The patient experience of musculoskeletal imaging: a mixed methods study

Dr Sandra Bourke
MBChB, FRACP, BSc

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ABSTRACT

Introduction:

Musculoskeletal (MSK) imaging tests are used for diagnosis and management of arthritis. Although the technical and performance properties of conventional radiography (CR), ultrasound (US), computed tomography (CT) and magnetic resonance imaging (MRI) are well recognised, few studies have examined the patient experience of undergoing these tests. The aim of this study was to understand the patient experience of undergoing MSK imaging tests and to identify factors that contribute most to the patient experience.

Methods:

This study consisted of two stages. Stage one involved detailed semi-structured interviews with 33 patients with inflammatory arthritis who had undergone a recent joint CR, US, CT or MRI scan about their experience of the test. Interviews were transcribed and thematic analysis used to identify key themes.

Stage two involved the generation of questionnaire items about MSK imaging from these interviews. Questionnaires were posted to 514 people with inflammatory arthritis who had undergone one of the four imaging modalities over a four month period. Respondents were asked to rate different aspects of the imaging tests on Likert scales. Variables associated with the overall patient experience of the test were analysed using linear regression models.

Results:

The interviews provided valuable information about the patient experience of MSK imaging. Patient knowledge about tests was informed by information they received from their doctor and their previous experience of imaging tests. Most patients were aware of potential harm from intravenous contrast or radiation. However, patients perceived imaging as part of standard clinical care and believed the benefits of tests outweighed the potential risks. Discomfort was described; both emotional discomfort due to claustrophobia and negative interactions with staff, and physical discomfort due to positioning. Some felt anxious waiting for tests or results. Viewing images resulted in improved understanding of disease and a sense of personal involvement in their arthritis treatment.

There were 108 questionnaire respondents. Analysis of the questionnaire items showed that there were no significant differences in item answers for the four different imaging modalities. Multivariate linear regression identified five question items that were independently correlated with overall experience. Two items correlated positively (‘staff

made the experience better' and 'part of usual care') and two correlated negatively ('discomfort during the test' and 'waiting for the test'). For those who saw their images 'seeing improves understanding' was positively independently associated with the overall experience.

Conclusions:

This study has identified factors before, during and after an MSK imaging test that contribute to the overall patient experience. Our findings show that MSK imaging tests are well tolerated by patients with arthritis who have a realistic perception of their value and potential risks. We recommend that patients having these tests are given sufficient information such as the approximate waiting time for their test and results and the potential risks of the test. The patient experience of MSK imaging for inflammatory arthritis could be optimised by ensuring positive interactions with radiology staff with careful consideration of patient comfort during the test, and viewing images with patients to improve their involvement in clinical care.

PREFACE

I was solely responsible for the acquisition of data in both stages of the study. In stage one I obtained consent from and conducted detailed semi-structured interviews with 33 participants following their MSK imaging test. All ensuing data was collated and analysed personally with advice and assistance from my research supervisor Professor Nicola Dalbeth and thesis supervisor Associate Professor William Taylor.

For stage two, I obtained a list of all rheumatology outpatients at Auckland and Waitemata district health boards who had had one of the four MSK tests done in the previous six weeks, and posted them an invitation letter, patient information sheet and questionnaire, over a four month period. I collected the returned questionnaires and was responsible for data entry. Data analysis was overseen by my supervisors.

A research article on stage one of the study has been submitted to the Journal of Clinical Rheumatology. As first author, I was responsible for drafting the article and revising it critically for important intellectual content. Stage two of the study will also be submitted to a scientific journal in the foreseeable future.

I am indebted to my supervisors for their expert guidance in formulating and writing this thesis.

I would like to acknowledge financial support from Arthritis New Zealand and the New Zealand Rheumatology Association that enabled me to undertake this research.

I would like to thank the participants who gave their time generously to participate in the study. I also acknowledge my family for their constant support.

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List of Abbreviations

MSK	Musculoskeletal
CR	Conventional radiography
US	Ultrasound
CT	Computed tomography
DECT	Dual energy computed tomography
MRI	Magnetic resonance imaging
OA	Osteoarthritis
RA	Rheumatoid arthritis
IA	Inflammatory arthritis
EULAR	European league against rheumatism
mSv	Millisievert
MSU	Monosodium urate crystals
OMERACT	The outcomes in rheumatology clinical trials group
DHB	District health board

Chapter One: Introduction

1.1 Introduction

Musculoskeletal (MSK) imaging tests are frequently undertaken in the clinical care of patients with inflammatory arthritis to diagnose and monitor their arthritis. Our study aims to examine the patient experience of undergoing these tests which include conventional radiology (CR), ultrasound (US), computed tomography (CT) and magnetic resonance imaging (MRI). The study is made up of two stages. In stage one participants who have had a recent imaging test are interviewed about their experience. Stage two uses the information from stage one to design a postal questionnaire survey, which is sent to patients who have had an imaging test. This study will provide valuable new information about the patient experience of MSK imaging and will inform clinical decisions regarding the selection of imaging modalities for diagnosing or monitoring arthritis.

The patient experience has been defined in previous studies as a reflection of events that happen independently and collectively across the continuum of care with a focus on individualized care and tailoring of services to meet patient needs and engage them as partners in their care. It is strongly tied to patients' expectations and is more than satisfaction alone (Wolf et al., 2014). The patient experience encompasses patients' feelings and perceptions, but these terms are not interchangeable.

1.2 Musculoskeletal imaging in patients with arthritis

This chapter will focus on the MSK imaging tests which are used to assess arthritic joints. It will look into the differences between them, the advantages and disadvantages of each and why a particular imaging test might be selected for a certain patient. It will explore why the patients' experience of MSK imaging tests is important and summarise patients' experiences of imaging tests from previous literature.

MSK imaging is widely used in rheumatology clinical practice and research settings. Imaging tools assist with both diagnosis and monitoring of arthritis. They are also frequently used as outcome measures in rheumatology clinical trials. The most commonly used

musculoskeletal imaging techniques include CR, US, CT and MRI. These four modalities differ substantially from each other, with variation in many factors including: the time required to complete scanning, the requirement for scanning in an enclosed space, exposure to noise, exposure to radiation, the requirement for joint manipulation or compression, the need for intravenous contrast injection, and the ability to acquire, manipulate and view images in real-time (Gellhorn & Carlson, 2013; MacKenzie et al., 1995; Thorp et al., 1990).

Two key aspects of inflammatory arthritis for which an imaging modality is relevant are joint inflammation and structural damage. According to the EULAR (European league against rheumatism) recommendations for imaging in rheumatoid arthritis (RA) CR of the hands and feet should be used as the initial imaging technique to detect structural damage such as erosions or joint space narrowing. If that is normal they recommend further imaging with either US or MRI (Colebatch et al., 2013) to detect damage at an earlier time point. In regards to detection of joint inflammation they note that US and MRI are superior to clinical examination by two fold (Colebatch et al., 2013). Nonetheless CR is still the imaging "gold standard" used to monitor structural progression in RA drug trials (Baker et al., 2015). In peripheral spondyloarthritis EULAR similarly recommends CR to monitor structural damage and US or MRI to aid diagnosis and monitor disease activity (Mandl et al., 2015).

In addition to joint inflammation and structural damage, gout has urate deposition. CR can give information on joint damage but not urate deposition or inflammation. US and MRI are best to identify synovial inflammation and/or erosions. Both US and DECT can give information on urate deposition (Durcan et al., 2015).

In the early stages of osteoarthritis (OA) developments such as osteophytes, subchondral sclerosis, or subchondral cysts are well visualized with CR. However, Braun and Gold (2012) recommend a combination of imaging techniques to provide a comprehensive assessment of the OA joint. CR can assess joint space width, which provides an indirect measure of the integrity of both hyaline and fibrocartilage and MRI can detect additional features such as bone marrow oedema like lesions which are areas of bone necrosis and fibrosis associated with progressive cartilage damage (Braun & Gold, 2012). Amin et al (2015) are in agreement reporting that 42% of symptomatic patients show cartilage loss on MRI despite CR being normal so if CR is used alone a substantial proportion of knees with cartilage loss will be missed (Amin et al., 2005).

Each imaging modality has specific advantages and disadvantages and the clinician and patient must decide together which modality is most appropriate for that patient. Exploration of the patient experience may therefore have direct clinical application, by informing decisions regarding selection of imaging methods for diagnosis and monitoring of disease, particularly where similar information is obtained from multiple modalities.

1.3 The advantages and disadvantages of musculoskeletal imaging tests

1.3.1 Conventional radiography

CR uses x-rays to visualise bones and other internal structures. CR is used interchangeably with x-ray in this thesis. CR is easily accessible and relatively safe so is usually the first investigation for a patient presenting with joint symptoms. Various pathological abnormalities can be assessed using CR, including peri-articular osteopenia, bone cysts, bone erosions, joint space narrowing, subluxation, dislocation, sclerosis and ankylosis (Bijlsma, 2012). It allows differentiation of different types of arthritis such as RA, OA, crystal arthropathies and psoriatic arthritis, based on specific pathology associated with these conditions. CR allows easy serial comparison for assessment of disease progression and is often part of the basic documentation of disease monitoring (Bohndorf & Schalm, 1996).

In RA the overall sensitivity, specificity and accuracy of CR at detecting erosions in wrist bones were 24%, 99% and 63%, respectively (Døhn et al., 2008). CR has a 87.3% agreement when compared to CT for the presence of erosion in gout (Dalbeth et al., 2009). However, there is an absence of specific radiographic findings in early disease. Erosions only become consistently visualised on CR of the metacarpophalangeal joints when 20-30% of the bone is eroded on MRI (Aletaha et al., 2010). As the presence of erosions is related to a poor long-term functional and radiographic outcome it is desirable to detect them early. In gout studies US has been shown to identify more small erosions than CR but both tests give comparable results when looking at large erosions (Schueller-Weidekamm et al., 2007).

One disadvantage of CR is exposure to ionising radiation however, the levels are low compared to an average annual background radiation of 2 millisieverts (mSv) and to other imaging modalities such as CT. An x-ray of an extremity exposes someone to 0.001 mSv and a chest x-ray (anteroposterior and lateral) exposes them to 0.1 mSv (Skinner, 2013). To put

this into perspective exposures of aircrew to cosmic radiation are typically around 1.8 mSv per year for domestic routes, and around 4 mSv per year for international flight routes (Arpansa, 2017). Another disadvantage of CR is that it is unable to assess disease activity (Colebatch et al., 2013), as it cannot detect inflammation.

1.3.2 Ultrasound

Ultrasound (US) is a safe, quick, easily accessible bedside procedure that visualises tissues as acoustic reflections. Its strengths are visualising synovitis of joints, bursae and tendon sheaths and bone erosions. Over the last decade US has become more accessible to rheumatologists and is now done routinely by many rheumatologists in their clinical practice.

US is more sensitive in detecting bony erosions in RA when compared with CR (Wiell et al., 2007). US is effective at detecting enthesitis in spondyloarthritis, such as Achilles tendonitis, which can go unnoticed because of the lack of precision and sensitivity of physical examination to detect it. Findings of tendonitis on US include thickening and loss of the uniform, linear echo pattern of the involved tendon (Pope et al., 2015). US can detect crystalline material as it reflects ultrasound waves more strongly than surrounding tissues and can be readily distinguished as a parallel hyperechoic line next to the bony contour (Thiele & Schlesinger, 2007). This is known as the double contour sign and has been confirmed by identification of intra-articular microscopic monosodium urate (MSU) crystals (Naredo et al., 2014).

Many arthritis patients deemed to be in clinical remission still have active joint disease without any obvious symptoms or physical signs. A recent study found that 75.4% of arthritis patients believed to be in clinical remission had ultrasound-positive synovitis at baseline and are at risk of further progression of joint damage due to ongoing inflammation (Okano et al., 2015). Using ultrasound to diagnose active subclinical synovitis can identify patients who may benefit from more intensive treatment, preventing further joint damage and subsequent disability (Okano et al., 2015), however escalating treatment in asymptomatic patients is not widely supported.

US can be used to directly visualise needle placement during injection or aspiration. Up to 70% of intra-articular corticosteroid injections are inaccurately placed, which may contribute to an inadequate response. One study comparing US guided injections to clinical examination guided injections found superior anatomical needle placement in US guided injections leading

to greater improvement in joint function for the patient (Cunnington et al., 2010). Other studies have shown improvement in joint symptoms following an intra-articular injection irrespective of whether the needle was in the targeted structure or not (Hegedus et al., 2010).

US is a dynamic study allowing the affected part to be imaged in real time, observing for pathologic movement in tendons, bursae, muscles, or joints. Further advantages of US are that it is less expensive than MRI or CT and patients can be given immediate feedback and started on a treatment plan at the same visit, if required (Lento & Primack, 2008).

One disadvantage of US is that it is highly operator dependent. A study looking at rheumatologists performing MSK US demonstrated moderate to good correlations between 14 independent observers. However they were classified as expert scanners. They then compared US and MRI results (45 joints in total) and found an overall agreement of 82% (Scheel et al., 2005). US has been found to be less reliable in obese patients (Sauvain et al., 2016). Several studies have shown a high level of inter-machine reliability regarding patellar tendon length measurement (Gellhorn & Carlson, 2013) and grading of power doppler (D'Agostino et al., 2008).

1.3.3 Computed tomography

A CT scan uses computer processed combinations of many x-ray images taken from different angles to provide tomographic images of the body. CT provides more detailed assessment of the severity of joint disease than CR because of its tomographic nature. It is especially useful for visualising bone and cartilage, in fact CT is usually the imaging modality of choice for evaluating bone (McKinnis, 2014) and it is the “gold standard” for detecting bone erosions in gouty arthritis (Dalbeth et al., 2009). It is often used as the reference method against which the performances of MRI and US, at detecting erosions, are compared.

In addition to information obtained from a conventional CT scan, dual energy computed tomography (DECT) gives us information about urate deposition. The use of two different x-ray energies can differentiate iodine, uric acid and calcium from soft tissues. The dual energies provide information about tissue composition beyond that obtainable with single-energy techniques (Coursey et al., 2010). DECT is highly accurate at detecting uric acid deposition, therefore is useful in gout. It is often used in patients with suspected gout who have a negative aspirate for MSU crystals (Bongartz et al., 2015). DECT use is not widespread as it is not available in many centres.

The main disadvantage of CT is radiation exposure; the radiation exposure of DECT has been calculated at 0.05–0.2 mSv per examined region (Durcan et al., 2015). It varies depending on the manufacturer and the specific parameters employed; such as tube current, pitch, and energy. If low tube currents are used, radiation doses are similar to those used to acquire single-energy images (Coursey et al., 2010). Henzler (2012) supports this view commenting that there is strong evidence that DECT is not associated with increased radiation dose levels when compared to CT (Henzler et al., 2012). A CT chest involves 8 mSv of radiation, which is equivalent to 400 chest x-rays. The additional lifetime cancer risk after having a CT chest is 1 in 1200 compared to a chest x-ray which is 1 in 100,000 (Skinner, 2013). There is a 5% excess risk of death from cancer with a 1000 mSv radiation dose (Lin, 2010).

In general the use of CT in evaluating patients with early inflammatory arthritis is limited, as more sensitive tools not requiring radiation are available such as US and MRI (Bijlsma, 2012). Another disadvantage is the inability to visualise soft tissue structures, other than bone and cartilage, with discernible clarity and so is not able to clearly demonstrate changes such as infection or inflammation (Bijlsma, 2012).

1.3.4 Magnetic resonance imaging

MRI uses a combination of a magnet, radiofrequencies and a computer to visualise bone and soft tissues in three dimensions using a multiplanar technique and is uniquely suited to imaging joints. MRI detects structural damage in the form of bony erosions on average two years before they appear on plain radiographs, enabling earlier escalation of treatment (Aletaha et al., 2010). It is also more sensitive than CR in demonstrating progressive erosive disease.

MRI has a clear advantage over CR and CT, in its ability to image soft tissues and fluid within the joint. Imaging studies comparing CR, US and MRI demonstrate that MRI and US are more sensitive at finding inflammatory or destructive changes compared to CR or clinical examination (Wiell et al., 2007). As per US, MRI can detect persistent inflammation of joints in people who are thought to be in clinical remission (Colebatch et al., 2013). MRI is unique in evaluating bone oedema which appears to be an independent predictor of erosion development and future functional outcome (Conaghan et al., 2003).

Unlike CR and CT, there is no exposure to ionised radiation, however intravenous gadolinium is often used as a contrast dye to differentiate synovial membrane enhancement from the surrounding tissues. Several studies of gadolinium-based contrast agents reported finding "deposits in post-mortem brain tissue samples or disrupted signal intensity ratios in certain brain areas" of patients who had undergone multiple imaging scans with the agent; the significance of this finding is not yet understood (Samson, 2015). There is also a risk of nephrotoxicity and allergic reaction to gadolinium (Rogosnitzky & Branch, 2016).

Another disadvantage of MRI is that many patients have feelings of anxiety, lack of control or claustrophobia during the scan, due to the enclosed space, high temperature and loud noise (Carlsson & Carlsson, 2013; MacKenzie et al., 1995; Quirk et al., 1989; Törnqviste et al., 2006).

