how the findings of the research fit within the Candidacy model of access. The resources and constraints identified, within the Collective Lifestyles framework, that individuals need to consider in order to negotiate and realise their health needs are then summarised. The conclusion reflects on the strengths and limitations of the study, the method of investigation, and the way personal experience has shaped the research process. It finishes with a series of recommendations and suggestions for further research.

REFLECTIONS ON THE STUDY FRAMEWORK

In qualitative research the goals of researchers and research participants are likely to differ. Moreover, patient participants do not only provide consent for their stories to be used as data in a research project, they also enter into a relationship with the researcher which may influence the context and expectations about how their stories

will be used. Patient participants were made aware of my status as an IA patient receiving care within the Wellington region early in the interview process. Participants in an interview are often concerned about how their narratives will affect their relationship with people who retain power over their healthcare and also how participation in the research might improve their own situation (Frank, 2002).

In this study some participants retained a sense of outrage around their contact with healthcare providers and wanted this conveyed. Three participants were looking for information or help to establish contact with rheumatology services and others were keen to present tales of successful relationships with care providers and compare these with previously unsuccessful relationships. The over-riding objective of patient participants was to provide information that might improve the experience of seeking and receiving appropriate care for their IA. All were keen to present their stories on onset of symptoms. The simultaneous roles of researcher and IA patient provided a privileged entrée into the interview relationship with a unique responsibility to manage the discourse in a way that reflected the participants' stories, rather than my own regardless of overlapping themes and experiences. It also required me to provide non-medical advice and reassurance about rheumatology processes, administration and professionalism. On the one hand, my failure to convince one participant to accept referral from a GP to rheumatology care is a personal regret. On the other hand, providing a platform for participants to talk about their health care, and journey to appropriate care, or assisting in re-establishing contact between a participant and the rheumatology service provided great personal satisfaction.

CANDIDACY

The review of literature relating to access to rheumatology care found that empirical methods have been used to identify populations that are unlikely to receive early treatment and qualitative methods used to attach meaning to the empirical data; however theoretical framing of the results is uncommon. This study was developed with the intention of melding theoretical frameworks with the interpretation of data within the places where people lived and experienced their health care. Few studies that have used Candidacy as a model for access have been published, and the

Collective Lifestyles framework, despite being used for health inequalities studies has not been applied in association with the Candidacy model of access. Published studies show that both concepts lend themselves to a qualitative or mixed methodology and provide a basis for innovative inquiry into the patient experience of barriers to healthcare. The barriers to rheumatology care, expressed within the Candidacy model are summarised in Figure 46. The measures of candidacy are discussed below.

IDENTIFICATION OF CANDIDACY

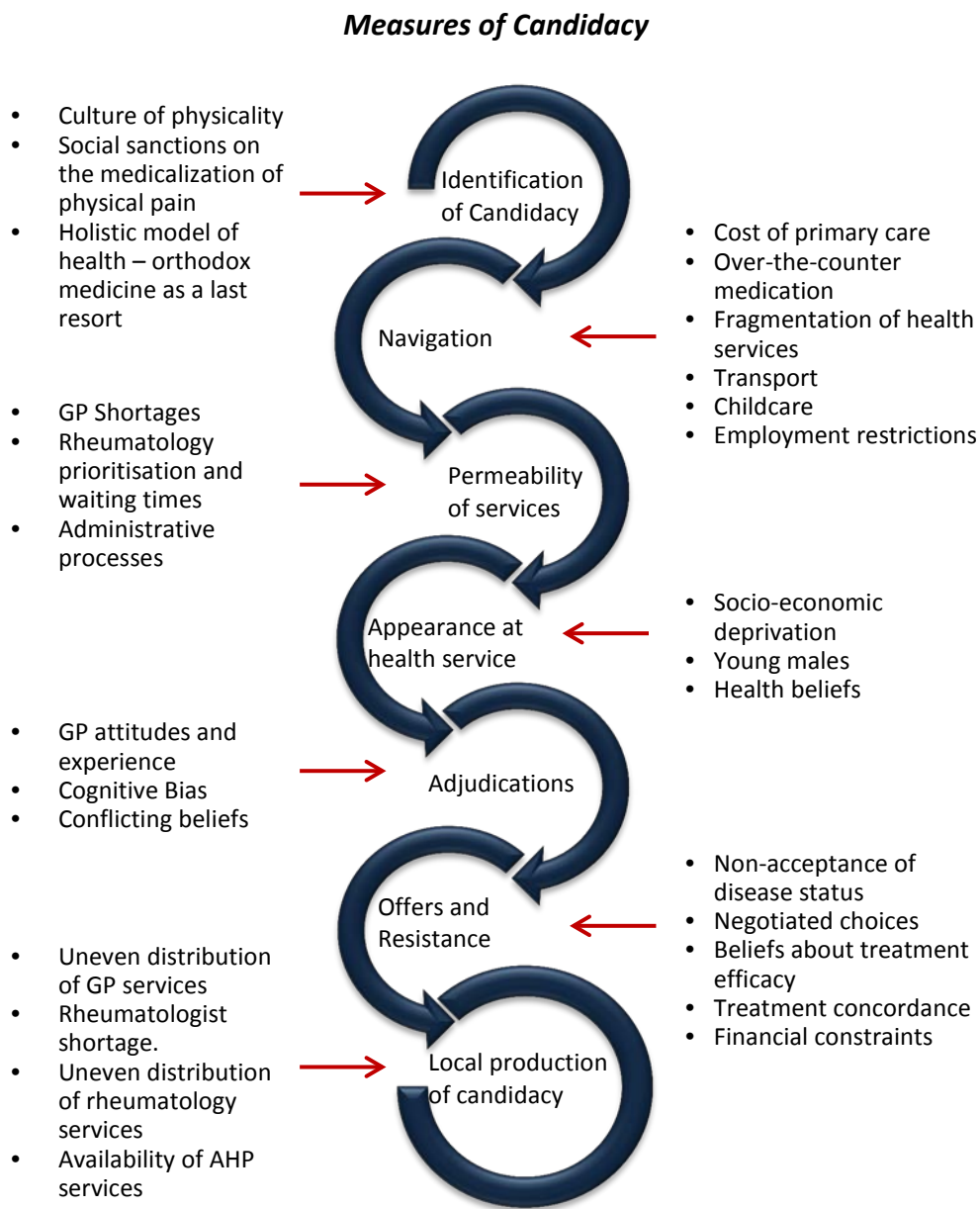


Figure 46: Candidacy and the barriers to accessing rheumatology care

Derived from (Dixon Woods, Cavers, et al., 2006; Dixon Woods, et al., 2005)

Identifying oneself as a candidate for healthcare requires recognition that symptoms need medical evaluation or intervention (Dixon Woods, Cavers, et al., 2006). The delay in this recognition was the main reason for delays in seeking healthcare advice. For a usually healthy, active individual, without any knowledge of IA, it is not unexpected that IA symptoms would be interpreted as an injury or overuse syndrome when they first arise. Most participants continued to hold onto this interpretation for periods of several months to several years.

The construction of a narrative about symptoms is dependent on contextual factors that arise from familial beliefs and behaviours toward illness, cues from previous experiences with injury and the health system, and input from social contacts. This narrative does not incorporate public health media input concerning IA (Knäuper, 2001).

The most frequently cited reasons for discussing details with a GP were that symptoms prevented the participant from engaging in a valued activity (e.g., it affected employment or sport, and the level of pain that was being experienced). Pain was often cited in relation to the ability to manage an event (e.g., travel on planes might be affected; or, the symptoms were mentioned to the GP in the course of a consultation for another health concern).

CULTURE OF PHYSICALITY

The initial reasons for delays in claiming candidacy reside in the cultural beliefs about how MSk pain should be managed. Men's, and to a lesser extent women's delays in seeking care were often attributable to the concept of being a New Zealander who values physicality, strength and stoicism. Later, when accepting DMARDs this same concept, for men, reinterprets itself as taking control of the condition to enable a return to usual activities as soon as possible (Addis & Mahalik, 2003). This cultural underpinning of views that impact on seeking care can be considered a naturalised and fundamental set of beliefs and values. These beliefs are inculcated from familial patterns of managing injury and other health needs and become self-evident truths that inform perceptions and actions (Bourdieu, 1977).

Patients who described themselves as 'sickly children' and had had frequent contact with their GPs described responding to their IA symptoms earlier in the onset phase

than patients who described themselves as infrequently consulting a GP. Patients' narratives show that participants who were inculcated from a young age with views that encouraged physicality and 'to get on with it' did not see themselves as candidates for medical care until symptoms were impeding their physical ability or until advice from social contact, AHP or a family member who recognised the symptoms as an IA encouraged them to visit a GP.

SOCIAL SANCTIONS ON THE MEDICALISATION OF PHYSICAL IMPAIRMENT

The culture of physicality was maintained through social contacts and described in terms of sports and employment settings where chronic disease and/or long-term medication impeded social connectedness (this includes the restrictions on alcohol consumption that are part of the treatment concordance requirements of methotrexate). The fear of social isolation is an important consideration for participants who maintain social relationships through these settings.

The culture of physicality was particularly destructive to future well-being when the participants felt that giving in to the symptoms would undermine self-esteem and promote isolation. For these participants the acknowledgement of pain, the reconceptualising of symptoms from injury to a long-term illness and submitting to an acceptance of candidacy for long-term rheumatology care were not acknowledged until permanent joint changes and disability were clearly obvious.

MEDICINE AS A LAST RESORT

Women more often considered health advice to be important in managing symptoms and often described early help-seeking. However they were more likely to call on the services of AHPs or complementary therapists rather than a GP if they had the financial resources to do so. Beliefs about treating the person, not the symptoms, health prevention and health maintenance drove this pattern of healthcare seeking, with medical intervention for illness seen as a last resort. A narrative built around the symptoms being related to overuse of the painful joint (for example computer work), or feelings of fatigue and general unwellness were attributed to stress rather than illness, and this narrative confirmed a health maintenance rather than medical approach to coping with symptoms. This use of preventative health providers,

although having a social and cultural prestige (S. J. Williams, 1995), ultimately delayed access to appropriate care.

Patients who serendipitously encountered social or AHP contacts who recognised the symptoms were given an impetus to see themselves as candidates for medical care. The important point here is that information is not readily available to suggest to individuals that their symptoms may be other than injury or overuse, and to seek care. For almost all participants an inability to continue with valued activities due to severe pain or acknowledged disability led to the identification of themselves as candidates for medical attention.

A drive to publicise the symptoms of IA, to understand family history of IA and expound the benefits of early medical intervention could improve patients' evaluation of MSk pain and inflammation. Emphasising the imperative of early treatment and options that can significantly ease pain and reduce disability could challenge patients' narratives concerning health prevention and health maintenance. Uncovering cultural explanations for delay may lead to more targeted approaches for public information about IA designed to reach 'at risk' groups that discussed symptoms and effects on activity in terms of identity.

NAVIGATION

The recognition of available services for assessing IA symptoms and the mobilisation of practical resources to enable use (Dixon Woods, Cavers, et al., 2006) were important in facilitating care for women and low-income patients. All male participants sought GP care as the first option when symptoms persisted and none cited cost of care (despite some acknowledging financial strains), or transport as a barrier to utilisation of primary care or rheumatology services.

COST OF PRIMARY CARE

The impact of user fees on the utilisation of primary health services varied by financial resources, gender and also on care options that resulted from the personal explanations for symptom onset. The recognition of services for evaluating IA symptoms once candidacy was acknowledged was, by default, high - simply because the primary health system is the gateway to other health services and GP services are

generally the least expensive primary healthcare service. The APHO structure provided low, or no-cost, access to medical advice for patients in socio-economically deprived areas. Low income patients who resided outside of these areas and middle income women with families found the cost of care a substantial barrier to early GP care. Patients enrolled in a PHO and with an allocated, or 'home' GP, have cheaper consultations than non-enrolled patients. Participants with no prior relationship with a GP also spoke of choosing to go directly to an AHP rather than a GP for MSk pain. These patients are often new to an area or, as in the case of younger participants, have had little requirement for GP care in the past.

Financial constraints for patients led to delayed GP consultations for economically disadvantaged women outside the APHO system, but also for middle income women with families who budgeted for their healthcare. Opting out of GP care and visiting an AHP became an important strategy for women who paid maximum GP fees. This strategy was justified by the narrative they had constructed about their IA symptoms being a result of injury or overuse and the expectation that a GP would refer them to an AHP, such as a physiotherapist. Consulting with an AHP directly was justified as cheaper healthcare requiring only one consultation with the AHP instead of two – one with the GP and one with the presumed AHP.

The use of medical services has a social and cultural profile with low income users and men using GP and A&E services as the first option when exploring reasons for their MSk pain. In part this could have been because they left the decision to seek care later, and were therefore managing health in terms of crisis health events (Dixon Woods, Cavers, et al., 2006). An American qualitative study described the process of women seeking rheumatology care as an activity "exhausting health care resources" (Salt & Peden, 2011, p. 216). Although the New Zealand consultation and referrals system is quite different to that in the U.S., the phrase is quite apt for middle and high income women. These women usually chose AHP or complementary practitioners and alternative remedies to alleviate symptoms before yielding to GP investigation of symptoms. This was considered practical because they were often already established users of complementary or allied MSk professionals like physiotherapists, osteopaths and massage therapists so managed their symptoms in a more routine way, compared to low-income and male patients - albeit with practitioners whose

access to referral procedures, even when they understood the symptoms they were seeing, was limited.

OVER-THE-COUNTER MEDICATION

Readily available over-the-counter medications to relieve pain and disability were cited as a disincentive to seeking care from GPs. Stoicism, a preference to avoid GP visits and the cost of medical care are commonly implicated in individuals self-managing their symptoms. These medications also resolved problems so deferring the need to mobilise resources and deal with time constraints that are barriers to accessing GP care.

TRANSPORT

The most important resource to be mobilised for attendance at GP services and later rheumatology services was transport. Self-driving can be problematic for patients with MSk pain and inflammation. Patients are likely to have a family member or other social contact to call on, or they can afford taxi fares, but this is not universal. For people who do not have access to private vehicles, public transport is often a viable alternative, but although public rheumatology clinics have regular bus services, the services from remote suburbs are sporadic and require multiple connections resulting in trips of more than an hour each way. This constrained availability affects time off work and childcare options for patients. Patients with inflammation in the lower limbs also find public transport difficult to use.

CHILDCARE

Taking care of others has previously been identified as an important reason women delay healthcare (Jatrana & Crampton, 2009). This has particular implications for women with young children. Parents without strong social or financial resources find managing appointments difficult on their own. Childcare and transport issues are logistically difficult. Especially when long waits occur at consultations and when inflammation makes handling children difficult e.g., when using public transport.

The time an individual has available to allocate to their healthcare varied considerably, and for most participants, appointment making and attendance were inconveniences rather than serious problems. This, however, was not the case for participants on contract or casual employment, who needed to minimise absences or

lose pay for missed hours. For these participants work is converted from a time constraint to a financial one. This situation can lead to patient strategies to minimise disruption by relying on more flexible GP care rather than rheumatology consultations (i.e., either forgoing rheumatology care altogether, or after initial contact with the rheumatology service, the patient relies on the GP for prescriptions and follow-up care).

PERMEABILITY OF SERVICES

Permeability of services refers to how easily a person can use a health service. This includes the organisational values and administrative processes of the service that may enhance or create barriers to utilisation (Dixon Woods, Cavers, et al., 2006). GP services in the Wellington region are relatively porous with few participants reporting administrative or organisational values that were barriers to care. However, those barriers that did exist disproportionately affected young and low income patients.

GP SERVICES

Permeability of GP services centred on two main themes: the availability of GP appointments when they were needed; and the availability of a home GP with whom the patient can build a consistent narrative about symptoms development over a period of time so limiting the need to relate symptom history to unknown GPs or locums as symptoms progressed. The availability of GP appointments was affected by GP shortages, with the Wairarapa and Upper Hutt the worst affected areas. In some forms of onset, the periodic ebb of symptoms over a short period, before returning, impeded the evaluation of symptoms if the appointment was delayed.

SELF RATIONING

Self-rationing is described as a need to maintain an identity as a reasonable and responsible user of healthcare services (Dixon Woods, et al., 2005, p. 83). Self-rationing was most often mentioned in terms of GP consultations when individuals believed their GPs were over-worked. This belief was alluded to by a rural participant who did not like to bother the GP if he was 'well' because he knew appointments were hard to come by. Self-rationing also appears when people do not wish to be seen as a nuisance by the doctor. Two older, non-European women were reluctant to

'bother' their GP when symptoms appeared, but as their experience in the health system increased with use, and the relationships with their GP practices became embedded they felt more able to express their needs enabling better healthcare delivery to be provided.

RHEUMATOLOGY PRIORITISATION AND WAITING TIMES

In addition to clinical indicators, three main factors are important when the GP offers a referral to the patient. These are the: administrative procedures, including communication with rheumatologists; referrals prioritisation; and perceived waiting lists. This situation may lead the GP to defer referral until the symptoms are urgent and the patient can receive higher priority. Due to beliefs about oversubscribed rheumatology services GPs may refuse to refer a patient with a history of non-attendance.

Waiting times were the dominant element in the permeability of rheumatology services. The prioritisation process was crucial to this process. Although the prioritisation process is based on clinical indicators of disease, the GP evaluation and patient circumstance are likely to affect the importance that triage specialists ascribe when weighing up the appointment timing for patients with similar clinical profiles, for example, a person in paid employment may be ranked above a person who is not, or a younger person ranked ahead of someone older. There is some evidence that female patients receive lower prioritisation, but the reasons for this are unclear. Lower prioritisation may reflect the greater referral of women for widespread pain disorders, unrelated to IA, some other clinical criteria, or a subjective assessment of need. Prioritisation is not transparent to patients. They are blind to the information the GP has put forward to the rheumatologist and do not have the opportunity to make a case for faster access to rheumatology services. GPs and patients are also unaware of where waiting times are shortest and do not have the option of travelling to further clinics for faster access. This situation has an impact on the equity of access between areas, with Wellington and Wairarapa patients having significantly longer waiting times than patients from other areas.

Professional judgements by the GP are not made in a vacuum and the apparently inadequate identification of IA at an early stage of symptoms, communication with

the patient and insufficient understanding of referrals procedures suggest systemic, rather than personal quality of care, issues that need to be resolved to improve referrals performance (Harrington, 2008). Adjudications by GPs are not made only on patient presentation, but also on the perception of rheumatology services and the perceived expectations of referrals requirements and treatment options. Not all GPs expressed confidence in communicating with rheumatologists about uncertain referrals, or about when to follow-up if a referral appeared delayed. The expressed reasons for this lack of confidence in communication were: uncertainty of the GP's own diagnostic skills; a lack of knowledge of the operating conditions of the WRRU; and uncertainty about whether the rheumatologist could improve the patient outcome.

Delayed referral as a result of resource constraints in the public sector rheumatology service has been highlighted as affecting referral decisions for individuals who the GP might consider as less justifiable. This situation can lead to some people paying for private rheumatologist assessment, and for others who rely on the public service having a delayed referral and being prescribed NSAIDs to alleviate the symptoms of inflammation instead of having the chance of receiving disease modifying agents that have a high probability of slowing joint destruction.

Prioritisation of patients shows that triaging does not always result in a ranking associated with a diagnosis of an IA. Missing information about the clinical markers of disease, patient well-being (pain, disability) and circumstances (available resources) may be improved by the implementation of electronic referrals systems, replacing paper-based systems (Dennison, Eisen, Towers, & Ingham Clark, 2006). At the time of writing, despite an ERS being available to GPs, several expressed reservations about using it. One GP was unaware there was an ERS, others mentioned a lack of trust in the process, difficulty in using the system, and a preference for the flexibility of the paper system. Research on changes to appointments systems appears to be promising, for example, enabling patients to manage the appointment timing (within the medical requirements for their condition) and facilitating after hours appointments, to allow a greater match between what patients need and available administrative resources (Dixon Woods, et al., 2005, p. 294; Hewlett et al., 2004).

OPERATING CONDITIONS

Dixon Woods et al argue that service delivery decisions are made without an understanding of how they will affect the management of the relationship between the health practitioner and the patient and this includes adjudications made by the practitioner to prioritise one candidate for health care above another. They also suggest that resource constraints limit patient involvement in quality decision-making.

Heavy patient loads in primary care limit the time a health professional can spend with a patient and complex administrative procedures in the referrals process can lead to mis-communication and frustration for patients, health professionals and administrators. Administrators and professionals may make assumptions about a person's ability to meet appointments and other conditions of treatment such as filling prescriptions and adhering to testing regimes associated with drug therapy. The scarcity of resources that health professionals interpret through policy guidelines and budgetary restrictions can prompt decisions about whether likely health outcomes of a referral will be of enough benefit to outweigh the cost of treatment. Individuals unlikely to gain significant benefits from rheumatology care due to non-attendance have been discharged before their IA is stabilised in order to release clinic resources for individuals who can gain significant benefits from rheumatology care. A more intensive management programme for people with non-compliant patterns of behaviour, although more time consuming and costly could improve patient outcomes.

APPEARANCE AT HEALTH SERVICES

Appearance of a candidate to a health service incorporates how credibly they can make a claim for medical attention and intervention. Individuals need to formulate their health problems in ways that are properly interpreted by health professionals. Barriers to the interpretation of the need for medical attention can come from both the patient and the medical professional. These interventions include social distance and power relations between the two (Dixon Woods, Cavers, et al., 2006).

Previous interactions with healthcare professionals inform the decision about whether there is value in engaging again when a further (or a recurrent) healthcare problem arises. This learning is exhibited at both a population and community level as people share experience, and has been described as an “ecology of access”, where necessary competencies for effective use of services may compete with skills that have been learned so as to avoid interactions that negatively affect people’s self-worth, sense of trust and community (Ricketts & Goldsmith, 2009).

Vulnerable groups can be at a disadvantage when presenting for medical attention and defer to medical decision-making (Dixon Woods, Cavers, et al., 2006). People with few social and economic resources and males who were in a young age group at the time of presentation, found it difficult to communicate their needs effectively to GPs and rheumatologists. Without a clear basis for symptom evaluation the GPs may look for the impact on patients’ lives, make subjective judgements about pain levels and consider reasons for the patient presenting with MSk pain, other than valid symptoms (for example to avoid work or claim accident compensation benefits). GPs clearly stated that these factors were taken into consideration when attempting to understand patients’ reasons for presenting with MSk symptoms. Moreover, given the propensity to downplay pain, the thought that it may be urgent for patients to have a speedy evaluation may be missing in the GP’s reckoning.

The evaluation of symptoms is subject to differences in interpretation between the patient and GP on a more prosaic level. GPs tend to talk about symptoms in terms of the impacts of pain on the body (where is it, how does it feel). Patients talked of pain in terms of the impact on activities (what pain prevents them from doing). Patients spoke of only discussing the pain location that was preventing activity, and in hindsight had ignored other ‘hints’ of IA that may have helped diagnosis. A second example of this disconnect in language is that a signifier of an IA is the term *stiffness* (e.g., in the morning for RA and in the evening for AS). Patients, in their narrative did not use this term at all when describing onset. A sense of language is crucial to the way social relations and knowledge is (re)produced and without it the patient’s capital is reduced. The poor connection between the language of the layperson and the language of the specialist can be seen as a deficit of capital that impedes effective

evaluation by the medical professional and a proper understanding of the medical options that are presented to the patient (Dixon Woods, Williams, et al., 2006).

There is some difference between genders in the frequency of difficulties communicating symptoms. All women, but only half of the men in the study considered they had an evaluation that dealt fully with their concerns about symptoms. Gender differences in the management of disease have been reported elsewhere. For example women are less likely to be referred for investigation and treatment for ischaemic heart disease (Gatrell, Lancaster, Chapple, Horsley, & Smith, 2002). There is some evidence that different presentations of disease are not fully understood, especially for SpAs, with women presenting with more peripheral disease and men with more classical axial symptoms (Queiro, Sarasqueta, Torre, Tinturé, & López-Lagunas, 2001). Patient participant narrative suggests these presentation differences may account for at least some of the delays in referral.

ADJUDICATIONS

The professional judgements of health professionals are the strongest influence on continued assertion of candidacy and access to secondary care and further treatment (Dixon Woods, Cavers, et al., 2006). Almost half the patients in this study were not referred to a rheumatologist by their GPs without input from another practitioner (AHP, locum or complementary therapist). Moreover GPs failed to refer nine out of 22 participants within three months of making a provisional diagnosis of IA.

ATTITUDES AND EXPERIENCE

In an ideal consultation the patient will present with discernible symptoms and a symptom history that are clearly understood by the health professional and interpreted knowledgeably and without prejudice. Validated criteria for identifying patients with early IA are available (Harrington, 2008), however only one GP used clinical or referrals criteria when evaluating a patient's IA symptoms. GPs were also unaware if the referral rate was appropriate when compared with other GPs. The level of interest in MSk conditions in general was low among GPs and accordingly only one-third of the interviewed GPs had taken part in a CME course in rheumatology. Understanding the physical examination procedures was beyond the scope of this study, but the delay in diagnosis when inflammation occurred in few

joints, and the omission of the physical examination in the narratives of both patient participants and GPs warrants further investigation.

New Zealand-trained GPs admitted that only brief sessions about MSk conditions during their medical training left them ill-prepared for variations in presentation of IA disease. Referrals statistics showing that a patient is significantly more likely to be referred by a GP with more than 15 years of experience supported the GPs' almost unanimous views that clinical experience improved their IA diagnostic skills.

Advising the patient to return if symptoms don't resolve, or the patient returning because symptoms haven't resolved, appears to result in a medical stalemate. On the one hand GPs are reluctant to change their initial evaluation and they also expect patients to manage their situation, taking control of the decision-making about symptoms severity and need for medical attention. On the other hand patients trust the initial evaluation by the GP, so can delay a return until symptoms become progressively worse. The disinclination to return to the GP also reflects a cultural respect for stoicism and beliefs about time being an important factor in the resolution of physical injury. Despite the availability of a 'home' GP (defined as a long-term relationship between the patient and GP) with the benefits of ready access to patient history and a trusted relationship between GP and patient (Schoen, et al., 2007), this relationship did not seem to lead to faster referral. In at least four participants' consultations with a home GP, the GP worked toward the wrong diagnostic conclusion based on previous knowledge of the patient rather than examination of the symptoms. The trust built up between the patient and GP meant the GP evaluation was not immediately questioned and locums were able to see the patient with a fresh pair of eyes, without the biases introduced by familiarity.

In lieu of clear symptom evaluation skills the quality of the communication process is essential in order to attain good outcomes for the patient. GPs tended to base their evaluation on the patient's explanation rather than symptoms presentation. Patients need to present as credible witnesses for IA, but often do not do so, mainly because they do not comprehend what they are presenting. Patients tended to suggest a plausible injury or overuse scenario for their symptoms, or talked about a co-existing problem. GPs described their pattern of evaluation as one of working from the most

likely scenario, so the chance of an IA that the GP has little experience of detecting being recognised early is unlikely at the earliest stage of symptoms.

The adjudication by GPs, and likewise rheumatologists' decisions to offer further treatment, include the perceived benefits of treatment. Despite current practice and referrals guidelines that emphasise referral without delay for patients who *may* go on to develop erosive disease, GPs and rheumatologists may prefer to delay until there is certainty that the patient has an IA that will result in erosive disease. Best practice also stresses the importance of early institution of DMARDs, but in some instances there is a belief that DMARDs should be delayed. These reasons can include a belief that the patient will not adhere to treatment protocols, or that the disease is best controlled by NSAIDs when it is not severe.

COGNITIVE BIAS

Despite the GPs highlighting atypical disease as problematic in diagnosis, the GP and patient participant interviews suggest common reasons for delays were factors associated with cognitive bias. A preference for a familiar diagnosis, confirmation bias and premature closure figured strongly in incorrect symptom evaluations.

Cognitive bias appeared to be an important factor in lengthy evaluation delays. This led to the continuation of the GP evaluation along an incorrect path, or to premature closure of the diagnostic evaluation without recourse to clinical procedures such as blood tests for inflammation or radiological investigations. GPs rightly defend the evaluation of atypical symptoms in terms of expecting the most likely cause first (for example an injury), with re-evaluation when the symptoms become clearer or worsen. For several patients a cognitive bias toward the original evaluation meant that the re-evaluation did not occur until beyond the optimal referral timeframe of three months from onset. Moreover if patients took a second opinion from an AHP or complementary therapist that IA was the cause of symptoms, these opinions were likely to be challenged by the GP and could negatively affect adjudications. Patients who could point to a family member with an IA found this was helpful in speedy referral to a rheumatologist. This situation however, was not universal.

CONFLICTING BELIEFS

Balancing conflicting beliefs and not wanting the patient to control the referral decision, but simultaneously taking seriously the patient's views requires the GP to balance referral factors (Espeland & Baerheim, 2003). The interpretation of the patient-centred model of health also impacts on GP adjudications. GPs can defer to patient perceptions and beliefs of the most beneficial treatments for IA, rather than providing encouragement for referral and ensuring that the patient is making decisions with information about rheumatology best practice in mind.

Rheumatologists also must negotiate patient beliefs and attitudes toward treatment options when advising on treatment. No patient participant rejected the advice to begin DMARD therapy at FSA, but by follow-up patients had begun to abandon treatment concordance partially or fully – ranging from neglecting the clinical tests regimen to completely stopping treatment. A quarter of patients had important side effects that had unacceptable delays in resolution. A lack of personal guidance, written material and information about where to go for advice are implicated in sub-optimal outcomes in establishing DMARD therapy.

Patients need clear direction about when to return for further evaluation if symptoms do not resolve (e.g., to return within a defined timeframe and/or on defined parameters about the progression of symptoms), as well sensitive advice on the potential consequences of deferring a visit if the symptoms are ultimately found to be RA. A call-back system for all patients who have been advised to return, and ensuring no cost for a return visit for the same complaint, could have ensured shorter gaps for return GP consultations, or for a patient discharged from a rheumatology clinic. Some GPs rely on diagnostic tests to ensure further contact with the patient, or upgrade prioritisation, but greater use of laboratory tests, although theoretically serving to increase the likelihood of return visits, may also increase the number of false negatives, especially of sero-negative RA patients, and further impede diagnosis if the GP places too much emphasis on these tests.

Patients and GPs display the same propensity for a quick, simple explanation of symptoms, but typically with different justifications. For the patient it legitimises the narrative and the delay in consulting. For the GP the time and cost implications of a

long appointment, with little probability of a serious condition being found, are reduced. Placing IA at the forefront of all but the most straightforward explanations for unresolved MSk conditions can be counter-intuitive for GPs without a rheumatological focus because the most statistically likely cause, in terms of presentation in primary care, is considered first. Sceptical questioning of the patient's story should be a manageable tactic during symptom evaluation to tease out more accurate diagnosis. Experienced, high referring GPs gave examples of using a wider context of the patient's general health and previous incidences of joint pain to change the evaluation procedure from one of accepting the patient's outline of events that led to the MSk discomfort.

OFFERS AND RESISTANCE

The offer of a referral to secondary health services can assume acceptance of that offer. Patients may resist offers of both referral and medication (Dixon Woods, Cavers, et al., 2006).

Referral for IA should begin, not with how a patient experiences symptoms, but with the imperative of minimising damage caused by uncontrolled disease. On this basis early referral to the correct specialist - a rheumatologist - is essential. A perceived low level of pain should not be a factor that diminishes the necessity to refer when an IA is suspected.

The GP has a responsibility to ensure the patient is knowledgeable about all resources that are available before acquiescence to a patient's beliefs about the disease and treatments available. The GP could work on the basis of ensuring the patient is aware that in a complicated condition like an IA, a GP is not the person best able to advise the patient about treatment options and outcomes.

Identifying a barrier as a structural or individual problem can be difficult, and often a referral problem will fall some way between the two points. That an individual GP might not telephone the WRRU to check on a non-response to a referral request is an individual failure, but to be unaware of the facility to telephone the WRRU to follow-up a delay in an FSA may reflect a structural weakness which could lead to a GP not having the information needed to successfully discharge a referral duty. Learning on

the job, through mistakes and bitter patient experience, rather than through training and information about the referrals process is no substitute for training and advice on evaluation and procedure.

RESISTANCE TO REFERRAL

Acceptance of an offer of referral was almost universal. All patients recruited from a rheumatology service had accepted the offer of referral in the first instance. One patient recruited from the community had declined referral despite a clear IA diagnosis and has continued to resist referral despite increasing pain, damaged joints and disability. Fear of social isolation and job loss are behind this resistance. Complexities in the integration of services and opaque communication between the patient and service provider can hinder patient interpretation of the choices available to them.

RESISTANCE TO MEDICATION

A more common form of resistance narrated by the participants was a decision to decline medication. GPs also spoke of patients refusing referral due to problems with the recommended treatment of IA with DMARDs. There were three reasons given by patient participants for resistance to medication: difficulty reconciling a perceived cause of IA with DMARDs (for example, a belief the IA is an infection could lead the patient to believe an antibiotic treatment would be more efficacious); fear of serious side-effects or experience of unwanted side-effects; and affordability.

Treatment concordance problems caused by beliefs about cause and fear of side-effects were resolved for some patients by improved communication over time with rheumatologists and administrative staff that led to more information and understanding of the disease process and how DMARDs work. Better management of side effects led to improved outlooks and less resistance to advice from the rheumatologist. For other patients, resistance to medication continued until increased disease activity and poor outcomes left little alternative. Several patients also lost faith in DMARDs because the efficacy was not re-evaluated after the 12-week period when maximum efficacy was expected. Long delays between rheumatology appointments led to continued pain, inflammation and physical impairment which was conceptualised as the treatment 'not working' rather than a requirement for

altered dose. These delays also affected patients' perceptions of the management of side effects that might be improved if consultation with the rheumatologist was more frequent.

Patients who take a non-conventional stance on treatment for IA tend to underestimate the potential effects of an IA, underestimate the side-effects of NSAIDs and overestimate the risk of DMARDs. Although couching their concerns in the language of medical proof, the exclusion of DMARDs when treating IA is essentially a values-based discussion, not a medical one.

An unappreciated problem with treatment concordance is the associated costs of rheumatology visits. These issues can lead to patients making strategic decisions to consult with their GP rather than a rheumatologist. Although the cost of medication is greater when sourced from a GP, this cost was offset by savings in transport, childcare and time away from employment.

Depression and anxiety are known to pre-dispose patients to non-adherence (World Health Organisation, 2003) and this resistance to treatment was extracted from the patient narrative. Patients who felt disempowered by their disease and in the treatment process struggled with the impact of an IA diagnosis and the lifestyle changes it imposed rejected offers of increased or supplementary treatments.

In summary, the themes of patient concerns about their rheumatology experience were accurate diagnosis, appropriate treatment, participation in their treatment, and the impact of IA and DMARDs on their work, social and family lives and wellness. To reduce these concerns the patient has to understand and agree with the decisions the GP and rheumatologist make, connect the decision with their personal health beliefs and agree with the treatments that have been advised. The quality of the decision-making and its patient-centeredness can be defined by how the needs, values and preferences of a well-informed patient are incorporated into decision-making implemented in the care pathway (Sepucha, Fowler Jr., & Mulley Jr., 2004).

LOCAL PRODUCTION OF CANDIDACY AND AREA VARIATIONS

The local conditions that affect health services may impinge on the interaction between GPs and patients (Dixon Woods, Cavers, et al., 2006). Both GP services and

rheumatology services have area variations. Good provision of low cost GP services in Porirua and Lower Hutt increases the likelihood that individuals with IA symptoms who live in these areas of relative social deprivation, will have minimal delays caused by system factors in their journey to effective IA treatment. Porirua has good public transport services, and primary care service providers who are aware of transport and appointment co-ordination difficulties and how to ameliorate the most desperate of these through SIA funding that can allocate transport services free of charge, and provide a care co-ordinator to provide encouragement, ensure treatment concordance and manage appointments for patients with chronic care needs. Wairarapa, an area with a substantial low-income population and critical GP shortages is also unfortunately, an area underserved by low cost GPs and rheumatology services, leading to the conclusion that system factors increase barriers to rheumatology care for individuals with IA symptoms who reside in this area. In this study, patients with low financial resources who indicated longer wait times between consultation and referral were from low income areas (Porirua, Wairarapa and Upper Hutt) although for the Wellington region in general, the undersupply of rheumatology services (Harrison, 2004) can affect the time available for rheumatologists to spend with patients and most definitely affects waiting times and appointment spacing. Waiting times and dissatisfaction with the service due to rushed consultations, long gaps between appointments and long waiting times to FSA increase non-attendance, which is significantly associated with the location variables of DHB, area, PHO and the clinic attended.

The research does not provide evidence that patients from particular areas are treated preferentially based on the area they reside or their demographic characteristics. A potential reason for this, aside from issues of ethics and GP integrity, is that GP practices are embedded in the areas they serve, and a high proportion, (more than 90 percent) of individuals have a 'home' GP, which makes an established, trusted, relationship likely. These high levels of enrolment have arisen from policy settings that established an enrolled population as a basis for funding.

Area does however, account for differences in service provision. These differences have created inequalities in access based on waiting times and potentially the spacing of appointments given the variations in consultation hours on a population basis,

with the Hutt Valley being the best served area and Wellington and Wairarapa the least served. These inequalities are partially mitigated in Wellington by the higher proportion of patients with private medical insurance. Insufficient rheumatology resources as well as the ideological setting for the provision of health services are implicated in this situation. DHB contracts evaluate the number of patients served rather than the quality of that service, as evidenced by variations in area waiting times and this leads, in particular, to increased risk of delays in diagnosis and treatment for Wairarapa and Wellington residents of lower socio-economic status. The area effects of uneven distribution of WRRU clinic hours across the region may also amplify the inequality of access for patients in the lower income, rural patients in Wairarapa, and to a lesser extent Porirua (given the proportionately greater clinic time at Kenepuru).

COLLECTIVE LIFESTYLES

The 22 patients who participated in this study provided a narrative that has been unpicked to open up a quite cluttered representation of access issues and barriers that delay referral to rheumatology care. In this discussion there are three main concepts that the Collective Lifestyles framework has exposed in terms of patient experience in relation to their social, cultural and financial resources (Frohlich, et al., 2001). Had utilisation models of access been used, these nuanced dimensions of experience may have remained hidden because they define the patient experience in terms of attitudes, behaviours (Aday, et al., 1998) and choice (Penchansky & Thomas, 1981). These concepts are: the setting of everyday experience; refashioned power relationships of shared decision-making and the strategic use of resources.

THE SETTING OF EVERYDAY EXPERIENCE

Participants reflected on their lack of knowledge of IA at the onset of symptoms. This unfamiliarity with IA was almost universal, even when close family members had an IA. This suggests a cultural or social barrier to the expression of physical pain, even when disablement is clear, and social sanctions about the management of physical pain and infirmity. Decisions to call on medical advice for non-urgent MSk pain are guided by a logic that has been internalised through 'rules of conduct' that guide

social order (Dixon Woods, Williams, et al., 2006). These decisions are also set in a 'field of play' in which the individual decisions are created and re-created in relation to their place, with the financial, social and cultural resources that are available to them. In other words, decision-making is set in a cultural and social milieu rather than being individual practices (Frohlich, et al., 2001). It is inevitable that at least some individuals will draw on ideas of causation from this social milieu that will conflict with the medical model of symptom causation. Subjective experiences that lead to conclusions about onset also feature strongly in the notions of how to progress to wellness once symptoms have developed (Lawton, Peel, Parry, Araoz, & Douglas, 2005).

Decision-making about how to deal with MSk disorders is embedded in social and cultural practice (Fraenkel & McGraw, 2007). The outcome of these practices can be delayed medical intervention and problems with treatment concordance, with two main factors highlighted in patient narrative. These factors are the belief in continuing everyday activities without reference to pain and infirmity until it can no longer be avoided (the main reason for delay for participants with a cultural sense of physicality), and a belief in taking responsibility for holistic and preventative health management and refusing to medicalise the symptoms of MSk discomfort. This second factor was expressed by well-educated participants (a form of cultural capital) with good access to financial resources.

POWER RELATIONSHIPS

There is a 'practical consciousness of decision-making' that involves a taken-for-granted internalisation of the relationships between the individual and structural authorities (S. J. Williams, 1995), such as medical professionals. This taken-for-grantedness results in the patient accepting decision-making about care choices by a medical professional without challenge. This decision-making process is inherent within the traditional biomedical model of professional decision-making about impairment and disease (S. J. Williams, 2000). Participants from lower income communities and men, more generally, were comfortable with this mode of decision-taking.

The ideological underpinning of shared care is that increased patient empowerment will lead to improved healthcare through independent, proactive participants making informed decisions, however increasing patient empowerment may not lead to more effective care pathways in chronic disease (Lawton, et al., 2005). A more patient-centred determination that incorporates medical and non-medical health care objectives is important to patient well-being. However, in reality, deferring to patient choice about how this care should be approached fails to take into account that there will be information gaps in patient decision-making, i.e. that patient choice may have only the illusion of *informed* patient choice. In this iteration of shared care, the medical professional does not bear responsibility for fully informing patients about their most effective treatment options. Partially informed patient choice is an important barrier to DMARD treatment for higher socio-economic participants who valued non-medical intervention ahead of pharmacological solutions, and in these instances the power relationship between the structural authority, that is the health professional, and the agent (the patient) who is reproducing a practical consciousness of decision-making made with reference to social, cultural and economic resources, has not been resolved. Instead, there is only a sense that appropriate decision-making has been transferred to the patient when in fact it is only the *responsibility* for decision-making that has been transferred.

The participants who declined DMARD therapy took on this responsibility and framed it as choice, despite the outcomes of that choice not being fully known, often because to the lay person, side effects are not easy to put into perspective. An interesting proof of concept study in a US outpatient clinic suggests individuals may be more risk averse when agreeing to treatments if there are risky side-effects. The study included 59 participants who viewed a video detailing the introduction of new medication with a serious side effect. The video was designed to test whether increased patient participation in decision-making about risky treatments altered the participants' likelihood of accepting the risky treatment. The study found that perception of choice about treatment options can lead to greater risk aversion - increasing concerns about treatment side-effects and decreasing agreement to accept the treatment. It is not clear if this effect is restricted to patients who are unprepared for involvement in treatment decision-making (Fraenkel & McGraw, 2007).

Improving communication skills and interpreting a patient-centred approach in a manner that increases control for the patient, but reduces their responsibility for the exposure to risk may be an important factor in improving the willingness of newly-diagnosis individuals to accept DMARDs (Nordgren, van der Plicht, & van Harreveld, 2007).

STRATEGIC USE OF RESOURCES

Barriers to accessing rheumatology care impact severely on patients with multiple aspects of vulnerability, (Grabovschi, Loignon, & Fortin, 2013) despite direct journeys to GP and then rheumatology care. These patients spoke of the multiple signifiers of vulnerability they were dealing with, and that many health care professionals are all too familiar with, as impediments to early treatment. These impediments included multiple chronic diseases, poverty, low social capital, family stresses, precarious working conditions (casual work contracts with short notice working hours and no facility for negotiated appointment leave or sick leave). Frohlich and colleagues, when discussing health disparities (2006), describes a 'health chasm' between vulnerable groups and the general population, where not only are the vulnerable lacking sufficient income to meet their health needs, they are also living in conditions that exacerbate poverty - suburbs with insufficient public services, such as public transport and affordable primary health care. These vulnerable individuals, while attempting to access public rheumatology care, are faced with administrative demands from health services that are subject to tight budgetary targets. The result is that, instead of facilitating care, substantial barriers are created for patients due to fixed appointment times, rescheduling of appointments at short notice and a policy of refusing to offer appointments after two or more instances of non-attendance, without consideration of the circumstances that may have led to the non-attendance. Vulnerable patients in this research describe the strategic use of their resources in ways that make sense to them e.g., sourcing prescriptions from GPs instead of rheumatology services, and being selective in accepting offers of appointments, to take into account the costs in resources like time, social networks and lost income. That is, they do what they are capable of, given their fundamental needs and resources (Frohlich, et al., 2001; Sen, 2004). These strategies are not necessarily

obvious to health providers. Rather it is the results of such strategies which are evident: poor treatment adherence and non-attendance and rheumatology services.

COMMENT ON FRAMEWORKS AND METHOD

The opening paragraphs of this thesis described idealised scenarios of a person who recognised the symptoms they were experiencing were worthy of early medical attention and contacted a GP. The GP then recognised these symptoms for what they were and made a timely referral to a rheumatologist who prescribed DMARDs and other appropriate treatment - and all this within a small window of opportunity that might enable a drug-mediated remission. The structuring of people's health-related chances and choices affects the way they begin their healthcare journey, and this is informed by normative beliefs and knowledge about health that are culturally determined and entwined with financial and social resources (Abel, 2007). A conceptual basis for the study that incorporated these beliefs along with the resources patients require, the effect of the places they inhabit in their everyday lives, and the power relationships they encounter, enabled the focus for the study, however an inductive approach would likely have yielded similar themes. It would be an interesting exercise to re-evaluate the narrative data with a grounded theory approach. A deductive framework however, more readily allowed for organisation and explanation of quite diverse themes. The Candidacy Model contributed essentially in pinpointing barriers, establishing where to seek explanations, and in suggesting solutions. Its thorough development process through the NHS Service Delivery Working Group allowed for intensive investigation and reflection on the context of access to health care for vulnerable groups. Given the emphasis on the context of the patient experience, a Collective Lifestyles approach was immediately recognised as an apt choice to investigate the process of "the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services" (Dixon Woods, et al., 2005, p. 6). A relational approach places health in a context that considers "multiple scales of contextual influence of place" that directly focuses the inquiry (Dunn & Cummins, 2007, p. 1821). Collective Lifestyles views these elements in a wider setting which more readily incorporates relevant relationship information (for example, themes around GP-patient) into the study that only marginally reflected place. Was this choice of

frameworks successful? Collective Lifestyles was developed in a health promotion setting. This is the first instance I know of where it has been used to examine access to a health service. The Collective Lifestyles framework allowed the circumstances of peoples' lives to be investigated without ascribing values based on the characteristics of the people themselves. An important aim in this research was to move away from judging by social and demographic characteristics toward a better understanding of how beliefs, opportunities for engagement and constraints impacted on care pathways. The framework incorporates the availability of social, cultural and financial resources and places them in the context of people's lived experience, which is consciously related to the places they live and move through. It successfully allowed for development of themes about how people make sense of, and use these resources in ways that may surprise service providers. It also enabled an exploration of power relationships and access barriers, but all of its components were not fully utilised. This probably reflects the tensions of interdisciplinary study, and perhaps these could have been managed with more clarity at the outset. However this process in itself was a valuable learning experience.

The use of qualitative methods is appropriate for reflecting the perspectives of people who are the recipients of policy and practice, especially when research into how policies and practices impact on the recipients is an early phase of the research journey. However while the patient story is the crux of the thesis, it is important to provide contextual framing and this requires some quantification. A relational approach would have strengthened the analysis of "the processes and interactions that occur between people and the social and physical resources in their environment" (Steven Cummins, Curtis, Diez-Roux, & Macintyre, 2007, p. 1835). The research was in many ways, a participatory process in providing research space to highlight the concerns of fellow travellers on the path to successful management of IA. Belonging to the group which was the subject of the research enabled connections with each participant, even though lifestyles varied. A concern which I keenly felt, was working outside my own ethnic groups. Not because the participants worried about this, but because I was aware of the lack of embeddedness in cultures other than my own NZ European background. However drawing on shared experience of class and the graciousness of the participants made this an enriching experience. A

deeper engagement with participants would not be possible without some experience of their journey. The unstructured heuristic approach to the interviews was, in a sense, not tested because I 'knew' the patient journey. Although these points may be criticised as reducing rigour in the interview and evaluation process, the deductive process does eliminate bias in the evaluation stage (Bitektine, 2008). Additionally, the participants' journeys were clearly not my own relatively straightforward journey from onset of symptoms to evaluation, referral and treatment within the bounds of strong social support, adequate financial resources and health-affirming engagement with medical practitioners within a place where my own physical and cultural barriers to healthcare services could readily be negotiated.

STRENGTHS AND LIMITATIONS

A strength of this study is the breadth of the investigation of the patient journey from onset of symptoms until the establishment of DMARD treatment. The use of a contextual framework uncovered reasons for delays in the patient journey based on participant beliefs, resources and the Collective Lifestyles of the social and economic groups they belong to, and in the areas in which they live. The research enabled the patient voice to describe how perceptions of symptoms lead to delays in care and to identify hidden barriers that increase the circumstances around treatment concordance and non-attendance at medical appointments. This research adds to the body of work investigating perception of MSk illness and attitudes toward care, by providing insights from a diverse region with distinct areas of cultural and social variation that affect both the interpretation of symptoms and patterns of help-seeking. The study reinforces the view that there is no over-riding pattern of delay in health care. Social and cultural input, patterns of deprivation, consumer models of healthcare decision-making, fragmented provision of MSk services and the geographic provision of rheumatology services are all important factors in delays to effective care for IA. This lack of consistency in the reasons for delays underscores the need for a multi-factorial response to meet the goal of improving the delay from symptoms onset to effective treatment and well-being for people with IA. The qualitative data may provide a basis for targeting and enabling higher resolution quantitative modelling to assess the importance of the participants' experiences.

The study has found the knowledge New Zealand GPs have about IA is variable. The significance of experience as a predictor of patient referral, allows for some consideration of the style and quantity of training GPs receive in formal medical education. That barriers exist between GPs and patients is not new knowledge, but how these barriers present themselves in a New Zealand setting suggests that a structured ongoing process of improving GP and patient education about IA symptoms and treatment options will lead to improvements in timeliness of referral.

A shortcoming in this research is that it did not obtain an understanding of the skill of a GP in carrying out a physical examination of inflamed joints. There is little research available that deals with GP competency in physical examinations despite a squeeze test, for example, being one of the more accurate methods of detecting synovitis in hands and feet (Emery, Breedveld, et al., 2002). "Early Arthritis: Early Act" is an initiative that is a collaboration between GPs and Rheumatologists in France to improve GPs detection and referral rates in early IA. This programme is also one of the few to tackle the ability of GPs to perform a physical evaluation of a painful joint. Before the programme only 19 percent of GPs were able to perform a squeeze test to detect EIA whereas after the programme 81 percent of GPs were able to perform this test. GPs were also more aware of national EIA guidelines, the impact of RA on life expectancy and a better understanding of "the window of opportunity" and that remission was achievable (Fautrel, Froger, Gaujoux-Viala, & Leutenegger, 2010).

SUMMARY

Although a broad range of patient experience was predicted from purposive sampling, the patient journeys proved to be unexpectedly complex. The context of everyday lives, experiences and histories is the basis for building a narrative around symptoms of (dis)ease. For a previously well person, medical encounters feature only minimally in the conceptualisation of symptom cause and progress (Lawton, et al., 2005). Only one-third of the participants had a direct journey from onset, to referring GP and then to a rheumatologist. Journeys to rheumatology ranged from six months to more than 10 years. Individual delays could be attributed to decision making at a particular phase in the patient journey, but overall the main cause of the delays could not be directly apportioned to the onset phase, the evaluation delay or referral delay.

The ideal scenario of rapid consultation with a GP, fast identification of IA and immediate referral was unusual. Access to health care is often attributed to problems associated with individuals who have particular social, demographic or economic constraints, with the implication that members of that group are wholly responsible for the issues they face in timely healthcare because they inherently tend to behave in a particular way (Bourdieu, 1977; Frohlich, et al., 2001). Certainly, the reasons for delayed access varied by gender, and social and financial status but the resources available to the individual were important modifiers of the patient experience.

Participants from areas of social and economic deprivation were affected more readily by local operating conditions where GPs were under pressure from longer lists that resulted in less timely and/or shorter consultations. Often patient circumstances and the health, social and employment settings combined to produce delays. The relationship between the location of health facilities and transport affected decision-making about treatment in rural and semi-urban areas. The administrative data indicates that area differences do not significantly affect referral rates, however discourse from participants with lower socio-economic backgrounds or cultural differences between them and their GP indicated conflicts in expectations of each other and longer evaluation and referral delays. However, there were exceptions to any generalisation that people from areas of higher socio-economic status would have a smoother and faster path to referrals. Participants with strong beliefs about symptom onset, treatment options (notably methotrexate) and poor matches in models of health and wellbeing, were affected by appearance at a health services and adjudications that could complicate referrals pathways.

There were strong gender differences in the negotiation of barriers to appropriate care. Males most often described cultural sanctions on the expression of pain and refusal to consult about symptoms until they could not perform valued employment or leisure activities. Women more often mentioned pain alongside reduced ability to perform valued activities as a reason for consultation. Higher income women also more often consulted an AHP rather than a GP about MSk symptoms, although this consultation was often done because it was perceived to be a cheaper option than consulting a GP. Once contact with a GP was made, women more often (although not universally) spoke of a referrals path to rheumatology complicated by delays and

preferences for non-medical interventions. It is notable that the two participants with the most enduring impediments to continuity of care after diagnosis were of different ethnicities and different generations, but were both low income women enrolled in the lower-resourced IPHOs and had family responsibilities and unstable family support. Neither were offered, or eligible for, extra assistance to encourage attendance, assist with family duties or to assist with the extra financial burdens that a chronic illness incurs.