1.4 Why the patient experience is important

Many factors influence the choice of imaging tests used to evaluate arthritic joints. In addition to accuracy and cost, patient preference and tolerance are important considerations, when requesting an imaging test (Makanjee et al., 2015). A negative patient experience can be caused by a mismatch between their expectation of a procedure and the actual experience of the procedure (Nightingale et al., 2012). Failure to meet patient expectations may impact on visit satisfaction and patients' health-related anxiety. As MSK imaging tests are done frequently in patients with arthritis it is important to ensure that the patient experience of these tests is satisfactory. Although the technical and performance properties of CR, US, CT and MRI are well recognised, very few studies have examined the patient experience of undergoing imaging tests. The majority that have been done focused on MRI (Carlsson & Carlsson, 2013; MacKenzie et al., 1995; Munn & Jordan, 2011; Törnqviste et al., 2006) and none were specifically in patients with arthritis.

The Outcomes in Rheumatology Clinical Trials (OMERACT) group is an international initiative that plays a critical role in development, validation and standardisation of clinical and radiographic outcome measures for clinical trials in arthritis. OMERACT has a central focus on patient participation at each stage of the OMERACT process (de Wit et al., 2014). In order for an outcome measure to be endorsed by OMERACT, the measure is assessed according to the OMERACT filter which includes three components; truth, discrimination and feasibility. Feasibility refers to the practicalities of a tool and patient burden is a core consideration in the assessment of feasibility (Wells et al., 2014). In the context of outcome

research, patient involvement is essential to ensure that measurement sets are relevant, consistent and patient-orientated (de Wit et al., 2013). The lack of data regarding patient experience is a major barrier to assessing the feasibility of various imaging outcome measures for studies in gout (Grainger et al., 2015). This may also be true for other forms of inflammatory arthritis.

Several studies have commented on the importance of patient participation in clinical decision making (Bairstow et al., 2010; Makanjee et al., 2015). Referral for an imaging test initiates a complex medical encounter that involves the patient interacting with multiple health care providers and technologies (Makanjee et al., 2015). Negative experiences during scanning can lead to aborted scans which have financial implications as valuable staff and equipment time is lost (Dewey et al., 2007). Makanjee et al. (2015) recommends a patient centred approach when conducting a diagnostic imaging test which involves engaging with and listening to the patient as an active participant and providing quality professional services.

1.5 Literature review of patients' experiences of imaging tests

An electronic narrative literature review was performed searching Pubmed and Science Direct using a combination of the following search terms: 'computed tomography', 'diagnostic', 'experience', 'imaging', 'magnetic resonance', 'patient', 'perception', 'radiography' and 'ultrasound'. The search was limited to papers in English from 1960 through to 1st of April 2016. The search was not limited to patients with arthritis. There were no specific inclusion or exclusion criteria. Bibliographies were also reviewed for relevant papers. In total there were fourteen relevant papers; of these ten included MRI and seven were exclusively about MRI. There were three each on CR and US and four on CT.

1.5.1 Patients' experiences during imaging

There is a lack of data on patients' experiences during CR and US. Murphy (2001) noted several patients were claustrophobic during CT, something that has not been significant in previous research (Murphy, 2001). Thorp (1990) explored the patient experience of CT and MRI. Patients rated specific features of the procedures as unpleasant; the highest rated were side effects of the dye, lying still during the procedure and the confined space. The only significant difference between CT and MRI patients was the confined space of the scanner

which was rated as unpleasant by a significantly higher proportion of MRI patients (Thorp et al., 1990).

Despite MRI being a non-invasive and painless test, patients often experience anxiety-related reactions. During an MRI scan 5 to 10% of patients experience severe distress, while up to 30% experience considerable apprehension (Melendez & McCrank, 1993). Anxiety reactions range from complaints about the duration of the test, the noise inside the bore and the high temperature to psychological distress, panic and claustrophobia (MacKenzie et al., 1995; Melendez & McCrank, 1993). The more serious reactions may result in images of reduced diagnostic value secondary to movement artefact or aborted studies, which may be costly to the patient and staff. Modern MRI machines which are more patient friendly have lower claustrophobia rates (Dewey et al., 2007), however they have not eliminated it.

Patients also report a wide range of other feelings during MRI, such as feeling as if they are in another world or a feeling of loss of control (Törnqviste et al., 2006). Patients are frequently surprised at the limited space within the magnetic coil, and many describe the experience as comparable to being in a "coffin or a tomb" (Murphy, 2001).

MacKenzie (1995) conducted one of the largest studies of patients' experience of MRI. More than 300 people filled out a pre and post MRI questionnaire. They found that pre-imaging anxiety was associated with a previous 'unpleasant' imaging experience. Fifteen common factors were identified as being 'unpleasant' for patients during an MRI scan; the four most frequent of these were symptoms of claustrophobia, pain, the scan itself and the noise in the scanner (MacKenzie et al., 1995). Interestingly, anxiety was not found to be associated with the patient's understanding of the test, the duration of the test or their previous imaging experience (MacKenzie et al., 1995). Pre-imaging anxiety scores differed depending on the body region being examined by MRI, for instance knee scores were significantly lower than those for spine or head (MacKenzie et al., 1995) suggesting that feelings of anxiety are more intense if the upper body is scanned. Munn (2011) performed a systematic review of qualitative studies looking at the patient experience of high technology imaging and found that different coping strategies were used in the studies, including visualisation, where the participants actively imagined themselves somewhere else, such as on a beach (Munn & Jordan, 2011).

1.5.2 Viewing their own images

Carlin (2014) explored patients' views on seeing their own CR, CT or MRI images. He found that patients who were shown their images had enhanced understanding of their medical problem. For example a patient commented that pain seemed easier to manage once they had seen the source. He also found that it changed the physician-patient interaction as the patient felt more involved in the consultation (Carlin et al., 2014).

In a similar note, Sahbudin (2016) reported reduced anxiety and improved understanding in patients undergoing ultrasound guided steroid injection. Much of this appeared to be associated with patients seeing the images for themselves (Sahbudin et al., 2016).

1.5.3 Important patient issues

Studies report that the interaction with radiographers is very important to patients whether they feel threatened by the imaging test or not (Carlsson & Carlsson, 2013). In MacKenzie's study (1995) patients identified specific staff actions which had helped them through the procedure. The most important staff behaviours to patients were a friendly manner, good communication throughout the scan, providing reassurance to the patient and prior explanation of the procedure (MacKenzie et al., 1995).

Patients perceive time to go more slowly during imaging tests, for instance in Carlsson's study (2013) MRI scanning time was experienced as being very long, even though the longest scan was only 30 minutes (Carlsson & Carlsson, 2013). Quirk's (1989) study also reported an impairment of the patients sense of time during MRI scanning; "When you're in there it feels like an eternity" (Quirk et al., 1989).

In a study comparing patient satisfaction during shoulder US and MRI, US was preferred ten times more than MRI. The authors attributed this to the shorter duration of the test and the fact that US is interactive, allowing conversation between the patient and examiner and opportunity for explanation (Middleton et al., 2004).

1.5.4 Knowledge about the test

Studies have shown that patients lack awareness of risks and benefits of different imaging tests. A recent study involved patients presenting for cardiac imaging tests to fill out a survey on radiation exposure. They found that 43% wrongly believed that MRI involves radiation, whereas 84% knew that plain x-ray was associated with radiation. Patients having a CT were

more likely to know that a CT utilised radiation than those having other tests (Bannon, 2015). This lack of knowledge is surprising as patients are consented for MRIs and CTs and therefore should be aware of the risks involved. Seventy nine percent believed the benefits of having the test outweighed the radiation risks (Bannon, 2015).

Another study surveyed emergency department patients on their knowledge of radiation exposure from medical imaging, and subsequent radiation-induced malignancies (Repplinger et al., 2016). They too found that participants had a limited understanding of the risks of CT and MRI. Only 14% correctly identified that CT has 100 times the amount of radiation of CR and only a quarter knew of the increased lifetime risk of cancer after 3-5 abdominal CTs. Approximately 78% believed that an MRI scan involved radiation and more than half thought MRI was associated with an increased cancer risk. The authors identified a significant relationship between correctly answered questions and having a college degree or experience as a health care professional (Repplinger et al., 2016).

Makanjee (2015) explored diagnostic imaging from the perspective of the healthcare provider and patient. They found a lack of evidence that the risks or benefits of tests or what to expect of the test were discussed with patients prior to the tests. This absence of information often resulted in the patient being more uncertain about the test. In the majority of cases patients were sent for x-rays without seeking their consent. Also they found that patients were kept in suspense about who would give them their results and when (Makanjee et al., 2015).

Nearly half of the patients in Quirk's (1989) study reported that they received no information on the MRI procedure. In retrospect patients reported they should have been given more information on the spatial construction of the MRI, the noise, duration and temperature. Sixty nine percent of patients thought they should have been forewarned about the extreme constrictiveness of the scan (Quirk et al., 1989). Quirk's paper recommends that as well as being informed about how the MRI scan works and the risks involved, patients should also be made aware of the anxiety-producing features of the experience. In Murphy's study (2001) patients most common recommendation was to have the procedure explained beforehand and to be shown around the equipment (Murphy, 2001).

In contrast to this, MacKenzie (1995) discovered that 76% of patients who were having an MRI considered that they knew what an MRI involved, compared to 14% who did not and

10% who did not respond. The majority (83%) appeared to understand the reason they were having the MRI scan done (MacKenzie et al., 1995).

In summary, previous studies have shown that patients have different experiences of MSK imaging tests. Claustrophobia and anxiety are experienced predominantly during MRI scans. Patients value good interactions with radiology staff, being provided adequate information about the test and viewing their own images.

1.6 Aim of the study

As evidenced above, there is scant literature on how patients feel about CR and US. There is slightly more data on CT and MRI. However, overall there is very limited data on the patient experience of these routine tests which are done frequently for patients with arthritis to aid both diagnosis and management. The aim of this study is to examine the patient experience of MSK imaging tests for investigation of inflammatory arthritis and to understand what factors contribute to the patient experience. Our overarching hypothesis is that patients with inflammatory arthritis have specific preferences for MSK imaging tests. Stage two of the study will quantify which factors contribute most to the patient experience and discover whether different modalities are associated with a different experience. The study results will provide valuable information about the patient experience of MSK imaging and will help inform clinical decision making about appropriate MSK imaging modalities for patients with inflammatory arthritis.

1.7 Outline of Chapters

Chapter one provides the background to this thesis and outlines the justification for the research question. Chapter two will detail the methodology of stage one; this involves semi-structured interviews with patients post imaging test. Chapter three will report the results of stage one detailing the patients' experiences and feelings in regards to CR, US, CT and MRI. Chapter four will describe the methodology of stage two; including the formation of the questionnaire and cognitive testing. Stage two involves a postal questionnaire regarding patients' experience of MSK imaging tests. Chapter five will report the results of the postal questionnaire survey. Chapter six will discuss and interpret the significance of our findings, address the limitations of the study and discuss potential clinical implications.

Chapter Two: Methodology for stage one

2.1 Introduction

The aim of this study is to examine the experience of musculoskeletal imaging for people with inflammatory arthritis. It utilised a mixed method approach involving two stages. Stage one, the qualitative component, involved semi-structured interviews of patients with arthritis who had recently had an imaging test to identify key themes that described their experience. These themes were used to develop a questionnaire for stage two, the quantitative component, to understand what factors contribute to the patient experience of MSK imaging tests for investigation of inflammatory arthritis.

This chapter will describe the methodology of stage one. It will detail inclusion criteria and definitions specific to the study. It will explain the interview structure and process. Subsequently it will describe how the interview data was analysed using thematic analysis.

2.2 Study Design

Qualitative research explores the meanings that people attach to their social experiences and how they make sense of their world. Meanings and interpretation are complex phenomena that cannot be dealt with statistically (Pope & Mays, 2007). Qualitative research involves the collection, analysis and interpretation of data which relates to the social world and the concepts and behaviours of people within it (Anderson, 2010). As there is little previous research on patients' experience of musculoskeletal imaging, this study was devised with an initial qualitative component to explore patients' beliefs, values and behaviours in greater detail, enabling us to identify relevant questions for the questionnaire in stage two. This study design, with qualitative research informing generation of a questionnaire has been successfully used in previous inflammatory arthritis studies (Aati et al., 2014; Aati et al., 2015). The main strength of a qualitative approach is that the inquiry is broad allowing participants to raise issues that matter most to them. The strength of quantitative studies lies in their rapid administration and evaluation time and legitimate, reliable data. Questionnaires produce a large amount of data in a short time for a low cost. The disadvantages of questionnaires include difficulty securing a high response rate and that the data produced often lacks depth on the topic of interest (Kelley et al., 2003). The main disadvantage of

qualitative analysis is that their findings cannot be extended to wider populations with the same degree of certainty that quantitative analyses can because the findings are not tested to discover whether they are statistically significant or due to chance (Ochieng, 2009). Mixed method studies are increasingly recognised as valuable as they combine the strengths of each methodology and minimize the weaknesses (Creswell & Plano Clark, 2007).

Inclusion criteria for participants were: being over 18 years of age, able to speak English and have had a recent (within the previous six weeks) peripheral joint imaging test for diagnosis or management of inflammatory arthritis. Participants in stage one had to be capable of providing written informed consent. There was no consent form for stage two, as the act of returning the questionnaire indicated consent.

Imaging tests for inclusion were conventional radiography (CR), ultrasound (US), computed tomography (CT) and magnetic resonance imaging (MRI). We did not include nuclear medicine tests such as positron emission tomography or dual energy x-ray absorptiometry scans in this study as they are not used routinely to diagnose or monitor arthritis.

For this study inflammatory arthritis included confirmed or suspected rheumatoid arthritis, psoriatic arthritis, gout, and undifferentiated inflammatory arthritis. Peripheral joints were defined as any joints distal to the shoulder (elbow, wrist, hand) in the upper limb and any joints distal to the hip (knee, ankle, foot) in the lower limb. A six week time period was chosen to ensure recall of the details of the imaging procedure. Many of the participants had more than one imaging procedure during this time, and in that situation, all relevant imaging procedures were included.

Participants for both stages were recruited from the rheumatology and radiology outpatient departments at Auckland District Health Board (DHB). Stage two participants were also recruited from Waitemata DHB. The study was approved by the New Zealand Health and Disability Ethics Committee (Approval number 15/CEN/188) and participants in stage one provided written informed consent according to ethics committee standard operating procedures.

2.3 Data collection for stage one

Participants who fulfilled the inclusion criteria were sent an invitation letter from their rheumatology service, asking them to get in contact with the investigator if they wished to be involved. To ensure that the breadth of patient experience was captured, purposive sampling was used to recruit a diverse range of participants of different ethnicity, sex, age and diagnosis. Targeted recruitment methods were used to ensure the inclusion of Māori participants.

Detailed semi-structured interviews were then conducted by a single interviewer (SB). This type of interview consists of open-ended questions that aim to explore the experience of the musculoskeletal imaging test but also allow the interviewer to diverge in order to pursue an idea or response in more detail (Britten, 1995). The flexibility of this approach, particularly compared to structured interviews, also allows for the discovery or elaboration of information that is important to participants but may not have previously been thought of as pertinent by the research team (Gill et al., 2008).

An interview schedule was developed following a review of relevant literature regarding the patient experience of imaging tests. Additional socio-demographic and clinical information such as age, ethnicity and type of arthritis was collected using an interview-administered semi-structured questionnaire. Participants were initially asked a warm up question about their arthritis and the impact that it has on their lives. This was done to encourage the participants to 'open up' and discuss their experience of the phenomenon in detail (Ryan et al., 2007). The remaining questions were divided into four sections; before the test, during the test, after the test and overall reflections of the test. The first section focused on why they were having the test and the information they were given prior to it. Section two covered the procedure in detail and how they felt during it. The next section was about receiving the test results; how they felt about the results and the way the results were explained to them, or if they had not received their results yet, how they felt about the wait. The last section covered their overall experience of the test; any likes or dislikes, any concerns about their safety. The interviews were highly interactive, the interviewer aimed to be responsive to the language and concepts used by the interviewee and in addition to the established questions, used prompts and probes to clarify concepts and elicit detail. The interview schedule is located in appendix A.

All interviews took place at a location separate from the imaging unit. Travel expenses and a $20 koha were provided to participants. Qualitative samples are often small (Fossey et al., 2002) but this is not a problem as the researcher is not attempting to generalise the findings. Data gathered from subsequent participants builds on the information from previous subjects and the accumulated data can offer a significant depth of information (Ryan et al., 2007). Ethical approval was given for 40 interviews however, if 'data saturation' was achieved prior to that point the interviews would be terminated early. This was defined as there being sufficient data to gain an adequate understanding of the dimensions of the emerging concepts and themes (Watling and Lingard (2012).

Each interview was recorded, with full consent. As the participants were known to the researcher doing the interview, total anonymity was not possible. They were assured that their identities would not be revealed in any publication and the raw data would not be released to any third party and we strived to maintain autonomy. Once the interviews were completed they were transcribed verbatim by a professional transcriptionist. Before being analysed transcripts were checked and any identifying personal information was removed.

2.4 Data analysis of stage one

There are two fundamental approaches to analysing qualitative data: deductive and inductive approaches. Our study used an inductive approach which is comphrensive and time consuming and most suitable when little or nothing is known about the study phenomenon (Burnard et al., 2008), as in this case. It involves analysing data with little or no predetermined theory, structure or framework and derives the structure of analysis from the data itself (Burnard et al., 2008).

Transcripts were analysed using thematic analysis which is a widely used method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). As applied in this study, thematic analysis is a systematic approach to understanding and organizing the text obtained from the interviews, into a coherent description of the participants' experiences and opinions. This includes a six-stage process as described by Braun and Clarke (2006); familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report (Braun & Clarke, 2006). The NVivo software tool (v8, QSR International) was used to facilitate analysis through computerised coding, organisation, searching and retrieval of data.

The first step of analysis involved reading and re-reading the interview data to become immersed and intimately familiar with its content. Then initial codes (labels) can be generated that identify important features of the data that might be relevant to answering the research question. This was done for the entire dataset. As coding proceeds, the analytic process enacted is one of 'constant comparison', which involves reading and re-reading data to search for and identify emerging themes in the constant search to understand the meaning of the data (Burnard et al., 2008). Constant comparison enables researchers to treat the data as a whole rather than fragmenting it, as one piece of data is compared with previous data and not considered on its own (Anderson, 2010).

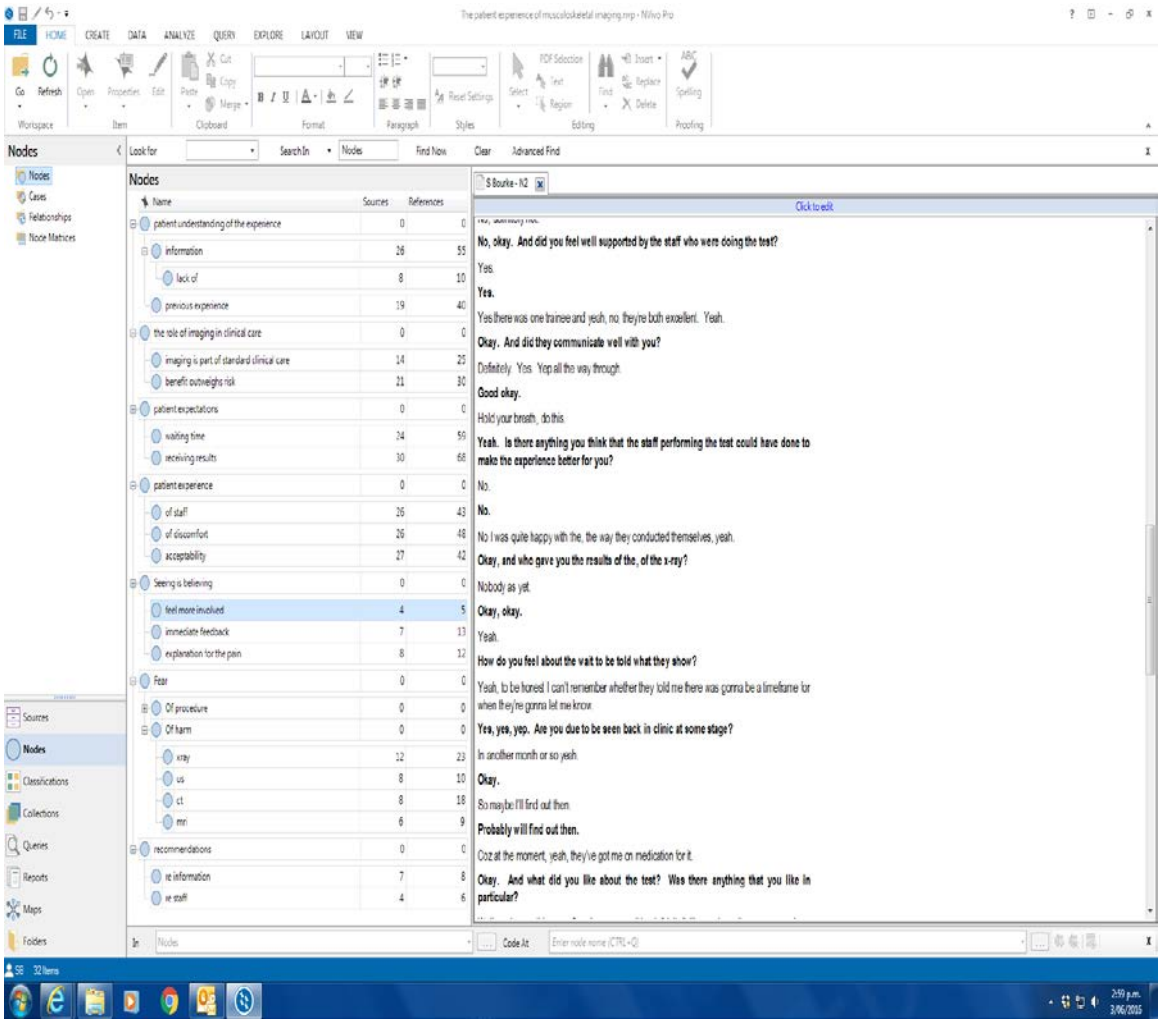

Figure 2.1. NVivo screen shot 1

This is a screen shot from the NVivo program demonstrating the coding process. It shows a list of themes and subthemes on the left hand side of the screen and an interview transcript on the right hand side. The interview data is coded line by line into one of the theme categories.

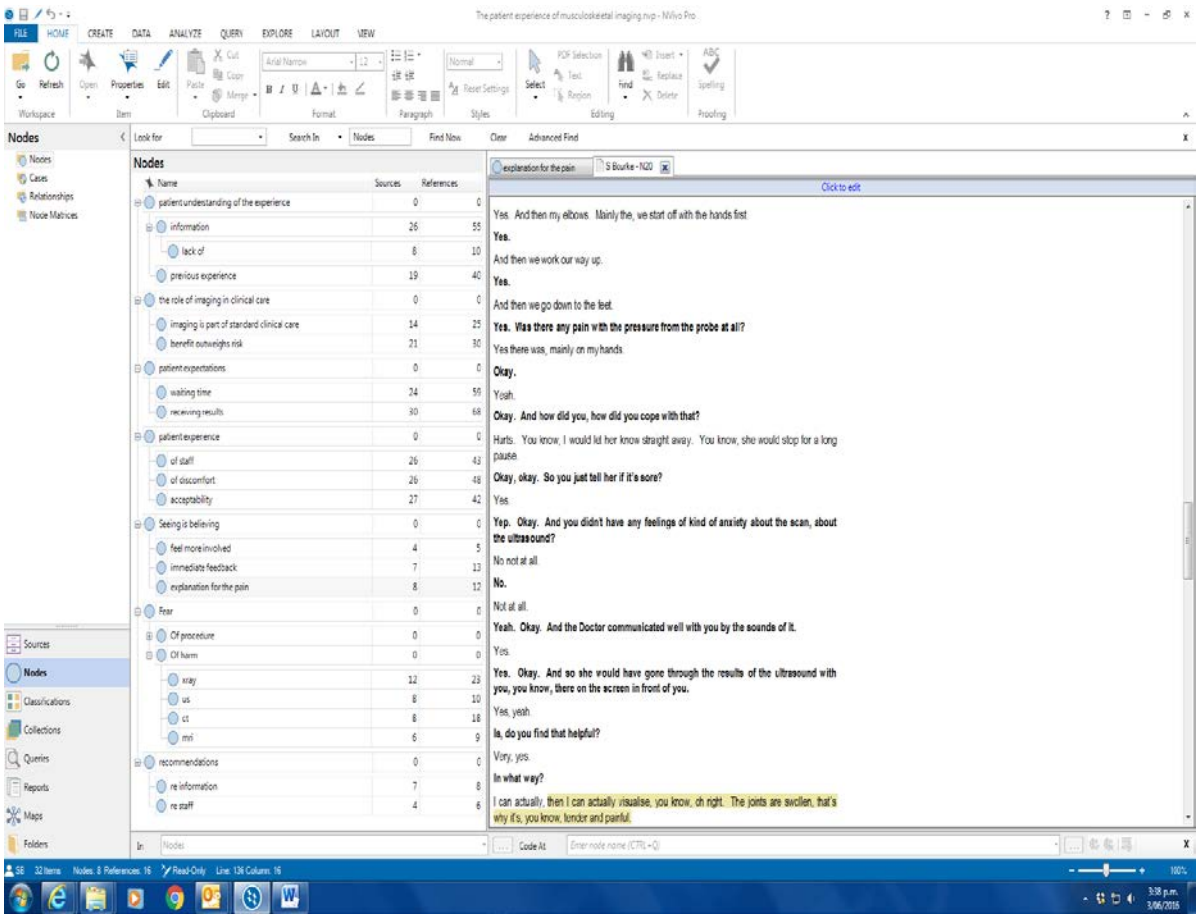

Figure 2.2. NVivo screen shot 2

This screen shot of the NVivo program shows a highlighted quote from patient 20. When this patient was asked how they found seeing their ultrasound image they commented "*then I can actually visualise, you know, oh right. The joints are swollen, that's why it's, you know, tender and painful"*. This data was coded under the theme 'seeing is believing' and the subtheme 'explanation for the pain'.

The next step was searching for themes. This involved examining all codes and collated data to identify significant broader patterns of meaning (potential themes). It then involved collating data relevant to each theme and reviewing the viability of each theme. The constant comparative process defines the breadth and characteristics of each theme, and facilitates the emergence of new themes when data are encountered that illustrate new concepts (Watling & Lingard, 2012).

The following step was reviewing the themes which involved checking the candidate themes against the dataset, to determine whether they told a convincing story of the data and answered the research question (what is the patient experience of MSK imaging tests?). Three members of the research team, including the interviewer, reviewed the interview data and initial themes to ensure there was agreement on coding and to limit researchers' bias. Any

differences in opinion were discussed and resolved by consensus. The themes were refined with some being split, combined and discarded. For example, one of the subthemes under ‘seeing is believing’ was ‘immediate feedback’. This subtheme described patient thoughts on the immediate feedback that they get when having an ultrasound performed in clinic. This subtheme was moved from the ‘seeing is believing’ theme to the theme ‘experience of waiting times’ which describes participant feelings on waiting for a test or results, as it fits this category better.

The last step involved defining the themes, working out the scope and focus of each theme, determining the ‘story’ of each and deciding on an informative name for each. The research team worked together on this process until the final themes and subthemes were identified.

2.5 Enhancing Rigour

Rigour is the means of demonstrating the plausibility, credibility and integrity of the qualitative research process (Ryan et al., 2007). The purpose of this study was to explore the patients’ experience of MSK imaging. As such the ability to capture and portray the participant perspective of MSK imaging was central to promoting authenticity and credibility; both important criteria for enhancing rigour (Milne & Oberle, 2005). This required that participants had the freedom to speak and that their voices were heard. Recording and transcribing the interviews ensured accuracy of the data as well as scientific and ethical integrity.

It has been argued that qualitative researchers should have their analyses verified by a third party to provide additional insights into theme and theory development and reduce lone researcher bias. There are two key ways of doing this; respondent validation - returning to the study participants and asking them to validate analyses, or peer debrief - whereby another qualitative researcher analyses the data independently (Mays & Pope, 1995). For this study a sub-set of transcripts was double coded to ensure consistency of coding decisions across the research team and any differences in opinion were discussed and resolved by consensus. This process ensured credibility; the issue of whether there is consistency between the participants’ views and the researchers’ representation of them (Ryan et al., 2007). The combination of qualitative and quantitative methods, as in this study, is referred to as triangulation. Triangulation can substantiate the validity of a study, ensuring that the research data is honest and genuine (Anderson, 2010).

To ensure that the analysis process is systematic and rigorous all collected data must be thoroughly analysed (Burnard et al., 2008). This includes the search for relevant 'deviant or contrary cases', which are different to the main findings or unique to one or several responders. These "negative cases'' are particularly important within the constant comparative process (Watling & Lingard, 2012). The NVivo software allowed for systematic data analysis; ensuring that deviant cases were not missed.

2.6 Reflexivity

Reflexivity is an important issue in qualitative studies. It refers to recognition of the influence a researcher brings to the research process (Kuper et al., 2008) . The interviewer in this study comes from a medical background specialising in rheumatology and general medicine. Therefore she is biased towards believing that MSK tests are helpful and part of standard clinical care for patients with arthritis. None of the participants who were interviewed were patients of the interviewer. However they were aware that the interviewer was a doctor, which may have skewed their answers towards the positive so as not to be seen as complaining about the medical system. The potential overuse of medical jargon during the interviews was dampened by the use of a prepared structured interview schedule. This also ensured all participants were asked identical questions.

2.7 Summary

This chapter outlines the methodology of this study. It clearly states why a mixed methods model was chosen. Inclusion criteria and participant recruitment are explained and justified. The method for gaining informed consent from participants and preserving subject anonymity is described. The semi-structured interview process is described. The decision to stop data collection prematurely is explained and justified. Data analysis, verification and methods for identifying themes from the data are discussed. The formation of the questionnaire and cognitive testing of the questionnaire are explained. Several methods for enhancing rigour are presented.

Chapter Three: Results of stage one; analysis of the interview data

This chapter will report the results of stage one, the qualitative component of the study. The demographics and disease characteristics of the 33 participants who were interviewed will be presented. Subsequently the themes and subthemes which were identified from the interviews using thematic analysis will be explored.

3.1 Participant demographics

Interviews were conducted with 33 participants between 19th January and 19th May 2016. There were six participants who had CR alone, ten who had US, ten who had CT and seven who had MRI. In total there were 18 participants who had CR, as this test was often done in addition to other imaging modalities.

Table 3.1. Participant demographic and disease characteristics.

Characteristic		N (%)
Sex	Female	17 (52%)
Ethnicity	NZ/European	23 (70%)
	Māori	4 (12%)
	Pacific people	2 (6%)
	Asian	2 (6%)
	Other	2 (6%)
Age	median (range), years	58 (25 - 83)
Diagnosis	Rheumatoid arthritis	15 (46%)
	Gout	11 (33%)
	Inflammatory arthritis (NOS)	6 (18%)
	Psoriatic arthritis	1 (3%)
Disease duration	**median (range), years**	9 (0.25 – 45)

Demographic and clinical characteristics of the interviewees are summarised in Table 3.1. Most participants were New Zealand Europeans. Other ethnicities identified were Māori, Pacific people, Asian and Other. The 'other' patients identified as Indian and Latin American. The median age was 58 years (range from 25 to 83 years). Sex distribution was well balanced

with 17 females and 16 males. Almost half of the participants had rheumatoid arthritis. The remainder had gout, undifferentiated inflammatory arthritis and psoriatic arthritis. Median duration of disease was 9 years (range from 0.25 to 45 years).

3.2 Emergent themes

The analysis of the transcribed interviews identified six key themes (Table 3.2); knowledge about the test, awareness of potential harm, the role of imaging in clinical care, discomfort, experience of waiting and 'seeing is believing'. Each theme was supported by data emerging from a number of patients. Representative patient quotes are in *italics*. The identity of the speakers is established following the quotes with F for female or M for male, followed by their age and imaging modality.

Table 3.2. Themes and Subthemes

Themes	Subthemes
Knowledge about the test	From information received From previous experience
Awareness of potential harm	Radiation exposure Contrast exposure
The role of imaging in clinical care	Imaging is beneficial Imaging is part of standard care
Discomfort	Emotional Physical
Experience of waiting times	For the test For results
'Seeing is believing'	Greater understanding of disease Greater involvement in disease management

3.2.1 Theme 1: Knowledge about the test

Participants' knowledge about the test was informed by information they received primarily from health professionals, but also from family, friends and the internet. Previous experience of imaging tests also informed patients' understanding. There were varying needs for information about the procedures: *"How much [information] is too much and how much is not enough?"* (F73 MRI). Most were happy with the information they were given: *"It all got explained to me very well before I went in"* (F37 MRI).

Some participants recalled very little information about the imaging test prior to having it done: *"None at all, none, none at all, just the letter saying where it is, and that's it"* (F39 MRI). Several could not remember whether they were given any information prior to the test suggesting that the information they received was not memorable: *"They may have done I can't recall"* (M66 CT). Some were more interested in getting the test done quickly than being fully informed: *"We really don't wanna delve into the ins and outs of it and just do the x-ray and we can go home"* (M56 CR&CT). Participants who had previous experience of the test in question were less concerned about it and required less information, as they knew what to expect: *"I knew what was gonna happen so, having been there before"* (F71 MRI).

Several participants recommended that further information should be provided about the test and potential risks: *"Even if the patient has had [one] before, it should be better to make sure that the patient is informed of any risks that may be involved"* (M55 CT).

A suggestion for improving patient knowledge was to have information books available in the waiting room: *"For those people who are concerned about it, they could just have you know, something they could read while they wait"* (M53 CT). Another was to be shown a photograph of the MRI scanner to prepare patients for the confined space: *"They should call you or text you or send you a letter like highlighting, perhaps with a photograph of the tunnel, because it's [claustrophobia] more common that you think"* (F39 MRI).

3.2.2 Theme 2: Awareness of potential harm

This theme described participants' awareness of potential harm from the test. Some, but not all, were aware of potential harm from radiation or contrast exposure. Those having CR and US expressed some confusion regarding radiation exposure during these procedures, however a high level of concern was not expressed: *"I mean I'm sure it's there and, well it is there, but yeah, I don't think I've ever had it really explained to me how much is there"* (F54 CR). *"He didn't leave the room or anything like dentists do when they take an x-ray of your teeth, which is a bit upsetting"* (F69 US).

Many were not concerned about radiation during CT scan, but whether this is due to lack of knowledge or relaxed participants is uncertain: *"No I don't worry about that. I think there's a lot of strange fears about radiation and its gone crazy"* (M80 CT). There was a lack of knowledge about radiation exposure during CT: *"I was a little bit surprised to see them putting on the lead, you know moving into the other room, you know, indicating that there was mild radiation and so on"* (M70 CT). MRI participants had no concerns about radiation.