The processes and interactions that occur between people and places over time may be more important to health outcomes than the compositional make-up of a place. How social and political constructs in place affect health journeys for people with similar needs requires an analysis of not just the political decision-making that has led to differences between the provision of public services in place, and allocation of funds in the public and private health spheres, but also the commercial decisions that affect the location of private services (S. Cummins & Milligan, 2000). For example the location of private hospitals in areas of the highest population densities, with higher incomes and medical insurance rates (Wellington) or in a rheumatology 'hub' in Lower Hutt that enables specialists to move more easily between public and private clinics, rather than necessarily assisting accessibility for patients. The conceptual shift toward working within the context of the lives of people with IA should be welcomed in rheumatology because it contributes to an understanding of everyday experiences that impact on communication, symptoms disclosure and treatment adherence. The competing factors of paid employment, family commitments as well as material and financial constraints can be integrated into an understanding of healthcare constraints and planning for future care that makes sense to the individual negotiating barriers to effective treatment (Lawton, et al., 2005).

The policy setting of wider health objectives by government emerged as an important factor in access differences for people with high priority health needs. Evidence that the implementation of PHOs has improved the utilisation and health outcomes for Māori, Pacific peoples and others in socio-economically deprived areas is to be applauded. However, the NZHS (2006) indicates unmet need for GP services in people with higher income and educational status; and warnings have been sounded about the access to health service for high priority individuals living outside of high

deprivation areas (Barnett & Barnett, 2004; Cumming, et al., 2008; Cumming, Stillman, Liang, Poland, & Hannis, 2010). This research provides evidence of barriers to early, effective rheumatology care for both of these non-prioritised groups. In addition, despite rural areas being assigned health priority status (Panelli, Gallagher, & Kearns, 2006), it is difficult to provide a timely, easily accessible service within the constraints of the current policy paradigms. The cost of GP visits, efficiency drives in public health services and fragmentation of primary and allied care services that are part of the consumer choice and privatisation models of health care that are currently part of the health policy mix (Barnett & Barnett, 2004; Barnett & Barnett, 2004; Quin, 2009) are implicated in these barriers.

RECOMMENDATIONS AND FURTHER RESEARCH

This chapter concludes by advocating for the integration of public health initiatives, IA education for GPs and patients, rheumatology care and well-being assistance to lessen the stress and uncertainty of an individual during onset of symptoms and then later with newly diagnosed patients and their families. The co-ordination of care may empower patients, increasing their potential to cope more easily with the realisation that they are living with a chronic disease with potentially serious outcomes, to understand the implications of IA for their everyday lives and enable them to employ strategies and treatments that improve their chances of lessening the disease impact on their bodies and their world.

Although this is a small, exploratory investigation, several themes that compared well with international research have been identified for further investigation. These are set out below.

PUBLIC INFORMATION

Improvement in the availability of information in the community and among healthcare providers about IA diseases and treatment and outcomes is vital to improve patient knowledge of the condition, and the options that are available to moderate the disease course. It is recommended that further research is done to

- Identify methods of integrating IA information into existing public health campaigns
- Assess means and benefits of educating patients and providing them with copies of referrals paperwork and results of clinical monitoring
- Present information to patients on the benefits and side effects of drugs
- Evaluate role of, and formal recognition for Arthritis New Zealand educators

Further, to improve participation in decision-making, the following could be considered:

- Dialogue with sports therapists and AHPs such as podiatrists, physiotherapists and osteopaths to increase awareness of IA
- Evaluation of the costs and benefits of a public education campaign to improve identification of IA in the community
- Advice to patients on trusted websites
- Copies of rheumatologist letters to GPs sent to the patient

GP DECISION-MAKING

Appropriate referral to a specialist public service is of crucial importance to ensure timely patient treatment, but also to ensure the best use of health resources. There may be a fine balance between ensuring timely assessment of a patient with MSk symptoms that are similar to those of a possible IA, and symptoms that are probably an IA. Referrals data suggests that GPs require more information about what an appropriate referral is, and to be clear on the referrals process. How to manage this transfer of information from rheumatologists to GPs is problematic and GPs in this study expressed a collective point of view that reading materials are unlikely to be utilised. In lieu of providing GPs with additional information an evaluation of the topics, quality and reach of the CME programme could be undertaken. More directly, methods to advise GPs of likely waiting times at each clinic and encouragement to refer to the least busy clinic, where appropriate, could be considered.

APPOINTMENT BOOKING, AUDITS AND TRIAGE

Several improvements to the appointment and triage processes have been implemented since this research was started, They include refining the triage process and expansion of the electronic booking system. The administrative data used to analyse non-attendance and waiting times suggests also:

- An audit of the triage system for gender bias
- Monitoring of waiting times by area as part of the service level agreement
- Reassessment of contact procedures with patients when confirming appointment scheduling
- Understanding the beliefs about, and effects of, appointment timeliness for groups at risk of non-attendance could be a productive line of inquiry.

CONTINUITY OF CARE

- Investigate an accredited referrers scheme for MSk practitioners – physiotherapists, osteopaths and podiatrists in the first instance
- Investigate methods to improve communication between rheumatologists and GPs
- Explore the feasibility of establishing early arthritis clinics to facilitate speedy referral that may also include the development of a process to create more flexibility for appointment times, or ‘walk-in’ clinics to take into account employment, childcare and transport limitations

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REPORT ON POST-DIAGNOSIS EXPERIENCE

INTRODUCTION

Finishing the patient journey at the door of the rheumatologist's consulting room does not quite complete the patient journey to appropriate treatment for an IA. The communication to the patient of what their diagnosis is, the treatment options and regimes, what these mean to their everyday life are all potentially interpreted and understood in ways that the rheumatologist may not expect, or find difficult to manage in a style that ensures on-going medical care, support and treatment adherence.

Treatment adherence is undoubtedly a significant focus of rheumatologists' concern, but the patient expectations of their rheumatology consultation and the presentation of treatment options can impact on their acceptance of DMARDs, and on the adherence to treatment. The World Health Organisation advises that when long-term therapies are prescribed, patient risk of non-adherence should be assessed and monitored as part of the initial and follow-up consultations (World Health Organisation, 2003). Patients have wider-ranging concerns than this narrow focus on treatment protocols and, if these concerns are met by the rheumatology service, they may be better enabled to cope with their IA. Although unmet needs may not influence the clinical outcome of the disease they may improve the ability to cope with a chronic disease and the associated long-term medication, as well as the desire to continue these treatments.

Access to IA treatment is not simply about access to DMARD therapy. Rather, it is also about access to resources that enable patients to correctly understand their treatment protocols and associated procedures, to cope with their illness and to get the assistance they need to deal with the physical, social and personal impacts.

This report aims to set out examples and explanations for patients' rejection of DMARDs as a treatment option and reasons for poor adherence to DMARD treatment protocols. An important objective is to present patients' assessments of their needs, highlighting those that are not met, particularly at the beginning of their IA

treatment. This is done using patient comments about their experience, and also by focussing on the narrative of one patient, Louise, who articulated concerns about disease and treatment management that were commonly expressed in interviews.

RESISTANCE TO DIAGNOSIS

No patient participants were surprised by the confirmation of their IA diagnosis at their rheumatology FSA, as by that stage their medical practitioner suspected IA or had made the referral to investigate symptoms that the participant already believed were IA-related after an, at times complicated journey to the rheumatology clinic (Figure 47). For the 21 referred patients, the rheumatologist confirmed the type of IA and introduced the concept of a life-long chronic disease which could be controlled with medication. Two patients resisted their prognosis, the first in the belief that the condition was not chronic, because previous inflammatory flares had come and gone, the second on the grounds that the IA was symptomatic of a more holistic illness, rather than systemic inflammatory joint disease (Table 37).

Table 37: Resistance to diagnosis

Participant	Non-acceptance of prognosis
Kim	“Right at the beginning I said I want to find out what this [IA] is. You know we must be able to treat the underlying thing, the underlying cause to get rid of the symptoms and basically when I said that to the specialist [the response was] ‘it’s too late for that anyway’. So, you know, it doesn’t give me a lot of hope or respect for the whole medical profession basically. And I have to say I didn’t have a lot to start with.”
Patrick	“My relapse [from a previous diagnosis of ReA] at that point wasn’t particularly severe and hadn’t lasted particularly long, I had no reason to believe that [the IA] wouldn’t perhaps go away by itself.”

Despite leaving the FSA with a prescription for DMARDs, both patients rejected the rheumatologist’s advice of methotrexate to arrest the disease. For Patrick and Kim there was a poor fit between their constructions of their disease, their personal health beliefs that affected their concept of appropriate treatment and in their opinion, the quality or delivery of information they received at their FSA.

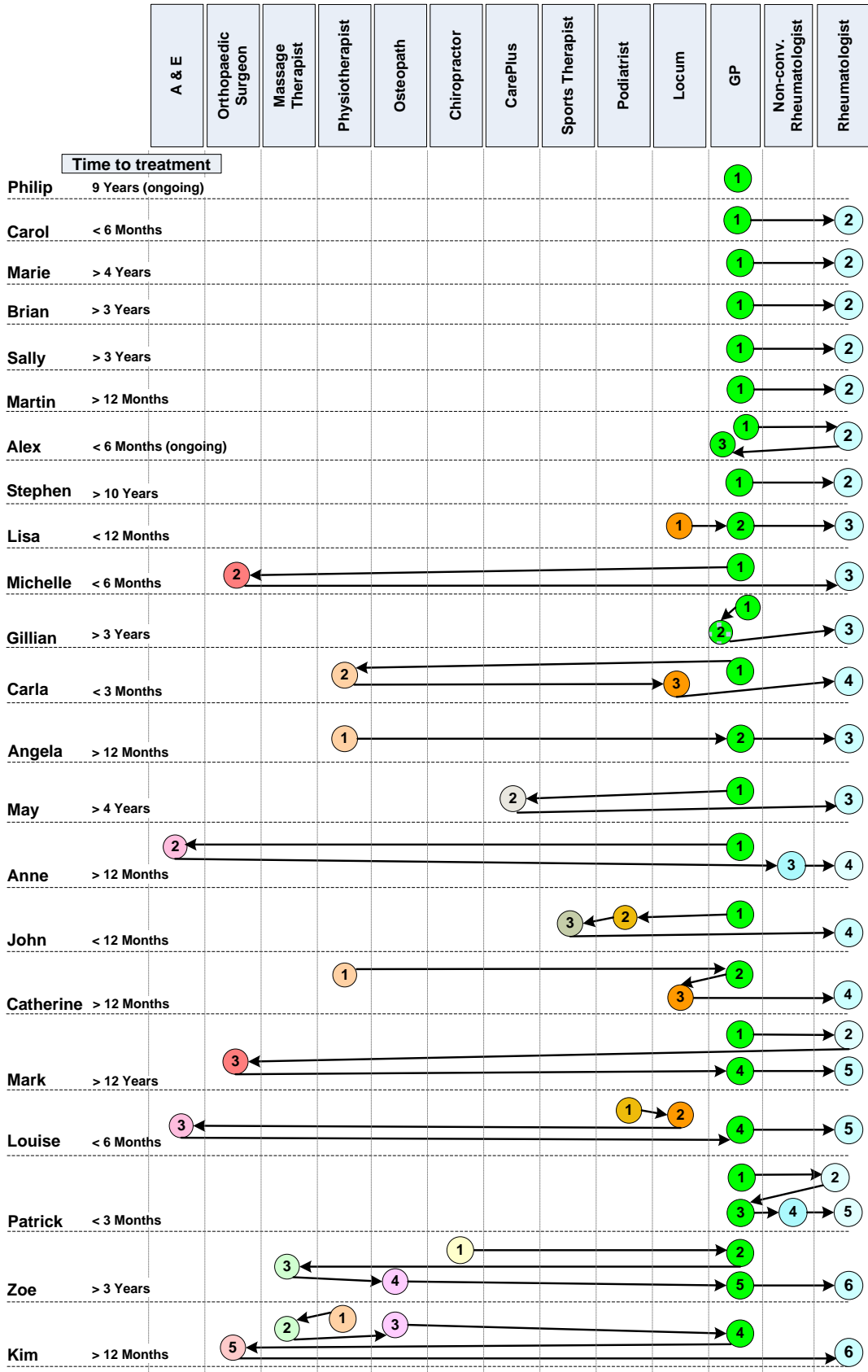


Figure 47: The patient journey

From identification of candidacy to referral to a rheumatology service, and implementation of DMARD therapy.

Patients who identified with a physically strong, active culture (that initially delayed help-seeking), often easily accepted DMARDs as a pragmatic approach that would allow a return to their usual activities as quickly as possible. The decision is also based on trust, with information from the same rheumatologist being interpreted in entirely different ways depending on the patient's approach to health issues. Patient participants accepted the advice on treatment because they believed the rheumatologist was the person with the knowledge they needed to get them physically able again (Table 38).

Table 38: Pragmatism and trust in IA diagnosis and DMARDs advice

Participant	Pragmatic Response to Diagnosis and Treatment
John	"I went to [a Sports Doctor] and she diagnosed it pretty much in about 10 minutes. She said you've got rheumatoid arthritis. Just like that. Bang. So that's where it started. She put me in touch with [a rheumatologist] Yeah, so we started on all the treatments there were... I really think [the rheumatologist] goes out to bat for patients, well and truly, I was more than happy and there's stacks of information there. [I got] straight facts about what was going on and the treatment and side effects, and I was more than happy with that."
Zoe	"My GP said I'm going to refer you to the best person there is. He referred me as a private patient and I got in to see him very quickly. Like within a couple of weeks. And I've been wonderful since. [I was Diagnosed] very quickly. He put me on a cocktail of drugs which I'm on still. I'm still on basically on what I started on – methotrexate, salazopyrin, naproxen and folic acid."
Mark	"There's no cure for it, so you've got to put up with it. And that's all there is to it. As long as you're sort of – it will probably be next year before I come back here... It was nine months since the last one. So um there still won't be anything that they can do so I've just got to keep putting up with it."
Carla	"And [the rheumatologist] very quickly got it under control. I went on the methotrexate... I've heard that [this rheumatologist] is the best – clinically the best – so I talked to my doctor. And also my friend he had it and he'd been to see different people and said [this one] was the best – an aggressive treater and that's what you want... I don't want to end up in a situation where someone is totally wishy washy and you're not confident in the information that they are giving."

Rheumatologists expect DMARDs will have a significant effect on IA symptoms within 12 weeks of beginning therapy and at this point can be modified with an increased dose and/or the addition of other DMARDs to improve results (Singh et al., 2012). This requires patience from the patient and adequate pain relief (corticosteroids are often as a bridge) until DMARDs control the IA. Despite the pragmatic response from patients that led to a straightforward acceptance of DMARDs there is a hint of an important problem in Mark's outlook. Patients may continue to take medication

without review at 12 weeks and with sub-optimal results. WRRU patient participants had considerably longer waiting times between FSA and follow-up appointment, with half of patients waiting six to nine months, than patient participants from private specialists who were all seen at a follow-up three months later.

The early phase of implementation of DMARDs is an acknowledged problem that is partially ameliorated by telephone contact with the Nurses Clinic at the WRRU. Not all patients from the WRRU are referred to the Nurses Clinic, and only two of the WRRU patient participants used this service. The Nurses Clinic is better resourced early in the week, and patients are told to call then and not to delay help-seeking for longer than a two or three days if they have a worsening condition, but patients are more likely to become anxious at the end of the week because specialist assistance is not readily available during the weekend (Staff 1).

“[The rheumatologist] said, ‘if there is any problem ring the nurse at Hutt hospital’, and he gave me a number and that. So I rung there and got an answerphone. So I left a message. A week later I still hadn’t heard anything, so I rung again and left another message and it was another three days before they got back to me. Well I thought that was a bit rough. And I sort of wanted to know what to do about these pills.”

Mark

Gaps in care also appear when the WRRU is closed. Patients with IA flares may find obtaining treatment problematic:

“I had a flare up – a beauty flare up and I rang my GP [in Wellington] and they said just go down to Kenepuru and get an injection they’ll give you one. And they wouldn’t even give it to me. They said you’ll have to go over to the Hutt. I said the unit is closed over there, they said no, no you can go to A&E in the Hutt. Once again [driving] around, and they said ‘oh no your GP should give it to you’, but I’ve asked [the GP] they said ‘oh no we don’t keep it here’.”

Anne

The WRRU staff have at times, limited options for patients who are having problems with medication and symptomatic control of their RA outside of the usual appointment cycle, and an estimated three out four calls are negative toward the provision of treatment, with a noted increase in the levels of stress of patients in recent years (Staff 1).

BARRIERS TO TREATMENT CONCORDANCE

Concordance refers to the “anticipated outcome of the consultation between doctors and patients about medicine taking, if both parties can be encouraged to work together as partners” (Pound et al., 2005, p. 134). Despite the majority of patient participants having a pragmatic approach to DMARD therapy, the agreement to use DMARDs for the management of IA can be a complex decision for some patients. To make an informed decision requires an understanding and acceptance of diagnosis and a clear understanding of the significant benefits of the therapy compared with no therapy, and weighing of the side effects, and as the patient narrative emphasised, at disease onset most patients were unaware of IA or the potential impact on their lives. Four patients had found information about IA and its treatment from sources that led them to emphasise the negative impacts of DMARDs and not fully recognise the severity of the IA, so they were not receptive to a recommendation that they begin DMARD therapy, particularly if they felt uninformed of the benefits of DMARDs, unsure about the prognosis for their disease, or their concerns were dismissed by the rheumatologist (Table 39).

Table 39: Patient reasons for refusing prescribed DMARDs

Participant	Comments rejecting prescribed DMARDs
Patrick	“So initially my consultation at Hutt hospital wasn't wonderful. They didn't explain anything to me about the effects. They got me to get a blood test and they sort of sent me out the door with a prescription and it was up to me to read up about it on the internet and I realised that this was a quite significant decision to be making and at that time I wasn't severely ill. I thought that was kinda using a sledgehammer to crack open a walnut so to speak, so I went and saw [a rheumatologist] who is a fan of the long term use of antibiotics. So for a long time I persisted, sort of, one way or another down the antibiotic avenue... So I wasn't really to know what there was at stake... [Subsequent] damage to my heart is from inflammatory processes. I paid a heck of a price for my stubbornness.”
Kim	“But I took the DMARD and I can't remember how many days I took it for, and I started vomiting and I just thought I'm not taking it. It gave me vile headaches and all sorts of stuff... so I just thought my body is reacting to it so I stopped that. So I'm a bit stuck either not being happy, or it being forced on you to take the drug treatment thing and not being able to find something that genuinely is that helpful... and I can't accept it mentally anyway... [the Rheumatologist said] there is no cause of the arthritis, no other treatment, or alternative treatment that will make any difference. And I don't believe that.”
Marie	“I work with two people who have been on methotrexate and it didn't work for them... I had heard people at work talk about methotrexate and some of the nasty drugs, you know injections into bone and I'm 'ahh I can't go into that' so it was probably more my,

Participant	Comments rejecting prescribed DMARDs
	I probably caused myself more pain than anybody else.”
Angela	“At [diagnosis] I wasn’t medicated, I didn’t ask for medication or seek it really, or feel that I needed it – typical really of most new Zealanders I suppose – that’s what [the rheumatologist] said, a lot of New Zealanders are very much anti-drugs, we wouldn’t touch them.”

Two of the three patients who made a decision to avoid DMARDs because of side effects eventually relented (Table 40). Marie had previously had cancer treatment and wanted to avoid ‘nasty’ drugs. Patrick had an episode of IA that resolved without DMARDs and assumed his latest flare would do so as well. The reasons for agreeing to try DMARDs, over timeframes of six months to two years, were quality of life (physical incapacity and pain) and life-threatening complications from uncontrolled IA.

Table 40: Reasons for accepting DMARD therapy after initial delay

Participant	Reason for accepting DMARDs after initial delay
Marie	“I got to the stage where I couldn’t get out of bed. I couldn’t get my shoes and socks on... I had no quality of life. The drugs have done wonders... They gave me a shot, I don’t know what was in it but it was great, and then they started the methotrexate and it was all uphill from there. It was just marvellous.”
Patrick	“The reason I’ve gone back to trying methotrexate now is that nothing that had been working has worked with it... A good incentive for me to find out the methotrexate effects this time around is I can’t afford to have any operations on my heart. That’s far worse and far more likely than any side effects listed under methotrexate.”
Angela	“But I started on them last year. Salazopyrin, yeah just because I kept getting a few sort of flare-ups, I suppose, where I was getting quite sore in sacroiliac joint and, you know, just moving I generally had a bit of neck and back trouble.”

Side effects of DMARDs are the primary concern in the evaluation of treatment options. This is an emotive issue without guidance and reassurance from medical advisors. Patients complained about leaving the FSA without their concerns being addressed, or even asked about. Their primary sources of information in these situations were confidantes in their social circles. All but two participants used medical or topical websites to help with their decision-making about treatment and three participants found drug information leaflets from their local pharmacists. This information tended to increase rather than allay concerns about complying with treatment recommendations; the reasons given for this were that side effects of pain

relief medications were known, compared with the unknown of DMARDs, and because the type and likelihood of side effects were not conveyed in a manner that resonated with the patient. These factors were especially important when the participant expected IA remission, which tended to lead them to discount the long term effects of NSAIDs and steroids.

“I guess it's the known nature of steroids that make me feel a little more relaxed about taking them rather than methotrexate. It's the sort of things you know are going to happen probably. They don't sound too horrible, whereas with methotrexate the things that might happen they sound awfully bad, you know? What they could almost do on the drug information leaflets is increase or decrease the font size with the likelihood. You look at them they're all the same size - I'm joking - but somehow they are all the same, you put the same sort of weight on them.”

Patrick

Although patient avoidance of DMARDs is of great concern, in this study it was not only patients who preferred to omit DMARDs from treatment plans. A consulting rheumatologist who did not follow orthodox treatment protocols treated two patients in this study with antibiotics and steroids rather than DMARDs – one patient had made a decision to avoid DMARDs and another who inadvertently made a self-referral to this rheumatologist after failing to secure a GP referral to the WRRU (Table 41).

Table 41: Patient comments on rejection of rheumatologists' offers to treat

Participant	Comments on DMARD implementation and adherence
Patrick	“I think that the fact that it didn't seem like such a concerning - it wasn't that bad at the time - combined with the fact that I didn't get particularly good information, combined with the fact that methotrexate does have significant side effects, combined with a slight wariness of medication in general, led me to think I'm not going to go down that route at that point in time. and then possibly I persisted too long with the antibiotics, the alternative course, probably because I had good results with them... prior to [heart valve damage] I would have told you that I had done exactly the right thing. Because at that point in time I was in complete remission and could to what I wanted with my life and was doing that, taking low dose antibiotics once or twice a week with next to no risk of side effects. I was feeling fine.”
Anne	“[The rheumatologist] gave me high dosage of prednisone and antibiotics and I'd see him every couple of months and I would have more antibiotics and more prednisone and he said to me start coming off the prednisone... Every time I went he'd say we'll get you off the prednisone. I'd get down to a certain level and I'd have a complete flare up and I'd be back to square one, and again, back on the high dosage... I'd say 18 months to 2 years I was going to him.”

Only one of these two patients made a deliberate choice to pursue a non-conventional treatment plan for his IA. The other mistakenly assumed the treatment she was receiving was established rheumatology treatment. It is unclear if GPs fully appreciate the unorthodoxy of this treatment when referring patients. Data collection indicates that at least eight GPs referred to this rheumatologist¹⁸.

“It's kind of like a path dependency, once you've committed yourself, I suppose ideologically, to change tack again is kind of akin to admitting you were wrong.”

Patrick

Failures in communication between patient participants and their rheumatologists can lead to missed appointments and poor treatment adherence. Brian only had appointments every nine months, cancelled appointments that stretched the delay to 12 months, in addition to frustrations boiling over:

“[the rheumatologist and I], we didn't click. He wouldn't even look me in the eye and that was really frustrating because like I said I only had one crack [an appointment] once a year. And then I had a lot to ask and all that, and he didn't really communicate very well, and so him and I didn't get on... It was kind of in once a year for 5 or 10 minutes then out again, a new script – but I never knew any better aye mate, I was probably me own worst enemy, I should have done a little research myself, but I didn't. I don't know, I suppose I needed somebody to blame... I had questions for them but I can't get over I never really walked out of there satisfied if you know what I mean.”

Brian

Instead of learning how to manage his IA, Brian became angry and disillusioned with his treatment regimen and his erratic appointment schedule. This led to poor treatment concordance and problems with attendance.

“And then I got to go to [a different rheumatologist who] has just been a revelation, just amazing ...You get that feeling [the rheumatologist] really does care y'know? Whereas before I never really got that feeling... I've learnt over the years that if you don't ask you're not going to get it. It's as simple as that. Because they can't read your mind. They don't know what you've got to get from them. So as long as you tell them and you play the game, you take your pills and do what they ask you to do.”

Brian

Brian's experience is an example of how the relationship between the patient and the rheumatologist and a focus on patient well-being is crucial for good outcomes.

¹⁸ Full diagnosis data was not available from the patient records due to restricted permission.

Participants who felt they were informed and had the opportunity to talk through wider health concerns related to their IA more often reported concordance with the rheumatologist's treatment recommendations.

The relationship between the patient and the Nurses Clinic was also important to the WRRU patient participants. The administrative procedures are run on the basis that patients can meet the requirements of the clinic in terms of attendance and treatment compliance. Gillian's precarious financial and social resources were not communicated to the WRRU. She stopped attending appointments soon after her FSA and continued on DMARDs with a GP prescription because it was closer to home, meaning less time off work and cheaper transport. Although GP care is more expensive, because she had other chronic conditions that were treated by the GP, this strategy made best use of her limited resources.

"Last year was a bad year for me. I was in and out of the doctors, and the year before. I was in and out of the doctors, but since the rheumatologist gave me that [Leflunomide] I haven't been so much in and out of the doctors."