Most participants who had MRI scans were aware of potential adverse effects from the contrast: *"that had been explained well to me here before I went, yip, that that would need to be done and that you can get a metallic taste in your mouth from the dye, you get told the side effects"* (F37 MRI).

3.2.3 Theme 3: The role of imaging in clinical care

This theme explored the participant perception of the role of imaging tests in arthritis. Many participants regarded the imaging tests as nothing out of the ordinary, just part of their usual rheumatology clinic care: *"I have one done every time, every time I go and visit the doctor she does an ultrasound on all fingers and all toes"* (F63 US). Participants understood the reason for having the test and what information they would expect to receive as a result: *"And obviously it's for a reason, to see if she needs to be more aggressive with my treatment, in case there is already pitting in the bones and things like that"* (F37 MRI).

They were keen to have imaging tests to provide them with more information about their condition: *"I was happy because I wanted to know what is happening"* (F58 US). Participants believed that the benefits of having the test outweighed the potential risks involved and preferred knowing more about their disease than less. Some even expressed fear of not having the test and the resultant knowledge that comes with it: *"You know, ignorance is bliss and it's*

also deadly and if you don't have tests and x-rays and things like that you'd never know what's gonna climb up and push you under the water" (M80 CT**).** Some felt as if they had no choice in the matter and did not challenge their doctor's decision: *"I suppose I just accept things that, you know, they say to have an x-ray unless it was absolutely ridiculous I probably wouldn't question it"* (F83 CR).

3.2.4 Theme 4: Discomfort

This theme explored the experience of physical and emotional discomfort during the test. A minority of participants reported emotional discomfort due to negative interactions with staff such as feeling rushed during the procedure: *"I know they've got a schedule that they have to keep to but, so they want to get you into the machine as quick as possible…they still ask you all the same questions, they're just a bit more pushy, a bit more rushed"* (F37 MRI). Participants recommended that radiology staff take their time and try to *"make [patients] feel relaxed, talk about life…laugh a bit…give them a pleasant environment"* (F39 MRI).

Another type of emotional discomfort experienced was feelings of anxiety or claustrophobia. The frequency of this differed significantly between the imaging modalities, occurring exclusively with CT and MRI as compared to X-ray and US. One CT participant developed claustrophobia: *"I'd say 3 on a scale of 1-10 sort of thing"* (M73 CT). Several participants had feelings of claustrophobia during MRI but despite this they all completed the procedure: *"I got super surprised when I saw the machine. The actual machine was like a closed tunnel, and when I saw that, I panicked and I started like shivering, and I was panicking because I have mild claustrophobia and nobody had prepared me for that"* (F39 MRI). Participants who did not suffer from claustrophobia could appreciate the confined space of the MRI machine: *"I didn't get freaked out about being enclosed in. But I did go, oh this is quite - I can understand why people don't like this"* (F37 MRI). Several coping mechanisms were described to reduce anxiety and increase their ability to comply with the procedure: *"As soon as I felt the table moving in, I shut my eyes; I just thought it was the easy way, rather than panic"* (F71 MRI).

Some reported physical discomfort with positioning and difficulty holding still for the time required to have the test: *"Cos when you have uncomfortable shoulders, things like that, laying there for twenty minutes, like superman, is not comfortable…I'm sure people who don't have arthritis, or don't have muscle and joint pain, could stay in that position for longer"* (F37 MRI).

3.2.5 Theme 5: Experience of waiting

This theme explored participants' feelings on waiting for their imaging test and their results. Participants who had x-rays and ultrasounds usually had them done on the day of their clinic visit, where as those having CTs or MRIs had a longer wait; usually from weeks to months. There was a clear preference for the imaging test to be done as quickly as possible: *"I think any waiting time causes some sort of stress"* (M60 MRI). However, despite this, most weren't concerned with waiting times ranging from minutes to weeks: *"It would have been weeks I think. I was not concerned"* (M70 CT). However, some waited significantly longer; one participant who waited 3 months for an MRI commented: *"it's quite a long time for those who are desperate and seeking an answer, and living with the pain"* (F39 MRI).

Apart from those who had clinic ultrasounds, most interviewees had not yet received their test results at the time of the interview. There were mixed reactions over the wait; some were frustrated and anxious to find out what the test showed: *"I feel that they could have, you know, texted me, or emailed me. They have all my information. They know how desperate I am for answers"* (F39 MRI). Others weren't sure when they were going to get their results: *"I'm not expecting to hear anything until I go back which is in three months"* (F54 CR) or assumed that the lack of contact from their doctor meant everything was okay: *"I work on the theory that if there's a problem they'll get hold of me"* (M56 CT). Those who had immediate feedback valued it. Immediate feedback primarily occurred for those participants having US: *"It was good getting direct feedback, cos you wonder what they're looking at"* (M72 US).

3.2.6 Theme 6: 'Seeing is believing'

Participants described viewing their own images positively; this applied predominantly to ultrasound scans that were done in rheumatology clinic. The rheumatologists doing the scans discussed the images and the findings with the patients. At the time of the interview, most participants who had CR, CT or MRI had not seen their images. Participants having US described that viewing images provided an explanation for their symptoms, and therefore a better understanding of their disease: *"I can actually visualise, you know, oh right. The joints are swollen, that's why it's, you know, tender and painful"* (F55 US).

Participants also described that viewing their images encouraged a sense of personal involvement in their clinical care, so they felt more involved in the consultation and in their disease management: *"I know what it's like when you're having an ultrasound with a baby and it's really important for the, for the mother to look at the screen. Well you know, that one's a completely different issue, but it's still as important to be able to see it and feel you're part of it…there's a sense of being involved"* (F63 US). A few CT participants who were given print-outs of their images also reported positively: *"it's worthwhile because you can relay that information through members of your family, you know, this is how my feet are"* (M76 CT).

3.3 Acceptability of the test

All participants said they would be willing to have the test again in the future, if they needed it: *"Quite happy if it was going to sort of be of any value to me"* (F83 CR). One participant did not wish to have another MRI of the wrist, but would be willing to have an MRI of a different joint: *"Fine, as long as it was a different part of my body…it was just the fact that it was a very uncomfortable position to lay in. So if it was an ankle or a knee, I think I would be fine, cos I could lay in a position that's more comfortable"* (F37 MRI).

3.4 Summary

This study provides valuable insight into the patient experience of undergoing an MSK imaging test. Their understanding of the test was informed by the information they received and their previous experience of imaging tests. Most were aware of potential harm due to intravenous contrast and radiation, however, they perceived imaging as part of standard clinical care and believed the benefits of having the test outweighed the potential risks. Some

felt anxious about waiting times for the test and for receiving results. Discomfort was experienced, both emotional discomfort due to negative experiences of interactions with staff and claustrophobia and physical discomfort due to positioning for the test. Visualisation of images improves understanding of disease and sense of involvement in their clinical care. Participants provided recommendations for improving the overall experience, including the need for more information prior to the test and advice for staff to show more empathy and to take their time.

Chapter 4: Methodology for stage two

This chapter covers the formulation and analysis of the survey questionnaire; giving explanations for the rating scale and questions which were chosen. It also discusses the results of cognitive testing of the questionnaire and changes that were made to the questionnaire as a result of this.

4.1 Development of the questionnaire

Once the six key themes were identified, the questionnaire for stage two was developed. Three members of our research team, including myself, created statements regarding musculoskeletal imaging that matched to the themes and subthemes. Each item was followed by a Likert rating scale with which respondents expressed the degree of agreement with the item statement. The selection of a response format involves consideration of their sensitivity, specificity, appropriateness for the subjects and feasibility (Nolan & Mock, 2000). A Likert scale was chosen as it is well known and easy to use.

A scale ranging from 1 to 10 for the questionnaire was chosen. This gave an even number of response options leaving the respondent without a 'safe' middle number. Previous research has shown that respondents have a greater tendency to choose middle response categories when offered them (Si & Cullen, 1998).

A wide scale range was used as previous research has shown that scales with few response categories yield the least reliable scores with significantly reduced reliability, validity, variance and discriminating power compared to scales with more response categories (Preston & Colman, 2000), although the literature on the optimal number of response categories does not provide clear-cut guidance on the precise number of categories.

When responding to a Likert-like item respondents may specify their level of agreement or disagreement with a statement. The range of the scale captures the intensity of the participants' feelings for a given item. Respondents' perception of shorter scales (up to four response categories) is unfavourable as these scales do not allow them to express the intensity of their feelings adequately (Preston & Colman, 2000). With a scale of 1 to 10, our participants had sufficient range to express the intensity of their feelings. A non-applicable option was added to the question items that this applied to. At the end of the questionnaire

there was space for participants to write down any recommendations they had to help improve the imaging experience. The questionnaire had a Flesch reading level of 6th grade, meaning it would be easily readable to an 11 or 12 year old. The pre-cognitive test questionnaire is located in appendix B.

The numbers of the scale do not represent real numbers and could be replaced by letters, without affecting the results. Question items were analysed separately rather than as a summated score, as there is no underlying quantity that a summated score seeks to represent; the questionnaire includes a variety of items covering different topics.

Each theme and subtheme was mapped to the questionnaire to ensure they were all covered. The questionnaire covered the participants' knowledge about the test, awareness of potential harm, the role of imaging in clinical care, discomfort, the experience of waiting and 'seeing is believing'. The themes and corresponding questions are shown in table 4.1. Each item has been given a short label for easier reference. For the theme 'knowledge about the test' there was an item about each of the subthemes; information about the test and previous experience of the test. For theme two, 'the awareness of potential harm', there were items about exposure to radiation and contrast and the overall safety of the test.

There were two items about 'the role of imaging in clinical care'; one regarding the benefits of imaging and one about MSK tests being part of usual clinical care for patients with arthritis. There were items about emotional and physical 'discomfort' and about staff manner during the procedure. Theme 5, 'the experience of waiting' was covered by an item about waiting for the test and the results. In regards to 'seeing is believing' there was an item about whether seeing the images helped them to understand their condition better and whether looking at the images with their doctor made them feel more involved in their care. At the end of the questionnaire there were several blank lines for participants to write any recommendations to improve the patient experience.

In addition there were a few extra items which did not match directly to a theme but which were felt to be important. These were regarding the acceptability of the test, staff manner, and whether participants were concerned about their results. The final question asked them to rate their overall experience of the test on a scale from 1 (very unpleasant) to 10 (excellent).

The layout of a questionnaire needs to be clear and well presented. The question items in this questionnaire were numbered and bolded making them easy to follow. The questions were grouped in a sequential order ranging from the start of the imaging test process to the end. A legible font was used and care was taken not to overfill the pages.

Validity, the amount of systematic or built-in error in measurement (Norland Tilburg, 1990) is an important consideration when developing a questionnaire. The research team considered the content validity of the questionnaire; that is, whether it actually measured what it was intended to measure. Dr Doyle, a co-author and musculoskeletal radiologist provided expert advice to help determine this. The questions and range of response options seemed, on their face, appropriate for measuring the patient experience of MSK imaging tests. The questionnaire covered all aspects of undergoing an MSK imaging test and all questions carried equal weight. Other aspects of validity, such as construct validity and criterion validity were not assessed since the questionnaire responses were not summated to an overall score.

Reliability refers to the degree to which the results obtained by a measurement or procedure can be replicated. Since each item was analysed separately, and were not summated, procedures such as Cronbach's alpha test of internal consistency reliability was not appropriate. Test-retest reliability for individual items was not assessed. The feasibility of the questionnaire can be assessed by looking at the response rate, the time taken to fill it out and data completeness, but this was not formally assessed in this study.

The aim was to collect questionnaire data from at least 100 people in order to perform multivariate analysis, using the rule of thumb of needing at least 10 subjects for each independent variable in the model. The survey was posted to consecutive patients undergoing MSK imaging until at least 100 responses were received and the time restriction for completion of the thesis was met.

4.2 Data analysis of stage two

Questionnaire data was entered into a Microsoft Access database and then transferred to the SPSS (v23, SPSS Inc., Chicago, IL) programme for analysis. Question answers were compared across the four different imaging tests. A Bonferroni corrected p value was used to minimise type 1 error. This was calculated as critical p value (0.05) / number of comparisons (18) = 0.0028. Non-parametric tests were used given the non-normal distribution of item responses. Two approaches were taken with this analysis; the first included all imaging tests,

which meant that some items within imaging groups came from the same respondent (multiple tests per respondent). The second approach required only one imaging procedure per subject whereby imaging tests were priority coded as follows MRI > CT > US > CR. For the first approach, only descriptive analysis is presented since the imaging grouping variable was not independent (responses from the same subject contained in more than one imaging group). For the second approach, statistical differences in item responses across the imaging tests were examined using the Non-parametric Independent Samples Median Test statistic. Spearman rank correlation calculations were used to demonstrate what aspects of the test had positive and negative influences on the overall participant experience. Multivariate linear regression analysis extended the correlation analysis to determine the independent association between different aspects of the test and participants' overall experience. As the 'Acceptability of the test' item was highly correlated and conceptually similar to 'Overall experience', this item was excluded from stepwise linear regression analysis. All regression models included the type of imaging test in addition to questionnaire item responses.

Table 4.1. Questionnaire items, corresponding themes and item labels

Item	Item (1 Strongly disagree-10 Strongly agree)	N/A option	Item Label	Theme
1	It was important to have this test to find out about my arthritis	No	Importance of test	The role of imaging
2	Having this test is part of usual clinical care for patients with arthritis	No	Part of usual care	The role of imaging
3	I was concerned about the waiting time for the test	No	Waiting for the test	Experience of waiting
4	I was given enough information about the test	No	Information provided	Knowledge of test
5	My experience of having the test before made me more comfortable this time	Yes	Previous experience	Knowledge of test
6	I found this test uncomfortable	No	Discomfort during the test	Discomfort
7	I felt anxious during the test	No	Anxiety during the test	Discomfort
8	The staff performing the test made the experience better for me	No	Staff made the experience better	
9	I am concerned about my test results	No	Concern about result	
10	I don't mind waiting for my test results	Yes	Waiting for result	Experience of waiting
11	I found it helpful getting my results at the time of the test	Yes	Immediate result	Experience of waiting
12	Seeing the images helped me understand my condition better	Yes	Seeing improves understanding	Seeing is believing
13	Looking at the images with my doctor made me feel more involved in my care	Yes	Seeing improves involvement	Seeing is believing
14	I would have this test again in the future	No	Acceptability of the test	
15	I am concerned about exposure to radiation during the test	Yes	Radiation concern	Awareness of harm
16	I am concerned about the contrast injection (dye) during the test	Yes	Contrast concern	Awareness of harm
17	I am concerned about the safety of the test	No	Safety concern	Awareness of harm
18	My overall experience of the test was? (1 Very unpleasant -10 Excellent)	No	Overall experience	

4.3 Results of cognitive testing

Cognitive testing was performed to ensure that each question was understandable and meaningful to the target population (people having MSK imaging for investigation of inflammatory arthritis). After obtaining written informed consent ten participants were interviewed for cognitive testing of the questionnaire. These participants were recruited from Auckland university where they were attending a study visit for gout research. They participated in semi-structured recorded interviews that examined the items in the preliminary questionnaire, to ensure readability and clarity of the questions. The recorded interviews were transcribed verbatim by a professional transcriptionist. The interview questions were revised and clarified based on these participants' comments. Once the questionnaire was finalised it was posted out to 514 patients with inflammatory arthritis who met the inclusion criteria, over a four month period.

At the start of the questionnaire there was a tick box section for participant demographic information. Under ethnicity there was a tick box entitled 'other' for people who did not fit into the designated ethnicities. An interviewee asked whether we would want these 'other' ethnicities to be specified. So a line was added after 'other' with the words 'please specify'.

'Diagnosis' was changed to 'type of arthritis' as several participants wondered whether people would understand the word diagnosis. Another comment was that patients may have more than one type of arthritis, so 'tick all that apply' was added to this section.

To distinguish between ultrasounds done in clinic and ultrasounds done in the radiology department, a separate tick box was created for each. This was done because different answers are anticipated for these tests in regards to receiving results and viewing images and therefore it is beneficial to have them as separate groups.

Prior to the Likert items was a sentence that read 'If you had 2 tests and 1 was an X-ray, please answer these next questions for the other test'. This sentence was included because X-rays are often done in addition to other imaging modalities such as US, CT or MRI. In that circumstance we would prefer the participant to fill out the questionnaire for the US, CT or MRI as they are less common tests. Several participants found this statement confusing so to clarify we added '(eg. Ultrasound, CT or MRI). If you only had an X-ray, please answer for the X-ray'. The font colour was changed from black to red to draw attention to this statement. The changes to the questionnaire items following cognitive testing are shown in Table 4.2.

Table 4.2. Changes made to the questionnaire items following cognitive testing

Changes	Pre-cognitive test	Post-cognitive test
1	Having this test is part of standard clinical care for patients with arthritis	Having this test is part of usual clinical care for patients with arthritis
2	'Safety concern' was before 'radiation concern' and 'contrast concern'	'Safety concern' moved to after 'radiation concern' and 'contrast concern'
3	I am concerned about the contrast injection during the test	I am concerned about the contrast injection (dye) during the test
4	Line spacing for recommendations too narrow	Line spacing for recommendations increased

Change number one involved changing standard clinical care to usual clinical care, as it was felt by participants to be easier to understand. Change number two involved changing the order of questions based on participant feedback. In the pre-cognitive questionnaire 'safety concern' came before 'radiation concern' and 'contrast concern' However the order was changed as a participant commented that they would have answered the 'safety concern' item differently if it came after the 'radiation and contrast concern' items, rather than before them. Change number three involved the word (dye) being added after contrast injection to ensure correct understanding of the word contrast. Another participant observation was that the lines on which to write any recommendations were too narrow, so these were spaced out further (change number 4). Once all these changes were made we had our final questionnaire, which can be found in appendix C. The patient information sheet which accompanied the questionnaire is found in appendix D.

4.4 Summary

This chapter describes the formation of the questionnaire from the six key themes identified in the qualitative part of the study. It describes the process of cognitive testing and the resultant changes made to the questionnaire.

Chapter Five: Results of stage two; analysis of the questionnaire data

This chapter will report the results of stage two, the quantitative component of the study. The demographics and disease characteristics of the respondents to the questionnaire will be presented. Subsequently the answers to the questions will be analysed and compared across the four different MSK tests. Correlation calculations will demonstrate what aspects of the test had positive and negative influences on the overall participant experience. Multivariate regression analysis will extend the correlation analysis to determine the independent association between different aspects of the test and participants' overall experience.

5.1 Respondent demographics

Questionnaires were posted out to patients with inflammatory arthritis who had had a recent MSK imaging test, from August 2016 to November 2016. In total 514 questionnaires were posted and there were 108 responses, giving a response rate of 21%.

Table 5.1 outlines the participant demographics. 60% of respondents were female. Median age was 61 years with a range from 30 to 89 years. Age was the only characteristic that did not have a tick box associated with it, which may explain why only 37 respondents recorded their age. The most common ethnicity was NZ/European at 70%. Other ethnicities identified were Māori, Asian, Pacific people and Other. Ethnicities listed under 'Other' included Russian, Latin American, Indian, South African, Sri Lankan and European. Some participants identified with more than one ethnicity. In this situation ethnicities were priority coded as follows; Māori > Pacific > Asian > Other > NZ/European > Uncertain according to the Statistics NZ guideline (Ministry of Health, 2010). The most common type of arthritis was rheumatoid arthritis (57%) followed by gout (18%) and psoriatic arthritis (12%). If participants had more than one type of arthritis, their arthritis was priority coded as follows; Rheumatoid arthritis > Psoriatic arthritis > Gout > Other > Uncertain. Seven percent of participants were uncertain about what type of arthritis they had. In total 165 imaging tests were done and sixteen people had more than one imaging test. X-ray was the most frequent imaging test, followed by ultrasound. Feet and hands were the most common region imaged with 66 tests each.

Table 5.1. Participant Demographics

Gender (responses= 104)	
Female	62 (60%)
Male	42 (40%)
Ethnicity (responses= 106)	
NZ/European	74 (70%)
Other	12 (11%)
Māori	11 (10%)
Asian	5 (5%)
Pacific people	4 (4%)
Type of Arthritis (responses= 101)	
Rheumatoid arthritis	58 (57%)
Gout	18 (18%)
Psoriatic arthritis	12 (12%)
Uncertain	7 (7%)
Other	6 (6%)
Imaging test (responses= 104)	
Conventional radiography	46 (44%)
Ultrasound	24 (23%)
Magnetic resonance imaging	21 (20%)
Computed tomography	13 (13%)

Values are the number (%) unless otherwise indicated.

5.2 Data analysis

Questionnaire answers were initially entered into a Microsoft Access database and then transferred via MS Excel to the SPSS programme for analysis. Not all respondents answered all questions, therefore denominators fluctuate in this section. The answers to each question item across all four tests were compared, see Table 5.2. This table shows the participants scores (median and range) for each question item and the number of responses to each item that were not applicable. As 16 people had multiple tests, participants may appear in more than one modality group. Table 5.3 shows identical information but does not contain duplicate imaging tests, as tests were priority coded as follows MRI > CT > US > CR. For example a patient who had an MRI and an x-ray would be priority coded as being in the MRI group.

There was a wide range of responses for most items. Table 5.3 shows there were no significant differences between the four imaging tests for most of the question items. Item 3 (waiting for the test) and item 8 (staff made the experience better) had p values of less than 0.05. However, these items did not reach the Bonferroni corrected p-value (p=0.0028) to indicate statistical significance, when corrected for multiple statistical tests.

Table 5.2. Median, range and number not applicable for each question item for all 4 tests (duplicates included)

Questions	CR (n=57)			US (n=39)			CT (n=20)			MRI (n=21)		
	Median	(range)	n(NA)	Median	(range)	n(NA)	Median	(range)	n(NA)	Median	(range)	n(NA)
Importance of the test	10	(4-10)	-	10	(7-10)	-	10	(3-10)	-	10	(5-10)	-
Part of usual care	9	(4-10)	-	9	(5-10)	-	9	(1-10)	-	7.5	(2-10)	-
Waiting for the test	2	(1-9)	-	3	(1-10)	-	2	(1-10)	-	5	(1-10)	-
Information provided	8	(2-10)	-	9	(1-10)	-	10	(2-10)	-	9	(2-10)	-
Previous experience	9	(4-10)	14	8	(1-10)	7	10	(1-10)	5	9	(1-10)	6
Discomfort during the test	2	(1-10)	-	2	(1-8)	-	1	(1-10)	-	2	(1-9)	-
Anxiety during the test	1	(1-10)	-	2	(1-10)	-	1	(1-10)	-	2	(1-9)	-
Staff made the experience better	9	(2-10)	-	9	(6-10)	-	10	(5-10)	-	10	(6-10)	-
Concern about result	6	(1-10)	-	7	(1-10)	-	6	(1-10)	-	8	(1-10)	-
Waiting for result	6	(1-10)	5	6	(1-10)	8	6	(1-10)	1	5.5	(1-10)	2
Immediate result	9	(2-10)	32	10	(5-10)	7	10	(1-10)	5	9	(5-10)	9
Seeing improves understanding	9	(2-10)	33	9	(3-10)	9	10	(2-10)	3	9.5	(3-10)	7
Seeing improves involvement	9	(1-10)	34	8	(1-10)	9	10	(1-10)	4	8.5	(1-10)	9
Acceptability of the test	9	(5-10)	-	9	(4-10)	-	10	(1-10)	-	9	(3-10)	-
Radiation concern	3	(1-10)	3	5	(1-10)	6	3.5	(1-10)	0	2	(1-10)	1
Contrast concern	6	(1-10)	46	5	(1-10)	21	2.5	(1-10)	8	5	(1-10)	6
Safety concern	2	(1-10)	-	2	(1-10)	-	1	(1-10)	-	2	(1-10)	-
Overall experience	9	(3-10)	-	9	(3-10)	-	10	(1-10)	-	9	(3-10)	-

n(NA) = number not applicable

Table 5.3. Median, range and number not applicable for each question item for all 4 tests (no duplicates)

Questions	CR (n=46)		US (n=24)		CT (n=13)		MRI (n=21)		
	Median (range)	n(NA)	Median (range)	n(NA)	Median (range)	n(NA)	Median (range)	n(NA)	p
Importance of the test	9.5 (4-10)	-	9 (7-10)	-	10 (3-10)	-	10 (5-10)	-	#
Part of usual care	9 (4-10)	-	9 (6-10)	-	8 (1-10)	-	7.5 (2-10)	-	0.91
Waiting for the test	1.5 (1-9)	-	2 (1-10)	-	1 (1-10)	-	5 (1-10)	-	0.03*
Information provided	8 (2-10)		9 (1-10)	-	10 (2-10)	-	9 (2-10)	-	0.09
Previous experience	9 (5-10)	13	8 (1-10)	4	10 (1-10)	4	9 (1-10)	6	0.11
Discomfort during the test	1 (1-10)	-	1.5 (1-7)	-	1 (1-10)	-	2 (1-9)	-	0.72
Anxiety during the test	1 (1-10)	-	1 (1-10)	-	1 (1-10)	-	2 (1-9)	-	0.28
Staff made the experience better	9 (2-10)	-	8.5 (6-10)	-	10 (5-10)	-	10 (6-10)	-	0.04*
Concern about result	5.5 (1-10)	-	7 (1-10)	-	5 (1-10)	-	8 (1-10)	-	0.08
Waiting for result	6 (1-10)	5	6 (1-10)	3	8.5 (2-10)	1	5.5 (1-10)	3	0.78
Immediate result	9.5 (2-10)	30	9.5 (5-10)	4	5 (1-10)	4	9 (5-10)	9	0.10
Seeing improves understanding	9 (5-10)	33	9 (4-10)	5	10 (2-10)	3	9.5 (3-10)	7	0.47
Seeing improves involvement	9 (4-10)	32	8 (6-10)	5	10 (2-10)	3	8.5 (1-10)	9	0.44
Acceptability of the test	9.5 (5-10)	-	9 (4-10)	-	10 (1-10)	-	9 (3-10)	-	0.71
Radiation concern	3 (1-9)	3	5 (1-10)	5	5 (1-10)	0	2 (1-10)	1	0.59
Contrast concern	6 (4-7)	43	6 (1-9)	17	3 (1-10)	7	5 (1-10)	6	0.76
Safety concern	2 (1-8)	-	2.5 (1-9)	-	2.5 (1-9)	-	2 (1-10)	-	0.87
Overall experience	9 (5-10)	-	9 (6-10)	-	9 (6-10)	-	9 (3-10)	-	0.07

P value could not be calculated. n(NA) = number not applicable. * P value < 0.05

Analysis of the question item scores show that overall participants found the tests acceptable and had low levels of concern about the safety of the tests. As we found in the interviews, participants believed the tests were important to have to find out more about their arthritis and regarded them as part of usual clinical care for people with arthritis. Participants valued seeing their images, receiving immediate results and having staff assist during the procedure. Discomfort and anxiety during the tests were minor concerns. The majority felt well informed about their test and were not concerned about the waiting time prior to the test. There was some concern about the results of the test, the waiting time to get results, and radiation and contrast exposure. Previous experience of the procedure was beneficial to the participant experience of the imaging test.

Table 5.4. Correlation of each questionnaire item with the participants' overall experience (Spearman rank correlation test)

Question label	Correlation Coefficient	P value	Number of Respondents
Importance of the test	0.35	<0.001	107
Part of usual care	0.39	<0.001	102
Waiting for the test	-0.32	0.001	107
Information provided	0.48	<0.001	107
Previous experience	0.53	<0.001	80
Discomfort during the test	-0.42	<0.001	107
Anxiety during the test	-0.35	<0.001	107
Staff made the experience better	0.56	<0.001	107
Concern about result	-0.18	0.060	107
Waiting for result	0.33	0.001	95
Immediate result	0.22	0.097	59
Seeing improves understanding	0.38	0.003	59
Seeing improves involvement	0.59	<0.001	58
Acceptability of the test	0.62	<0.001	105
Radiation concern	-0.36	<0.001	98
Contrast concern	-0.34	0.050	33
Safety concern	-0.32	0.001	105

Table 5.4 shows the bivariate correlations for the 'overall experience' item and all other questionnaire items. Participants associated seeing their own images with a positive overall experience; after 'Acceptability of the test', the strongest positive correlation was 'Seeing the images improves involvement in care'. These results show the positive impact that staff had on participants' overall test experience with a positive correlation of 0.56. 'Anxiety during the

test' influenced the overall experience in a negative way, as did 'Radiation concern' and 'Safety concern'. 'Discomfort during the test' had the strongest negative correlation with overall experience.

5.2.1 Multivariate analysis

There was no clear indication about which question items would be most associated with the participants' experience of the imaging test, therefore a stepwise approach was used to identify items that were independently associated with overall experience. Stepwise linear regression analysis was performed on all question items (excluding the questions with non-applicable answers and 'Acceptability of the test') to determine question items which were independently associated with the participants' overall experience. Four items were found to be independently associated with overall experience, see Table 5.5. 'Staff made the experience better' and 'Part of usual care' had positive correlations with overall experience. 'Discomfort during the test' and 'Waiting for the test' had negative correlations with overall experience. These four variables accounted for 36% of variance in the regression model. 'Staff made the experience better' was the strongest single independent predictor of the overall experience accounting for 20% of variance

Table 5.5. Stepwise linear regression analysis of question items (excluding non-applicable questions) independently associated with overall experience of the test

Model Number	Dependent variable	Predictors	Standardized ß	R^2 change	p	Model
1	Overall experience	Staff made the experience better	0.35	0.20	<0.001	Adjusted R^2 = 0.36 F= 14.9 p= <0.001
		Discomfort during the test	-0.29	0.11	0.001	
		Waiting for the test	-0.18	0.04	0.03	
		Part of usual care	0.17	0.03	0.04	

Items included in this analysis: imaging modality and all questionnaire items that did not include a not applicable response.

The assumptions of linear regression were tested by examining the distribution of residuals and the assumption of homoscedasticity. Figures 5.1 and 5.2 show that the residuals fit a normal distribution curve, as is assumed in linear regression models.

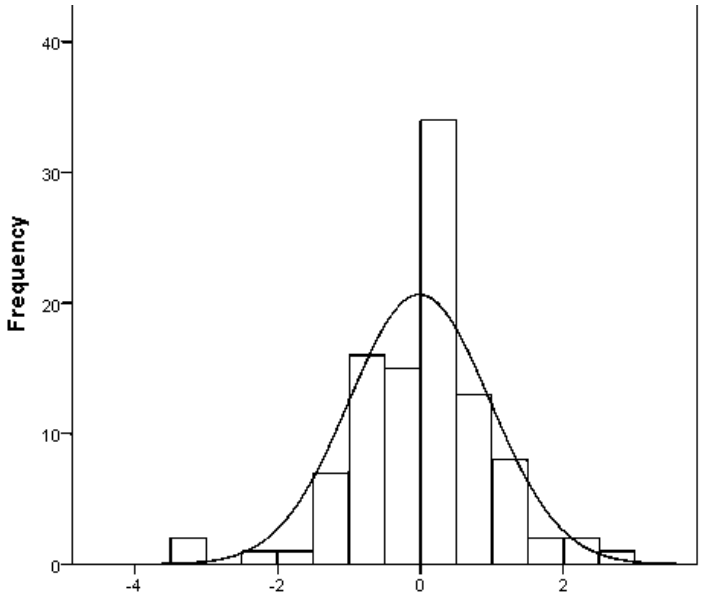

Figure 5.1. Histogram of residuals from the model shown in table 5.5

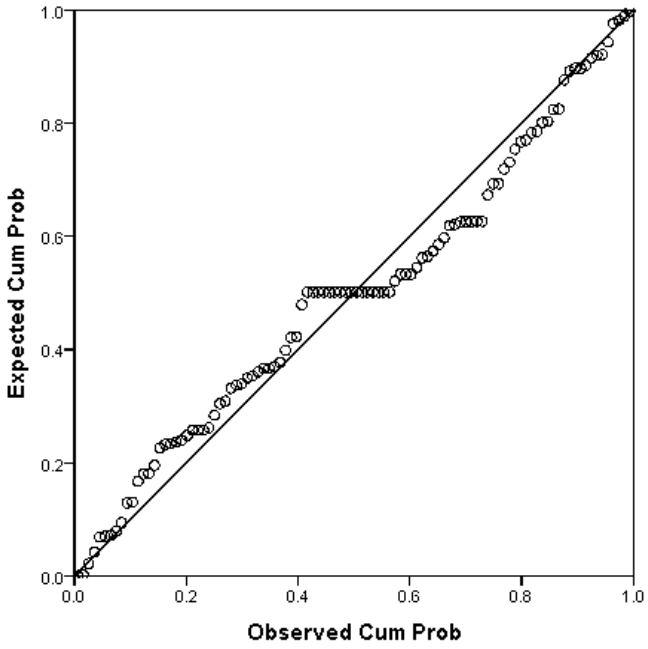

Figure 5.2. P-P plot of residuals from the model shown in table 5.5

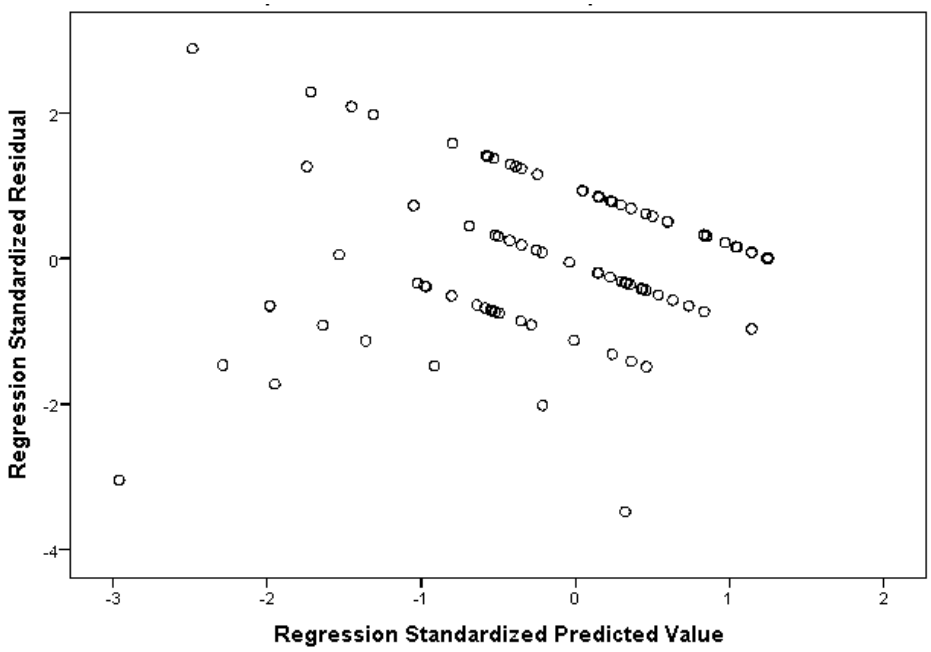

Figure 5.3. Scatterplot of standardised residuals from the model shown in table 5.5

Figure 5.3 shows that the assumption of homoscedasticity for the model shown in table 5.5 appears to be met.