Gillian

Gillian presents as a strong, independent but guarded person. People who do not advocate for themselves, are not enrolled in an APHO, or do not meet requirements in terms of physical disability can 'fall through the gaps' in terms of assistance for transport or coordinated care programmes. Concerted coordination between the GP and the rheumatology service may have uncovered her difficult situation and led to better access to the service and adequate control of her IA. WRRU staff members are aware that some patients have complex needs. For example, patients regularly cite transport difficulties due to cost and/or disability as a reason for non-attendance, but providing coordinated action is dismissed as beyond the capability of the WRRU, especially if it results in extra costs and resources like transport. Gillian eventually discontinued her paid employment due to increasing pain and disability. Ironically this provided time for her to resume her visits to the rheumatology clinic and to regain and maintain adequate control of her IA.

MANAGEMENT OF DMARD IMPLEMENTATION

For DMARDs to provide optimal suppression of disease activity with maximum safety and with minimum side effects, they need to be administered as prescribed and monitored, through regular blood tests, for efficacy and rare but potentially serious side-effects (Emery, et al., 2000; Haibel & Specker, 2009; Diane Lacaille, 2000). The treatment protocols are quite complex for people who are unfamiliar with more than short-term or over-the-counter medications (appendix 9). While recognising the need for monitoring the effects of DMARDs through monthly blood tests, patients were nevertheless uncertain of what was being monitored beyond ‘inflammation’ and ‘side effects’.

Patients described problems with methotrexate, salazopyrin, NSAIDs and prednisone in their first few weeks of implementation of their drug regimen. These problems included side effects such as nausea and stomach irritation, incorrect dispensing of drugs and being physically unable to swallow pills (Table 42).

Table 42: Patient problems beginning medication

Patient	Comment on problems beginning treatment
Anne	“I had this prednisone and I got really, really ill on it, not that I knew that that’s what it was. I got really ill on it –I couldn’t work, and I was cooking - I was absolutely a ball of perspiration and I was really crook and my husband would say ‘you can’t go on like this’. I kept saying to him ‘I want to die’... I was sick for about five or six days and I would go over to [the GP] and he said ‘you’re just trouble, I don’t know what’s wrong with you’... The chemist had given me 20mg tablets so I was on 80mg of tablets a day. No wonder I was high as a kite. And I said to the doctor – I can’t get over it – ‘I said I’m on fire’ He said ‘oh sit on a bag of frozen peas then. That’ll cool you off’ ... He [GP] didn’t recognise the symptoms [of overprescribed prednisone].”
Mark	“I only had the two [types of medication] to start with. The one you took once a week [methotrexate] then I went on to the other ones. That seemed to stop everything except you get indigestion, two hours after I ate anything. I went back to my GP and said ‘we’ve got a problem. One of these prescriptions is giving me indigestion what can we do about it?’ So we went onto [omeprazole] and that sorted it.”
Angela	“So I started on it, but it’s like a slow sort of process you start one a week and then two and so on until you get up to the maximum dose of four, which is what he recommended. And I did really well getting up to the three but the moment I took the fourth one I had a terrible weekend of abject misery, feeling nauseous, revolting... and I didn’t know what to do because [the rheumatologist] hadn’t really said to me you know if you get to this point what should you do, so my immediate reaction was not to take it... I rang Healthline and in the end the recommendation was to go and see a doctor. And of course it’s the weekend ... So I went to the after-hours [GP clinic] and the doctor there actually rang the registrar at the hospital and explained what had happened and asked for advice and he said ‘she needs to go back to just taking one and then build up the dose more slowly. To do it over weeks than over a single week at a time.’ And that in fact is what I did and I got up to the four and there’s no problem.”

Patient	Comment on problems beginning treatment
Kim	"I took the DMARD and I can't remember how many days I took it for, and I started vomiting and I just thought I'm not taking it. It gave me vile headaches and all sorts of stuff."
Gillian	"I used to have it in big pills but I had to tell [the rheumatologist] I couldn't swallow them, because they were too long, I can only put little pills down that I'm taking."
Louise	"At the beginning and still, I've had trouble getting it right to work for me. I was taking it Friday nights because you know, for a couple of days – I wasn't spaced out – but I had no drive so I'd do it for the weekend and I couldn't do anything, there's no washing done there's no nothing done, stuff like that and yeah, it's very good everyone helping out but in the end you don't want to be sitting around all day you know? I'd get up and do something for a couple of hours and that would be it I'd be wiped out so I've started taking it on Wednesday now. I know it sounds odd – I don't cruise through Thursdays and Fridays but being at work I can't stop but also I plan to sort of work from certain times and I can finish earlier if I have to. I just sort of plan it that way and I actually get to have a weekend. I get a sort of balance of life."

Patient participants from the WRRU had waits of between six and nine months for their follow-up to appointments after being prescribed DMARDs, which for most resulted in an unmet need for advice soon after diagnosis and on first implementation of DMARDs. This is an acknowledged problem that is partially ameliorated by telephone contact with the Nurses Clinic at the WRRU, however only some WRRU patients are referred to this service and only two participants made use of it. There is a presumption that patients who are not referred to the Nurses Clinic call their GPs for follow-up (Staff 1). Patients may be reluctant to take this course of action because they may have lost trust in the GP's ability to treat if the evaluation of symptom was incorrect. Or they cannot afford extra GP visits in terms of employment, cost or social factors such as reliance on others for childcare or assistance with transport due to pain and disability.

The results of these implementation problems were that two patients did not continue with their medication and one was hospitalised. Patients were unclear about who they should contact with these problems and resolutions included telephoning the national health line, contacting GPs after a period of waiting, or else discontinuing the drugs regimen without further advice.

The delay between appointments also means that patients must procure prescriptions from their GPs, which results in significant extra costs, which can lead to patients rationing their resources.

“If I couldn’t get a script from [WRRU] I just go to the GP. But that costs. For high users you know you can get the high user cards. . I think I got mine last December and it ran out at the end of January. And I’m thinking, well the bureaucracy in operating a system like that. Why don’t they just spread the cost out over everybody? It’s just stupid.”

Stephen

Despite the concern about side-effects, participants had only a general idea of what their monthly blood tests to measure treatment efficacy and side effects were actually measuring. Three participants were confident they knew what clinical markers were being monitored, most others were aware they were for ‘side effects’ and inflammation, and relied on the rheumatologist to advise if they were ‘ok’ at their appointment. Two patients who resisted medication would have preferred to have more information about them (Table 43).

Patient comments show that patients often did not comply with monitoring requirements for DMARD therapy and the main reason for not complying was forgetfulness, further reasons were a dislike of needles and in Louise’s comments, a sense of futility shows in her reluctance to adhere to treatment requirements.

Table 43: Responses toward monitoring DMARD therapy

Participant	Response toward monitoring DMARDs
Louise	“I was supposed to get them done every month but I keep forgetting, I’m ‘oh I better go’ and I get this little stern letter ‘can you do a blood test for me in the next few days.’ And I know what it’s for, yeah I should just put it as a pop-up [diary] but it’s just another needle [that I don’t want].”
Mark	“I haven’t been for 2 months, 3 months. [The rheumatologist] said the last blood test was improved on the previous ones, so we’re in control there... But living out of town and not going to town very often and if I do go to town I’m going to do something and then I’ve got to be back home again – I don’t want to make a special trip in.”
Angela	“I’m good with taking my pills and things, but wasn’t so good with the blood tests. I’d forget to get them done and didn’t for about 6 months but then I got into a routine so I don’t have any more problems with that.”
Catherine	“I know one of them is for checking your liver function because I know last time I went [the rheumatologist] said it was a bit raised, and I went ‘oh’ and was told it’s nothing to worry about. And I know one is for your inflammatory level which started off at towards 40 and is now under 5.”
Carla	“I’ve not [had side-effects]. I worry about the methotrexate. I know that I’ve already had skin cancers so I really am quite careful. I hate that impact – potential impact of it. And I have regular blood tests, probably reduce what I drink.”
Brian	“One time I hadn’t been for a test for 3 months and I got a call from the nurse rarking me up, telling me to get down there. I don’t really dwell too much on [the blood tests], but [the rheumatologist] likes to have one done a week before [my appointment]– and fills me in ...

Participant	Response toward monitoring DMARDs
	the inflammation was up a little bit but I put that down to me being a little bit slack on when I'm meant to have my injection. I missed it out a couple of times. Bit silly of me I do know that."
Kim	"I get blood tests – I don't know what they are, I don't get much information back. I feel like there could be others that could be investigated as well. But y'know there's – all you know is you're being tested for the inflammation rates or whatever but the symptoms vary."
May	"Every month. That's the only thing I always make sure I have my blood tests. [The rheumatologist] said to me everything going well. My blood tests are no problem now."

FOLLOW-UP CARE

A question posed by Bukhari and colleagues in the title of their (2007) paper, was "*Is it ever appropriate to discharge patients from Rheumatology?*" was answered with the conclusion that patients should not lose contact with their specialist team because even sub-clinical activity may cause joint damage, and DMARD therapy and monitoring is outside the realm of GPs. This is not to suggest that there is no role for GPs in patient care, but development of long-term, supervisory protocols are necessary for this to be successful.

Alex is one of two patients who were discharged from the WRRU. He is in his early 20s and has had an IA for two years. He was referred quickly to the WRRU by his GP, and after diagnosis and a prescription for NSAIDs was discharged back to his GP's care with instructions to return if his condition deteriorated. Alex felt the rheumatologist was rather dismissive:

"I used to go on pretty much when 'well you've got it, there's not a hell of a lot we can do about it apart from give you anti-inflammatories and painkillers and that's about it"

Alex

This has led to a situation in which the GP and participant are ambivalent about what to do in the presence of persistent symptoms over a two-year period. Increasing pain has led to him relying on NSAIDs and pain killers to enable him to work. Alex takes a mix of painkillers shortly before his shift begins, including doubling his NSAID dose instead of taking it as prescribed:

"I'll take two codeines, occasionally I'll take two diclofenacs [as well], I know you're supposed to have one every 12 hours, [but] I don't really feel the effect for 5 or 6 hours... but my body seems to burn through any reaction from it real quick as well."

Alex

Alex has not been referred back to a rheumatologist. His GP monitors his condition but there the clinical markers have not indicated a re-referral, in the GP's opinion:

"When I go back to the GP for more painkillers and bits and pieces he just sends me off for more blood tests to check what the markers and things are like, and that's really about it and then I might get a phone call in a couple of days saying your markers aren't up there's not really much we can do. My body's stuffed up... It's kind of you've [the rheumatologist] told me what it is, but you haven't really told me - well I suppose you don't really know how it comes about and bits and pieces - but you haven't really told me what the treatment options are apart from anti-inflammatories. It's sort of like you want me to wait until it gets worse before I come back and then I bet you it's going to be I call you up for an appointment and it's three months before I can get one."

Alex

Alex appeared to underplay his symptoms, only speaking of pain when it interrupted his work and it is likely that a similar low-key approach is taken during a medical consultation. His situation suggests that a more proactive relationship with the WRRU may lead to better management of his disease. The expectations of both the patient and GP in meeting certain criteria for re-assessment are perhaps misunderstood.

ADJUSTMENT

Illness perceptions research has shown that patients with chronic disease that is attributed to external factors and who perceive poor treatment control are more distressed by their illness than patients with acute illnesses or who can make lifestyle changes to improve outcomes. In other words, people who feel more in control of their illness and treatment, and who can help themselves create an illness-free future have better emotional well-being (Moss-Morris et al., 2002).

Rheumatologists are necessarily focussed implementation of intensive DMARD therapy for patients whose IA is likely to progress to erosive disease. This focus can be difficult for patients who are engaged in coping with their disease. With a long lag

time between implementation of DMARDs and full effectiveness, after an often extended delay to FSA, patients may already be considerably distressed and unsure about coping with their changing role from a well person to one with a chronic disease on long-term medication. Moreover, when DMARD therapy fails to control the disease they must adjust their lives to incorporate pain, disability and an uncertain future. Patients often spoke of wider concerns - about how manage their lives and general health and advice about their concerns for the long-term impact on their physical, social, financial and family situations.

They would also have appreciated discussion around the information that they were receiving from their social groups and from reading about different IA causes, cures and experiences. Nineteen participants had told of 'cures' and 'immune boosters' some of which they derided, but had no clear answer for.

"I did try other things. And [my friend] is right into everything. We were already on the fish oil and so he'd read everything virtually and I actually decided I wasn't that interested to be frank. I just wanted to get on with life, I didn't want to become obsessed with it, I didn't want to become sick with it. Not to become my life focus".

Carla

"I even went to a Chinese acupuncturist for about 3 years every fortnight getting bee-stings on my acupuncture points, I was willing to try anything to reduce the pain, the swelling, the discomfort and everything."

Stephen

Participants did, however, perceive mind and body therapies as important components in managing their IA. Louise was one of four patients who did not try a supplement or alternative therapist to ease IA symptoms.

"Oh everybody puts a word in. 'You should try this and you should try that.' I'm not really one for flying off. I do have a great faith in medical science, though you know I'm not closed to other options. But yeah, I'm just not one of those people that flies around, 'try these mussel tablets, or this stuff,' you know? I just think I'll persevere. If I can do anything to take the edge off, I will. But, everyone's got an opinion, everyone knows 'oh yeah I've got it in my little finger'..."

Carla

In their search for understanding their disease, for pain relief and to take positive action well-being practitioners were sought by almost half the patient participants, with rheumatologists referring both patients that attended pain management clinics and two more to physiotherapy clinics. Other patients independently sought practitioners. In all, 20 participants had used at least one form of mind or body therapy (Figure 48) or supplements or other (Figure 49) complementary or alternative therapies. Only two participants mentioned discussing these choices with a medical practitioner before beginning these therapies.

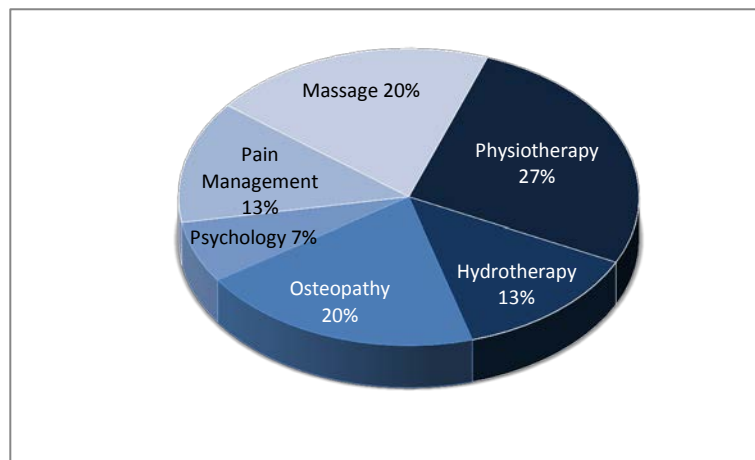


Figure 48: Patient use of mind and body therapists after diagnosis

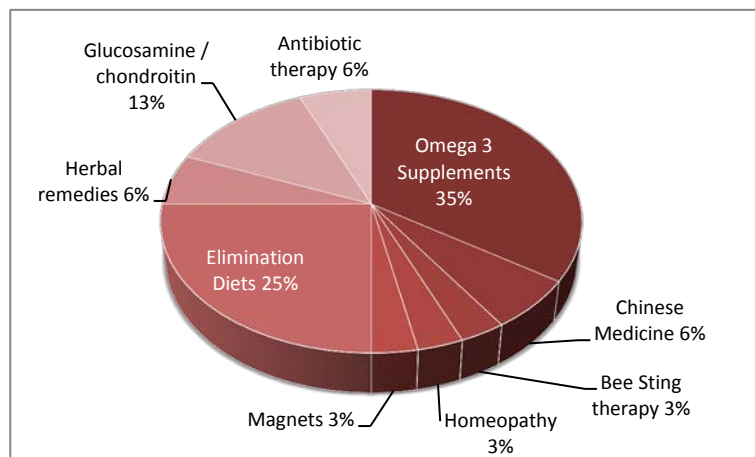


Figure 49: Use of supplements, alternative and complementary therapies

Patient uncertainty about their illness and their medication is exacerbated by the quantity of information that they are required to process within the rheumatology consultation. Women more frequently spoke of problems obtaining information

Coping alone with IA - Louise

“At one stage with all the drugs and everyone’s giving me their 20cents worth I went, because I tried doing gentle exercise to control it, to keep everything moving, especially with walking and stuff, you know going for gentle walks, we live on the beach so can go for a walk on the road way or I can go for a walk along the beach um I found that walking on the beach is not a very good idea, it twists everything, my ankles and knees and stuff all turn so it’s not really stable. You know just gentle walks, just trying to do light stuff but consistently, as you know if you build up it tends to get better. It didn’t seem to be getting any better I was still getting that stiffness in the mornings and general stiffness during the day if I stopped at all I took a little while to get started”

She has found suitable advice difficult to find, and none forthcoming from her rheumatology clinic. She has received advice from in her family and social circle, the internet and Arthritis New Zealand.

“I though you know I’ll go and I rang up the arthritis foundation and got an appointment with one of their nurses which go around to the different chemists. I thought you know they’ll have something, just sort of something to complement the drugs and everything. Because you know like [my rheumatologist] is really good, he knows what he’s doing and everything but he’s really looking at which drugs going to work. He can’t work out what I can do between the three months when I don’t see him apart from take the drugs. Anyway so I went and saw the arthritis nurse and I sat down and said ‘I’m not coping with this. I’m just thinking that with the disease, with the drugs on top of it, you know? I’m not actually having a life outside of this arthritis. I go to work and that’s what I can do and that’s my life’. I said I’ve been trying to exercise and I said but is there anything else I that can do? Since I’ve had it I’ve probably put on about 10 to 15 kilos. Just inactivity and I think there’s a lot of fluid in my knees. But anyway, I said but is there any other? And she said ‘well you can go to a hydrotherapy pool’ and I said well where are they? ‘umm they’re at the old people’s homes mostly or at the hospital but you’re not really eligible for that.”

Figure 50: Help-seeking for IA healthy living information

about accounts of the need for support in managing pain, managing fatigue, diet and exercise and coping strategies. Louise’s narrative provides a typical account of these issues (Figure 50).

No participants attending private clinics talked about being given advice about accessing allied health care or pain management, whereas pain management and information about living with arthritis was available for at least some patients from the WRRU, with two participants attending pain management courses (Table 44).

Specific treatments, for example physiotherapy or podiatry, to alleviate associated symptoms were not addressed at the rheumatology service.

Table 44: Reflections on information

Participant	Reflections on gathering information
Louise	“When you’re got the drugs at the beginning they give you sheets or you look up on the internet about what they are you like [the rheumatologist] had been reasonably explanatory but when you’re taking in that much information you don’t actually hear everything. Like they say if you’re doing something major at the specialist, if you can take someone in so they can listen for you... because you don’t hear everything. I think probably a little more information about what the drugs do, rather than what the drug companies sort of put out. I know the arthritis foundation put a bit out. But you know after you’ve started taking them you tend to know a bit more about it and all these side effects And it’s just probably knowing that a little better at the beginning. ...I don’t know, really too much information at that stage is not a good thing. I just found that I was wondering what is it is they are actually doing and why am I taking that with other things and why are they all working together. Because now I sort of understand after 2 years what’s going on, but it would have been a lot more helpful a bit earlier on.”
Stephen	“The other thing is he never told me that he’s got me on the salazopyrin to prevent the iritis. I, I picked up a journal off ProMed or something when I was searching for some stuff and saw that salazopyrin is thought to be useful in controlling iritis. That perhaps is my fault, not asking why I am on this, I thought it was for the systemic treatment. I might not have been so casual dropping it off when I went into remission.”
Lisa	“Yeah they told me to not go on the websites blah blah but I needed to ... They were going on holiday it was like holiday time or something and I was the last patient of the day ... I went home and I went straight on the net. So it was like a support site but I gave up on it after a while I just thought well stuff it I’ll just wait until this medication kicks in... I don’t even know what my arthritis was called. I asked [the rheumatologist] and he told me and I’m like there is no way I’m going to remember that.”
Sally	“I use google to check out information but don’t get much from anywhere else. I googled methotrexate but to be honest I can’t remember what the side effects are. It works! No-one makes any comments about the medication I’m on. I have a friend who has RA for 20 years and she has had the gold injections and that. Her hands are really gnarled. I’m so lucky we have methotrexate now. She is on it too and is much better...I thought that there would be information packs when you’re diagnosed. There is so much information everywhere but it is so ‘blah’... it’s so random.”

DEPRESSION AND FATIGUE

Two of the fundamental unaddressed issues participants have struggled to deal with are fatigue, either as a response to dealing with pain or due to methotrexate, and feelings of depression.

“Shortly after I was really diagnosed I was depressed I got really depressed and I was on, oh, some anti-depressant for a long time”.

Anne

Anne was the only participant who had a specific diagnosis of depression. Patients who expected a remission that did not eventuate, and patients who were struggling to have their illness brought under control spoke with more sadness and frustration at outcomes than those patients who understood they were dealing with a life-long, serious but controllable illness (Table 45). Three patients acknowledge they had suicidal thoughts, while another could not see how to live to old age without better control of pain, disablement and fatigue. There is little confidence that a patient who shows signs of depression in a rheumatology consultation will have a priority level that ensures they will be seen within a relevant timeframe if referred from the WRRU to a public rheumatology service (Staff 4). Therefore this may be seen as a task for the GP.

Table 45: Problems managing fatigue and treatment

Participant	Comment on negative treatment decision-making
Louise	"I've had –when [the rheumatologist] drains my knees and stuff and goes 'oh that looks really good' and it's this big vial of stuff of my knee and he goes 'oh well there's no calcification, it looks all good' I'm 'ok' but I get a little sick of it, I'm not scared of them but it's quite –you have to get yourself ready for them. I have been and seen him and he goes 'how are you?' and I say 'good, quite good at the moment' because I really don't have the strength to lie there and let him jab a needle into put cortisone in or take out fluid and stuff... I know that's terrible, but what do you do? You know just some days you can cope with it better than others, if I can't deal with it I let it go."
Kim	"But the other big issue that worries me about all this is the whole lot of side effects from these drugs... I've got headaches, vagueness. I've got bleeding from the bowel... I've got bruises all over my body most of the time... I really wasn't happy with the 'here's another pill to fix a pill' type of effect. Anyway, so I just feel like it's a bit of a negative just about everything I've said has been a bit of a negative, but that's that whole build-up of the frustration. But I don't feel like you've got any control or as much understanding as you could have. They don't actually teach you about anything, and they just go you can take this pill come back in three months and we'll see how it went. That, to me, is a very one-sided relationship. "
Carol	"I phoned up the specialist nurse and told her 'I've got to go off methotrexate, the fatigue is so bad I'll have to give up work if I don't' and she said that that was ok, which was a change, because other times I've mentioned fatigue they've said 'oh you've just got to get over it'. This time they took me seriously."

An important side effect of methotrexate (and IA itself) is fatigue. A quarter of participants highlighted the problem of fatigue prevention and management. Aside from the impacts on work, relationships and emotional well-being unaddressed pain

and fatigue lead to negative treatment decisions, either discontinuing DMARDs or not having the emotional energy to engage in treatment decisions.

Patient participants may rely almost entirely on the rheumatologist for IA care, and exclude the GP, with whom a trust relationship may not exist for IA care, especially if there was a failure to initially evaluate symptoms as IA. GPs almost always receive reports about patients' clinical tests

THE ROLE OF THE GP IN RHEUMATOLOGY CARE

Where a rheumatology service did not meet needs for advice on exercise, nutrition, coping skills and depression, patients did not see their GPs as a source of alternative advice, despite GPs often being the best placed health professional to understand their health needs, particularly for patients who had a regular GP with knowledge of any other health concerns. GPs receive the results of laboratory tests for monitoring IA status and DMARD side effects, and receive clinical letters from the rheumatology consultation, but there seems to be little co-ordination between the rheumatology service and the GP about on-going patient care (Table 46)

Table 46: GP comments on responding to patient coping skills and depression

GP	GP Comments on responsibility to respond to patient coping skills and depression
GP1	"Some people do keep coming back and others you don't see for ages as they're going back and forth to the rheumatologists. And rheumatologists being specialists, they're not going to sit with a patient and discuss depression."
GP4	"I wouldn't expect a rheumatology clinic to treat a patient for depression. It's nice to have the human contact and empathy but if I worked in a rheumatology clinic I would tell the patient that I had concerns and advise them to seek professional advice. I wouldn't feel it was my responsibility to address their issue. A GP has to take overall responsibility of a patient."
GP5	"There are gaps in care. Who's interpreting the results? That's another problem we have at times, when you get abnormal results, is the specialist clinic following up on those or because they've popped up on our desk should we do a follow-up? Inevitably we try and do a double-check because yet again if they haven't heard we say then contact the department."
GP9	"I wonder if that kind of service would be a good thing for a rheumatology nurse to follow up. If the patient doesn't have any other ongoing problems they may not see me. I'll see their bloods but I won't see them. So maybe after the initial diagnosis a follow-up in the community may be a valuable thing."

The most serious example of the importance of coordination between rheumatologists and the patient, and uncertainty over the responsibility for patient care concerned a participant with anaemia:

“The nurses phoned me with my last result, my last blood test, even though I hadn’t come in, they rang me and said my iron levels were very low and that I needed to see my GP. Within a week I was in hospital with a haemorrhage. But it was here [WRRU] that rang and told me that so that was really good. Because my doctor doesn’t believe in iron tablets because he thinks it’s the arthritis that makes you tired and, yes it is, but you still need to have iron tablets if your count’s really low. Because I was admitted to hospital and mine was down to 40. It was pretty low, it was hard breathing, I had a blood transfusion and 3 days in hospital... I don’t know I’ve never had a blood test. I must admit, yeah that’s a bad thing, when I was in hospital I had to have a blood transfusion, they gave me iron tablets but I haven’t had a blood test since, no one said ‘we want you to have a blood test in two months-time to make sure your iron’s up there.’ No follow-up. So bad.”

Marie

Although Marie was advised to visit her GP, she was not aware of the urgency, nor, at the time, what steps she should take to reduce the anaemia.

Reasons for patients diagnosed with IA failing to obtain advice from their GPs were varied, including previous frequency of visits, confidence in the GP, effectiveness of the treatment and reluctance to have to repeat IA history to a new GP. Patient participants who rarely visited a GP before IA was diagnosed, continued to have infrequent consultations with the GP. Patients who had a good response to treatment found little reason to access GP care. Several participants expressed a lack of confidence in their GPs’ IA knowledge considering the GP found it difficult to manage the initial diagnosis or due to the GP’s failure or delay in providing a referral to a rheumatologist. Patients can be reluctant to repeat their IA history to a new GP or locum and this is a specific barrier for patients without a home GP, or do not have a Careplus coordinator to manage their chronic care needs. Further barriers to GP care revealed in the interviews are, social (childcare, absence from work, reliance on others for transport) and economic (costs of visiting the GP and additional health costs due to IA) (Table 47).