Table 5.6 is identical to table 5.5, apart from the addition of two independent variables; 'Seeing improves understanding' and 'Seeing improves involvement'. These variables were added to determine whether participants seeing their images was an independent predictor of overall experience, as previous research has shown that patients who see their images find it beneficial in regards to disease understanding and improved patient-doctor interaction (Bourke et al., 2017).

Two variables remained constant as independent predictors of overall experience; 'Staff made the experience better' and 'Discomfort during the test.' 'Staff made the experience better' remained the strongest single independent predictor accounting for 22% of variance. In this model 'Seeing improves understanding' was also found to be a positive independent predictor of overall experience. These three variables account for 43% of the variance in participants' overall experience.

Table 5.6. Stepwise linear regression analysis of question items independently associated with overall experience of the test in participants who viewed their images

Model number	Dependent variable	Predictors	Standardized ß	R^2 change	p	Model
1	Overall experience	Staff made the experience better	0.32	0.22	0.005	Adjusted R^2 =0.43; F=14.3; p= <0.001
		Discomfort during the test	-0.38	0.16	0.001	
		Seeing improves understanding	0.30	0.08	0.008	

Items included in this model: all items as per analysis shown in Table 5.5, plus 'seeing improves involvement' and 'seeing improves understanding'.

Figures 5.4 and 5.5 demonstrate that residuals from the model shown in table 5.6 form a normal distribution curve, as is assumed in linear regression.

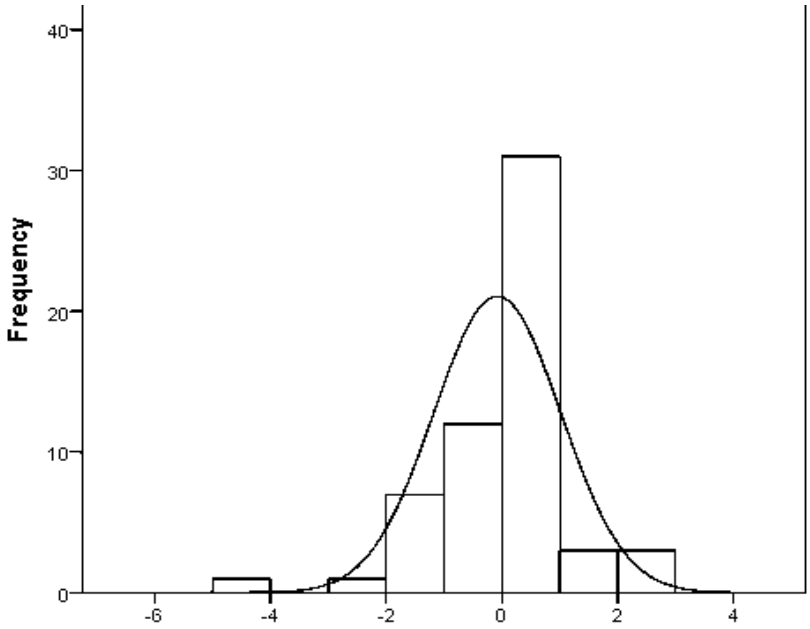

Figure 5.4. Histogram of residuals from the model shown in table 5.6

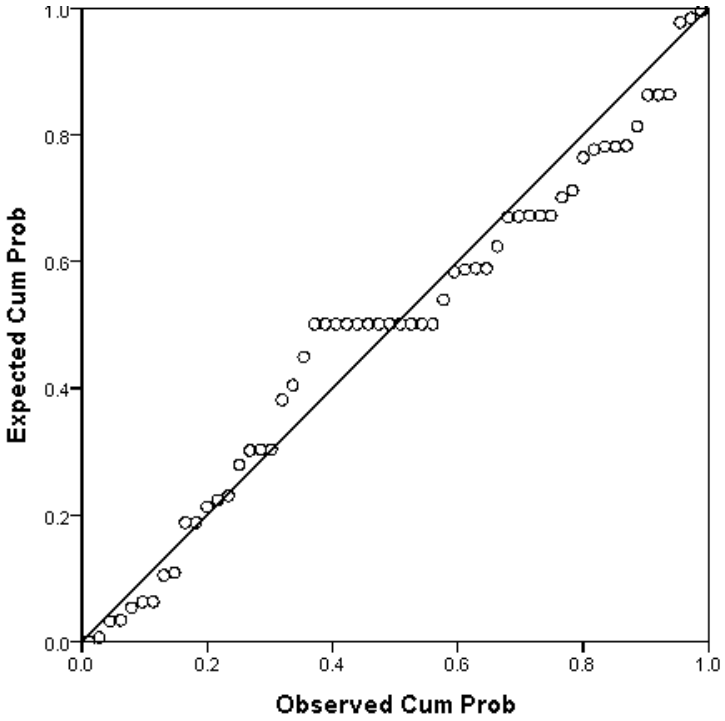

Figure 5.5. P-P Plot of residuals from the model shown in table 5.6

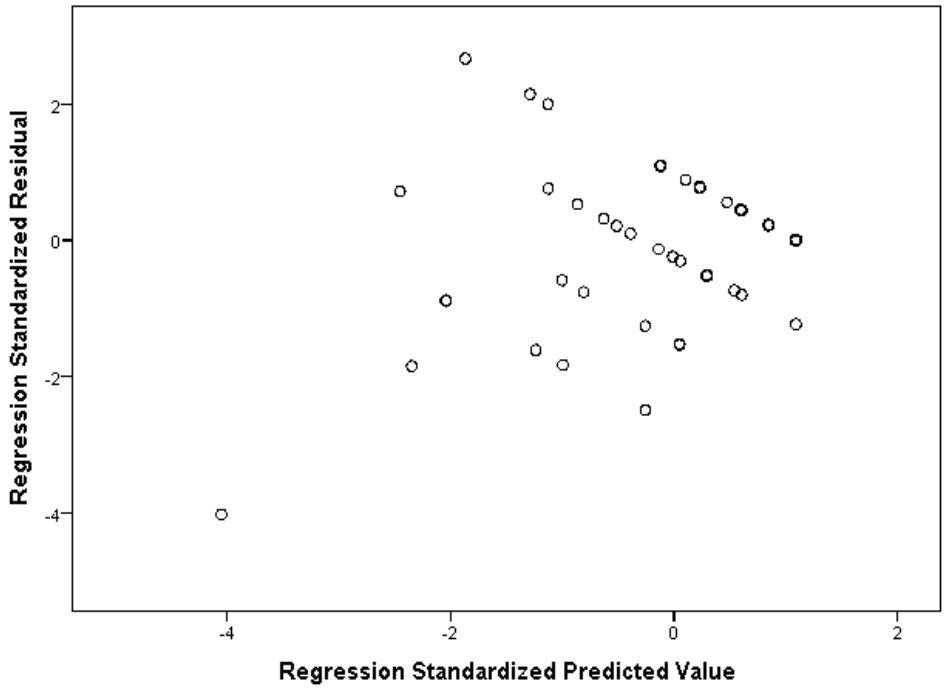

Figure 5.6. Scatterplot of standardised residuals from the model shown in table 5.6

Figure 5.6 shows that the assumption of homoscedasticity for the model shown in table 5.6 appears to be met.

5.3 Participants' recommendations and comments

Approximately 50% of questionnaire respondents made comments/recommendations about their experience. Some were frustrated at the long wait for the result. '*The x-ray I had was a good experience but I would like my results faster - 2 months waiting and I still don't have results.'*

Another participant received their result in a letter from the doctor which they could not follow. *'I couldn't understand the results because I don't know the medical jargon and I found this rather frustrating.'* One recommendation was to give patients a copy of their test images to take home. '*I think all patients should be given copies of their imaging on a CD rom for future reference.'*

Participants who saw their images appreciated this. '*When I do see my images it helps me to see my progression and makes me feel involved, as any decisions I may have to make are then more informed.*'

Discomfort was reported during the test. '*We must stretch our joints for the x-ray and hold certain positions that really are very uncomfortable and painful for us.'* Many participants acknowledged the friendly staff that helped them through the procedure.

'*The staff were absolutely wonderful speaking to me during my MRI which was very reassuring.'*

'The people administering the test are very kind and made me feel safe.'

Most participants appeared to be content with the information they received, however some wanted more. '*More information re how imaging works, what they are looking for and radiation, so risk can be balanced against need to know proper diagnosis.'*

As in the interviews, participants regarded previous experience as beneficial. '*Prior hospitalisation and imaging from prior conditions made me feel pretty relaxed about imaging.'*

5.4 Interpretation of results

Tables 5.2 and 5.3 show that those who had an MRI had a higher median score for 'Waiting for the test' than for the other three imaging tests. This is likely because those that had MRIs waited longer for their tests, in comparison to the other modalities. Thompson (1995) reported that patient satisfaction is determined by the magnitude and direction of the gap between expectations and perceptions of performance; he found that patients were least satisfied when waiting times were longer than expected and vice versa (Thompson & Yarnold, 1995). Therefore if patients are made aware of the usual waiting time for an imaging test they should be less concerned about it. This could also apply to waiting for results.

Table 5.3 demonstrates that only 4/28 (17%) of participants who had an US answered not applicable to the item 'Immediate result', suggesting that 83% of those who had an US received results at the time of the test. Of the four imaging modalities, the US group had the highest number of participants who received immediate feedback on their test. CT was next with 70% of participants receiving immediate feedback, followed by MRI (57%) and CR (35%). Several CT participants were recruited from Auckland university where they had a dual energy CT scan done as part of a gout study. Study volunteers are routinely shown their images by the research team; this likely differs from rheumatology clinical practice and may explain the high number of CT participants who had immediate feedback of results. The response to this item for MRI may have been affected by multiple imaging modalities, as only nine participants had MRI alone.

Table 5.2 shows that six participants (15%) who had an US answered not applicable to the item 'Radiation concern', as did 1 MRI participant (5%), suggesting a lack of knowledge on the potential risks of tests. On the other hand, no CT participants gave a not applicable answer for 'Radiation concern' indicating that they knew that a CT scan involves radiation. This is consistent with research that has shown that those having CT scans are more likely to know that it involves radiation than those having other tests (Bannon, 2015).

5.5 Summary

This chapter reported the results of stage two, the quantitative component of the study. The demographics and disease characteristics of the 108 respondents were presented. The answers to each question item were analysed and compared across the four different MSK tests and there were no significant differences when the Bonferroni correction was used.

Most question items correlated with the overall experience item, with the strongest correlations for the following items: 'Acceptability of the test', 'Seeing improves understanding', 'Previous experience', 'Staff made the experience better' and 'Information provided'.

In stepwise linear regression analysis including imaging modality and all questionnaire items (excepting 'Acceptability of the test') that did not include a not applicable response, four items were independently associated with the overall experience (Table 5,5). 'Staff made the experience better' was the strongest single independent predictor and accounted for 20% of variance in overall satisfaction with the imaging test. Three further items, 'Discomfort during the test', 'Waiting for the test' and 'Part of usual care' were independently associated with the overall experience. These four items accounted for 36% of variance in the regression model.

In an analysis of the participants who had viewed their images, 'Staff made the experience better' was again the strongest single independent predictor of the overall experience and accounted for 22% of variance (Table 5.6). Two further items, 'Discomfort during the test' and 'Seeing improves understanding' were also independently associated with the overall experience. These three items accounted for 43% of variance in the regression model. The regression residuals fit within a normal distribution curve and the assumption of homoscedasticity was met.

Chapter Six: Discussion

6.1 Limitations and Strengths

This study has potential limitations. An unavoidable limitation in the qualitative component of the study is the researcher's presence during data gathering, which may affect the subjects' responses (Anderson, 2010). Stage one and two participants responded to an invitation to participate in the study, and it is possible that the experience of those who did not respond to the invitation may have differed from those who participated in the study (non-response bias). The key limitation for stage two was the low response rate (21%). Those with very negative or positive experiences may have been more likely to respond. Nevertheless, the low response rate should not substantially influence the analysis of factors associated with the patient experience. A previous study researched mail survey response rates published in seven general health education journals and found that a noteworthy percentage of studies had a response rate of less than 50% (Price et al., 2004).

Both stages of the study were retrospective, so despite the short time period between the test and interview or questionnaire, participants may have forgotten some aspects of their experience. Stage two involved patients attending two public healthcare rheumatology units in New Zealand; the experience of waiting times for tests and results may differ in different healthcare systems. Many study participants were not concerned about radiation exposure; the reason for this is unclear and could have been explored further during the qualitative interviews.

Only 37/108 (34%) of questionnaire respondents filled out their age. Unlike the other demographic characteristics, age did not have an associated tick box, which may explain its low response rate. As it was an anonymous postal questionnaire there was no ability to be able to explain questions that participants might misinterpret, hence prior cognitive testing of the questionnaire was undertaken to try to reduce potential differences in understanding and misinterpretation of the questions. As this study was conducted in a single centre, the findings may not be fully generalizable to other units or healthcare systems.

The ability to capture and portray the participant perspective of MSK imaging was one of the study's strengths and also central to promoting authenticity and credibility; both important criteria for enhancing rigour (Milne & Oberle, 2005). Recording and transcribing the interviews verbatim ensured accuracy of the data as well as scientific and ethical integrity. Being a mixed methods study provided a more complete and comprehensive understanding of the patient experience of MSK imaging, than either approach would have alone and led to a questionnaire with greater construct validity.

6.2 How this fits with what we know and implications of these results in clinical practice

This study has shown that patients undergoing musculoskeletal imaging tests for investigation of inflammatory arthritis have a wide range of experiences. Patients with arthritis believe MSK imaging tests are beneficial and part of standard clinical care. Despite some anxiety, all participants in our study completed their imaging procedures. The motivation for doing so may be their belief that the test result is important to their disease management. In general, participants were not concerned about waiting several weeks for an imaging test, but did appreciate immediate feedback of results. Processes to provide more rapid feedback of imaging results may improve the patient experience of the test, and lead to a greater sense of involvement in their clinical care.

Some study participants had a lack of understanding about the potential risks of tests such as radiation exposure. Several previous studies have reported a lack of patient understanding of diagnostic tests (Quirk et al., 1989; Repplinger et al., 2016). Other studies have highlighted initiatives by patients to learn more about their examination from alternate sources, such as the internet or from family or friends (Rosenkrantz & Flagg, 2015), indicating their desire to become more educated about their care. This study has raised the issue of patients receiving adequate and tailored information about imaging tests.

In those patients who viewed their images, 'seeing the images helped me understand my condition better' was positively associated with the overall experience. These findings add to

prior qualitative studies of patients undergoing imaging procedures, which report that viewing images can improve patient understanding of their disease process, impact on patient health behaviour intentions, and positively influence the nature of the interactions between the patient and clinician (Bourke et al., 2017; Carlin et al., 2014; Devcich et al., 2014). In the area of musculoskeletal imaging, a previous questionnaire study also reported that viewing images in real-time during ultrasound-guided joint injection improved patient understanding of the procedure and reduced anxiety about the test in the majority of patients (Sahbudin et al., 2016). Collectively, these data strongly support the process of viewing images with the patient. One way to improve the patient experience of undergoing MSK imaging is to show patients their images more frequently. Providing printouts or copies of relevant images may further enhance patient understanding of disease processes and management.

This study showed that some participants were frustrated by the wait for their results and/or their test. Chesson (2002) discovered that the majority of patients who had an outpatient US, CT or MRI expected to receive their results within two weeks of the test (Chesson et al., 2002). This unrealistic expectation likely contributes to patients' dissatisfaction with waiting times. This discrepancy between expectation and reality could be avoided if referring clinicians state clearly when patients are likely to have their test and receive their result.

Interaction with staff during the test was the strongest independent factor associated with a positive overall experience in both regression models. These findings are consistent with a previous MRI study that emphasized the value of positive interactions with radiology staff; with reassurance, prior explanation of the procedure, communication throughout and staff manner identified as important (MacKenzie et al., 1995). People often need support during scanning from staff members, who have a large impact on the scan experience, either in a positive or negative way (Munn & Jordan, 2011).

The median disease duration for participants in stage one was 9 years. It is possible that patients who are newly diagnosed with inflammatory arthritis have different experiences of MSK imaging tests to those with long-standing disease. This is something that could be explored in further studies.

Physical and emotional discomfort were experienced by participants during the imaging procedures. Emotional discomfort caused by claustrophobia is common during MRI (Dewey et al., 2007; MacKenzie et al., 1995; Melendez & McCrank, 1993). Newer MRI machines have lower rates of claustrophobia, due to a more patient friendly design (Dewey et al., 2007), however they have not removed it completely. A recent meta-analysis of people undergoing MRI, reported that approximately 1 out of 100 people scanned experienced a claustrophobic reaction resulting in premature termination of the procedure (Munn et al., 2015). Patients with more information about MRIs have been shown to be less anxious (Grey et al., 2000). Based on our study observations we recommend patients are provided with sufficient information about claustrophobia-inducing features of MSK tests such as confined space, noise and heat. A photograph of the CT or MRI machine may be beneficial when explaining this experience in patient educational material.

In both regression models, 'Discomfort during the test' was a strong independent predictor of the overall patient experience. Discomfort during peripheral joint imaging may be a particular issue for patients with inflammatory arthritis due to joint tenderness, pain on movement during positioning, and stiffness after the prolonged inactivity that is required for some scans. Some degree of joint pressure or manipulation may be required for acquisition of good quality images. However, careful consideration of pain relief prior to scanning and attention to reduce patient discomfort during scanning may be of benefit in improving the patient experience of these tests. There is no previous literature on discomfort during MSK imaging; however we can extrapolate from other studies. Prior information on discomfort has been shown to help women perceive less discomfort during mammography (Keefe et al., 1994). Hence, if patients with arthritis receive education about discomfort associated with imaging tests, it may lessen their experience of discomfort.

6.3 Conclusion

The aims of this study which were to understand the patient experience of undergoing MSK imaging tests and to identify factors that contribute most to the patient experience were met. This study has identified factors before, during and after an MSK imaging test that contribute to the overall patient experience. Our hypothesis that patients with inflammatory arthritis would have specific preferences for MSK imaging tests, was supported by the data analysis. Participants in this study preferred to receive more information about tests, to have positive interactions with staff and to be shown their images.

Many of the factors associated with the experience of MSK imaging in our study are modifiable, and focusing on these factors may improve the patient experience. Based on the study observations, the investigators recommend that patients having MSK imaging tests for investigation of inflammatory arthritis are given sufficient information about the test including the approximate waiting time for the test and results, the possibility of experiencing discomfort during the test, and the potential risks of the test. Careful attention to patient comfort by staff during positioning and scanning may be of particular importance for patients with joint pain due to inflammatory arthritis. The patient experience could be further improved by providing rapid feedback of results and showing the patients their images, to improve understanding about their condition and involvement in their clinical care.

Bibliography

Aati, O., Taylor, W. J., Horne, A., & Dalbeth, N. (2014). Toward development of a Tophus Impact Questionnaire: a qualitative study exploring the experience of people with tophaceous gout. *J Clin Rheumatol, 20*(5), 251-255. doi:10.1097/RHU.0000000000000127

Aati, O., Taylor, W. J., Siegert, R. J., Horne, A., House, M. E., Tan, P., . . . Dalbeth, N. (2015). Development of a patient-reported outcome measure of tophus burden: the Tophus Impact Questionnaire (TIQ-20). *Ann Rheum Dis, 74*(12), 2144-2150. doi:10.1136/annrheumdis-2014-205671

Aletaha, D., Neogi, T., Silman, A. J., Funovits, J., Felson, D. T., Bingham, C. O., 3rd, . . . Hawker, G. (2010). 2010 rheumatoid arthritis classification criteria: an American College of Rheumatology/European League Against Rheumatism collaborative initiative. *Ann Rheum Dis, 69*(9), 1580-1588. doi:10.1136/ard.2010.138461

Amin, S., LaValley, M. P., Guermazi, A., Grigoryan, M., Hunter, D. J., Clancy, M., . . . Felson, D. T. (2005). The relationship between cartilage loss on magnetic resonance imaging and radiographic progression in men and women with knee osteoarthritis. *Arthritis Rheum, 52*(10), 3152-3159. doi:10.1002/art.21296

Anderson, C. (2010). Presenting and evaluating qualitative research. *Am J Pharm Educ, 74*(8), 141.

Arpansa. (2017). Flying and health.

Bairstow, P. J., Persaud, J., Mendelson, R., & Nguyen, L. (2010). Reducing inappropriate diagnostic practice through education and decision support. *Int J Qual Health Care, 22*(3), 194-200. doi:10.1093/intqhc/mzq016

Baker, J. F., Tan, Y. K., & Conaghan, P. G. (2015). Monitoring in established RA: Role of imaging and soluble biomarkers. *Best Pract Res Clin Rheumatol, 29*(4-5), 566-579. doi:10.1016/j.berh.2015.09.002

Bannon, E. (2015). Explaining, Discussing Medical Imaging is Key to Patient Understanding Retrieved from https://rsna2015.rsna.org/dailybulletin/index.cfm?pg=15Wed03

Bijlsma, J. (2012). *Eular Textbook on rheumatic diseases* (J. Bijlsma Ed. 1st ed.).

Bohndorf, K., & Schalm, J. (1996). Diagnostic radiography in rheumatoid arthritis: benefits and limitations. *Baillieres Clin Rheumatol, 10*(3), 399-407.

Bongartz, T., Glazebrook, K. N., Kavros, S. J., Murthy, N. S., Merry, S. P., Franz, W. B., 3rd, . . . McCollough, C. H. (2015). Dual-energy CT for the diagnosis of gout: an accuracy and diagnostic yield study. *Ann Rheum Dis, 74*(6), 1072-1077. doi:10.1136/annrheumdis-2013-205095

Bourke, S., Taylor, W., Doyle, A., Gott, M., & Dalbeth, N. (2017). The patient experience of musculoskeletal imaging: A qualitative study. *(submitted).*

Braun, H. J., & Gold, G. E. (2012). Diagnosis of osteoarthritis: imaging. *Bone, 51*(2), 278-288. doi:10.1016/j.bone.2011.11.019

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Britten, N. (1995). Qualitative interviews in medical research. *BMJ, 311*(6999), 251-253.

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *Br Dent J, 204*(8), 429-432. doi:10.1038/sj.bdj.2008.292

Carlin, L. E., Smith, H. E., & Henwood, F. (2014). To see or not to see: a qualitative interview study of patients' views on their own diagnostic images. *BMJ Open, 4*(7), e004999. doi:10.1136/bmjopen-2014-004999

Carlsson, S., & Carlsson, E. (2013). 'The situation and the uncertainty about the coming result scared me but interaction with the radiographers helped me through': a qualitative study on patients' experiences of magnetic resonance imaging examinations. *J Clin Nurs, 22*(21-22), 3225-3234. doi:10.1111/jocn.12416

Chesson, R., McKenzie, G., & Mathers, S. (2002). What do patients know about Ultrasound, CT and MRI? *Clinical Radiology, 57*, 477-482.

Colebatch, A. N., Edwards, C. J., Ostergaard, M., van der Heijde, D., Balint, P. V., D'Agostino, M. A., . . . Conaghan, P. G. (2013). EULAR recommendations for the use of imaging of the joints in the clinical management of rheumatoid arthritis. *Ann Rheum Dis, 72*(6), 804-814. doi:10.1136/annrheumdis-2012-203158

Conaghan, P. G., O'Connor, P., McGonagle, D., Astin, P., Wakefield, R. J., Gibbon, W. W., . . . Emery, P. (2003). Elucidation of the relationship between synovitis and bone damage: a randomized magnetic resonance imaging study of individual joints in patients with early rheumatoid arthritis. *Arthritis Rheum, 48*(1), 64-71. doi:10.1002/art.10747

Coursey, C. A., Nelson, R. C., Boll, D. T., Paulson, E. K., Ho, L. M., Neville, A. M., . . . Schindera, S. T. (2010). Dual-energy multidetector CT: how does it work, what can it

tell us, and when can we use it in abdominopelvic imaging? *Radiographics, 30*(4), 1037-1055. doi:10.1148/rg.304095175

Creswell, J. W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks CA: Sage.

Cunnington, J., Marshall, N., Hide, G., Bracewell, C., Isaacs, J., Platt, P., & Kane, D. (2010). A randomized, double-blind, controlled study of ultrasound-guided corticosteroid injection into the joint of patients with inflammatory arthritis. *Arthritis Rheum, 62*(7), 1862-1869. doi:10.1002/art.27448

D'Agostino, M., Wakefield, R., & Backhaus, M. (2008). Combined evaluation of influence of sonographer and machine type on the reliability of power Doppler ultrasonography for detecting, scoring and scanning synovitis in rheumatoid arthritis patients: results of an inter-machine reliability exercise. *Ann Rheum Dis, 67 (Suppl II)*.

Dalbeth, N., Clark, B., Gregory, K., Gamble, G., Sheehan, T., Doyle, A., & McQueen, F. M. (2009). Mechanisms of bone erosion in gout: a quantitative analysis using plain radiography and computed tomography. *Ann Rheum Dis, 68*(8), 1290-1295. doi:10.1136/ard.2008.094201

de Wit, M. P., Abma, T., Koelewijn-van Loon, M., Collins, S., & Kirwan, J. (2013). Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. *BMJ Open, 3*(5). doi:10.1136/bmjopen-2012-002241

de Wit, M. P., Abma, T. A., Koelewijn-van Loon, M. S., Collins, S., & Kirwan, J. (2014). What has been the effect on trial outcome assessments of a decade of patient participation in OMERACT? *J Rheumatol, 41*(1), 177-184. doi:10.3899/jrheum.130816

Devcich, D. A., Ellis, C. J., Waltham, N., Broadbent, E., & Petrie, K. J. (2014). Seeing what's happening on the inside: patients' views of the value of diagnostic cardiac computed tomography angiography. *Br J Health Psychol, 19*(4), 810-822. doi:10.1111/bjhp.12080

Dewey, M., Schink, T., & Dewey, C. (2007). Claustrophobia during magnetic resonance imaging: cohort study in over 50,000 patients. *Journal of Magnetic resonance imaging, 26*, 1322-1327.

Døhn, U., Ejbjerg, B., Hasselquist, M., Narvestad, E., Møller, J., Thomsen, H., & Østergaard, M. (2008). Detection of bone erosions in rheumatoid arthritis wrist joints with

magnetic resonance imaging, computed tomography and radiography. *Arthritis Res Ther, 10*(1).

Durcan, L., Grainger, R., Keen, H. I., Taylor, W. J., & Dalbeth, N. (2015). Imaging as a potential outcome measure in gout studies: A systematic literature review. *Semin Arthritis Rheum*. doi:10.1016/j.semarthrit.2015.09.008

Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Aust N Z J Psychiatry, 36*(6), 717-732.

Gellhorn, A. C., & Carlson, M. J. (2013). Inter-rater, intra-rater, and inter-machine reliability of quantitative ultrasound measurements of the patellar tendon. *Ultrasound Med Biol, 39*(5), 791-796. doi:10.1016/j.ultrasmedbio.2012.12.001

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J, 204*(6), 291-295. doi:10.1038/bdj.2008.192

Grainger, R., Dalbeth, N., Keen, H., Durcan, L., Lawrence Edwards, N., Perez-Ruiz, F., . . . Taylor, W. J. (2015). Imaging as an Outcome Measure in Gout Studies: Report from the OMERACT Gout Working Group. *J Rheumatol, 42*(12), 2460-2464. doi:10.3899/jrheum.141164

Grey, S., Price, G., & Matthews, A. (2000). Reduction of anxiety during MR imaging: a controlled trial. *Magnetic resonance imaging, 18*(351-5).

Hegedus, E. J., Zavala, J., Kissenberth, M., Cook, C., Cassas, K., Hawkins, R., & Tobola, A. (2010). Positive outcomes with intra-articular glenohumeral injections are independent of accuracy. *Journal of shoulder and elbow surgery, 19*(6), 795-801.

Henzler, T., Fink, C., Schoenberg, S. O., & Schoepf, U. J. (2012). Dual-energy CT: radiation dose aspects. *AJR Am J Roentgenol, 199*(5 Suppl), S16-25. doi:10.2214/AJR.12.9210

Keefe, F. J., Hauck, E. R., Egert, J., Rimer, B., & Kornguth, P. (1994). Mammography pain and discomfort: a cognitive-behavioral perspective. *Pain, 56*(3), 247-260.

Kelley, K., Clark, B., Brown, V., & Sitzia, J. (2003). Good practice in the conduct and reporting of survey research. *International journal for quality in health care, 15*(3), 261-266.

Kuper, A., Lingard, L., & Levinson, W. (2008). Critically appraising qualitative research. *BMJ, 337*, a1035. doi:10.1136/bmj.a1035

Lento, P. H., & Primack, S. (2008). Advances and utility of diagnostic ultrasound in musculoskeletal medicine. *Curr Rev Musculoskelet Med, 1*(1), 24-31. doi:10.1007/s12178-007-9002-3

Lin, E. C. (2010). Radiation risk from medical imaging. *Mayo clinical proceedings, 85*(12), 1142-1146.

MacKenzie, R., Sims, C., Owens, R. G., & Dixon, A. K. (1995). Patients' perceptions of magnetic resonance imaging. *Clin Radiol, 50*(3), 137-143.

Makanjee, C. R., Bergh, A. M., & Hoffmann, W. A. (2015). Healthcare provider and patient perspectives on diagnostic imaging investigations. *Afr J Prim Health Care Fam Med, 7*(1). doi:10.4102/phcfm.v7i1.801

Mandl, P., Navarro-Compan, V., Terslev, L., Aegerter, P., van der Heijde, D., D'Agostino, M. A., . . . European League Against, R. (2015). EULAR recommendations for the use of imaging in the diagnosis and management of spondyloarthritis in clinical practice. *Ann Rheum Dis, 74*(7), 1327-1339. doi:10.1136/annrheumdis-2014-206971

Mays, N., & Pope, C. (1995). Rigour and qualitative research. *BMJ, 311*(6997), 109-112.

McKinnis, L. (2014). *Fundamentals of MSK imaging* (4th ed.).

Melendez, J. C., & McCrank, E. (1993). Anxiety-related reactions associated with magnetic resonance imaging examinations. *JAMA, 270*(6), 745-747.

Middleton, W. D., Payne, W. T., Teefey, S. A., Hildebolt, C. F., Rubin, D. A., & Yamaguchi, K. (2004). Sonography and MRI of the shoulder: comparison of patient satisfaction. *AJR Am J Roentgenol, 183*(5), 1449-1452. doi:10.2214/ajr.183.5.1831449

Milne, J., & Oberle, K. (2005). Enhancing Rigor in Qualitative description. *Journal of wound, ostomy and continence nursing, 32*(6), 413-420.

Ministry of Health. (2010). Ethnicity code tables. Retrieved from http://www.health.govt.nz/nz-health-statistics/data-references/code-tables/common-code-tables/ethnicity-code-tables

Munn, Z., & Jordan, Z. (2011). The patient experience of high technology medical imaging: A systematic review of the qualitative evidence. *Radiography, 17*(4), 323-331.

Munn, Z., Moola, S., Lisy, K., Riitano, D., & Murphy, F. (2015). Claustrophobia in magnetic resonance imaging: A systematic review and meta-analysis. *Radiography, 21*(2), 59-63.

Murphy, F. (2001). Understanding the humanistic interaction with medical technology. *Radiography, 7*, 193-201.

Naredo, E., Uson, J., Jimenez-Palop, M., Martinez, A., Vicente, E., Brito, E., . . . Pascual, E. (2014). Ultrasound-detected musculoskeletal urate crystal deposition: which joints and what findings should be assessed for diagnosing gout? *Ann Rheum Dis, 73*(8), 1522-1528. doi:10.1136/annrheumdis-2013-203487

Nightingale, J. M., Murphy, F. J., & Blakeley, C. (2012). 'I thought it was just an x-ray': a qualitative investigation of patient experiences in cardiac SPECT-CT imaging. *Nucl Med Commun, 33*(3), 246-254. doi:10.1097/MNM.0b013e32834f90c6

Nolan, M. T., & Mock, V. (2000). *Measuring patient outcomes*.

Norland Tilburg, E. V. (1990). Controlling error in evaluation instruments. *Journal of extension, 28*(2).

Ochieng, P. O. (2009). An analysis of the strengths and limitation of qualitative and quantitative research paradigms. *Problems of education in the 21st century, 13*.

Okano, T., Inui, K., Tada, M., Y, S., Mamoto, K., Koike, T., & Nakamura, H. (2015). Additional intensive treatment for rheumatoid arthritis patients with positive power doppler signals reduce the radiological joint damage even after achieving clinical remission- SCRUM study- [abstract]. *Arthritis Rheumatol, 67*(S10).

Pope, C., & Mays, N. (2007). *Qualitative research in health care* (3rd ed.).

Pope, T., Bloem, H., Beltran, J., Morrison, W., & Wilson, D. (2015). *Musculoskeletal imaging* (2nd ed.).

Preston, C. C., & Colman, A. M. (2000). Optimal number of response categories in rating scales: reliability, validity, discriminating power, and respondent preferences. *Acta Psychologica, 104*(1), 1-15. doi:Doi 10.1016/S0001-6918(99)00050-5

Price, J., Murnan, J., Dake, J., Dimmig, J., & Hayes, M. (2004). Mail survey return rates published in health education journals: An issue of external validity. *American Journal of Health Education, 35*(1), 19-23.

Quirk, M. E., Letendre, A. J., Ciottone, R. A., & Lingley, J. F. (1989). Anxiety in patients undergoing MR imaging. *Radiology, 170*(2), 463-466. doi:10.1148/radiology.170.2.2911670

Repplinger, M. D., Li, A. J., Svenson, J. E., Ehlenbach, W. J., Westergaard, R. P., Reeder, S. B., & Jacobs, E. A. (2016). Emergency Department Patients' Perceptions of Radiation From Medical Imaging. *WMJ, 115*(1), 22-28.

Rogosnitzky, M., & Branch, S. (2016). Gadolinium-based contrast agent toxicity: a review of known and proposed mechanisms. *Biometals, 29*, 365-376.