Table 47: GP care after rheumatology consultations

Participant	Comment on GP consultations after diagnosis
Gillian	“I did have a run in with one of the doctors. He was asking too many questions and I said ‘Well, all you need to do is press things on the computer and it will come up.’ I do not like to answer questions when they’ve already got it.... I used to have problems with them doing that to me. That's why I said to him, 'I gotta have confidence myself in the doctor and I haven't got any confidence in you.' And I said, 'I'd like to have my own doctor back because I can talk to her.’”
Louise	“[The GP] says you must come and see me. And I’m like ahh I can’t be bothered. So and sort of what they know about the drugs and the treatment is fairly limited anyway. So that’s just another one to explain it all to.”
Stephen	“Every time I went to get my script every three months it was costing me nearly a hundred dollars... [When I’m at the WRRU] I'll hit them up for a script. That will save me a few bucks. For high users you know you can get the high user cards...I think I got mine last December and it ran out at the end of January. And I'm thinking well the bureaucracy in operating a system like that. Why don't they just spread the cost out over everybody. It's just stupid”.

The unexplored relationship between the patient, rheumatologist and GP can lead to important gaps in patient care. An almost a tacit belief exists that a rheumatology clinic is managing the IA and the GP the general health and well-being of the patient, but there is no confirmation of this. For example, none of the clinical letters examined suggested to the patient that they may need other professional care, yet the patient narratives clearly show patients were having difficulties in adjusting to their illness.

DISCUSSION

Rheumatology patients with IA have complex needs that may not be immediately clear at FSA when the patient is absorbing information about diagnosis and medication. In the weeks after FSA patients sift information and reconcile what they have understood from the rheumatologist with their own values, and with regard to their responsibilities and resources. The themes that developed from patient narratives about access to rheumatology care that meets their needs post-FSA are presented in Figure 51. Rheumatology administration, the construction of health and illness in the consultation, and appropriate holistic health therapies are wider concerns for well-being for the patient, but the perceived focus of rheumatologists was on diagnostic certainty and drug risks and benefits. Managing change is a central

concern for the patient participants but in depth analysis of this theme is outside the scope of this thesis

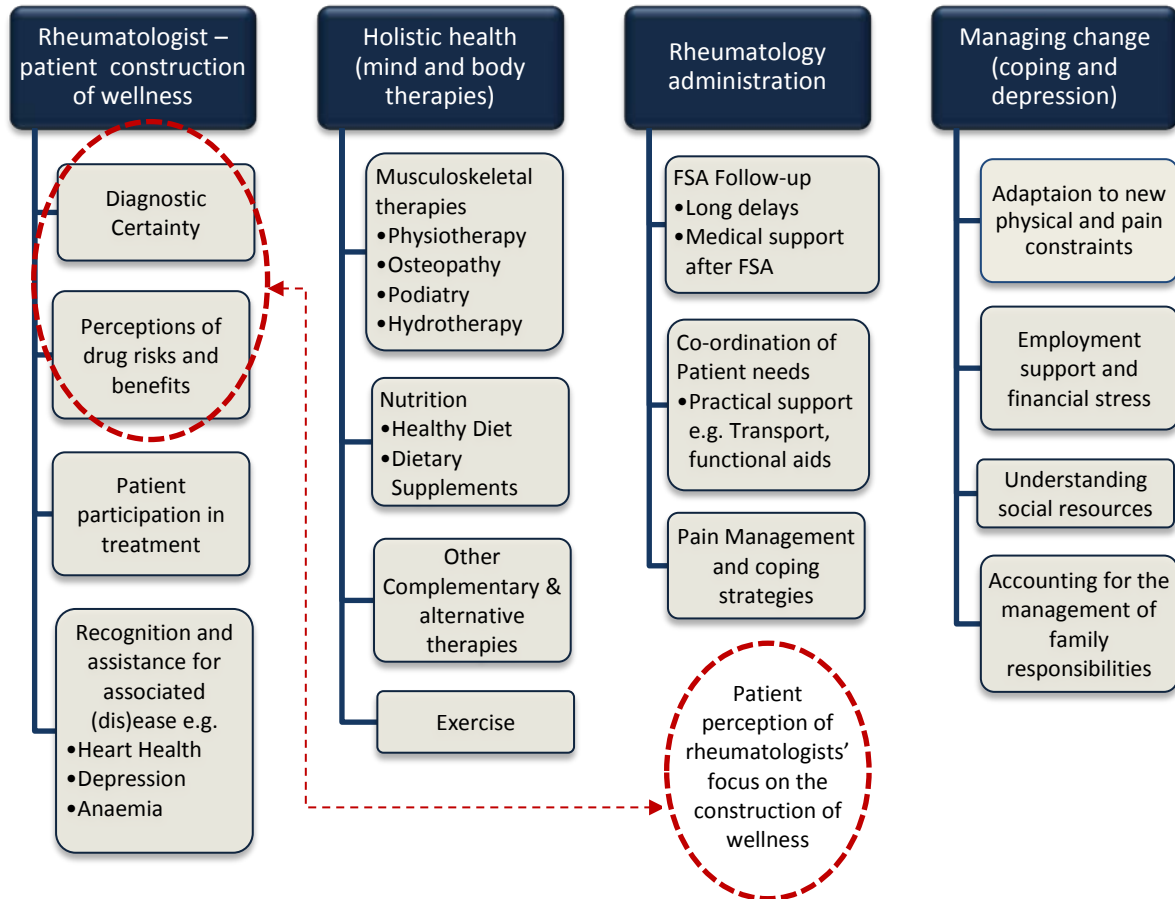


Figure 51: Categories of patient participant concerns after diagnosis of IA

CONSTRUCTION OF WELLNESS

Rheumatologists recommend methotrexate, or another DMARD such as Salazopyrin, where methotrexate is contra-indicated, to be the first treatment choice for patients with a potentially erosive IA like RA, to suppress disease activity and possibly achieve remission (Diane Lacaille, 2000). They advise that methotrexate, with folic acid supplementation, is a relatively safe drug to use long term in low doses for IA (Emery, et al., 2000), and that serious side-effects are rare, with careful screening of patients and regular monitoring of liver and blood disorders so that any potential harm can be detected and adverse impacts on patient avoided. (Varatharajan et al., 2009).

A reluctance to take medicines, especially those with significant, albeit rare side effects, is well known by doctors and widespread in the general population. The World Health Organisation considers that poor adherence to treatments is the most important factor in lower than expected clinical benefit of medicines for chronic disease (World Health Organisation, 2003).

Patient narratives showed that approximately half the patients interviewed were concerned about inadequate participatory decision-making. Participants who have a questioning response to their diagnosis found the linear, biomedical decision-making approach of the rheumatologist was crowded with uncertainties and criticised the biomedical approach for its narrow recommendations about disease suppression through DMARDs alone. These participants were keen to have a multi-pronged strategy to increase their knowledge of the disease and improve wellness in a holistic manner. The dissimilar approaches underlie different goals of patient and provider when deciding on treatment options. (Frantsve & Kerns, 2007).

Because the reasons for rejecting DMARDs are rarely singular, managing the response to the patient's reasoning for excluding DMARDs can be complex. If for example, the patient experiences unacceptable side-effects, this can confirm a pre-existing preference for alternative or complementary therapies, so rather than seeing the side-effects as something that can be ameliorated, for example by an increased dosage of folic acid, or changing the dosage or timing, or delivery (by infusion instead of orally) of methotrexate, these options can be seen as a 'slippery slope' to reliance on more drugs, and so patients with a preference for low levels of medical intervention may reject them. Patients may also have a lack of trust in medical science, and drug therapy in particular, that drives the rejection of DMARDs within days of them being prescribed, with any side-effects being supplemental. For two participants the combination of these factors entangled with disagreement about the disease cause, diagnosis and uncertain prognosis, leading to fractious relationships with medical advisors. For participants without a clear concept of their disease as an immune disorder expressed as joint inflammation and pain in the early stages, the IA narrative becomes one of a systemic disease and a literal poisoning of the body rather than an immune disorder, or conversely a localised joint disorder. With either of

these discourses the participants perceive a metaphorical 'poisoning' of the body with methotrexate as unwarranted or counterproductive.

Participants with these views are well educated and consider it important to question established paradigms in medical treatment. However they perceived their rheumatologists as unwilling to discuss these health beliefs with them in a knowledgeable and careful manner. This effectively left the decision-making about treatment options to the participant. Patient outcomes have been shown to be improved when they participate in decision-making but there is a fine balance in managing patient involvement in decision-making about using treatments they may regard as risky. A proof of concept investigation has given evidence to suggest that if the decision about beginning a therapy with significant side-effects is left to a patient who worries about the decision-making process as well as having concerns about the treatment, then the patient is more likely to forgo the treatment due to the decision-making responsibility increasing the (already present) high perception of risk (Fraenkel & Peters, 2009). If this research is validated it may provide important insights in decision-making about DMARDs in the doctor-patient relationship, with implications for the role of the specialist in reconciling fundamental differences in the conception of IA, its treatments and outcomes (Fraenkel & McGraw, 2007) by finding ways to manage patient education and perceptions of the risks.

Trust in the rheumatologist is an important factor in treatment decision-making, concordance, patient satisfaction and continuity of care. It is also strongly correlated with disease activity, as well as trust in the healthcare system (Martin et al., 2008; McKinstry, Ashcroft, Car, Freeman, & Sheikh, 2006). A cross-sectional study of patients with RA in Michigan found that physician trust was a significantly greater predictor of confidence in DMARD decision-making than DMARD-specific knowledge, demographic characteristics (age, gender, socio-economic status and ethnicity), or disease-related factors (Martin, et al., 2008). In this current study, a marked contrast with participants who rejected DMARDs, was that participants who began and maintained DMARD therapy, even when disease activity remained high, had almost complete faith and deep respect for the rheumatologist's advice. Patients with a strong focus on physicality across the range of socio-economic and educational backgrounds notably showed no hesitation in beginning DMARDs, despite longer

delays in initially seeking care for their IA symptoms. These patients were also unconcerned about how much information they were receiving from the rheumatologist about their condition, and expressed little desire to have more information, for example about their disease or from side-effects monitoring, except in hindsight after a medical setback. Although fearing side effects and a clear understanding they should monitor for these with monthly blood tests, only three out of 23 patients understood that these tests were to monitor both the effectiveness of their DMARDs and potential side-effects. Compliance with a monthly routine was low with more than half the participants, and five of the seven men taking DMARDs, agreed they did not adhere to a four to six week testing regime and relied on reminders from rheumatology clinics or GPs before getting these done.

However, when DMARDs failed to ease inflammation within the expected timeframe, and pain, disability and curtailed lifestyles intruded the participant could lose trust in the rheumatologist. Three participants, while continuing with rheumatology care, found maintaining confidence in that treatment difficult as constant adjustments in medication failed to bring about satisfactory reduction in disease activity. All three participants had problems communicating their concerns with their rheumatologist and for two, as the expectation that they would achieve remission diminished, the realisation they needed to accept they had a long-term chronic disease resulted in difficulty adjusting to and communicating their illness status, leading to a rejection of additional medical interventions that could improve their well-being. This outcome fits the findings of the revised illness perception questionnaire (IPQ-R), which seeks to quantify illness representations that link perceptions of illness with, among a range of psychological outcomes, the ability to cope with illness. The IPQ-R research established that patient awareness that their illness is chronic, with cyclical timelines and beliefs that the illness has severe consequences that are out of personal control has strong negative consequences for patients' emotional responses" (Moss-Morris, et al., 2002). Sensitivity to patient concerns, providing adequate clinical information and patient centeredness helps to build the patient's trust in the medical practitioner. An important link to the loss of trust, and one exhibited here, is that patients are more willing to disclose information when the patient perceives the medical practitioner is patient-centred (Berrios-Rivera et al., 2006).

Patients invariably believe that the rheumatology clinic will provide suggestions or resources to facilitate information and well-being at both diagnosis and as symptoms persist. When their concerns are not addressed in rheumatology care they often 'go it alone', or respond to information, advice and comment from other sources, whether verifiable or not. All patient participants practised some kind of alternative or complementary therapy without knowing the likely impact on their IA, with the most common being omega3 supplements (11 participants) and elimination diets (eight participants), with three patients, including two who rejected DMARDs, using more than three CAM therapies.

HOLISTIC HEALTH

Patients cannot absorb all the information they receive at the FSA, but with a follow-up appointment at least three to six months away, family and social contacts, pharmacies and websites become important sources of information. Websites can be a source of empowerment for patients with chronic diseases and difficult treatment options because they can reduce the power differentials between doctor and patient, and can encourage dialogue (Crooks, 2006). However they may also be used to make decisions that give the individual a perception of greater control of their illness and treatment. If the information is inaccurate or weighted toward the side-effects of DMARDs rather than their purpose, patients may choose to delay this treatment and consider this decision an informed one. This period without professional input into information-gathering and formulating a response to information from the FSA suggests a need for contact with the patient during the first few weeks after diagnosis to answer questions about diagnosis and treatment, ensure the DMARD regime is implemented and respond to questions and concerns that may have arisen since the FSA. Referral to allied health professions such as physiotherapists is also not routine, or coordinated. Without recourse to such advice patients get their information from non-verified sources. Treatments such as antibiotics may be seen by patients as a logical response to an IA, particularly one with onset that coincides with an infection or has an infectious agent as a trigger such as in a reactive arthritis that persists. (Diane Lacaille, 2000). Complementary and alternative therapies that might be not be in the patient's best interest, for example elimination diets that remove key nutrients can be rationalised in similar ways despite there being little evidence to support their

efficacy (Hagen, Byfuglien, Falzon, Olsen, & Smedslund, 2009). Patients could also use these treatments, beyond experimentation, to obtain a level control over their treatment options outside the bounds of the rheumatology clinic. Patients were also interested in exercise and physical therapy but were uncertain how to exercise safely and within their pain levels. Dynamic aerobic exercise has been shown to improve muscle strength, stamina, and the response to pain in patients with RA so could be an important component of treatment of patients with an IA (Hurkmans, van der Giesen, Vliet Vlieland, Schoones, & Van den Ende, 2009).

RHEUMATOLOGY ADMINISTRATION

DMARD doses may need to be adjusted after three months if they do not significantly improve the patient's condition. However, the patient may not fully perceive benefits of DMARDs because they may not have timely follow-up appointments at the WRRU. Patients can be taking drugs as prescribed for many months without significant improvement in their condition because of delays in their follow-up appointments at the WRRU. Follow-up appointments of longer than three months were only experienced by patients attending WRRU clinics. This distinction raises a concern about unequal treatment after FSA for publically-funded patients compared with patients attending private clinics. Nurses recounted instances of patients who did not attend because they were unaware that their treatment was long-term or required monitoring for efficacy even if the patient felt well.

Inaptly timed appointments have a disproportionate effect on WRRU patients. Private patients were all seen at three-monthly intervals at least until a satisfactory treatment regime was established. Public patients had appointment spacing of between 6 months and one year, despite unstable treatment regimes. Multi-disciplinary outpatient services and nurse-led clinics and pain management services are important components of the rheumatology services but patients are not routinely referred to these services (Staff 1). Only three of the WRRU patients had been referred to any of these services outside of the advice to call the unit if there were any problems. Some WRRU rheumatologists regularly referred patient to the nurses clinic and pain management services, whereas others do not refer, making access to extra advice on living with IA somewhat irregular. No private patients were

given advice to seek pain management or coping services. Only one patient from a private clinic independently contacted Arthritis New Zealand, and one from a public clinic was assessed by ANZ for disability needs through her primary healthcare service. No patients were handed written material about their condition or treatment after their FSA. In the WRRU and several private clinics pamphlets from ANZ were displayed for patients to pick-up, but patients were not explicitly advised of these.

Patients who have not had previous experience with secondary medical services find that they are learning how to 'play the game' and making errors that affect their future outcomes by risking access to appointments and continuity of medication while they do so. For patients, an understanding of what is expected of them in terms of consultation procedures and treatment adherence is crucial to the successful negotiation of the rheumatology services and patient obligations. Delayed follow-up and an absence of routine rheumatology services between appointments also increases patient costs. Cost becomes a greater barrier to healthcare once diagnosis is made and medication had begun due to the patient having to source repeat prescriptions for medication from the GP. In the most extreme cases, this can lead to fragmented DMARD use and intermittent pain relief.

In terms of treatment concordance, the patient narrative expresses a pervasive sense that rheumatologists may believe that the patient will be motivated to follow regimens for illness control, especially one that impacts on their lives so comprehensively as an IA, but patients may not be ready to take on the regimens that compliance demands. This indicates a lack of appreciation of the distance between "treating the biomedical problem and an under-emphasis on addressing the behavioural requirements of the treatment protocol" (World Health Organisation, 2003, p. 145). Careful consideration of patient wellness needs and a partnership in response to the new reality of long-term chronic disease and medication that includes timely responses to patient education, treatment issues and allied health care are important factors in building trust and improving treatment concordance and health outcomes.

COPING AND DEPRESSION

Unaddressed medical concerns associated with the diagnosis of IA were revealed in the patient narrative. There was little coordination between GPs and the rheumatology service to ensure patients received appropriate care for these IA-related health events and patients can be reluctant to see a GP because of cost, not having a trusted relationship with a GP, or they have lost confidence in the ability of the GP (or the medical profession in general) to manage IA. Rheumatologists and GPs have found that there is limited availability of physiotherapy, occupational health and hydrotherapy for IA patients. But more urgently, patient coping and depression is highlighted in the patient narrative as an important gap in patient care. GPs are unlikely to see a patient with IA routinely, unless they have other chronic health conditions and rheumatologists, public and private do not routinely refer patients to specialists in mental health or coping skills except for an unknown proportion of WRRU patients referred to the Nurses Clinic-led IA education courses. While research about IA and depression in New Zealand is difficult to source, Canadian researchers found one in 10 patients with arthritis reported clinically relevant symptoms of depression, twice the rate of the general population, and patients with arthritis were also more likely to experience suicide ideation. Depression correlated more with pain, and suicide ideation correlated more with functional disability. The authors found patients with arthritis and depression were likely to be younger and poorer than other patients and were unlikely to be receiving adequate care for depression. (Fuller-Thomson & Shaked, 2009). Patients with depressive symptoms have been found to have higher CRP levels and higher pain levels than patients without these symptoms, this is despite having otherwise similar clinical markers of disease (Kojima et al., 2009). Along with pain, fatigue (Wolfe & Michaud, 2009) and functional limitation (Margaretten et al., 2011) are also implicated in self-reported depression. Whether disease progression, pain and fatigue increases the likelihood of depression, or depression increases the experience of pain and disease progression has yet to be clarified, but these studies addressing depressive symptoms in rheumatology patients will have a positive impact for patient well-being (Margaretten, et al., 2011) and may improve the efficacy of treatment (Rathbun, Reed, & Harrold, 2012).

POST-DIAGNOSIS CARE

Rheumatological care is predominately confined to rheumatology services. Participants rarely considered GP involvement in their care plans, nor did GPs expect to see their patients about their rheumatology needs. There is space for greater cooperation and coordination of post-diagnosis care to ensure an individual's health needs are met and barriers to care identified. Although rheumatologists write to GPs with an assessment of the patient's condition, participants were unlikely to talk to their rheumatologist about health and care outside of the direct medical implications of their IA - therefore there is no obvious trigger to ensure continuity of care outside of the sometime infrequent rheumatology appointments. WRRU patients seldom talked of health service delivery in terms of structural barriers within the health system. Several participants attending private clinics did comment on the structural underpinnings of rheumatology care in the public system, noting their own privilege in having care provided in a timely manner without concern for restricted budgets and staff shortages that led to long waiting times at public clinics. An interesting difference between the public and private approach to new diagnosis was the availability, through the WRRU of information about pain management and physical therapy and follow-up on the FSA (although this was by no means universal) by the Nurse's clinic. A care package that includes education about the diagnosis, treatment protocols and prognosis to ensure patients have understood what they have been told; and identifies barriers to treatment for individual patients and how to support the diagnosed individual until DMARDs, or other medications are controlling inflammation, could be valuable additions to the rheumatology service. Post diagnosis care packages are available for other long-term conditions elsewhere. For example, the UK National Institute for Health and Care Excellence (NICE) recommends a multidisciplinary team for newly-diagnosed people, with a named coordinator. This team should include access to physiotherapy, occupational therapy, podiatry and psychological interventions, with periodic assessments of these requirements as well as periodic assessments of the effects of the disease on their lives (National Collaborating Centre for Chronic Conditions, February 2009). In New Zealand an example mentioned in GP interviews was the information and services provided for newly diagnosed patients by the cancer societies. However, relying on the voluntary sector can be a precarious way to manage patient care with evidence from the

evaluation of Diabetes New Zealand services that the provision of education and resources for chronic disease through voluntary groups may not reach the most at need populations and can produce geographic inequalities in care provision and uptake (Ross Barnett, Pearce, & Howes, 2006).

RECOMMENDATIONS FOR INVESTIGATION

TRANSITION FROM WELLNESS TO CHRONIC DISEASE

Unmet patient need post FSA revealed that research is needed to investigate the possible implementation of:

- Close monitoring of patients in the month after diagnosis to ensure problems with medication are speedily resolved, with advice and encouragement.
- Formalisation of arrangements with GPs for patient care between appointments (Much of the current patient management expectations are unspecified and create uncertainty for patients)
- Assess the impact of increased costs to patient if GPs take on a more formal role in patient care between rheumatology appointments.
- A review of procedures to ensure that patients who have a positive IA diagnosis, but have symptoms controlled with NSAIDs are not discharged from rheumatology. Rather regular monitoring should continue in rheumatology
- Printed advice provided in laypersons' language on medications (what they do and what the side effects are with an individual summary of treatment protocols, monitoring requirements and advice to minimise side effects).
- Identification and provision of services for patients who show signs of depression or who are not coping with their diagnosis and treatment
- Consideration of co-ordinating support structures for employment and childcare problems
- Assess means and benefits of educating patients and providing them with copies of referrals paperwork and results of clinical monitoring
- Present information to patients on the benefits and side effects of drugs

- Propose a holistic health approach that incorporates allied health professionals, resilience and coping skills, social advice such as employment, and financial and childcare options for patients
- Evaluate role of, and formal recognition for Arthritis New Zealand educators
- Evaluate the benefits of the WRRU nurses clinic monitoring of patients between appointments
- Wider health policy concerns that include the cost of delayed access to advanced drugs, in societal as well as health terms, and staffing needs (rheumatologists and support staff).

APPENDIX 1: NATIONAL REFERRALS GUIDELINES FOR INFLAMMATORY ARTHRITIS

(Elective Services, 2001)

Priority should be given to early referral of patients with inflammatory, destructive joint disease. Evidence increasingly shows that early intervention with disease modifying agents is required in order to get good outcomes. Patients with systemic inflammatory conditions and severe pain and dysfunction will also be given priority.

Immediate and Urgent cases must be discussed with the Specialist or Registrar in order to get appropriate prioritisation and then a referral letter sent with the patient, faxed or e-mailed. The times to assessment may vary depending on the size and staffing of the hospital department.

National Referrals Guidelines: Rheumatology (Abridged)				
Diagnosis	Evaluation		Management Options	Referrals Guidelines
Acute Single Joint				
Psoriatic Arthritis Ankylosing Spondylitis	Blood:	FBC, ESR, LFTS		Local injection therapy – category 3
Sub-Acute Single / Few Joint(s)				
Oligoarticular synovitis	History:	- Trauma - Psoriasis - Colitis/Iritis - GU/GI Infection	Analgesia NSAID	Uncertain diagnosis – category 3
	Exam	- Synovial Swelling - Joint tenderness - Other joints	Physiotherapy	Local injection therapy – category 3
	Blood:	- FBC, ESR, RhF, LFTs.		
Multiple Joint				
Rheumatoid Arthritis	History:	- as above - Incl family history - Systemic symptoms - Pattern of joint involvement	Early referral to Rheumatology service	Most cases of polyarticular synovitis should be assessed by the rheumatology service – category 2
	Exam	- Rashes - Anatomical swelling - BP	Institute NSAIDs	Polyarthritis with systemic symptoms or signs merits early discussion with a rheumatologist
	Blood:	- FBC, ESR, RhF, ANF, U&Es, LFTs, CRP	Beware High Dose Prednisone (>10mg)	

NATIONAL ACCESS CRITERIA FOR FIRST ASSESSMENT (ACA)

Category Definitions: These are recommended guidelines for HHS specialists prioritising referrals in primary care.

Immediate	- <i>within 24 hours</i>
Urgent	- <i>within 4 weeks</i>
Semi-urgent	- <i>within 12 weeks</i>
Routine	- <i>within 24 weeks</i>

Priority	Category	Criteria	Examples (not an exhaustive list)
1	Immediate	Acute rheumatological emergencies with threat to life or major organs	Giant Cell Arteritis Systemic Vasculitis SLE Septic Arthritis Polyarticular gout and systemically unwell
2	Urgent	Potential destructive inflammatory arthritis requiring urgent DMARD treatment or corticosteroids	Seropositive RA Polymyalgia Rheumatica Polyarticular Gout Inflammatory Polyarthritis
3	Semi-urgent	Suspected inflammatory rheumatological problems Non-inflammatory conditions with major social impact (e.g. loss of employment) Referrals from hospital specialists	Acute soft tissue problems requiring intervention
4	Routine	Non-inflammatory disease	Osteoarthritis Soft Tissue Rheumatism Fibromyalgia Other chronic pain syndromes Chronic osteoarthritis

Note: Prioritisation is often influenced by knowledge of an individual patient's social circumstances.

APPENDIX 2

PARTICIPANT INFORMATION AND CONSENT

Access to Rheumatology Services in the Greater Wellington Region Information Sheet for Participants

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

What is the Aim of the Project?

This is a doctoral research project to provide information about how people with inflammatory arthritis in the Wellington region gain access to services which help them with their condition. I would like to collect information about the circumstances of patients, for example financial, cultural, physical, residential and attitudes of those around you which help you to use, or prevent you from using, Rheumatology Services in Wellington.

I would also like to discover which patients are likely to have, or are most at risk of having, rheumatology needs unmet due to poor access, how access to rheumatology services impacts on patients' lives and whether the level of access affects decisions about using other health services.

Finally, I am interested in finding out what steps can be taken to improve access to rheumatology services in the Greater Wellington Region.

What Type of Participants are being sought?

The participants being sought are people who have been told by their doctor or specialist that they have an inflammatory arthritis such as Rheumatoid Arthritis, Psoriatic Arthritis and Ankylosing Spondylitis. A further group are those who have the symptoms of inflammatory arthritis but do not have regular medical care for that condition. People who have arthritis as a result of 'wear and tear' (osteoarthritis) rather than inflammation are not being asked to take part in this study.

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to be interviewed about your experiences in obtaining treatment for your arthritis, and to give your views about factors which may have helped or prevented you getting the right medical care, such as the nature of your illness, the relationship with your doctor and other issues. The interviews will be tape-recorded and should take between 30 minutes and one hour to complete. You are welcome to bring a support person with you if you wish.

I would also like to discuss referrals with doctors. If you agree, I may like to use your experiences as part of the interview, to find out how long your doctor was aware of your condition and why certain treatment plans were decided.

If you have been referred to a Rheumatology service I would also like to find out from the rheumatologist why certain treatment plans were decided. If you agree, this would also require looking at your rheumatology notes to count the number of times you have visited and what medications you have been given.

Can Participants Change their Mind and Withdraw from the Project?

Joining this study is voluntary. You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

The data which will be collected includes only the information you provide in the interview and the nature of your treatment for arthritis which you agree to let your doctor or rheumatologist provide.

Everything you tell the interviewer and any data collected from doctors and Rheumatologists will be confidential. Only the researcher and supervisors of the project will have access to the data. The results of the project may be published and will be available in the library but you should expect your anonymity will be preserved. You are most welcome to request a copy of the results of the project should you wish.

The data collected will be securely stored in such a way that only those mentioned above will be able to gain access to it. At the end of the project any personal information will be destroyed immediately except that, as required by the University's research policy, any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed.

Reasonable precautions will be taken to protect and destroy data gathered by email. However, the security of electronically transmitted information cannot be guaranteed. Caution is advised in the electronic transmission of sensitive material.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Researcher:

Valerie Milne
Wellington Regional Rheumatology Unit
Telephone (04)566 6999

or

Supervisor:

Dr Andrew Harrison
Wellington Regional Rheumatology Unit
Telephone (04)566 6999

This proposal has been reviewed and approved by the Central Region Human Ethics Committee

**Access to Rheumatology services in the Greater Wellington region
Consent Form for Participants**

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:-

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. The data on audio tapes will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for five years, after which it will be destroyed;
4. This project involves an open-questioning technique where the precise nature of the questions which will be asked have not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used.
5. In the event that the line of questioning does develop in such a way that I feel hesitant or uncomfortable I have a right to decline to answer any particular question(s) and also that I may withdraw from the project at any stage without any disadvantage to myself of any kind.

The results of the project may be published and available in the library but every attempt will be made to preserve my anonymity.

I understand that reasonable precautions have been taken to protect data transmitted by email but that the security of the information cannot be guaranteed.

I agree to take part in this project.

.....
(Signature of participant)

.....
(Date)

[This proposal has been reviewed and approved by the Central Region Human Ethics Committee]

APPENDIX 3

GP INFORMATION QUESTIONNAIRES

GP Information

Name:

Q1. Gender	Male	<input type="checkbox"/>
	Female	<input type="checkbox"/>
Q2. Age	(Years)	<input type="checkbox"/>
Q3. Ethnicity	New Zealand European	<input type="checkbox"/>
	Maori	<input type="checkbox"/>
	Samoan	<input type="checkbox"/>
	Cook Island Maori	<input type="checkbox"/>
	Tongan	<input type="checkbox"/>
	Niuean	<input type="checkbox"/>
	Chinese	<input type="checkbox"/>
	Indian	<input type="checkbox"/>
	Other	<input type="checkbox"/>
	(Please Specify)	<input type="checkbox"/>
<hr/>		
Q4. Total years in General Practice	(Years)	<input type="text"/>
Q5. Total years in this Practice	(Years)	<input type="text"/>
Q6. In which country did you obtain your medical degree?	(Please Specify)	<input type="text"/>
<hr/>		
Q7. In which year did you obtain your medical degree?	(Please Specify)	<input type="text"/>
Q8. Approximate list size	(Please Specify)	<input type="text"/>
Q9. Approximate number of patients seen per week	(Please Specify)	<input type="text"/>
Q10. How many hours do you normally work in this practice per week?	(Hours)	<input type="text"/>
Q11. Do you have a special interest in Musculoskeletal disorders?	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

Practice Information

Practice Name

- Q1. Type of Practice
- | | |
|----------------------------|--------------------------|
| Independent Practitioner | <input type="checkbox"/> |
| Community / Not for Profit | <input type="checkbox"/> |
| Group Practice | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> |
-

Q2. Size of Practice

Approximate number of GP FTEs (please specify)

- Q3. Age profile of Practice
- | | |
|-------------------------------------|--------------------------|
| 1/3 of patients < 5 years old | <input type="checkbox"/> |
| 2/3 patients between 5 and 65 years | <input type="checkbox"/> |
| 1/3 patients older than 65 years | <input type="checkbox"/> |

- Q4. Services
- | | |
|--|--------------------------|
| Mainly GP | <input type="checkbox"/> |
| Wider Professional Team | <input type="checkbox"/> |
| Does your practice, or any GP in your practice, have a special interest in musculoskeletal disorders? (please specify) | <input type="checkbox"/> |
-

Q5. Approximately how many patients are enrolled in your practice? (please specify)

APPENDIX 4

PERCEPTIONS AND EXPERIENCES AFFECTING GP REFERRALS

The following factors have been highlighted in international research as being important mediators in the referral of patients with inflammatory arthritis. Please indicate how well you agree or disagree with the following statements.

1. Early rheumatoid arthritis is easily detected

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

2. The most appropriate treatment for early inflammatory arthritis is NSAIDs

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

3. Most inflammatory arthritis should be treated in primary care

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

4. Treatment options used in New Zealand do not effectively slow or halt the progress of joint damage in RA

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

5. The possible side-effects of disease modifying anti-rheumatic drugs (DMARDs) outweigh the benefits in most cases of inflammatory arthritis

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

6. Early inflammatory arthritis is easily differentiated from other musculoskeletal complaints

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

7. It makes no difference when DMARD therapy is started as it will be just as effective if given when IA is more established.

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

8. I am less likely to refer a patient to Rheumatology if co-morbidities exist

1	2	3	4	5
Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree

9. I am more comfortable referring cases I am not sure about when I have a good relationship with the rheumatologist
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
10. Patient preferences about treatment influence my decision to refer
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
11. My referral decisions are always made in accordance with clinical guidelines
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
12. An important reason for referring to Rheumatology is patient reassurance
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
13. Only when patients have abnormal inflammatory markers in blood test results should they be referred to Rheumatology (e.g. rheumatoid factor, high ESR, high CRP)
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
14. It is better to wait and determine the progress of inflammatory arthritis before beginning DMARD therapy
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
15. An important reason for my referrals to Rheumatology is lack of confidence in making an inflammatory arthritis diagnosis
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
16. I am more likely to refer a younger patient quickly to rheumatology than an older patient.
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
17. The family history of a patient with joint inflammation is an important factor in early referral
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
18. I am less likely to refer people who I think are unlikely to attend specialist appointments
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |

19. If I had more time available to treat the patient in primary care I would not refer as quickly
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
20. I am less likely to refer a patient to Rheumatology if the patient has a mental illness
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
21. I have no problems communicating with Rheumatologists when I am unsure whether to refer
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
22. Patient gender is a consideration in referring quickly to Rheumatology
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
23. If a patient is reluctant to be referred to Rheumatology I would work hard to change his/her mind
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
24. I am confident the public health system will provide adequate care for patients with inflammatory arthritis
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
25. Long waiting lists affect my recommendations about referring to public rheumatology services
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
26. I am more likely to refer a patient who can afford to pay for private rheumatologist care
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
27. I feel I have enough resources to make sound rheumatology referral decisions
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
28. If I am unsure about a referral I am more likely to discuss this with colleagues, rather than rheumatologists.
- | | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Disagree | Disagree | Neither agree nor disagree | Agree | Strongly agree |
29. I feel the number of referrals I make for inflammatory arthritis is other GPs in the Wellington region
- | | | | | |
|---------------------|----------------|------------|----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 |
| Much more than most | More than most | Similar to | Less than most | Much less than most |

GP Interview Guideline

The focus of this interview is patients with inflammatory arthritis who rheumatologists think will benefit from disease-modifying drugs such as methotrexate. This includes, for example rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis. This discussion is informed by themes raised in interviews with IA patients.

Diagnosis

1. What sort of training have you had in identifying IA conditions?
2. I understand there are 'classic' and other presentations of IA. Which people, in your experience are most likely to present with a difficult to diagnose IA?
3. Why are these cases difficult? And what are the characteristics of the person or condition that makes this so?
4. How do time pressures and workload factor in the diagnosis process?
5. Does IA usually come up as a primary reason for the patient visit? Or is it often an add-on to the initial reason to visit?
6. How does your practice work to deal with difficult referral decisions? Individual decision or a process for review/informal discussion?

Communication with the patient

7. Are there problems communicating with particular patients that lead you to adopt a 'wait and see' approach? If so, what characteristics are likely to cause this?
8. Conversely are there patients that you are more likely to refer quickly, based on the way they express themselves, rather than solely on clinical factors?
9. Patient self-explanation for pain and/or swelling – how likely is this to factor into your consideration?
10. Do you place emphasis on the patient's family history of IA?

11. How important in your referral decision are patient preferences e.g. an expressed dislike of hospitals, certain meds, or a preference to try complimentary approaches?

Referrals process

12. Are you likely to wait for the results of blood tests before referring?
13. What are your impressions of the referrals process?
14. Is it easy to get information to help you with your decision to refer and prioritising the patient?
15. What do you think of the clinical guidelines? Are you likely to do an urgent referral for patients who don't meet the 'urgent' criteria but are in obvious distress, or are you likely to treat them in the practice
16. What are your thoughts around treating pain before the patient has been referred. Particularly the use of steroids?
17. What factors do you think would give the most improvement in the referrals process - patient/GP/rheumatologist?

Gaps in care

18. Who is responsible for ongoing patient care?
19. Do you see gaps in the care provided for IA patients? Examples could be physiotherapy, emotional adjustment, pain control?
20. Who do you think should provide these support services?
21. Do you initiate discussion with patients on these points, or do you think that patient has responsibility for this?

Other

22. Have you had any experiences of patients using alternative practitioners for there IA diagnosis or treatment? What are your views on this?
23. Do you think MOH policy deals adequately with IA?
24. Are there any other factors you think should be taken into account when examining the referrals process?

APPENDIX 6

NEWS OF GP SHORTAGES

The doctor is out ...

Patients face increased struggle to find a GP

Last updated 00:08 10/04/2008

THE
DOMINION
POST

Patients in the lower North Island will face even longer waits to see the family doctor as the health system struggles with an ageing population and mass retirements threatening to swamp general practice.

In the Hutt Valley, Kāpiti Coast and Manawatu, areas with the most chronic shortages, patients are already waiting up to two weeks for appointments - if they are lucky enough to be enrolled with practices at all.

Kapiti mother Karen Close said she had to wait a year to be registered with a GP after moving from Tawa three years ago, and then three months to be approved for discounted consultations.

"The worst thing was when Max, who was nine months old then, got sick at night. We went to a local medical centre, saw a different doctor every time and had to pay the casual rate."

The chairwoman of the Independent Practitioners Association Council, Bev O'Keefe, said with the average GP now 50 years old, primary health was threatened with a "looming retirement tsunami".

"We can't replace the doctors and nurses we're losing now but retirements over the next few years threaten to overwhelm us."

A Medical Council workforce survey found GP numbers nationally increased 6.2 per cent between 2005 and 2006 - but that was still 60 GPs fewer than six years previously.

Hutt Valley had the sharpest decline, falling in two years from 67 to 60 GPs per 100,000 people.

About 3000 Hutt residents are not yet enrolled with a practice, and several clinics have closed in recent years because retiring GPs were unable to find anyone to take over.

Lower Hutt GP Hans Snoek said some doctors worked into their seventies - but others got burned out.

"I haven't had a decent holiday since 2005 because I can't get a locum."

Of the 39 practices in the Hutt Valley, three briefly reopened to new patients this month.

Waiting times for non-urgent appointments for enrolled patients vary from a couple of days to two weeks.

Hutt Valley District Health Board chief executive Chai Chuah said the overflow was straining Hutt Hospital's emergency department.

The board is exploring various remedies, including running a "wrap-up" practice, subsidising extra staff or work space, and training GP registrars locally.

(The Dominion Post, 2008)

Wairarapa Times-Age

Alarm at doctor shortage

JOE DAWSON | Monday, December 11, 2006 18:00

South Wairarapa is in danger of losing its doctors if more cannot be attracted to the region.

The doctor shortage plaguing rural areas internationally is reaching a "critical" point in South Wairarapa, where the number of full time GPs has dropped from five to three.

The Featherston Medical Centre's Dr Michael Berry said the South Wairarapa's three remaining doctors; himself, Greytown's Iynkaran Pathmanathan and Martinborough's Steve Phillip, have banded together in an effort to stop the rot and attract more doctors to the region.

Dr Berry said the situation is approaching dire straits.

"Things have become quite critical in South Wairarapa.

"Greytown, Martinborough and Featherston are threatened, and we're trying to come up with some ideas to reduce that threat.

"The situation is quite fragile at the moment."

The main problem is that if more manpower cannot be attracted to the area, the chances of another doctor leaving go up, placing ever more pressure on those remaining.

"If one goes all three are likely to go. It's like dominoes."

The upshot of that would be the pressure drifting north to Masterton, and people in the south, particularly those with no transport or not much money, being put at a serious disadvantage when it comes to healthcare.

He said South Wairarapa is struggling to compete with the intense global competition there is for rural GPs, particularly the salaries on offer in places like Britain and Canada and good graduate rates in Australia.

The three GPs first floated the idea of banding together to try to stem the flow about eight months ago, but the recent losses of Dr Mortimer-Lamb from Featherston and Dr Snook from Greytown have brought matters to a head.

"We've decided we're going to have to make things happen ourselves," Dr Berry said. "Together we've got a chance, individually we're doomed.

"We've been meeting with leaders of the community to see if there are any ways we can make the place more attractive."

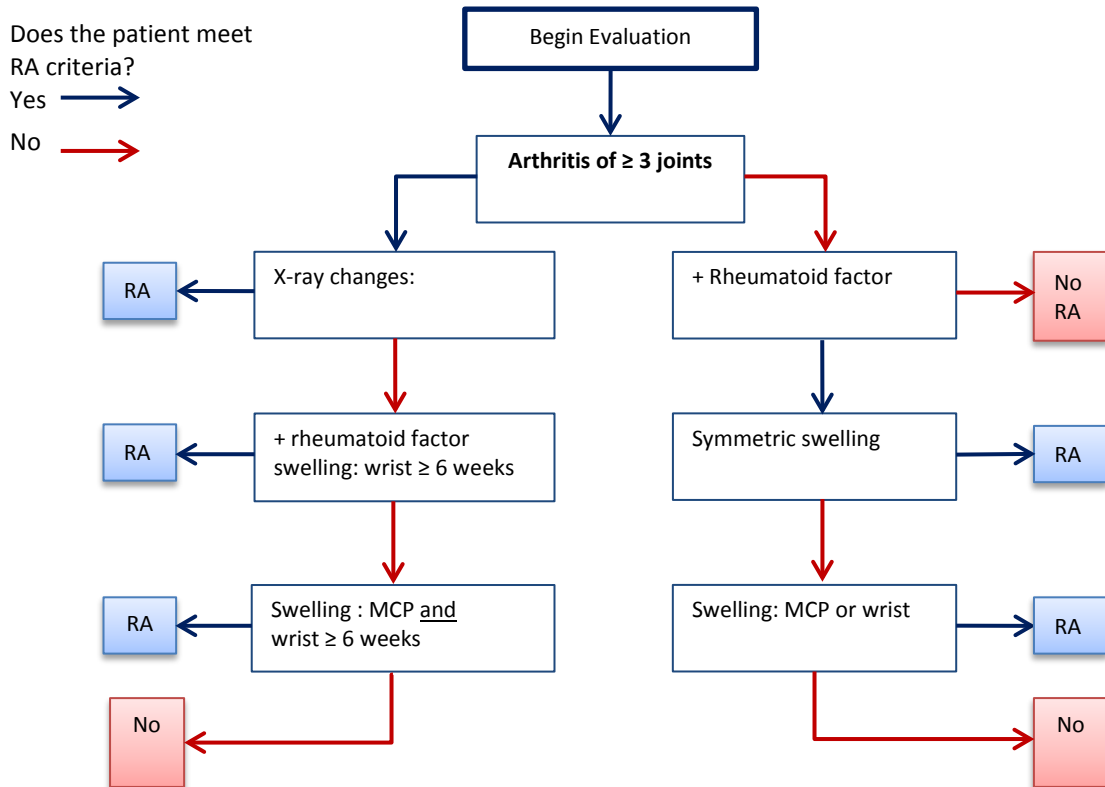
He was reluctant to divulge what ideas have been mooted as negotiations with various groups are at a "delicate" stage, he said.

"We're looking for innovative solutions, and once we know the public will know."

The PHO is supporting the doctors' moves, he said.

(Dawson, 2006)

APPENDIX 7 CLASSIFICATION CRITERIA



Simplified schematic of the ACR 1987 classification tree for Rheumatoid Arthritis.

Source: Arnett, et al (1988)

Blue lines indicate a positive response, leading to a classification of RA and red lines indicate a negative response leading to the rejection of a RA classification.

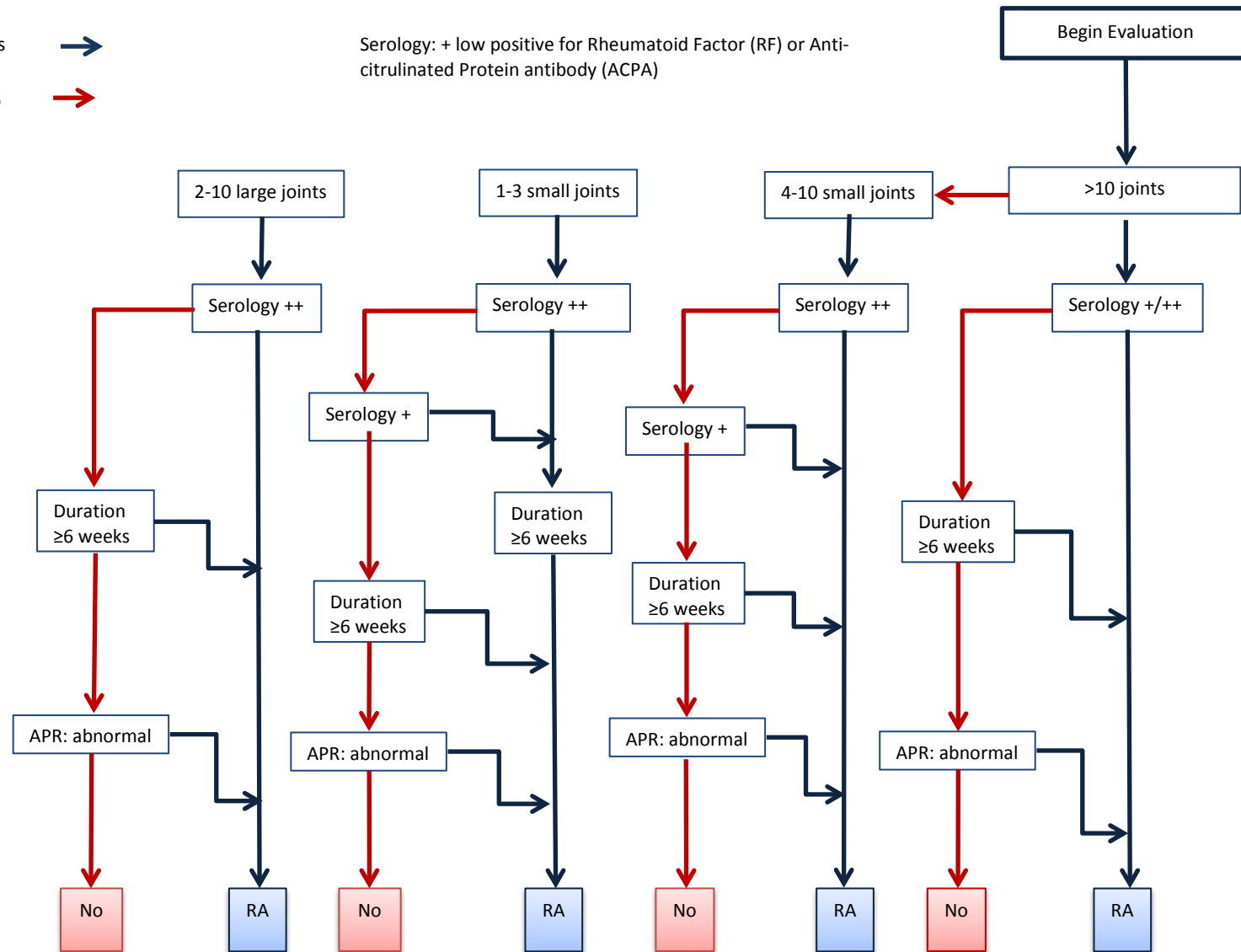
Does the patient meet RA criteria?

Yes →

No →

APR: Acute Phase Response

Serology: + low positive for Rheumatoid Factor (RF) or Anti-citrullinated Protein antibody (ACPA)



Revised classification criteria for Rheumatoid Arthritis. Derived from Aletaha, D., Neogi T., Silman, A. J., Funovits, J., Felson, D. T., Bingham III, C. O., et al. (2010). 2010 Rheumatoid Arthritis Classification Criteria: An American College of Rheumatology/European League Against Rheumatism Collaborative Initiative. Arthritis & Rheumatism 62(9), 2569-2581

APPENDIX 8

WAITING TIMES DATA

Effect	Unadjusted (univariate)		Adjusted for gender, ethnicity and age		Adjusted for all except DHB and clinic location *		Adjusted for all except DHB, clinic location * and on time	
	WR	p-value	WR	p-value	WR	p-value	WR	p-value
Gender								
Female	1.00		1.00		1.00		1.00	
Male	0.88 (0.80–0.97)	0.009	0.89 (0.81–0.98)	0.015	0.87 (0.77–0.97)	0.012	0.88 (0.81–0.99)	0.026
Ethnicity		0.076		0.094		0.96		0.54
Other	1.00		1.00		1.00		1.00	
NZ Maori	0.90 (0.76–1.05)	0.17	0.90 (0.77–1.06)	0.2	0.98 (0.81–1.19)	0.84	0.90 (0.79–1.11)	0.43
Pacific Peoples	0.85 (0.73–1.00)	0.054	0.86 (0.73–1.01)	0.059	1.02 (0.83–1.24)	0.88	0.85 (0.77–1.10)	0.36
Age (per 10 years)	0.98 (0.96–1.01)	0.19	0.98 (0.95–1.01)	0.12	0.99 (0.96–1.02)	0.58	0.98 (0.96–1.02)	0.46
DHB		<0.0001		<0.0001		<0.0001		
Hutt Valley	1.00		1.00		1.00		1.00	
Capital & Coast	1.66 (1.51–1.83)	<0.0001	1.65 (1.50–1.81)	<0.0001	1.43 (1.27–1.60)	<0.0001	1.66 (1.50–1.82)	<0.0001
Wairarapa	2.33 (1.99–2.75)	<0.0001	2.32 (1.97–2.72)	<0.0001	1.73 (1.43–2.10)	<0.0001	2.33 (1.95–2.71)	<0.0001
Area		<0.0001		<0.0001		<0.0001		
Lower Hutt	1.00		1.00		1.00		1.00	
Upper Hutt	1.03 (0.88–1.20)	0.75	1.02 (0.87–1.20)	0.77	0.99 (0.82–1.19)	0.89	1.03 (0.85–1.17)	<0.0001
Porirua	1.46 (1.26–1.69)	<0.0001	1.47 (1.26–1.70)	<0.0001	1.26 (1.06–1.50)	0.009	1.46 (1.25–1.68)	<0.0001

	Unadjusted (univariate)		Adjusted for gender, ethnicity and age		Adjusted for all except DHB and clinic location *		Adjusted for all except DHB, clinic location * and on time	
Kāpiti	1.65 (1.40–1.95)	<0.0001	1.63 (1.38–1.93)	<0.0001	1.49 (1.21–1.83)	0.0001	1.65 (1.36–1.92)	<0.0001
Wellington	1.79 (1.59–2.01)	<0.0001	1.76 (1.56–1.98)	<0.0001	1.48 (1.28–1.71)	<0.0001	1.79 (1.54–1.97)	<0.0001
Wairarapa	2.36 (2.00–2.80)	<0.0001	2.34 (1.98–2.78)	<0.0001	1.72 (1.41–2.10)	<0.0001	2.36 (1.93–2.73)	<0.0001
Clinic Location		<0.0001		<0.0001		<0.0001		
Hutt	1.00		1.00		1.00		1.00	
Kenepuru	1.68 (1.49–1.89)	<0.0001	1.69 (1.50–1.91)	<0.0001	1.47 (1.28–1.70)	<0.0001	1.68 (1.46–1.87)	<0.0001
Wellington	2.18 (1.93–2.46)	<0.0001	2.16 (1.92–2.44)	<0.0001	1.57 (1.35–1.84)	<0.0001	2.18 (1.88–2.41)	<0.0001
Greytown	3.03 (2.50–3.66)	<0.0001	3.00 (2.48–3.63)	<0.0001	1.89 (1.52–2.35)	<0.0001	3.03 (2.43–3.57)	<0.0001
PHO Type								
Independent	1.00		1.00		1.00		1.00	
Community	0.92 (0.80–1.05)	0.21	0.96 (0.83–1.11)	0.57	1.05 (0.89–1.25)	0.54	0.92 (0.92–1.24)	0.41
Timeliness								
On Time	1.00		1.00		1.00		1.00	
Late	3.72 (3.29–4.20)	<0.0001	3.72 (3.30–4.21)	<0.0001	3.19 (2.80–3.64)	<0.0001	3.45 (3.15–3.77)	<0.0001

* DHB and clinic location not adjusted for each other or area

APPENDIX 9

INITIAL DMARD TREATMENT PROTOCOLS

Illustrative treatment protocol for patients prescribed DMARDs to treat newly-diagnosed IA
<u>Methotrexate</u>
<ul style="list-style-type: none"> • 7.5mg once per week administered in 5mg and 2.5mg tablets • Up to 12 weeks before fully effective • Specific warning: avoid alcohol • Routine blood tests required to monitor side-effects (especially liver injury) and efficacy • Increased doses may be required after three months if IA is not sufficiently controlled.
With
<ul style="list-style-type: none"> • Folic acid 5mg supplement to reduce side effects 2-3 days before the methotrexate dose
Or
<u>Salazopyrin (Sulfasalazine)</u>
<ul style="list-style-type: none"> • A maximum of 2000mg in four tablets taken twice per day. First week one tablet once per day stepping up to one tablet twice per day in the second week, three tablets (one tablet once per day and two tablets once per day) in the third week and the maximum dose of two tablets twice per day in the fourth week. This dose is maintained. • Four to 12 weeks before maximum efficacy • Routine blood tests required to monitor side-effects (especially reduced blood counts) and efficacy
<u>Additionally (for pain)</u>
NSAIDs e.g. Diclofenac - one 75mg tablet twice per day after food
With
<ul style="list-style-type: none"> • Omeprazole – one 20mg capsule as cover for potential gastro-intestinal side-effects once per day before food
<u>Or (usually a short-term measure)</u>
Prednisone
<ul style="list-style-type: none"> • Up to 10 mg per day, in one or two tablets once or twice per day, tapering in 1 mg decrements per fortnight/month

Sources: (American College of Rheumatology, 2012; Emery et al., 2000; Haibel & Specker, 2009; Diane Lacaille, 2000; Lim. S. S. & Conn, 2001)

PRIVATE SPECIALIST REFERRED LABORATORY TESTING CESSATION OF SUBSIDIES

Critique of the Hutt Valley and Capital & Coast DHB
Impact Evaluation Report: Impact on
Rheumatology patients

Disclaimer: This is a personal response based on information gathered as part of a doctoral research project about access to rheumatology services in the greater Wellington region (in progress), and it reflects personal experience as a rheumatology patient. This document has not sought, and does not assume, that opinions in this document are those of rheumatologists or any other staff in the Wellington Regional Rheumatology Unit (WRRU).

Valerie Milne
Wellington School of Medicine
8 September 2009

SUMMARY

1. This response to the Capital and Coast and Hut Valley DHB *Evaluation of the effect of private specialist referred laboratory tests: Cessation of subsidies* (IER) identifies some shortcomings and discrepancies in the evaluation and contends that the impact on rheumatology patients is greater than that suggested in the report. Specialists have, from the outset, stated their concerns with the charging regime were costs (to patients), GP and specialist boundaries of care and the risk of harm from less testing. The IER has not adequately addressed these concerns through research and evidence in the case of rheumatology patients with inflammatory arthritis (IA).
2. The charging regime was justified as a correction to the anomaly of private 'diagnostic tests' in laboratories being paid for by the DHB because other diagnostic tests such as X-rays, ultrasound and MRIs are paid for by private patients. On this point tests for IA patients should be excluded – they are not for diagnosis, but for monitoring the efficacy and side-effects of medication.
3. There is question of a duty of care which needs to be addressed about the provision of drugs for private patients and ensuring accessible monitoring for the known, potentially serious, side-effects of those drugs.
4. The 6-month first assessment guideline quoted in the report is irrelevant as a basis for assuming patients are seen in a timely manner in rheumatology. Patients with IA need to begin medication much sooner than this, preferably within 28 days of onset (Elective Services, 2001) to prevent joint destruction and disability.
5. There is no analysis to support the implied conclusion that rheumatology patients are no more than mildly inconvenienced by the charging regime.
6. The IER assumes that private medical companies will pick up the charges. After almost 3 years this has not happened and there seems little indication that they will. The C&C and HV DHBs have created a geographic anomaly within New Zealand
7. The findings presented by the IER do not clearly reflect the situation for rheumatology in general and IA patients in particular. The review team has not separated out in their analysis the discrete group of IA patients from other rheumatology patients who do not require regular blood testing.
8. The justification for the implementation of the charging regime was to correct the anomaly of public funding for tests. However, by transferring the costs of blood tests from the DHBs to private patients the charging regime has created new anomalies and inequities by some patients having private care with free blood tests while others have to pay.
9. Because IA patients are high priority patients, due to disability and the need for beginning treatment quickly, non-IA patients are more likely to be impacted though longer waiting lists or being referred back to their GPs.

10. IA patients pay proportionately much more in testing charges for their private care than the average the IER has used as justification private testing in affordable. For IA patients the laboratory tests they need cost double, per annum, their consultants' charges.
11. It is implied in the report that if people can afford to have private specialist care, they are very likely to be able to afford lab testing. In reality, there are patients without medical insurance who choose private care not because they can afford it but because it an earlier initial assessment is more likely which is a key factor in minimising impacts on employment.
12. The report suggests there has been no impact on patient volumes for the DHB and the Wellington Regional Rheumatology Unit (WRRU). The WRRU has had an increased number of IA patients whereas private specialists have had a decline in IA referrals.
13. The report states that charging private patients allows for money to be used for other initiatives with greater public health benefits. For as long as the charging regime remains, at the very least the benefits to the DHBs should be used to ameliorate costs in waiting time borne by non-IA patients, not on health initiatives unrelated to rheumatology.

PURPOSE

This document is a response to the evaluation of private specialist referred laboratory testing from the viewpoint of Inflammatory Arthritis (IA) patients who require a range of monthly blood tests. It sets out some discrepancies in the report and contends that the impact on rheumatology patients is greater than that suggested in the evaluation. The evaluation did not ask patients for their views about charges for laboratory tests. The document includes some comments that were elicited from private patients who have been interviewed by the author as part of an ongoing research project about access to rheumatology services.

BACKGROUND

In November 2006 a regime of charging patients of private specialists for laboratory testing was implemented in the Capital & Coast and Hutt Valley district health boards regions. This was of particular concern to patients with inflammatory arthritis (IA) and their rheumatologists because the disease modifying anti-rheumatic drugs (DMARDs) used to control the condition require blood tests each month to monitor the efficacy and side effects of the drugs. The Impact Evaluation Report (IER) of Private specialist referred laboratory tests: cessation of subsidies was released in March 2008. The report is justification for the regime implemented by the Hutt Valley DHB and Capital & Coast DHB, in their contract with Aotea Pathology, of charging private patients for private specialist ordered laboratory testing (PSRCS).

Although commonly referred to as 'privately referred laboratory testing' the IER states the justification of charges was to correct the anomaly of DHB subsidised laboratory tests for private patients whereas other diagnostic procedures were paid for by the patient:

"The policy corrected a longstanding anomaly in which private laboratory test had been funded but other private diagnostic procedures, such as X-rays, ultrasounds or MRIs were not" (Capital and Coast DHB & Hutt Valley DHB, 2008, p. 2)

With this justification it is arguable as to whether the DHBs funding should be removed from patients whose laboratory tests are not for diagnostic purposes. IA patients' laboratory tests monitor the efficacy and side effects of state-provided and subsidised medication. The initial diagnostic tests are normally ordered by GPs as part of the referral documentation. To charge patients for test to monitor the known potential side effects state-funded medication could open up debate about the provision of state's responsibility (legal and medical) to monitor the medication it supplies. It is reasonable to argue that monitoring should be funded irrespective of the private or public status of the specialist who requests the tests. This is not simply an academic argument. In a analogous vein, the IER goes to some length to explain that GPs may be in medico-legal limbo by ordering tests for medication they do not prescribe, on the grounds that the lines of responsibility between GPs and specialists for dealing with adverse test results are blurred.

People with inflammatory arthritis (IA) (Rheumatoid Arthritis, Psoriatic Arthritis and Ankylosing Spondylitis are the most common forms of IA) are treated with disease-modifying anti-rheumatic drugs (DMARDs). DMARDs reduce inflammation and prevent joint damage. Delays of as little as three months are associated with poorer outcomes in terms of disease progression and radiologic damage (Suter, et al., 2006). These drugs are prescribed with the proviso that the patient has monthly blood tests to monitor inflammation, and to monitor blood counts and liver function for possible side-effects.

Before the implementation of the PSRCS there was particular concern expressed by rheumatologists (among others) that the charging regime would have undue impact on patients with rheumatoid arthritis. Specialist concerns were focussed on costs, GP and private boundaries of care and the risk of harm from reduced testing. A submission to exclude rheumatology patients from charges was declined by the Oversight Advisory Group (Laurie, 2007). The IER has highlighted two issues; hospital waiting times and duty of care. It considered costs to be reasonable for most patients, and the hardship allowance introduced to ameliorate the impact of the charging regime as an adequate response to the question of high costs for some patients. The hardship allowance is a means-tested allowance for patients who have paid \$500 over six months. It is considered on a case by case basis and there is no guarantee that any patient who fits the criteria for this allowance will actually receive it.

The review of IER found that there was no particular disadvantage to rheumatology patients by removing DHB-funded blood tests for private patients and implementing a charging system for these patients. The IER suggests a general overview of the Jul 05 to Jan 08 actual against budgeted First Specialist Assessments (FSAs) from Rheumatology show there is no significant change in Rheumatology volumes (Capital and Coast DHB & Hutt Valley DHB, 2008), suggesting there has been no significant transfer of private patients to public clinics.

ACTUAL REFERRAL NUMBERS

Most non-IA patients in the rheumatology do not require regular blood tests to monitor the drugs they are prescribed. The PRSC review document uses the Jul 05 to Jan 08 actual against budgeted First Specialist Assessments (FSAs) from the WRRU as evidence the policy is not having a negative impact on patients and concluded, that after allowing for monthly variation due to factors such as staff leave and additional elective services funding:

“There does not appear to be any evidence of the policy having an impact on public hospital outpatient volumes at CCDHB and HVDHB. Volumes have not changed significantly, nor have they exceeded projected targets” (p8).

The report does not state that it has evaluated only IA patients, or if its evaluation is of all patients referred to rheumatology. The assumption here is that it is all cases –

osteoarthritis, fibromyalgia, and other conditions not requiring blood tests are included in the FSA assessment. The effect of this is to dilute the impact of the charging regime on those patients that are most affected by it.

If only the IA cases are included in the analysis actual changes in to referrals to Rheumatology have increased since charging began (Table 1). During the period Dec 05 to Nov 07, there was a 30 percent increase in referrals for IA to the WRRU, and a decrease of around five percent of IA referrals to private rheumatologists.

	Public IA Referrals			Private IA Referrals		
	Year ending 30 November 2006	Year ending 30 November 2007	Percent Change	Year ending 30 November 2006	Year ending 30 November 2007	Percent Change
Annual total	268	355	32.5	210	199	-5.2
Avg / Mth	22.3	29.6	32.7	17.5	16.6	-5.1

Table 1: IA referrals Dec 05 - Nov 07

A simple analysis of this data shows that after allowing for monthly variations there is evidence of an increase in IA referrals to the WRRU, and a decrease in IA referrals to private rheumatologists in the year ending 30 November 2007 compared with referrals in the year-ending 30 November 2006 (Figure 1).

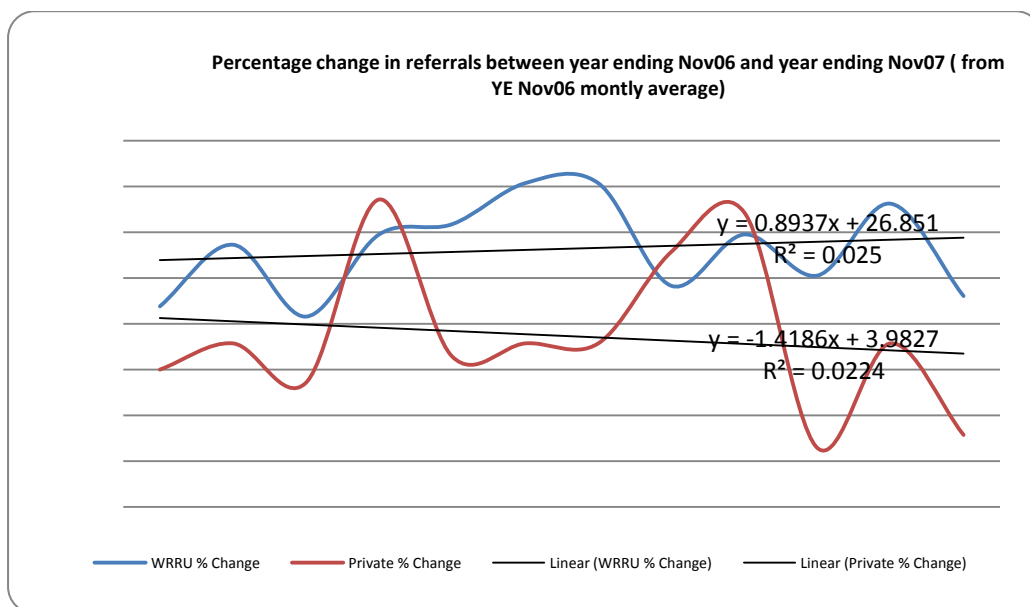


Figure 1: Change in referrals since laboratory charges were implemented
Source: HVDHB Patient Management System

This does not tell us whether patients have been referred to the WRRU directly from GPs or have had their FSA with a private rheumatologist and then switched to the

WRRU. WRRU referrals data shows that referrals from private rheumatologists to the WRRU have increased more than 250 percent (from a low level) between the year-ended 30 November 2006 and 30 November 2007, suggesting at least some patients are having their FSA privately then transferring to the WRRU¹⁹. Reasons for these referrals could include transferral directly relating to the laboratory charging regime, the impact of other diagnostic charges or the time it takes to get a FSA from referral.

WAITING TIMES

Moreover the waiting times for those with non-urgent rheumatological conditions are increasing (Figure 2). After an initial fall with the addition of 1 FTE in rheumatology in 2006, the median wait times for priority 2 and 3 patients in the year-ending 30 Nov 2008 have increased from Nov 06 by 50.1 percent and 2.9 percent respectively (Table 2). To imply a causal relationship is speculative, but the research needs to be done before it is widely assumed that there is no increase in wait times, as stated in the IER.

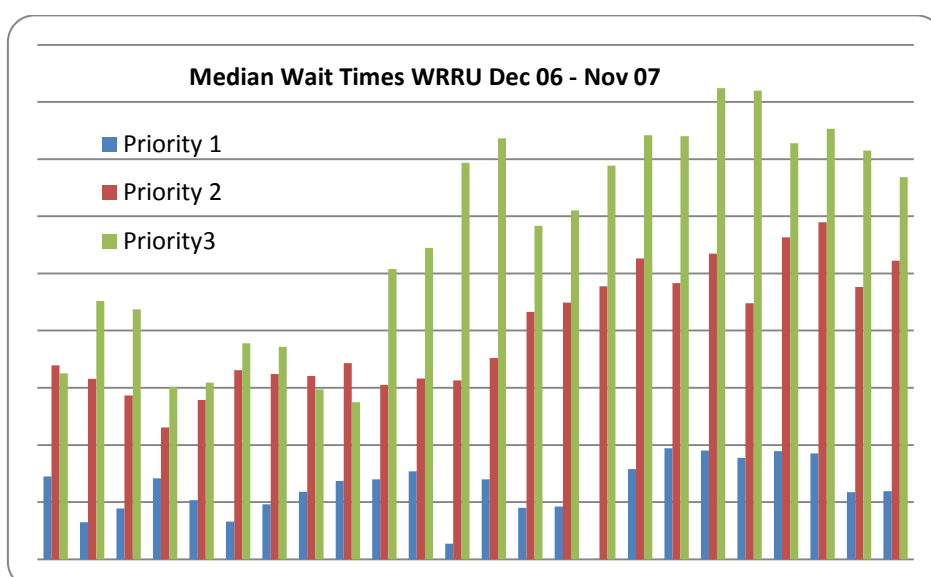


Figure 2: Median Wait Times Dec 05 - Nov 06.

Source: HVDHB Patient Management System

Median Wait Times (No. of Days) – WRRU						
Year Ending	Priority 1	%Change	Priority 2	%Change	Priority 3	%Change
November 06	32.8		64.0		142.3	
November 07	22.2	-32.3	63.2	-1.25	75.0	-47.3
November 08	31.6	42.3	96.05	52.0	146.45	95.3

Table 2: WRRU Referrals %Change.

Source: HVDHB Patient Management System

If waiting times have increased due to more IA patients using the public health system, due to the cost of blood tests, then the cost in terms of time may be being borne by non-IA patients. Rheumatoid arthritis is usually a priority one referral and

¹⁹ Confidential data. The important point is that the IER has not assessed referrals from private specialists to the public system

other IA either priority one or two. The wider impact of this situation is those with non-inflammatory conditions, such as osteoarthritis, osteoporosis, fibromyalgia and some connective tissue disorders have had their waiting times increased. Referrals which give no indication of an inflammatory condition the patient are now being referred back to the GP. In the 2005/06 financial year 4 patients were referred back to their GPs, in the 2008/09 financial year 42 patients were referred back to their GPs.

COST TO PATIENTS

At implementation there was an expectation that the average charge for laboratory tests would be approximately ten dollars per patient, per encounter:

“Private patients paid an average of \$16.51 per test and had an average of 3 tests per visit in the first year of the policy. For most individuals seeking private treatment, this is likely to amount to a small proportion of the total cost of their private care” (Capital and Coast DHB & Hutt Valley DHB, 2008, p. 2)

The Health Funds Association of New Zealand (HFANZ) has estimated the average cost at the higher figure of \$35.37 (Styles, 2007). But with both cases, for IA patients this is a gross underestimate of the costs and laboratory test charges now make up a significant proportion of the total cost of private care. A person with IA typically sees a Rheumatologist on a 3-monthly cycle at a cost of around \$400 per year, until the condition is controlled, when the number of rheumatology visits may decline. The annual cost of blood tests is twice that amount. The likely cost to an IA patient is over \$65.00 per month (Table 3) (Aotea Pathology, 2008).

The list is not exhaustive. IA patients may require further tests, for example anaemia is common in RA patients and may require investigation (another \$23.35 for iron and ferritin studies). This is a significant sum, particularly for patients on limited work-based medical insurance schemes or who are paying for their own private care. There is a means-tested hardship of \$500 after 6 months but this is set too high for most IA patients, and even if they met the criteria, they are not guaranteed relief from payments. The IER does not evaluate the rationale of the hardship allowance or the level at which it is set.

The IER does not address the timeframes of a patient’s testing regime. This is an important proviso as most IA patients prescribed DMARDs to control their condition will be taking this medication for life, and therefore will require unlimited monthly tests.

Chargeable Component	Cost
Administration Fee	13.90
Complete Blood Count	13.00
CRP	7.26
ESR	8.63
Liver Function tests	23.82
Cost per Month	66.61

Chargeable Component	Cost
Total per Annum	799.32

Table 3: Typical IA Blood Tests
Source: Aotea Pathology, 2008

It is also important to note that some patients have decided to pay for a private specialist, without the aid of medical insurance. Untreated IA results in severe pain and loss of function, frequently from onset, and it is this that drives patients to get the fastest possible treatment, not necessarily the ability to pay.

"...it was a 6-month waiting list or whatever to see a rheumatologist".

Q - do you go through the public system now?

"no, no, from that point onwards I've paid my own way, at least in terms of getting my appointments to the rheumatologists"

Resp 6, SP

The administration fee is particularly irritating for IA patients; it is in part to cover the cost of bad debt but given that IA patients present to Aotea Pathology and pay before their tests, it is unlikely they incur much of this debt. There is no provision for IA patients to have the tests without payment. The review methodology stated it would "compare revenue including admin charges with costs including bad debts" (Laurie, 2007, p. 2) however the IER reported:

"The DHBs do not have access to Aotea Pathology's detailed accounts to determine whether the annual patient encounter fees are merely adequate or excessive" (Capital and Coast DHB & Hutt Valley DHB, 2008, p. 13).

Without access to Aotea Pathology accounts there is little the DHBs can do to ensure this cost is reasonable.

An assumption was made at the start of the charging regime that private medical insurers would adjust their allowances and fees to cover the costs of charges for laboratory tests. This has not happened, which increases the likelihood of more private IA patients shifting their care to the public sector if they cannot get laboratory tests ordered by their GP.

The IER also states there is "a high degree of patient acceptance" (Capital and Coast DHB & Hutt Valley DHB, 2008, p. 2) to the charging regime. The view that there is a high level of acceptance seems to be based on the aforementioned low level of bad debt and low level of complaints to the DHBs. This is an erroneous conclusion. Qualitative research shows that IA patients do consider the testing regime unfair, but there is no forum where their concerns will be addressed sympathetically (see below). Of seven private patients in the CCDHB and HVDHB regions interviewed for a

qualitative study about access to rheumatology service, two have less frequent testing, two do not have to pay for their tests, and one is struggling to meet costs.

RISK OF HARM THROUGH REDUCED TESTING

Specialists were concerned about the risk of harm if patients cut down on testing, but this has not been addressed in the IER. Although the authors of the report wrote to GPs and specialists for their views about adverse health outcomes, few responded (8 specialists). Whether any of the specialist responses were from Rheumatologists is not stated in the report. The report states there is little other than anecdotal evidence to support the view that any patient harm was attributable to reduced testing but potentially harmful effects of reduced testing may take many months to show. The report concluded that it would be enough to promote the hardship allowance to ensure patients were not put at severe disadvantage, but IA patients will probably be just below the stated level of \$500 per 6 months - year after year (assuming costs do not rise and the hardship allowance remains static). Patients are deciding on less testing if they have to pay.

"... I pay for my blood tests I only do 2 a quarter. I know you're supposed to do them every month – but 2 a quarter."

Resp 1, Female, RA

"I used have the monthly blood tests regularly but now I'm paying for them that's stretched out to 6 weeks."

Resp 2, Female, AS

The blood test regime has also placed an extra burden on people who have disabilities which mean they have to pay more costs than others. A patient who has a workplace scheme to cover specialist visits only, provides an example of why private patients may transfer back to the public sector:

"I don't even have a car, ok?, but I wouldn't have been able to drive ahh and ... I can go on the bus but then it's difficult – I remember one time I was waiting for the bus after I'd had some x-rays and I couldn't get up the step to get on the bus y'know it was terrible, he didn't have a kneeling bus. Yeah. So it costs a lot of money for cabs, it costs money to have the blood tests because they have the system here is that if you are referred by a specialist you have to pay, and it costs more money for the medicine because a specialist does the prescription compared to the GP.... If you haven't got money, how are you going to pay?"

Resp 3, Female, AS

There are equity issues when some patients can have private care, but not pay for laboratory tests whereas others must pay and in the process make adjustments to their level of care. People feel an injustice has been done, and some have found ways

around it through GPs ordering the tests, or because they are able to get them through the public system (due to co-morbidities treated in the public sector) although they see a private rheumatologist as well.

Nowhere in the evaluation is there any indication that the reviewers actually asked the patients affected by the policy, certainly it is not outlined in the evaluation framework. Only an analysis of letters of complaint to the DHBs was included in the methodology (Laurie, 2007). There does not appear to have been any feedback or complaints mechanism widely distributed to private patients on the matter of charges, the review team does not indicate whether it looked beyond letters of complaint to the DHB (e.g. to the Minister or Ministry of Health). But more likely a factor in the lack of complaints is the realisation by some that it is a government-approved initiative, and so there is little to be gained by complaining locally.

“... but then when they changed it and the government changed the thing and you have to pay for it, I thought well ok to me it didn't make sense I'm paying for my own treatment anyway and the government doesn't chip in for any of that and now I've got to pay for the blood tests it's ridiculous. I could say I'm going to go public and you can pay for everything you know not only the blood tests.”

Resp 5, Male, RA

“I pay \$40 per month for blood tests, but I can afford it, I don't think it is fair though, but what can you do?”

Resp 4, Female, RA

The few and tapering off formal complaints could easily be a reflection of the lack of a publicised forum to complain and an acceptance that charges will remain rather than acceptance of the policy.

GPs AND SPECIALIST BOUNDARIES OF CARE

The IEP strongly opposes GPs ordering tests for specialists. The DHBs have issued strongly-worded letters to GPs to dissuade them from this practice on the grounds there is a medico-legal risk in ordering tests without follow-up.

“It is appropriate for GPs to refuse to order tests for specialists, not just to avoid cost shifting, but more importantly to ensure clarity about which practitioner is responsible for patient care” (Capital and Coast DHB & Hutt Valley DHB, 2008, p. 3).

For some GPs ordering tests for rheumatologists is not a lot different to writing prescriptions for the DMARDs these patients have to take, which they do routinely (with the agreement of the rheumatologist) when a patient's rheumatology appointment cycle is greater than three months. It could be argued that if the GP

writes the prescription, then the GP should in fact be responsible for ordering the tests.

"... but anyway I thought oh well I have to pay and then I found out that the blood testing people here [at a suburban centre] can't take payments you've got to go to Porirua to pay for it. It's just like nuts. And then I found a back door as you do um yeah I found another way of doing it so yeah... it's coming from the doctor now he is the primary recipient of the tests and the cc is to Rheumatologist."

Resp 5, Male, RA

For patients with more than one health condition it is simply more convenient, and safer, for the GPs office to be the repository of test results.

"No my blood tests come through my GP and CRP and ESR are minor elements of the blood test that I get these days ... so blood tests go through my GP, yes and um ... I guess I still bounce in and out of the public system."

Resp 6, Male, SP and co-morbidities

"He has all the notes and that and he's always checking up on me and what not, he's pretty good and I can talk about it."

Resp 7, Female, IA and co-morbidities

The philosophy of shared care, rather than care boundaries, is evident in accounts of patient care. GPs are already copied in on test results and follow-up. With established treatment and stable IA, GPs can take on a greater role in patient care, as they do with other chronic disease like heart disease, asthma and diabetes. Ordering tests rather than receiving a copy is simply a procedural change, not a change in the care the GP is already providing for the patient.

"Yeah I think there is a distinct benefit in primary care becoming more involved and not just GPs but also nurses. [blood tests are] ... pretty automatic, they can be generated on a monthly or 3-monthly basis."

GP1

"When people are stable and sending them back to the GP with a management plan ... I mean we can manage a lot of stuff so we can do that. I don't mind taking on a few of my stable folk if that lets the hospital get on with more acute people."

GP2

GPs are regularly copied in on laboratory test results. Even now GPs will consider it their responsibility to follow-up on tests they have not ordered:

"Inevitably we try and do a double-check ... if they [patients] haven't heard we say then contact ah the department. Let them know there is a problem, if you have no success let us know and we'll follow it up."

GP1

"I mean the person who orders the tests is meant to follow them up but it's good if we get a copy because if you come in with another complaint we need to know these things. [with ordering for private patients] I sort of think if they are the usual tests that I would do - your standard inflammatory factors and blood counts and things I should be doing that because this is my patient and I've got other issues that that patient might have".

GP3

DECLINE IN TESTING

The IER shows there has been a decline in private specialist testing. As the above data and statements show IA patients are likely to have moved back into the public system, they have reduced their tests (with a greater risk of greater joint damage or delayed identification of side effects), or have GPs willing to take on the responsibility of ordering blood tests. The authors of the IER have however declined to attribute the fall in private tests to the charging regime. It shows part of the decline is attributable to national level initiatives, but tests at a national level have declined by 4.5%, and in the Wellington region have declined by 7.4% in the year since charging was introduced (Capital and Coast DHB & Hutt Valley DHB, 2008, pp. 7-8). The report does not provide an adequate explanation for this drop over and above initiatives taken nation-wide. The IER speculates reasons such as financial incentives to reduce cost and unnecessary testing and has discounted the impact of charges, but does not provide the evidence to support or disprove this scenario.

CONCLUSION

The IER was produced as an evaluation of the charges for laboratory testing for privately referred patients. The IER has not correctly represented the situation for inflammatory arthritis patients. The IER has made a number of unsupported assumptions in its reporting of costs, and shifts from private to public care.

As a group, IA patients' costs are significantly more than the average charges, and are double the cost of consultants' fees. Rheumatology research shows that patient referrals to the public WRRU have increased whereas referrals to private specialists have decreased in the year since the implementation of charges, suggesting a transfer of patients from the private to the public sector.

In submissions before the introduction of the charging regime, concern was expressed that patients would be at risk of harm if they reduced or eliminated

laboratory tests due to charges. Despite a drop in laboratory tests greater than the national average, the IER states that there is no evidence that there is a link to the introduction of charges, or that there is any increased harm that can be attributed to the charging regime. Although there is speculation, the IER provides no evidence that charges have not affected patient behaviour. However, interviews with IA patients have shown that financial costs of tests are in fact changing the behaviour of IA patients and some have reduced the number of tests they have to below that recommended by their specialists. The potential for increased harm remains.

The IER expressed concerns about GPs ordering tests for specialists and the medico-legal consequences of this. For patients with a chronic disease this argument does not stack up. GPs offices are a suitable repository for test results, and results are already copied to GPs even if they have not ordered them, because the results can be used for the evaluation of co-morbidities and are a part of pro-active, shared patient care. If GPs work within a framework of shared care, they will be routinely write prescriptions for the medications authorised by rheumatologists and provide access to other services useful to IA as part of their usual practice. Ordering laboratory tests can be interpreted as part of good patient care, providing a seamless interface for the patient, rather than boundaries which reduce access.

The evaluation methodology excluded direct contact with patients. This reduces any conclusion about the impact on patients to supposition only. Similarly Aotea Pathology did not produce financial information to justify charges, particularly the administration charge. To produce a comprehensive evaluation supporting the charging regime which this evaluation has attempted to do, the IER would need to communicate with patients and provide evidence that the charges are financially justified.

RECOMMENDATIONS

1. Remove IA patients from the charging regime. The justification of the charging regime is to remove diagnostic test anomalies, not the monitoring of drug efficacy and side effects.
2. Assess actual IA referral numbers to the WRRU, waiting times and denial of referrals for low priority patients to obtain a true picture of the load on rheumatology which, in part, may be attributable to the increase in laboratory charges for private patients
3. Assess the impact on non-IA patients of increased IA referrals to the WRRU
4. Obtain information from Aotea Pathology to ensure charges, particularly the administration charge, are justifiable on a financial basis
5. Communicate with patients affected by the charging regime to assess impact and hardship. Impacts would include those the IER has evaluated, but from a patient perspective; the affordability of tests, shifts from the private to public sector, changes in frequency of tests and increased risk of harm.
6. Until IA patients are exempt from charges, reduce barriers to the hardship allowance. It is set too high for IA patients, and administered on a 6-monthly

basis, although IA patients' tests are required for many years. This needs to be factored into the model used to assess hardship.

7. Acknowledge in information to GPs about ordering laboratory tests that along with medico-legal risk, as part of good patient care, particularly for patients with chronic disease and co-morbidities, it is appropriate that GPs order tests on behalf of specialists.

PATIENT AGE, ETHNICITY AND WAITING
TIMES DETERMINE THE LIKELIHOOD OF
NON-ATTENDANCE AT A FIRST
SPECIALIST RHEUMATOLOGY
ASSESSMENT

ORIGINAL ARTICLE

Patient age, ethnicity and waiting times determine the likelihood of non-attendance at a first specialist rheumatology assessment

Valerie MILNE,¹ Robin KEARNS² and Andrew HARRISON¹

¹Department of Medicine, Wellington School of Medicine, University of Otago, Wellington, and ²Geography and Environmental Science, School of Environment, University of Auckland, Auckland, New Zealand

Abstract

Objective: To identify demographic and geographic factors associated with non-attendance for first specialist assessment (FSA) at a publicly funded rheumatology clinic and identify changes in service provision that might improve attendance rates.

Method: Administrative data for 1953 new referrals over a 2-year period was collected from a New Zealand public rheumatology unit. Patient characteristics and location variables were tested for significance and odds ratios were generated to determine the relationship between non-attendance and referrals data.

Results: Patients in the 20–29 years age-group were least likely to attend appointments ($P \leq 0.001$, OR 2.81, 95%CI 1.59–4.98). Māori and Pacific Peoples were each almost twice as likely to miss a FSA ($P = 0.02$, OR 1.87, 95%CI 1.11–3.15 and OR 1.89, 95%CI 1.11–3.22) as New Zealand Europeans. Non-attendance was independently associated with longer waiting times to FSA; with residential location and the uneven provision of services being strong predictors of longer waiting times ($P \leq 0.001$).

Conclusion: Non-attendance is associated with ethnicity, age and waiting times. It is likely that high deprivation influences ethnic variations in attendance but reasons for young people's non-attendance were difficult to identify. Patients domiciled further from the main rheumatology clinic were also less likely to attend. The influence of ethnicity and deprivation may be underestimated in this study as high Maori and Pacific ethnic populations live closer to well-resourced clinics. Focusing administrative resources on at-risk groups and restructuring the clinical service to improve uneven waiting times would be expected to improve attendance rates across the region.

Key words: age, ethnicity, New Zealand, non-attendance, waiting time.

INTRODUCTION

Non-attendance at a rheumatology clinic first specialist assessment (FSA) results in a lost opportunity for early diagnosis and treatment of rheumatological conditions and is detrimental to the efficient and cost-effective delivery of rheumatology services. Each patient who

does not attend an appointment adds to misallocation of clinic resources, increasing costs and waiting times for other patients.^{1,2} It is particularly important to remove barriers to early assessment of inflammatory arthritis patients, for whom commencement of disease-modifying anti-rheumatic drugs (DMARDs) within 3 months of onset of symptoms results in less radiological damage, improved function and less disability than patients who begin treatment later.^{3,4}

There is a lack of published data on risk factors for non-attendance, defined as failure to attend an appointment without prior notification, in rheumatology

Correspondence: Ms. Valerie Milne, Department of Medicine, Wellington School of Medicine, PO Box 7343, Wellington South, Wellington 6242, New Zealand. Email: milva891@student.otago.ac.nz

clinics. In other services, multiple factors influence non-attendance.⁵ Administrative data is limited in building an understanding of the causes of non-attendance but can identify groups that are over-represented in poor attendance statistics and may provide insight as to how resources might be distributed to improve attendance rates. Factors identified in previous studies include age, either younger^{6,7} or older patients,⁸ and ethnicity.⁹ Gender has not featured strongly as a predictor of non-attendance.⁵ Associations of non-attendance with area-level variables like urban and rural differences have also been highlighted in several studies.^{8,10} The structure of the service under investigation may also exacerbate non-attendance, with long waiting times^{1,10,11} and the quality of clinic administrative procedures¹² identified as impeding attendance.

Patient forgetfulness can account for up to half of non-attendance.^{2,13,14} To improve attendance rates the Wellington Regional Rheumatology Unit (WRRU) follows up written notification of appointments with telephone calls 1–3 days before the appointment, and if unconfirmed the appointment is cancelled.

The WRRU provides a regional rheumatology service to the three District Health Boards (DHBs) in the Wellington region (population 470 240): Capital & Coast (CCDHB), Wairarapa (WDHB) and Hutt Valley (HVDHB). The intervention rate across the DHBs provides benchmark data to ensure equity of referral numbers, and financial disadvantages ensue if fewer patients than expected are referred. Clinics are located at Hutt, Kenepuru and Wellington Hospitals, and the Greytown Medical Centre. Patients are generally referred to the clinic nearest their residential address but urgent cases from all districts are likely to be referred to Hutt Hospital, where the service is based.

The CCDHB (population 289 200) has the largest population in the region and provides services for three distinct geographic areas: Wellington, Porirua and the Kāpiti Coast. Wellington has, on average, the wealthiest and most educated population in the region with small pockets of relative deprivation. It has low ethnic diversity, good public transport links and lower private vehicle ownership. Porirua has the highest proportion of Māori and Pacific Peoples in the Wellington region. Nearly one in five residents are of Māori descent and one in four is of Pacific descent. It also has the youngest median age and high levels of relative deprivation. Kāpiti has the lowest median income in the CCDHB region and this may reflect the high number of retired people in this coastal area.^{15,16}

The HVDHB (population 141 500) incorporates Upper Hutt and Lower Hutt cities. One in six of Lower Hutt's residents are of Māori descent, while Upper Hutt has one in seven Māori residents. Residents of both cities are on average older than those of Wellington, have fewer post-school qualifications and lower incomes.¹⁵

The WDHB (population 39 540) serves a large rural and semi-rural region. It is suffering from gradual aging and depopulation. It has the lowest median income in the Wellington region, low ethnic diversity and the lowest level of post-school qualifications.^{15,17}

New Zealand primary healthcare services are grouped in primary health organizations (PHOs) and between 90% and 97% of the Wellington region's population is enrolled in PHOs.¹⁸ Important objectives for PHOs are the reduction of barriers to primary care and improving access to secondary services. Independent practitioner PHOs (IPHO) are most often organized on a geographic basis, but Access PHOs (APHO) have a focus on not-for-profit services in communities of interest that have poor health outcomes, and are often organized around the needs of low-income Māori and Pacific Peoples.¹⁹ The aim of the current study was to determine, through using administrative data, whether patient or referral characteristics could predict non-attendance at a public rheumatology service and to identify aspects of the referral process where modifications might improve attendance rates.

PATIENTS AND METHODS

Data for this retrospective case-study was retrieved from the HVDHB patient management system. All new referrals to the WRRU for the period December 2005 to November 2007 were evaluated. Retrieved data included the age, gender and ethnicity of the patients, the referral sources, referral priority and waiting time from referral to FSA. The clinic to which the patient was referred was also derived from the administrative data. The patient area and PHO were derived from the recorded general practitioner (GP) details. These variables enabled an assessment of non-attendance on three levels: individual characteristics, area-level variables and service provision. Informed consent was obtained from all interviewees and ethical approval for this study was granted by the Central Region Ethics Committee.

After removing duplicates and operator errors the administrative data included 1953 FSAs. Referrals were cross-referenced with patient records to verify final appointment status and, where possible, to complete

missing data. In some cases (< 10%) area-level data was not able to be verified. These cases were included in the study. FSAs cancelled by the WRRU or the patient were excluded from the analysis, as were records where the patient was referred while an in-patient and treated on the same date, or was deceased before the appointment date. Referrals excluded from the study were more likely to be for older patients ($P = 0.05$) or patients who had longer waiting times from referral to appointment date ($P = 0.003$). Ultimately 1821 referrals were included in the non-attendance analysis.

Statistical analyses were generated in SPSS v.19, (2010: SPSS Inc., Chicago, IL, USA). Statistical significance of association with non-attendance was tested using chi-square tests for the categorical variables and the Mann–Whitney non-parametric test for age data and waiting time for an appointment. Variables that were significant were included in logistic regression models that produced odds ratios (OR) with 95% confidence intervals (CI). The resulting ORs were tested for the effects of confounders that were significantly associated with non-attendance. Further analysis tested the effect of individual and area-level determinants on waiting times. Since waiting times were not normally distributed, the analysis used a log transformation. This generated ratios of the geometric mean (GM) with 95% CIs. Multiple linear regression models were run to adjust for confounders.

RESULTS

The WRRU FSA non-attendance rate was 7.1%. Patient characteristics that were significantly associated with FSA non-attendance were patient age ($P \leq 0.001$) and ethnicity ($P = 0.002$). PHO enrolment was significantly associated with non-attendance and patients referred from APHOs were more than twice as likely to miss FSAs as patients referred from IPHOs ($P \leq 0.001$).

Māori and Pacific Peoples were nearly twice as likely as NZ Europeans to default on an FSA. A level of interaction between ethnicity and age in the adjusted OR is apparent (Fig. 1) with a 6.4% reduction in the odds of non-attendance for Pacific Peoples, after adjusting for age group. Adjusting for the PHO-type reduced Pacific Peoples' chances of non-attendance from almost twice that of NZ Europeans to < 1.3 times the NZ European non-attendance ($P = 0.52$), and for Māori the odds of non-attendance for PHO-type reduced from 1.9 to 1.6 times the NZ European rate ($P = 0.19$). For Māori and Pacific Peoples, adjusting for waiting time increases the odds of non-attendance by 3–6% ($P = 0.02$). This

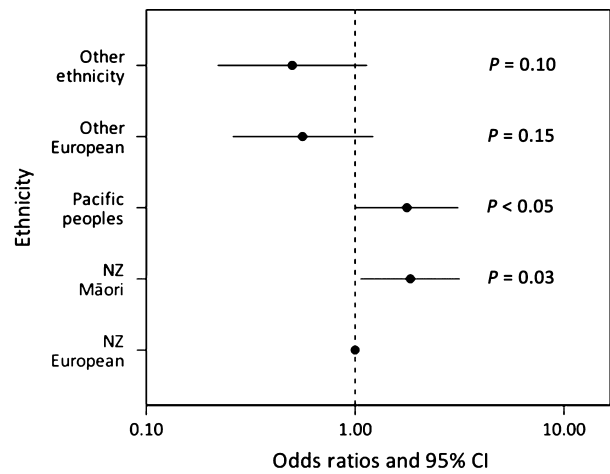


Figure 1 Non-attendance by ethnicity – adjusted for age.

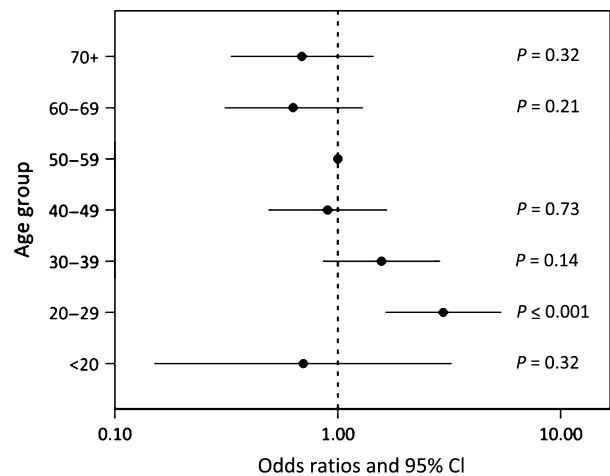


Figure 2 Non-attendance by age group – adjusted for ethnicity.

increase reflects the suppressive effect of the shorter waiting times that benefit these two groups of patients.

The mean age for a non-attender was 44.2 years (SD = 17.4) compared with 51.6 years (SD = 17.0) for an attended FSA. Patients aged 20–29 were nearly three times as likely to miss an FSA as 50–59 year-olds ($P \leq 0.001$) (Fig. 2). These odds of non-attendance barely changed after adjusting for PHO-type, waiting time and the appointment being within the priority timeframe.

Patients from APHOs are 2.4 times less likely to attend an FSA than patients from IPHOs, and after adjusting for ethnicity, remain twice as likely to attend compared with patients from IPHOs (Fig. 3). The time-

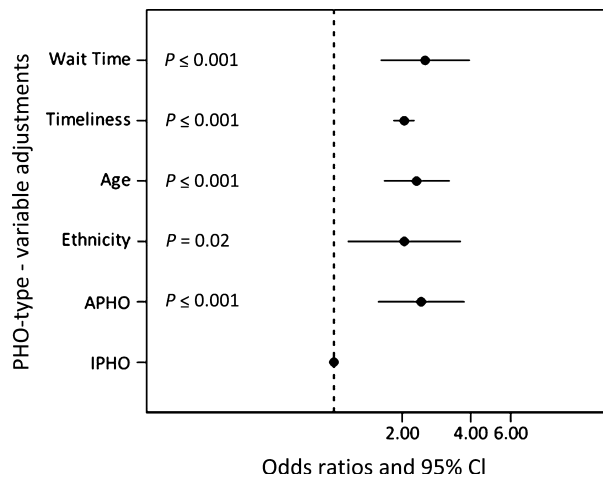


Figure 3 Non-attendance by PHO type – unadjusted and adjusted for ethnicity, age, wait and timeliness.

liness of the appointment is also a significant factor in non-attendance, with patients whose appointments are outside the priority timeframe 1.7 times less likely to attend ($P = 0.01$, OR 1.73, 95%CI 1.14–2.61).

The length of the waiting from referral to FSA was significantly correlated with non-attendance ($P \leq 0.001$). Attending patients had a median wait of 51 days (mean = 67.9, SD = 57.2) compared with a median wait of 75 days (mean = 84.6, SD = 57.1) for non-attenders. Waiting times are usually derived from the priority assigned to the presenting symptoms. Priority 1 (P1) patients are expected to be seen within 4 weeks, P2 within 12 weeks and P3 24 weeks.²⁰ Priority ranking varied only marginally between ethnic groups and age groups and these variations did not disadvantage groups with high non-attendance rates.

Waiting times, after adjusting for priority ranking, were not significantly associated with patient age and ethnicity, but were associated with the geographic attributes of the referral: DHB ($P \leq 0.001$), Area ($P \leq 0.001$), PHO ($P \leq 0.001$) and Clinic ($P \leq 0.001$). Patients referred to the Hutt clinic were significantly more likely to be seen within the expected priority timeframe compared with Wellington (OR = 2.17, 95%CI 1.95–2.43) and Greytown clinics (OR = 3.03, 95%CI 2.55–3.59). The Hutt clinics also saw 20% more patients within the expected timeframe than Kenepuru ($P \leq 0.001$). On average women have longer waiting times than men, most likely because there are almost 40% more P3 FSAs for women ($P \leq 0.001$), but they are as likely as men to be seen within the expected priority timeframe ($P = 0.27$).

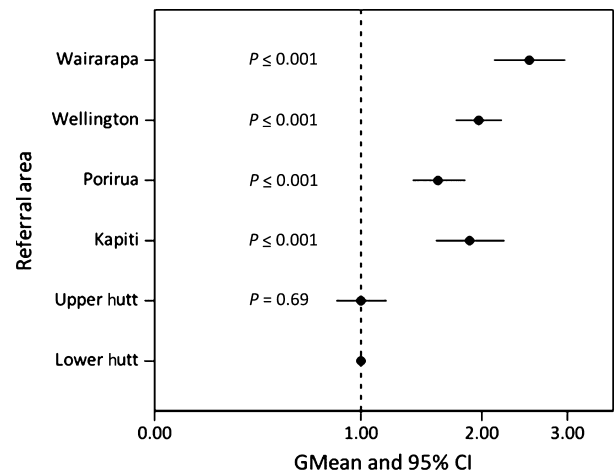


Figure 4 Waiting times by referral area.

Patients from Lower and Upper Hutt were significantly more likely to have a shorter wait to FSA (Fig. 4), and waiting times between DHBs also considerably varied. Patients referred from Capital & Coast DHB and Wairarapa DHB waited significantly longer for FSAs than Hutt Valley DHB patients ($P \leq 0.001$). This result reflects the very long waiting times at Wellington (mean wait = 100 days) and Greytown clinics (mean wait = 119 days).

DISCUSSION

Rheumatology non-attendance of 7.1% compares favorably with the mean non-attendance rates in the Wellington region. The HVDHB recorded 13.5%, non-attendance, CCDHB 9.5% and WDHB 9.8%. The WRRU non-attendance rate is similar to the mean national rheumatology OPD non-attendance rate of 7.3% (range = 3.0–15.7%).²¹

Primary analysis of administrative data identified patient age, ethnicity, PHO and waiting time as the main factors associated with non-attendance. Māori, Pacific and younger patients were less likely to attend than other ethnic or age groups, but did not have longer waiting times; moreover the areas and clinics with the longest waiting times did not have significantly higher likelihood of non-attendance. Age and waiting time independently influenced non-attendance, while PHO type smoothed the ethnic variations in non-attendance.

Drivers of non-attendance for Māori and Pacific Peoples' non-attendance differ; Māori non-attendance is only marginally improved after adjusting for non-attendance of young people, whereas for Pacific Peoples, who have a higher proportion of 20–29 year-olds there

is an appreciable reduction in non-attendance. Administrative data does not usually provide information about the contextual background of patient groups and a focus on the recorded patient characteristics is insufficient to explain why negative healthcare responses might arise.²² However, the distinction between APHOs and IPHOs allows some comparisons to be made in terms of population groupings and area-level deprivation, because PHOs reflect the socio-economic characteristics of the population groups they serve. The funding formula for APHOs encourages location of health services in deprived areas,²³ and up to two-thirds of patients enrolled in Wellington region APHOs are from high-needs communities (Māori, Pacific Peoples and/or living in the most deprived areas), compared to a quarter of IPHO patients.¹⁸ This stratification between IPHO and APHOs provides a basis for investigating whether rheumatology services are effectively reaching high-needs patients, and area deprivation should be a focus of further research about Māori and Pacific Peoples' non-attendance. Although there appears to be a connection between high needs and non-attendance, alternative explanations for these groups having greater non-attendance rates are that language barriers make the notification and reminder process more likely to fail, particularly for Pacific Peoples, or that customs, religious beliefs and cultural expectations²⁴ influence non-attendance. These issues have been recognized in primary care programs designed to improve access to healthcare within the Wellington Region.²⁵ The argument against language barriers is that patients of 'other ethnicity', who are non-European, non-Māori and non-Pacific Peoples, and who may reasonably be expected to experience language barriers, have the second highest rate of attendance.

The timeliness of FSAs has a noticeable effect on Māori non-attendance and is a factor in young people's non-attendance. A possible explanation is patients' beliefs about the reasons for longer than expected waiting times. Perceptions of institutional racism have elsewhere been cited as a reason for low engagement of Māori patients in the health system and Māori are 10 times more likely to self-report experiences of discrimination than European healthcare users.²⁶ A study of hospitalization rates in Christchurch found that while European rates were strongly related to deprivation, hospitalization rates for Māori patients living in areas of high deprivation were similar to those for Māori patients living in less deprived areas. Suggested reasons for this included cultural barriers or perceptions of discrimination.²⁷ A study of young rheumatology patients

transferring to adult services has shown that young people regard long waiting times as a lack of respect and that attendance is affected by perceived discrimination.²⁸ Understanding the beliefs about, and effects of, appointment timeliness for groups at risk of non-attendance could be a productive line of inquiry. Beliefs and expectations around symptoms,²⁹ having an episodic illness that subsides with time, or the availability of primary care treatment that suppresses symptoms, may also account for non-attendance in these groups, for example there is a recognized tendency for Māori and Pacific Peoples to use pain relievers in preference to appropriately prescribed preventative medications.³⁰

The association between non-attendance and waiting times is not an unexpected finding and has previously been cited as independently influencing non-attendance.¹ This study shows that the WRRU service structure is the predominant cause of long waiting times. Longer waiting times for FSAs reflect increasing travelling times for rheumatologists from the WRRU base at Hutt Hospital to outlying clinics. This finding is in keeping with previously published data on rheumatology service volumes,³¹ and reinforces a conclusion that waiting times result from an unequal distribution of rheumatologists' time. The WRRU base at Hutt Hospital has the greatest share of service volumes with more than twice the clinic hours per head of population than the combined hours of all other clinics, mainly due to the location of rheumatologists' offices, more capacity for acute cases and availability of ancillary resources at Hutt such as allied health professionals. The data suggests Māori and Pacific Peoples' non-attendance rates are suppressed by shorter waiting times because a large proportion of these populations live in proximity to clinics with the most adequate resources (Hutt and Kenepuru). A similar suppressive effect for younger patients occurs, with half of all patients aged 20–29 seen at Hutt and only 3% seen at Greytown where waiting times were longer. This suggests that any adjustment to improve waiting times by reducing variations in clinic resources needs to account for probable increases in non-attendance of Māori, Pacific Peoples and other high non-attenders unless mitigating measures are taken.

Strategies to ameliorate deprivation effects that reduce access could improve non-attendance rates for Māori and Pacific Peoples as well as high-needs patients. A study of Māori non-attendance at OPDs in Auckland found almost half of respondents were unable to get to the clinic due to factors associated with deprivation, for example, access to transport. The study concluded that focusing on policies to reduce non-attendance in

deprived areas could be equally suitable for Māori and patients of other ethnic backgrounds.³²

Limitations of this study include reliance on accuracy of administrative data. Input errors were found; however, cross-checking with patient notes strengthened accuracy of the data. Location details were missing for < 1% of patients, and timeliness data was unavailable for approximately one in five patients. Patient characteristics, in particular ethnicity, may not have been correctly entered. During the period when this data was collected the WRRU did not derive ethnicity data from PHO databases which have since been shown to be statistically more accurate in identifying Māori than DHB databases,³³ the likely impact being that Māori referrals are underestimated in this study. The administrative data are the WRRU's record of events, not the patient's. By interrogating only these data the patient's voice is missing in the interpretation of the attendance record; nevertheless, valuable information can be easily and quickly obtained to monitor service quality, identify strategies to reduce non-attendance, ensure at-risk patient groups are effectively targeted and suggest opportunities for implementing improvements at the policy level.

Monitoring of attendance data could be used to help determine patients that are at risk of non-attendance and provide a basis for strategies to reduce barriers to non-attendance. Clerical resources may be more effective if focused on at-risk demographic groups, which include people living in areas of high deprivation, with an emphasis on Māori and Pacific Peoples. Further research may identify cultural or language barriers that impact on Māori and Pacific Peoples' non-attendance in addition to economic deprivation. However, information on attitudes toward rheumatology care, beliefs about symptoms and probable treatment options may reveal barriers to attendance. Identifying these barriers may be particularly important for patients in the 20–29 years age-group. It is likely that different approaches will be required to reduce non-attendance related to age and ethnicity.³⁴

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