Rosenkrantz, A. B., & Flagg, E. R. (2015). Survey-Based Assessment of Patients' Understanding of Their Own Imaging Examinations. *J Am Coll Radiol, 12*(6), 549-555. doi:10.1016/j.jacr.2015.02.006

Ryan, F., Coughlan, M., & Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: Qualitative research. *Br J Nurs, 16*(12), 738-744. doi:10.12968/bjon.2007.16.12.23726

Sahbudin, I., Bell, J., Kumar, K., Raza, K., & Filer, A. (2016). Observing real-time images during ultrasound-guided procedures improves patients' experience. *Rheumatology (Oxford), 55*(3), 585-586. doi:10.1093/rheumatology/kev368

Samson, K. (2015). FDA investigating risk of brain depositis of gadolinium MRI contrast agents. *Neurology Today, 15*(17), 25-26.

Sauvain, M. O., Tschirky, S., Patak, M. A., Clavien, P. A., Hahnloser, D., & Muller, M. K. (2016). Acute appendicitis in overweight patients: the role of preoperatve imaging. *Patient safety in surgery, 10*(13).

Scheel, A. K., Schmidt, W. A., Hermann, K. G., Bruyn, G. A., D'Agostino, M. A., Grassi, W., . . . Backhaus, M. (2005). Interobserver reliability of rheumatologists performing musculoskeletal ultrasonography: results from a EULAR "Train the trainers" course. *Ann Rheum Dis, 64*(7), 1043-1049. doi:10.1136/ard.2004.030387

Schueller-Weidekamm, C., Schueller, G., Aringer, M., Weber, M., & Kainberger, F. (2007). Impact of sonography in gouty arthritis: comparison with conventional radiography, clinical examination, and laboratory findings. *Eur J Radiol, 62*(3), 437-443. doi:10.1016/j.ejrad.2006.12.005

Si, S. X., & Cullen, J. B. (1998). Response categories and potential cultural bias: effects of an explicit middle point in cross-cultural surveys. *The international journal of organizational analysis, 6*(3), 218-230.

Skinner, S. (2013). Radiation safety. *Aust Fam Physician, 42*(6), 387-389.

Thiele, R. G., & Schlesinger, N. (2007). Diagnosis of gout by ultrasound. *Rheumatology (Oxford), 46*(7), 1116-1121. doi:10.1093/rheumatology/kem058

Thompson, D. A., & Yarnold, P. R. (1995). Relating patient satisfaction to waiting time perceptions and expectations: the disconfirmation paradigm. *Acad Emerg Med, 2*(12), 1057-1062.

Thorp, D., Owens, R. G., Whitehouse, G., & Dewey, M. E. (1990). Subjective experiences of magnetic resonance imaging. *Clin Radiol, 41*(4), 276-278.

Törnqviste, E., Månsson, Å., Larsson, E.-M., & Hallström, I. (2006). It's like being in another world-patients' lived experience of magnetic resonance imaging. *J Clin Nurs, 15*, 954-961.

Watling, C. J., & Lingard, L. (2012). Grounded theory in medical education research: AMEE Guide No. 70. *Med Teach, 34*(10), 850-861. doi:10.3109/0142159X.2012.704439

Wells, G., Beaton, D. E., Tugwell, P., Boers, M., Kirwan, J. R., Bingham, C. O., 3rd, . . . van der Heijde, D. M. (2014). Updating the OMERACT filter: discrimination and feasibility. *J Rheumatol, 41*(5), 1005-1010. doi:10.3899/jrheum.131311

Wiell, C., Szkudlarek, M., Hasselquist, M., Moller, J. M., Vestergaard, A., Norregaard, J., . . . Ostergaard, M. (2007). Ultrasonography, magnetic resonance imaging, radiography, and clinical assessment of inflammatory and destructive changes in fingers and toes of patients with psoriatic arthritis. *Arthritis Res Ther, 9*(6), R119. doi:10.1186/ar2327

Wolf, J. A., Niederhauser, V., Marshburn, D., & LaVela, S. L. (2014). Defining patient experience. *Patient experience Journal, 1*(1).

Appendix A: The interview schedule

Interview Guide Questions for 'The patient experience of musculoskeletal imaging' study: part 1

Introductions
Answer any questions participants have
Explain the purpose of the interviews
Take consent
Explain the recording device

First I have a few questions about you and your arthritis:

Questionnaire

1. Date of interview

2. What is your age?

3. What is your gender?

4. Please indicate the ethnic group(s) you belong to

5. What type of arthritis do you have?

6. How long have you had it for?

7. What was the date of the test?

8. What joint did you have imaged?

9. What test did you have done?

10. Did you have an injection of contrast as part of the test?

Interview questions

Can you tell me about your arthritis? How does it impact on your life?

Section 1: Pre-test

- Please can you start by telling me about why the test was arranged?
- How did you feel when you were told you needed to have an imaging test?
- Were the advantages and disadvantages of different tests discussed with you?
- How long did you wait before the test?
- How did you feel about the waiting time?
- How did you feel about the test while you were waiting?
- What information did you receive about the test before you had it?
- How did you get this information (prompts: Internet? Other patients? Rheumatologist? Radiology department?)
- How did the information make you feel?
- Do you have any suggestions for improving the information provided?

Section 2: Having the test

- What was it like, just getting to the place where the test was done?
- Please can you tell me a little bit about what happened when you had the test? (break down into sequential sections: getting prepared including changing/exposure, positioning, during scan, after scan)
- How did you feel when you were having the test? (prompts based on previous research – any feelings of claustrophobia/feeling trapped; anxious; lack of control ; discomfort related to positioning; ?pain – if any of these feelings reported – how did you manage e.g. your feelings of anxiety?)
- Did you feel well supported by the staff performing the test? Do you feel they communicated well with you? Is there anything you think the staff performing the test could have done to make the experience better for you?

Section 3: Post-test

- Who gave you the results of your test? When was this? What did they tell you?
- What do you feel about how the test results were explained?
- What you do feel about the test results?

Section 4: Overall reflections about the test

- What did you like about the test?
- What didn't you like about the test?
- Do you have any concerns about the safety of the test? (prompts: radiation, iv contrast)
- If you had to have this imaging test again, how would you feel?
- If your family or friends needed to have this imaging test, what advice would you give them?
- What advice would you give health professionals to help them improve your experience of the test?
- Do you have any other comments about your experience of the test?

Appendix B: Pre-cognitive test questionnaire

Questionnaire

MEDICAL AND HEALTH SCIENCES

Locality:	University of Auckland	Ethics committee ref.:	15/CEN/188
Lead investigator:	Dr Sandra Bourke	Phone: 02102225304	

Please start by answering the following questions about yourself

Age: **Gender:** ☐ Female ☐ Male

Ethnicity: ☐ NZ/European ☐ Māori ☐ Pacific People ☐ Asian ☐ Other

Diagnosis: ☐ Rheumatoid arthritis ☐ Psoriatic arthritis ☐ Gout ☐ Other ☐ Uncertain

Joint that was imaged: ☐ Foot ☐ Ankle ☐ Knee ☐ Hand ☐ Wrist ☐ Elbow

***Imaging test that you had:** ☐ X-ray ☐ Ultrasound ☐ CT ☐ MRI

*If you had 2 tests and 1 was an X-ray, please answer these next questions for the other test

Please think about your recent imaging test (X-ray, Ultrasound, CT or MRI) and circle a number between one and ten for the following statements.

1. **It was important to have the test to find out about my arthritis**

Strongly Disagree — Strongly Agree

1 2 3 4 5 6 7 8 9 10

2. **Having this test is part of standard clinical care for patients with arthritis**

Strongly Disagree — Strongly Agree

1 2 3 4 5 6 7 8 9 10

3. I was concerned about the waiting time for the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

4. I was given enough information about the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

5. My experience of having this test before made me feel more comfortable this time

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

6. I found the test uncomfortable

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

7. I felt anxious during the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

8. The staff performing the test made the experience better for me

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

9. I am concerned about my test results

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

10. I don't mind waiting for my test results

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

11. I found it helpful getting my results at the time of the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

12. Seeing the images helped me understand my condition better

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

13. Looking at the images with my doctor made me feel more involved in my care

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

14. I would have this test again in the future

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

15. I am concerned about the safety of the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

16. I am concerned about exposure to radiation during the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

17. I am concerned about the contrast injection during the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

18. My overall experience of the test was

Very unpleasant Excellent

1 2 3 4 5 6 7 8 9 10

19. Please write any recommendations for improving the patient experience of the test below.

_____
_____
_____
_____
_____
_____
_____

Appendix C: Final questionnaire

Questionnaire

MEDICAL AND HEALTH SCIENCES

Locality:	University of Auckland	Ethics committee ref.:	15/CEN/188
Lead investigator:	Dr Sandra Bourke	Phone: 02102225304	

Please start by answering the following questions about yourself

Age:

Gender: ☐ Female ☐ Male

Ethnicity: ☐ NZ/European ☐ Māori ☐ Pacific People ☐ Asian ☐ Other _____ (please specify)

Type of arthritis: Tick all that apply ☐ Rheumatoid arthritis ☐ Psoriatic arthritis ☐ Gout ☐ Other ☐ Uncertain

Joint that was imaged: Tick all that apply ☐ Foot ☐ Ankle ☐ Knee ☐ Hand ☐ Wrist ☐ Elbow

*** Imaging test that you had** Tick all that apply ☐ X-ray ☐ Ultrasound (in clinic) ☐ Ultrasound (in radiology dept) ☐ CT ☐ MRI

***** If you had two tests and one was an X-ray, please answer these next questions for the other test (eg. Ultrasound, CT or MRI). If you only had an X-ray, please answer for the X-ray.

Please think about your recent imaging test (X-ray, Ultrasound, CT or MRI) and circle a number between one and ten for the following statements.

1. **It was important to have the test to find out about my arthritis**

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

2. **Having this test is part of usual clinical care for patients with arthritis**

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

3. I was concerned about the waiting time for the test

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

4. I was given enough information about the test

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

5. My experience of having this test before made me feel more comfortable this time

Strongly Disagree								Strongly Agree		
1	2	3	4	5	6	7	8	9	10	Not Applicable

6. I found the test uncomfortable

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

7. I felt anxious during the test

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

8. The staff performing the test made the experience better for me

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

9. I am concerned about my test results

Strongly Disagree								Strongly Agree	
1	2	3	4	5	6	7	8	9	10

10. I don’t mind waiting for my test results

Strongly Disagree								Strongly Agree		
1	2	3	4	5	6	7	8	9	10	Not Applicable

11. I found it helpful getting my results at the time of the test

Strongly Disagree								Strongly Agree		
1	2	3	4	5	6	7	8	9	10	Not Applicable

12. Seeing the images helped me understand my condition better

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

13. Looking at the images with my doctor made me feel more involved in my care

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

14. I would have this test again in the future

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

15. I am concerned about exposure to radiation during the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

16. I am concerned about the contrast injection (dye) during the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10 Not Applicable

17. I am concerned about the safety of the test

Strongly Disagree Strongly Agree

1 2 3 4 5 6 7 8 9 10

18. My overall experience of the test was

Very unpleasant Excellent

1 2 3 4 5 6 7 8 9 10

19. Please write any recommendations for improving the patient experience of the test below

---

Appendix D: Participant information sheet for stage one

Study title:	***The patient experience of musculoskeletal imaging: interviews***		
Locality:	University of Auckland	Ethics committee ref.:	15/CEN/188
Lead investigator:	Dr Sandra Bourke	Contact phone number:	02102225304

You are invited to take part in a study on the patient experience of different imaging tests for arthritis. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is five pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the purpose of the study?

The purpose of this study is to find out the experience of patients with arthritis who have had imaging tests including X-rays, ultrasound, CT scans and MRI scans.

The information from this study will help doctors decide which imaging test to order for people with arthritis.

What will my participation in the study involve?

You have been chosen to participate as you have had an imaging test of a joint (X-ray, ultrasound, CT or MRI) done within the last 6 weeks.

We would like to interview you to find out your experience of that imaging test. This will be a one off interview and will take about one hour. The interview will be taped. The tapes will be held in a secure storage place at Auckland University for 10 years and then destroyed.

What are the possible benefits and risks of this study?

This study will give us information on what patients like or dislike about different imaging tests.

Doctors can use this information to make sure they order tests that patients are happy with.

We will keep your medical information private and you will not be identified in any study reports.

Who pays for the study?

It will not cost you anything to do this study. We will cover your travel expenses and give you a $20 gift voucher in appreciation of your participation.

This study has been funded by a grant from Arthritis New Zealand.

What if something goes wrong?

If you were injured in this study, which is unlikely, you would be eligible **to** apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What are my rights?

Participation in this study is voluntary (your choice). You are free to decline to participate or withdraw from the research at any time without any disadvantage to you.

You have the right to access information about you collected as part of the study.

What happens after the study or if I change my mind?

All data will be kept private and stored securely for 10 years before being destroyed. The study will take over a year to complete. We will send you a letter with results of the study at the end of this time.

We plan to publish results from this study in scientific journals so that the information is freely available to other doctors, scientists and the public. Patients will not be identified in any report or publication and all information about your identity will be kept strictly confidential.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Sandra Bourke

Telephone number: 02102225304

Email: s.bourke@auckland.ac.nz

Or: Professor Nicola Dalbeth

Telephone number: 9232568

Email: *n.dalbeth@auckland.ac.nz*

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively you may contact the administrator at He Kamaka Waiora (Māori Health Team, Auckland District Health Board) by telephoning 09 486 8324 ext 2324.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Although the health and disability ethics committee has approved the information provided in this informed consent form and has granted approval for the investigator to conduct the study, this does not mean the ethics committee has approved your participation in the study. You must evaluate the information in this informed consent form for yourself and decide whether or not you wish to participate.

Appendix E: Consent form for stage one

MEDICAL AND HEALTH SCIENCES

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.		
I consent to the research staff collecting and processing my information, including information about my health.		
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.		
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I understand the compensation provisions in case of injury during the study.		

I know who to contact if I have any questions about the study in general.

I understand my responsibilities as a study participant.

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature: Date:

Appendix F: Participant information sheet for stage two

MEDICAL AND HEALTH SCIENCES

Study title:	The patient experience of musculoskeletal imaging: questionnaire		
Locality:	University of Auckland	Ethics committee ref.:	15/CEN/188
Lead investigator:	Dr Sandra Bourke	Contact phone number:	02102225304

You are invited to take part in a study on the patient experience of different imaging tests for arthritis. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to complete an anonymous questionnaire about your experiences of your imaging test. You can keep a copy of this Participant Information Sheet.

This document is three pages long. Please make sure you have read and understood all the pages.

What is the purpose of the study?

The purpose of this study is to find out the experience of patients with arthritis who have had imaging tests including X-rays, ultrasound, CT scans and MRI scans.

The information from this study will help doctors decide which imaging test to order for people with arthritis.

What will my participation in the study involve?

You have been chosen to participate as you have had an imaging test of a joint (X-ray, ultrasound, CT or MRI) done within the last 6 weeks.

We would like you to fill out a questionnaire on how you found that imaging test. The questionnaire should not take longer than 10 minutes to complete. We ask you to complete the questionnaire after your test and post it back to us in a self-addressed envelope.

What are the possible benefits and risks of this study?

This study will give us information on what patients like or dislike about different imaging tests.

Doctors can use this information to make sure they order tests that patients are happy with.

We will keep your medical information private and you will not be identified in any study reports.

Who pays for the study?

It will not cost you anything to do this study.

This study has been funded by a grant from Arthritis New Zealand.

What if something goes wrong?

If you were injured in this study, which is unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What are my rights?

Participation in this study is voluntary (your choice). You are free to decline to participate or withdraw from the research at any time without any disadvantage to you.

What happens after the study or if I change my mind?

All data will be anonymous and stored securely at Auckland University for 10 years before being destroyed.

We plan to publish results from this study in scientific journals so that the information is freely available to other doctors, scientists and the public. Patients will not be identified in any report or publication and all information about your identity will be kept strictly confidential.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Sandra Bourke

Telephone number: 02102225304

Email: s.bourke@auckland.ac.nz

Or: Professor Nicola Dalbeth

Telephone number: 9232568

Email: *n.dalbeth@auckland.ac.nz*

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively you may contact the administrator at He Kamaka Waiora (Māori Health Team, Auckland District Health Board) by telephoning 09 486 8324 ext 2324.

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Although the health and disability ethics committee has approved the information provided in this informed consent form and has granted approval for the investigator to conduct the study, this does not mean the ethics committee has approved your participation in the study. You must evaluate the information in this informed consent form for yourself and decide whether or not you wish to participate.

If you agree to participate in the study, please complete the attached questionnaire.

Appendix G: Ethics approval

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

23 November 2015

Professor Nicola Dalbeth
Department of Medicine
University of Auckland
Auckland 1023

Dear Professor Dalbeth

Re:	**Ethics ref:**	**15/CEN/188**
	Study title:	The patient experience of musculoskeletal imaging: a mixed models study

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

Summary of ethical issues (outstanding)

The main ethical issues considered by the Committee and which require addressing by the Researcher are as follows.

— The Committee's approval of this application is conditional to the phase one generated questionnaire being submitted and approved by the Health and Disability Ethics Committee before phase two of the study can begin.

This can be done via a post approval form-amendment in your ONLINE FORM account.

Please note, it is possible that phase two may still require a consent form depending upon the nature of the questions generated from phase one.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your **next progress report** is due by **22 November 2016**.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee