The Totara House Healthy Eating Study.

A qualitative investigation into the feasibility of adapting the Senior Chef programme for patients in a mental health setting.

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Abstract

**Background:** People experiencing early or first episode psychosis (FEP) are at increased risk of metabolic complications resulting from an interaction of illness symptoms, medication side-effects and lifestyle choices. Few studies have explored practical lifestyle interventions utilising nutrition education strategies to improve health outcomes in this population. This study aimed to assess the feasibility of implementing a healthy eating intervention programme in Totara House (a CDHB outpatient service for young adults with first episode psychosis by analysing stakeholder feedback, to determine whether a programme could be developed from a pre-existing learn to cook programme Senior Chef.

**Methods:** Participants involved key stakeholders of Totara House: staff, patients and family members/carers, who were recruited by advertisement or through recommendation from Totara House staff. A combination of individual interviews amongst patients and caregivers and a single focus group amongst staff members was used to explore participant thoughts, opinions, values and experiences, about the importance of nutrition (in this population), and suggestions for programme component ideas. Participants completed a questionnaire to assess their current level of nutrition knowledge.

**Results:** The data were analysed using thematic analysis. Three main themes emerged: “Personal Values” which explored patient worldviews, motivators and barriers; “Knowledge and Experiences of Health and Nutrition” which covered factors that can influence patients’ thoughts and attitudes towards achieving health goals;
and “Programme Specific Details” included recommendations from participants for what they wanted to see in a healthy eating intervention programme. These themes and values support implementing a programme with a relaxed social atmosphere, including relevant practical information, and simple, affordable, healthy recipes they can try out at home. The questionnaire scores showed an average level of nutrition knowledge amongst all groups with a mean score of 53% (n=24). A one-way ANOVA revealed no between group differences (p = 0.46): patients 49% (n=8), staff 55% (n=10), family/carers 56% (n=6), range 32%-73%.

**Conclusion:** A healthy eating intervention programme would be highly valued by Totara House staff, patients and family members/carers. The feedback for the desired programme content aligned with the pre-existing Senior Chef model indicating its potential adaptability into this population. To ensure that the content adheres to current evidence-based nutrition advice, a registered dietitian should be involved in developing, running or overseeing the programme.
Preface

This study is the first phase of ongoing research to establish a healthy eating programme at Totara House. Responsibilities for this thesis project are as follows.

The primary supervisor of this study Dr Jane Elmslie (Clinical Senior Lecturer, Department of Psychological Medicine, University of Otago Christchurch and Clinical Leader of Dietetics, Specialist Mental Health Services, Canterbury District Health Board) was responsible for the following:

- Developing the idea for the study in collaboration with Jasna Robinson-Wright
- Study concept, design and choice of methodology
- Completion and submission of the ethics proposal and Māori consultation
- Supervision of the candidate throughout, with regular meetings
- Assistance with participant recruitment
- Guidance and editing of the written thesis

The co-supervisor Professor Roger Mulder (Professor, Department of Psychological Medicine, University of Otago Christchurch) provided:

- Guidance on the psychiatric aspects of the project in the initial stages of the study design.
- Guidance on the written thesis

The candidate (Aimee Borich) in accordance with Masters of Dietetics requirements was responsible for the following:

- Recruitment of participants
• Creation of focus group and interview questions
• Conducting the focus group and interviews with participants
• Questionnaire data consolidation and analysis
• Coding written transcripts and thematic analysis using Nvivo Qualitative Analysis Software
• Writing the thesis
Acknowledgements

To my amazing supervisor Jane Elmslie, I literally could not have done this without you. Your passion for your profession and intelligence is inspiring and I feel I have learnt so much from you over this past year. Thanks for your patience while I reacquainted myself with qualitative research (and my psychology roots!), and providing valuable feedback and insight on my experiences during this arduous thesis journey.

To Jasna Robinson-Wright and Leah O’Neill, who found the time in their busy schedules to show me everything that is Senior Chef, it was a valuable insight and helped shape my approach to this project.

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Finally, but most importantly, thank you to all of the participants who helped out with this study. It was a privilege to meet you all and listen to your stories and experiences. For some of you it meant letting a complete stranger come into your bubble and answer what must have seemed like frivolously random questions, it was never taken for granted. I hope that we can create a programme that will reflect everything you have shared here so that we can help future patients with their journey to wellness. I wish all you all the very best for your futures-whether it be in your own recovery or supporting someone that is going through theirs.
Dedication.

To my late father,
You always wanted to provide the best for me in life and for me to achieve every dream that crossed my mind. Knowing that with you in my corner I could be unstoppable was the most comforting feeling any daughter could have asked for. You inspired me to become a dietitian and I hope I do you proud.

And to my mother,
You are one of the strongest women I know and you inspire me every day.
I love you more than words can ever express.

“Like my father’s come to pass seven years has gone so fast…
As my memory rests, but never forgets what I lost,
Wake me up when September ends.”
—Billie Joe Armstrong
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<thead>
<tr>
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<tbody>
<tr>
<td>BMI</td>
<td>Body Mass Index (kg/m²)</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CDHB</td>
<td>Canterbury District Health Board</td>
</tr>
<tr>
<td>FEP</td>
<td>First Episode Psychosis</td>
</tr>
<tr>
<td>FGA</td>
<td>First Generation Antipsychotic [medication]</td>
</tr>
<tr>
<td>SGA</td>
<td>Second Generation Antipsychotic [medication]</td>
</tr>
<tr>
<td>SMHS</td>
<td>Specialist Mental Health Service</td>
</tr>
<tr>
<td>SMI</td>
<td>Serious Mental Illness</td>
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</table>
1. Introduction

Previous research indicates that people experiencing psychosis or serious mental illness (SMI) are at an increased risk of developing chronic physical illnesses resulting from a complex interaction between the psychological, physical, genetic and pharmacological effects of psychosis and its treatment (1). People experiencing First Episode Psychosis (FEP) are usually treated with antipsychotic medications which place them in a vulnerable position: although they require the medications to recover psychologically, the resulting side effects can affect them physically, making treatment compliance more difficult. If these side-effects are not monitored closely—weight gain and blood glucose parameters in particular, patients are at an increased risk of developing health complications such as Metabolic Syndrome, Diabetes Mellitus, and Cardiovascular Disease (1, 2). Patients with FEP are generally young adults and have not previously taken antipsychotic medications. As such they are in a critical treatment window for the prevention of chronic physical illness related to the side effects of medications, and physical health interventions should be initiated concurrently with, or soon after commencement of medication treatment (3).

To date there has been little research into the prevention of medication related weight gain and accompanying metabolic factors in patients with FEP. Some services provided lifestyle interventions adapted from successful weight management programmes in the general population, while others used pharmacological measures to control side effects such as Metformin or Orlistat (4), which often carry their own set of risks (5). Behavioural and lifestyle interventions that focus on changing daily
behaviours (such as learning how to cook), have the potential to create greater changes beyond biological parameters, by increasing self efficacy and self-esteem, learning new skills, social bonding with peers, provide routine, and regaining a feeling of independence (6,7).

Therefore the intention of the current study was to:

- Explore the thoughts, opinions, values and experiences of the stakeholders at an early intervention into psychosis service facility (Totara House) to identify the best approach to prevent weight gain and metabolic complications.
- Examine the feasibility of implementing a lifestyle and learn-to-cook intervention programme into Totara House
- Assess whether a pre-existing learn to cook programme (Senior Chef) could be adapted to meet the needs of this population
2. Literature Review

The purpose of this literature review is to evaluate existing research relating to lifestyle intervention programmes in people with first episode psychosis including:

- The effect of psychosis on behaviour and cognition in young adults
- The effects of common antipsychotics on metabolic risk factors
- The effectiveness of healthy living and cooking programmes on dietary behaviour change
- The use of patient/participant input into programme creation
- Nutrition knowledge in those with psychosis/serious mental illness

2.1 Literature Search

The process for this literature search involved the databases Pubmed, Scopus, and Medline (Ovid Medline® 1946-present with daily update, Ovid Medline, Medline Pending, PsychINFO 2002-2015/1867-2015/1806-2015) using the keywords/search terms: first episode psychosis; psychosis; mental health; early intervention in psychosis; serious mental illness; mental; mental health; AND; lifestyle; lifestyle intervention; lifestyle programme; metabolic syndrome; diet; cooking; food; nutr*; weight; weight gain; weight intervention; nutrition knowledge; behaviour; programme; physical health.

A secondary search for reviews or summary articles about learn-to-cook programs was conducted using the aforementioned databases and additionally Science Direct, incorporating the search terms: cooking class; cooking classes; cooking; AND;
psychosis; psycho*. Also included in this secondary search were systematic reviews on metabolic effects of antipsychotic medications: antipsychotic AND metabolic AND intervention; mechanisms; prevalence AND systematic review.

Further suitable studies were found using the reference lists of relevant papers, the University of Otago Library Article Linker and Interloan service, Ovid, Scopus, Science Direct and Google Scholar. Commentaries, letters to the editor, case reports, programme outlines/study proposals, and studies in languages other than English were excluded from analysis, as were studies where the primary outcome variables were mental health parameters (i.e. psychosis symptoms) not physical parameters (e.g. weight, blood glucose levels, BMI, cholesterol levels).

2.2 Cognitive and behavioural implications of psychosis

2.2.1 Definition of Psychosis

Psychosis can be defined as a detachment from reality caused by mental illness that can involve: delusions (a belief that remains intact despite contrary evidence in reality), hallucinations (involuntary sensory experiences without external stimulus), disorganized thinking (evident through speech patterns), disorganised or abnormal motor behaviours (such as agitation, decreased reactivity to environment, mutism, stupor, grimacing, excessive movements without stimulation), and negative affect (decreased emotional expression, avolition, lethargy, anhedonia, asociality, and lack of ‘expressive’ motor movements-such as hand gestures) (8). Psychosis can be considered to be temporary or short term as a result of a substance, illness or a
stress-induced state (more than one day, less than a month) which can be treated quickly and may not recur. Alternatively, it could be longer-term (six months or more), chronic or lifelong, requiring long term treatment-typically with antipsychotic medications. First episode psychosis, in extension, is used where the patient has experienced their first psychotic episode of a severe mental illness (SMI) (8).

2.2.2 Behaviour and Cognition

Diagnostic symptoms related to psychosis appear to have an impact on neurobiological and cognitive functioning long term (8). Individuals may require life-long assistance with activities of daily living and protection from any consequences resulting from their impairments or illness. Common impairments include: poor interpersonal relationships (from an impaired ability to read/understand others’ intentions), reduced capacity to work, poorer self-care, inappropriate affect, anxiety, phobias, mood-swings, distorted perceptions, dysphoria, avolition, impaired declarative and/or working memory, disturbed sleeping and eating patterns, communication difficulties, slower mental processing (including sensory and vocational), poor concentration, lethargy, depersonalisation and lack of insight (i.e. they may recognise that others believe they are “crazy” but fail to see it themselves). This lack of insight, coupled with other impairments, is an important predictor of poor treatment adherence (8).

2.2.3 Implications for Young Adults

Psychosis symptoms most commonly develop during late adolescence to early adulthood, with occurrences prior to adolescence rare. Although the symptomatic
state may be short-term, there can be permanent impairments which can be worsened by the earlier onset of symptoms (due to the brain still developing), leading to a failure to achieve the expected level of functioning (8). These impairments can have lasting effects on education, hinder the formation of lasting social relationships with peers (social isolation) and create problems for continuing employment. Although there is a perceived social stigma against those with mental illness and the need for antipsychotic medications, young adults may find it especially challenging to cope with these perceptions if they have low self-esteem, which could lead to a lack of adherence with treatment regimens resulting in relapses or hospitalisation (9-11). This age group feels that they lack the support needed to increase their motivation to cope with their illness (12), and prefer a more hands-on/practical approach to illness management and interventions, as opposed to more traditional written education materials favoured by family members or older adults (13).

2.3 Medication Mediated Side effects

Antipsychotic medications can be divided into two generations. The first generation antipsychotic medications (FGA’s) such as Haloperidol and Chlorpromazine were effective in treating psychosis symptoms, but when used long term, patients were at substantially increased risk of developing extrapyramidal symptoms leading to motor control dysfunction (14). The second generation antipsychotic medications (SGA’s) such as Clozapine and Olanzapine increased the efficacy at treating psychosis symptoms and removed the extrapyramidal side effects, however patients can experience significant metabolic side effects that could develop into chronic diseases.
if left untreated (1, 14). This increased efficacy in treating psychosis makes SGA’s the more popular choice for those experiencing FEP, however the cost of this efficacy is that patients report experiencing an insatiable appetite with no feeling of satiety, and lethargic behaviour, which can lead to excessive consumption of unhealthy foods and forgoing regular exercise in favour of sedentary activities (12, 15-18).

2.3.1 Medication-mediated adverse effects

The most commonly reported side effects of antipsychotic medications are weight gain, sedation, increased appetite, and decreased satiety, however other adverse effects can include: metabolic syndrome, sexual dysfunction, Type 2 Diabetes Mellitus, hyperprolactinaemia, dyslipidaemia, and cardiovascular effects including hypertension and arrhythmias (1, 2). In FGA’s specifically there is the added risk of Parkinsonism, dyskinesia, akathisia dysphoria and dystonia if used long term (19).

2.3.2 Prevalence of SGA side effects in those with FEP

Patients experiencing treatment for FEP are valued by researchers as they can assess the effects of the medications in drug-naïve populations. It has been shown that FEP patients can begin to experience distinct changes to their weight and metabolic parameters within three months of beginning treatment (15, 20-22), and that incidence rates of these side effects can be as high as 80%, indicating a higher vulnerability in those without prior exposure to antipsychotic medication (10). Given that people who experience FEP, or are drug naïve have a three to four fold increase in weight gain compared to those with chronic psychosis (10), it is critical any interventions occur early within treatment. There is some evidence that their BMI prior
to treatment can influence the severity of weight gain: If the BMI is low, some of the weight gain could be seen as recovering weight, whereas if the BMI is high the weight gain can be more pronounced (17, 23). A meta-analysis that investigated the prevalence of Metabolic Syndrome and obesity between FEP patients, un-medicated psychosis patients and chronic/long-term medicated patients, found that the chronic patients showed prevalence rates of almost double that of the un-medicated or FEP patients (24), indicating the presence of a treatment duration effect (1, 25, 26). It is highly recommended that in addition to monitoring weight gain, all patients receiving antipsychotic medication should be regularly monitored for changes in metabolic parameters such as fasting glucose and HbA1c (glycated haemoglobin) to prevent the development of co-morbidities (27, 28). It is expected that those monitoring these patients will know when to intervene and seek appropriate treatment options (29).

### 2.3.3 Mechanisms of SGA medications influencing metabolic risk factors

Patients on SGAs can gain 10-15% of pre-treatment body weight within 12 months of beginning treatment (70% of which in the first three months) with the weight likely to plateau after several years (22, 30, 31). The broader mechanisms involved in creating this rapid weight gain (and accompanying metabolic outcomes) can be divided into three categories: patient factors (age, gender, genetics, BMI-current and pre-illness), illness factors (symptom severity, FEP status), and treatment variables (choice of medication, dosage, duration, use of multiple medications/polypharmacy) (17).

New research into the molecular genetics of patients with psychosis seeks insight into potential genetic susceptibilities, and to develop an understanding of how antipsychotic medications affect the human body. The improved efficacy of SGA’s
indicates that they have more widespread neurological influences than FGA’s, and the resulting effects could disrupt regular homeostatic neurotransmitter functions and hormone regulation. Although this research field is still in its infancy-and largely confined to animal studies, there are promising discoveries that specific genomes and neuro-receptors could help explain patients’ experience of homeostatic dysregulation. There is also emerging evidence that those with psychosis may have a genetic vulnerability for the illness within the genome that is also involved with glucose metabolism regulation which could increase their risk of developing diabetes-independent of medication use (18, 23). This would also help to explain the high diabetes rates observed in first degree family members who have not experienced psychosis (4, 32, 33). The other theories currently being researched involve the disruption of: dopamine and histamine receptors, pancreatic β cell functioning, opioid neuropeptides, and other hormone channels that can affect hypothalamic signalling pathways in the central nervous system (such as insulin/glucose regulation and satiety signalling) (15, 32). If these molecular genetic components can be understood it could lead to the development of specifically targeted antipsychotic medications with fewer side effects. Illness factors relate to the severity of psychosis symptoms and how they can influence the extent to which side effects are experienced, as those with the most severe symptoms and those who are drug naïve appear to be more susceptible to side-effects (34). This is where the treatment effects become apparent as in order to treat these symptoms they may require: higher medication doses (31, 35), more potent medications (which can attenuate greater weight gain) (35, 36), alternative bioactive forms (i.e. injection vs tablets) (31), ongoing long-term treatment
(31, 37), or the use of multiple medications (38). Although patient, illness and treatment factors can work in combination to increase the risk of metabolic illnesses, investigations into the exact underlying causes are ongoing.

2.4 Lifestyle Interventions

Typically studies which have evaluated the effect of lifestyle interventions on antipsychotic-induced weight gain have been undertaken in those with chronic long-term psychosis/mental illness. This is because their mental health is considered to be more stable, their lifestyle habits will be more ingrained and they have already gained weight, therefore creating the ideal platform to determine an intervention’s effectiveness at achieving weight loss. Undertaking lifestyle interventions in those who are drug-naïve or suffering from FEP however, may provide insight into whether they can prevent the weight gain or attenuate it, depending on the timing of the intervention (i.e. with commencement of treatment or after it had already begun) (39).

Although lifestyle interventions should be introduced as early as possible, it will be substantially more challenging for FEP patients to benefit if they are still symptomatic, warranting a need for a variety of adaptable interventions to be available that can continuously meet their needs (40). It is unfortunate however that there are concerns that interventions are only effective while the patient is actively participating, or for a short time thereafter, indicating that any benefits from the intervention will be lost or nullified over time (41, 42). Further longitudinal research is needed.
2.4.1 Lifestyle interventions for weight management

Interventions in patients with psychosis often include a combination of dietary advice, physical activity and cognitive behavioural therapy (CBT), with a mixture of individual and group sessions (43, 44). Four meta-analysis reviews of interventions in psychosis of unspecified-duration show that there is the potential for significant reductions in weight and waist circumference in patients who have gained weight, and to slow the progression of weight gain in those beginning new medications (43-46). Interventions that target FEP specifically should be implemented immediately after beginning treatment to have the greatest impact on weight management; however this literature review was only able to find seven studies that specifically targeted FEP patients: five interventions (22, 47-50), one follow-up (41) and one using concurrent non-weight related data from a previous study by the same authors (51).

Two intervention studies showed that behavioural lifestyle interventions can attenuate medication-related weight gain. The first, conducted by Alvarez-Jiminez and colleagues investigated the effectiveness of an early intervention program for weight management in drug-naïve FEP’s by randomising participants to olanzapine, risperidone or haloperidol, before being randomised into intervention and control groups. The intervention group gained significantly less weight than the control group; this effect remained when analysed by medication type. Those on olanzapine gained the most weight overall (in both groups), and there was no significant difference between groups in those taking Haloperidol (22). However, a study conducted at the one year follow-up found that these group differences had disappeared and weight gain was comparable between groups which continued into the second year follow up
(41). The second study by Curtis and colleagues implemented a 12 week intervention and found there was significantly less weight gained in the treatment group compared to controls receiving regular treatment. Further, only 13% of the treatment group showed clinically significant weight gain, compared to 75% in the control group (48).

Two studies showed that significant weight loss was possible: Teasdale and colleagues found that significant reductions in waist circumference were possible in patients who had been medicated for up to a year (47), while Wu and colleagues investigated the effectiveness of lifestyle interventions compared to pharmacological interventions (Metformin), and found that the most effective treatment for weight control and/or weight loss was the combination of Metformin and lifestyle, followed by Metformin alone, lifestyle with placebo, and placebo alone (50).

The last intervention found no statistically significant reductions in weight or BMI compared to the control group (49), however in this study patients were required to have been on their medications for at least one year to meet inclusion criteria (while the criterion for the other studies was less than four to six weeks) which given the rapidity of weight gain could explain the lack of statistical significance.

The final study involved analysing a different component of the dataset from the 2016 Teasdale et al study (47), and found that as a result of their intervention there was a significant decrease in consumption of ‘discretionary’ foods, overall food intake, and total calories consumed, with a significant increase in overall diet quality (51).
2.4.2 Cooking interventions

It has been observed in those with psychosis that their dietary choices are not the healthiest options-with a higher intake of saturated fats and sugars, and fewer fruits, vegetables and fibre, which some researchers view as attributable to their risk of metabolic syndrome when coupled with the medication-induced increased appetite (52-54). This dietary pattern appears consistent with a “convenience” pattern of eating rather than preparing home-cooked meals, which is supported by a study that found only 25% of their participants with psychosis cooked one or more meals per day and 33% never cooking at all (55). It is suggested in studies involving the general population that improving cooking skills can improve diet quality and increase variety of foods consumed (56-62). A review conducted by Reicks and colleagues (59), assessed 28 cooking intervention studies (on a wide variety of populations) and found that overall they can have positive influences on food/cooking knowledge, cooking skills, self-efficacy, health parameters and dietary intake. However, they noted that due to the wide variety of research methods, intervention designs, and evaluation tools utilised by these studies, it was difficult to establish a specific relationship between the intervention effects and long-term changes in dietary behaviours-especially as only 12 of the studies included a control group (only six of which used randomisation of participants). They also noted a high likelihood of selection bias within the reviewed studies based on the premise that most recruited participants would have had a prior interest in cooking or nutrition in order to volunteer.

It has been noted that there are significant psychological and physical barriers that
can prevent people implementing newly acquired skills and knowledge into their daily lives. These include: a lack of social support, needing special or separate foods from the rest of the household, low food security, busy schedules and a perceived lack of self-efficacy (59, 63, 64). Given this knowledge it was surprising to find very few of the lifestyle interventions reviewed for the present study included cooking skills or classes as a core component of their programmes, with most offering them instead as additional components to the specific-intervention sessions (47-49, 51, 65, 66) or as a one-off session (67). Only one study specifically looked at the effect of implementing a cooking class in a psychosis population (68), where patients had their diets assessed through a 24 hour recall method at baseline, and immediately following a six week cooking course. They discovered that although patients were meeting their energy needs at baseline, it was largely from nutrient-poor foods high in sugar and sodium, and failed to meet their recommended daily intakes of micronutrients, whereas after the course participants significantly increased their intakes of calcium, vitamin D, grains, fruits and vegetables. Other positive effects identified by participants were increased self-efficacy with grocery shopping, making healthier food choices, using nutrition information panels, meeting “5+ a day” targets for fruit and vegetables, food safety procedures, cooking skills and reducing added salt (68).

Teaching those with FEP to cook for themselves might be an effective and long-lasting intervention, and research suggests it might be well received by this age group (13). It has also been identified that regularly held classes are more effective at initiating change than a single cooking demonstration (69), which supports the
findings that interventions need to be of longer duration with this population in order to create more permanent change (44).

2.4.3 Interventions utilising patient input

There were only six studies found that included patient or staff feedback in creating or improving an intervention programme. It was a more common approach to use a pre-existing or pre-validated programme. Three of these studies involved the patients and staff input and opinion in the initial creation of the programme content and delivery methods, and continued adapting and refining the interventions based on post-programme feedback (65-67). This was especially well demonstrated in the lifestyle programme evaluated by Pendlebury and colleagues where a patient-created intervention had been running successfully for four years (at the time of their publication) noting minimal drop-out rates, ongoing weight loss, and continuing patient input and control over the direction and content of the course to ensure it meets their specific needs (67). Three studies had already implemented intervention programmes and sought patient feedback on: how things could be improved (68), or why patients did not attend the programme-identifying barriers such as illness symptoms, medication side-effects, and not being ready to implement change-seeing no immediacy in their current situation (69, 70).

2.5 Psychosis and nutrition knowledge

There were very few studies found in the literature that specifically address or measure nutrition knowledge in those with psychosis. In this instance only four were found; three qualitative and one quantitative. The qualitative studies comprised
interviews with patients with psychosis or SMI and included questions about their knowledge and attitudes towards nutrition and cooking topics. Each of the studies concluded that there was a moderate level of knowledge about the fundamentals of nutrition such as eating fruits and vegetables, limiting processed foods, using low-fat cooking techniques and limiting sugary sweets and drinks. However patients did not actively adhere to this knowledge in reality, citing internal and external barriers as the reasons (12, 70, 71). The qualitative study conducted by Brown and colleagues (72) used validated 15 item questionnaires that covered various nutrition and health topics pre and post-test and found a significant increase in knowledge scores after attending their intervention programme. From these few studies it would appear that sufficient basic nutrition knowledge is held by this population, however there is a lack of motivation to implement this knowledge in daily life. Strategies for overcoming these barriers might be a beneficial inclusion in lifestyle intervention programmes to help patients visualise how to put the educational content into practice.

2.6 Conclusion

It has been well documented in the literature that patients experiencing psychosis—particularly FEP, are at increased risk of metabolic complications as a result of their illness and antipsychotic medication use. There is emerging evidence into the molecular genetics of how these medications can affect homeostatic mechanisms and pathways which could lead to developing more effective medications, but there is still considerable research required.
There is less research however into behavioural lifestyle interventions that can help to improve health parameters and manage weight gain, as implementing simple lifestyle changes could make a difference to the patients’ health outcomes and influence their daily activities. Successful interventions thus far have incorporated multiple treatment components which focus on: nutrition and diet intervention (including practical and hands-on experience such as supermarket tours and cooking lessons or demonstrations), opportunities for physical activity, and elements of cognitive behavioural therapy and motivational interviewing.

People with psychosis appear to have a moderate understanding of their health needs, but find that barriers around their illness and current lifestyle or living arrangements reduce motivation to make any meaningful changes. These concerns should be addressed and incorporated into lifestyle interventions to improve the programmes reach and likelihood of these changes being adopted longer term after the intervention phase is over.
3. Objective Statement

People experiencing FEP are at increased risk of health complications as a result of antipsychotic medication side effects. If left untreated or unmonitored these can develop into chronic diseases that result in premature mortality. The literature suggests that behavioural interventions may help those with FEP to better control their weight or reverse weight gain. However the predominant focus of these interventions has been dietary advice or increasing physical activity, as opposed to broader practical life skills such as learning how to cook. This could be a more effective long term strategy to manage weight and health. Furthermore, if the interventions were tailored specifically for the needs of those with FEP and SMI they could have wide-reaching benefits for future health.

Therefore the primary objectives of this study were to:

1. Collect and analyse stakeholder thoughts, opinions, values and experiences on nutrition and health topics relating to FEP.

2. Assess the feasibility of establishing a healthy eating and cooking programme at Totara House: an early intervention in psychosis outpatient service.

3. Compare stakeholder feedback against a pre-existing cooking education programme (Senior Chef) to assess its suitability for this population’s needs.

4. To assess current nutrition knowledge of stakeholders.
4. Methodology and methods

This chapter outlines the underlying research methodology and methods utilised in this study. The rationale for the choice of study design, data collection and analysis methods, and participant recruitment are also explained.

This study is the first phase of an ongoing research project to establish a user-created nutrition and healthy eating programme, specifically for the patients who use Totara House. This phase sought to assess the feasibility and practicality of introducing this type of programme into this facility, therefore the areas of interest were:

1. Is health and nutrition something this population is concerned about?
2. What topics would they consider relevant or interesting to learn more about, and how best to communicate these topics to them.
3. What were the motivating factors and perceived barriers against attending a programme like this, or to improving ones health?
4. In what “phase” of their journey to recovery would this programme be most useful for them long-term (i.e. shortly after the psychotic episode or later on once more “stable”)?

Although there was a preliminary focus on obtaining opinions and feedback on what was desired to be included within a programme, attention was also given to other factors that participants expressed as important from their experiences with mental illness.
4.1 Setting and Context

The present study was based at the Totara House Early Intervention in Psychosis Service: a facility under the Canterbury District Health Board (CDHB) in Christchurch (New Zealand) which provides a multi-disciplinary outpatient support service free for youth aged 18-30 years who are experiencing first episode psychosis. The facility can support around 90 patients at any given time, offering services that are individualised to the patients’ needs, and can include: case management, psychological counselling, social activities and group therapies, medication management, family support groups, peer-support and peer-learning sessions, and other services to help regain their independence (73).

Senior Chef is a free eight week course, initially developed within the CDHB and now run through Pegasus Health, aimed at those aged over 65 years who either are new to cooking for themselves or want to improve their confidence in the kitchen in cooking for one or two people. Sessions are held once per week in small groups of eight to ten people, and are centred around a nutritional or lifestyle theme, such as creating healthier recipes, meal planning, shopping, and cooking on a budget. The structure of each session involves a combination of educational content and cooking simple recipes finishing with a shared meal. Each participant is provided with a cookbook and information sheets from each session to take home. Social events are also planned with “graduates” following the course to continue the friendships developed during the course and can provide further educational opportunities (74).
4.2 Methodology

4.2.1 Study design

This study primarily utilised an experiential qualitative approach (75) and Thematic Analysis technique, which sought to explore and analyse the feedback surrounding nutritional health of those who use the Totara House Service, with the objective of establishing a user-created healthy eating programme for this facility.

The intention of the study was to gain insight into the thoughts, opinions, values and experiences about nutrition and health from those whose lives involve mental illness, discovering where these opinions were similar across groups and where they differed. At present there is very little research on the effectiveness of health intervention programmes in this population—let alone using qualitative methodology as a foundation to create these programs. Qualitative research was seen as the best choice for this study as it allows what is expressed by the participants to be analysed and interpreted with the deeper understanding that people have been shaped by their experiences (76), and provides the flexibility of methods to adapt to the needs of vulnerable populations such as Totara House patients/clients (75, 77). Focus group and semi-structured individual interview data collection methods allowed participants to express themselves freely and generate their own unprovoked responses to open-ended questions, while allowing the researchers to clarify or expand on participant responses in real time. This is in comparison to a quantitative approach that would require participants to fill in a survey based on pre-selected questions that they may not have felt allowed them to express what they wanted to say as openly. It was
considered more advantageous to utilise both of these data collection approaches, rather than one type alone, as each participant group sampled is considered equally valuable and have their unique experiences and insights to offer, however each has different needs and vulnerabilities that need to be taken into consideration. So while a focus group might be perfect for staff members, patients might find a group environment anxiety-provoking, and therefore be less likely to speak up and voice their own opinions. Using a multi-methods approach allows participants to have a genuine opportunity to have their voices heard and feel identified within the study (77).

To assess the current level of knowledge amongst all groups involved in the study, and to ensure that any nutrition education resources created would be suitable for the target audience, participants completed a previously validated nutrition knowledge questionnaire designed to cover a wide range of nutrition topics that the general public may have been exposed to through public health initiatives (78, 79) (Appendix A).
4.3 Methods

4.3.1 Ethics Approval

In accordance with university policy, ethics approval was sought prior to the commencement of this study by the primary project supervisor Dr Jane Elmslie. This involved submitting an ethics proposal to the University of Otago Human Ethics Committee-HEALTH that contained the following information: study summary and protocol (including data handling procedures, ‘risk of harm’ assessment for participants, confidentiality measures, informed consent procedure), sources of funding, locality assessment, study design and peer review of study design, and Māori consultation (Appendix B). After the study had officially commenced an amendment to the original proposal was sought to include anonymised patient medication data (Appendix B.3)

4.3.2 Participant selection criteria

Recruitment required three groups of participants who use the Totara House service:

1. Staff members working at Totara House
2. Family members or carers of patients under the care of Totara House
3. Patients currently under the care of Totara House.

The rationale behind the inclusion of all groups who use Totara House services related to the belief that no one group alone would know what is “best” for the patients’ needs, but combining the opinions of all groups it would "fill the gaps" that another group might not have considered as being necessary or important, allowing for the creation of an all-encompassing service that would meet the needs of all who
use Totara House. As there are a high proportion of Maori patients under the care of Totara House, purposive sampling was utilised to ensure appropriate Maori representation and presence in the data collection. The only eligibility criteria for anybody willing to participate were that they: spoke fluent English, were able to read and understand the information sheet and sign the consent form. For patients specifically, they had to be under the care of Totara House, aged between 18-30 years, and be “well” enough to participate in an interview setting/environment.

4.3.3 Participant recruitment

Initially the researcher met with Totara House staff during a weekly staff meeting to introduce the study, explain what we were looking to achieve, and organise a time for their focus group. From that meeting, flyers were printed and distributed around the Totara House facility (Appendix C), and all staff were emailed information about the study to pass on to potential participants. The primary method of participant recruitment therefore was purposive sampling utilising the “snowball” method (75), where staff (who had already participated) would recommend the study to suitable patients or family members. This method also applied to Māori participant recruitment, where the researcher met with the Totara House Pūkenga Atawhai (the specialist Māori mental health worker) to request suitable Māori participants. Contact details of interested participants were passed on to the researcher who then contacted the participant directly to arrange a suitable interview time. A further recruitment method included contacting Respite Facilities who housed patients under the care of Totara House to see if any of the workers/ carers would be interested in participating, contact
details were provided and the researcher made direct contact to arrange a suitable time for an interview.

All participants were reassured that all data would be anonymised, and given that Totara House is a relatively small facility it was felt that any demographic details that could potentially identify the person involved would not be collected. It was emphasised to potential participants that there was no obligation to participate, and their decision would have no effect on their treatment at Totara House. All participants were allocated a numerical ID code to safeguard their anonymity, with only the researcher knowing the coding system and the identities belonging to each code.

4.3.4 Data collection

The data collection comprised one structured focus group held amongst Totara House staff members, and semi-structured individual interviews conducted with all other participants: patients, family members/carers and other staff members who were unable to attend the focus group but still keen to participate. Every interaction was conducted by the same interviewer (the researcher) and was audio-recorded for later verbatim transcription. Participants were reminded of this before recording commenced. Each participant was allocated an ID code of three numbers based on: the type of interaction (focus group or interview), stakeholder group, and participant number (within that group).
So as not to introduce any bias or priming to the participants’ responses to the questions, the Nutrition Knowledge Questionnaire was completed at the end of their interview or focus group.

The focus group was scheduled to be conducted during a regular weekly staff meeting at Totara House facility, with the intention that it would enable the majority of staff to be available to participate. This was the preferred choice for staff members as this was a set time that they knew they would be available and would only take around 45 minutes to an hour to complete, using structured questions (Appendix D) (80). These questions were created through consultation with the primary supervisor, who was informed by prior experience and expertise working with Totara patients—taking into account the format and context of Senior Chef. They were not pre-tested so as to avoid priming the target groups. The questions used for the individual interviews were modelled on this established set of questions—retaining their open-ended nature, and modified as appropriate for each participant.

An Individual interview structure was considered more appropriate for patients as the vulnerabilities that can be coupled with mental illness could have made a group environment feel intimidating as mentioned previously, especially if participants felt the questions to be of a personal nature. The decision to use individual interviews for the family members/carers was made from a practical standpoint as it proved difficult to find a time to hold a focus group that would be suitable for enough people (to meet quorum) to attend.
All interviews were held at a quiet location of the participants choosing and the length varied depending on how much the participant had to say on the topic, if they were not feeling talkative or showed withdrawn body language then personal judgement was used as to how to proceed with the remainder of the interview. The recordings were transcribed by a third party (who signed a confidentiality agreement) as a means to maintain anonymity and reduce researcher bias. Missing words or typographical errors were corrected by the researcher who conducted the interviews while allocating the transcripts with the participant ID numbers and removing any identifiable terms such as names from within the text. To further strengthen the validity of the present study the transcripts were offered back to the participants to determine whether they were a true and accurate record of the conversation. Participants were able to make additional comments or recommendations but were unable to make changes to the transcripts themselves. This process is known as member checking, informant feedback or respondent validation and is used by researchers to help improve the accuracy, and validity of the data (81).

At the completion of data collection the names of the patient participants were provided to the Clinical Manager of Totara House to gather current medication data that would be anonymised before being supplied to the researcher. This additional data was included to provide context to support the opinions expressed by the patients about their experienced metabolic changes as a result of being on the medications.

At the end of the study all participants were provided with a letter of thanks that included a brief summary of the results of the study (Appendix E).
4.3.5 Data analysis

The transcripts were analysed utilising an Iterative Inductive Thematic Analysis technique with origins in Grounded Theory (75, 82). This method allowed the researcher to gain a deeper understanding of the responses from all of the participants (76), and collate these responses into useable data for adapting the Senior Chef programme. The iterative approach was necessary as transcribed data was being received while data collection was still taking place, therefore there was a conscious association between acknowledging emerging themes from the data already received, and reflecting on the interviewing techniques and questions that influenced those responses (82).

Inductive Thematic Analysis was the preferred analytical method as it utilises a bottom-up approach where the data shapes and creates the themes, as opposed to a Deductive Content Analysis wherein the themes or categories are pre-determined before analysis begins- so the data is being collated to fit into these categories (an approach more suited to analysing media sources, speeches, public records etc.) (77). The connections of Inductive Thematic Analysis to Grounded Theory ensures the focus remains on the participants and that their voices are the predominant driving force behind the themes being created (82).

Coding of the transcripts followed an open, axial and selective coding protocol to generate the themes (82). Each transcript was read and open-coded independently by the researcher and supervisor to reduce bias. Emerging themes were discussed at a later meeting. Open coding involved sweeping the data for patterns, similarities and
differences, and applying labels/codes to identify these patterns along with memos of thought processes. Axial coding sought to establish connections between these labels and categories, while selective coding organised the connected categories into overarching themes, themes and sub-themes (75, 82).

It was anticipated that a topic as personal as nutrition would generate a wide range of responses from the participants, some more relevant and practical than others. All ideas and opinions expressed were taken into consideration during the analysis, however the process of coding allowed for targeted and refined themes from the data to stand out.

The transcripts were read through thoroughly prior to coding to familiarise the researcher with the context and intention of the responses provided by the participants. Memos were made during this process of notable quotes and meanings that related to the research aims and areas of interest. This initial level of analysis and open coding was done using a pen and paper method before transposing it into Nvivo Qualitative Analysis software (83). This allowed the researcher to visualise the data as a complete set, identify data that could be coded multiple ways (overlapping codes) and make written notes within the margins of the pages which assisted further coding processes using the software. This “rescreening” of the data through the software allowed for codes to be clarified, clustered or separated as necessary to aid in revealing the sub-themes, themes and overarching themes which could be mapped out to provide a visual representation of the data relationships. The final step of analysis was to review the themes generated to ensure they best encapsulated what
was being expressed by the participants, relative to the research aims and areas of interest.

Responses from the Nutrition Knowledge Questionnaires were entered into a Microsoft Excel 2010 spreadsheet to calculate descriptive statistics, analysis of question-by-question comparisons and to assess any group differences using a one-way ANOVA.

4.3.6 Nvivo Analysis

The transcripts were uploaded into Nvivo Pro Qualitative Analysis Software, version 11 (83) as individual documents once they became available from the transcriber. Therefore each document was open-coded individually (initially by pen and paper as outlined previously) but not in chronological or numerical order (of participants' ID codes).

Once all transcripts were received and open-coded, axial coding could commence, which involved creating “nodes” that represented the codes and emerging themes that were able to be analysed to establish connections and relationships between the codes, allowing for further selective analysis. This final stage involved organising the nodes into sub-themes, themes and overarching themes that would best reflect what the participants wanted to convey within the context of the research aims and areas of interest, in a clear and coherent thematic map. This map was subject to further review to ensure that the themes were accurately classified and categorised and not overlapping one another.
5. Results

This chapter presents the main findings from the present study in three sections. The first covers participant characteristics and medication data, the second describes the thematic analysis findings covered in individual sub-sections. The third section presents the scores and statistical analyses of the Nutrition Knowledge Questionnaire.

The thematic analysis sections show the overarching theme, the supporting themes and the sub-themes generated from the interview and focus group transcripts:

“Personal Values” covers what can influence patient’s worldviews. “Knowledge and experiences of health and nutrition” explores factors that can shape patient’s understandings and feelings on the topic. “Programme-Specific Details” include recommendations from participants for the proposed programme. A selection of quotations either in original or abridged forms are included in this section to support the themes and provide examples and insights to the reader of what the participants wanted to express. To preserve anonymity only the participant category label and ID code are included with the quotes.

It should be noted that although Māori themes were made apparent from the thematic analysis, it is impossible to accurately and adequately describe the full spectrum that these Māori values encompass within the scope of this thesis. They are culturally rooted holistic concepts that a Pakeha (non-Māori person) such as myself, cannot competently understand without having the connection to the spiritual philosophies that are an integral part of Māori culture.
5.1 Participants

As mentioned previously, this study was based in a specialised outpatient service involving a vulnerable population, so limited demographic data was collected to preserve anonymity.

Twenty six participants completed the study; ten Totara House staff members-eight of whom completed the focus group (three social workers, one clinical psychologist, one clinical psychologist intern, two nurses, and a psychiatric registrar), with a further two social workers interviewed at a later time (total staff: five female, five male). Other participants included nine patients (six males, three females) and seven family members/carers (five females, two males). Although no formal ethnicity data was collected, four participants identified themselves as Māori (or holding Māori beliefs) during their interactions with the researcher.

Efforts were made to avoid “double-ups” (where both patients and their family members were recruited for the study) which could narrow the data spectrum; however three instances of this occurred due to low participation rates and the aforementioned small sample population available to participate. Two potential participants dropped out of the study before their scheduled interviews, while a further two were unable to find a suitable time to be interviewed during the data collection timeframe-despite numerous attempts from both participants and the researcher.

5.1.1 Patient Medication Data

Of the nine participants who were patients, eight provided consent to release their anonymised medication data to the researcher. The data that were made available
was only the current medications they were taking at the time of the interview, not the medications they were placed on at the peak of their psychosis or thereafter (Table 1). It was acknowledged by staff that it was very common for patients to switch medications numerous times as their recovery progressed.

**Table 1. Anonymised Patient Medication Data, presented in a randomised order.**

<table>
<thead>
<tr>
<th>Patient</th>
<th>Medication Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Olanzapine</td>
</tr>
<tr>
<td>2</td>
<td>Paliperidone</td>
</tr>
<tr>
<td>3</td>
<td>Aripiprazole, Venlafaxine and Lorazepam</td>
</tr>
<tr>
<td>4</td>
<td>Fluoxetine and Risperidone</td>
</tr>
<tr>
<td>5</td>
<td>Aripiprazole</td>
</tr>
<tr>
<td>6</td>
<td>Risperidone, Fluoxetine and Zopiclone</td>
</tr>
<tr>
<td>7</td>
<td>Valproate and Olanzapine (PRN only)</td>
</tr>
<tr>
<td>8</td>
<td>Lamotrigine</td>
</tr>
</tbody>
</table>
5.2 Thematic Analysis

5.3 Personal Values

This encompassed themes that participants considered to be important to understanding the psyche of patients, what motivated them, what the barriers toward achieving their goals were, and how their cultures and experiences influenced their daily lives and relationships with others. This theme is summarised in Table 2.

*Table 2. Summary of Themes and Sub-Themes - Personal Values*

<table>
<thead>
<tr>
<th>Māori/cultural values</th>
<th>Whānau (Whakawhānaungatanga koha, manaakitanga, tikanga, equality of all people)</th>
<th>Hauora/Waiora (te whare tapa wha, te taha tinana tangata whaora,)</th>
<th>Kai</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers</strong></td>
<td>To becoming healthier</td>
<td>To attend the programme</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gender differences</td>
<td></td>
</tr>
<tr>
<td><strong>Motivators</strong></td>
<td>To becoming healthier</td>
<td>Intrinsic motivators</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>To attend the programme</td>
<td></td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
<td>Therapeutic (clinical relationships) with Totara House and its staff</td>
<td>Belonging and social accountability</td>
<td></td>
</tr>
<tr>
<td><strong>Relevance to the patient and their situation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5.3.1 Maori Cultural values

This theme explored the cultural concepts and philosophies that were expressed by those with an understanding of Māori values. As mentioned earlier, this is only an introduction to these concepts as a more intensive analysis would require extensive Māori consultation and secondary research that is beyond the scope of this thesis.
**Whānau**

This theme encompasses the importance of connectedness with those around you and the inclusiveness of belonging to a “family” (Whānau). Participants spoke about the importance of relating to those around you to feel supported, so that you are able to grow and learn together.

“From a Māori Perspective…everyone’s at the same level, doesn’t matter who you are, where you come from, and we treat everyone with respect, with dignity and we encourage people to be themselves.” Staff 119.

“You’ve got to make them feel like you are a team, like a Whānau.” Carer 123.

This feeling of Whānau is achieved and maintained through relationships (Whakawhānaungatanga), lifting one’s spirit and showing them respect (Manaakitanga), and mutual giving-of love and acts of appreciation (Koha and Tikanga).

“When people come we will Manaaki them, we will lift their Mana up, we will pay them respect, we will treat them with kindness…and we make it so they want to come back.” Staff 119.

“Whakawhānaungatanga which is a very long Māori word for engagement and the relationship you have with people that you are working with. Huge. It’s quite a big thing, but I wouldn’t just say that for here I would say that for anyone trying to engage with Māori clients. It’s about building the relationship, talking to them about ‘how’s your family?’, ‘what did you get up to in the weekend?’, that’s all part of that social thing as well.” Staff 1110.

**Hauora/Waiora**

This theme encompasses the holistic Māori value of health and wellbeing. It was valued highly by participants within the context of mental health and recovery.

“I consider myself still Tangata Whaiora—so that’s a person seeking wellness.” Patient 133.
“Maori means being natural, doing things naturally, there is definitely a place for doing things clinically but I think they can work hand in hand. Some people need to take medications, some people need to see the physiotherapist, psychologist, social worker, get injections and all that stuff, that’s all good and then there is the way of doing things naturally, from your heart.” Staff 119.

Within this context of holistic health and recovery there is a Māori concept of Te Whare Tapa Wha, where the foundations of health and wellbeing are likened to the foundations of a house/Whare; if one component is out of sync the rest may suffer as a result (and the ‘house’ will fall).

“…From a Kaupapa Māori holistic approach, they are all intertwined and that’s part of the nutrition, Te Taha Tinana. When that’s all out of whack and you are not doing all that, then everything else is just going to fall over—it all works together.” Staff 119.

Kai

In Māori culture food is seen as a unifying concept. It is often at the centre of social gatherings, can be used as a marker of respect (Manaakitanga), and used as an offering of love/gifts (Koha, Tikanga). The participants showed an eagerness to use shared meals as a way of enhancing social bonding, and appreciated that providing good food can be an uplifting experience.

“Food is certainly a draw to a social group in places like this, it’s a bit of a drawcard, a very Maori concept as well.” Staff 1110.

“…Your Mana, or your respect comes from the food you are actually providing. So if you’ve got these people that have come…and you’ve got a packet of biscuits and that’s what you feed them on, what kind of Mana do you have?... it’s also about celebrating milestones…my student left the other week—we are going to thank him for his work here, we organised a barbecue. For us it is about Kai and food brings people together—sit down at the table, have a feed and actually talk. That’s where all the stuff gets going.” Staff 119.

“I do have those friends who are like “I’ve got a meal planned tonight” and it’s just a can of spaghetti or baked beans and I’m like ‘come round to mine and we will have food!” Patient 138.
5.3.2 Barriers

Barriers in this context refer to psychological factors—real or imagined, and physical or situational barriers that could interfere with a person’s ability to live their life the way they might have desired, particularly seeking improved health and wellness.

Barriers to becoming healthier

The participants reported that the primary barrier to achieving good health was a lack of motivation, which some attributed to the sedating side-effects of the medications.

“I am really unmotivated after this episode… I don’t want to do anything at the moment, but I used to want to do things, that’s the weird part. Like before all this I wanted to do everything, I wanted to get up, I wanted to—you know what I mean? At the moment we just don’t want to.” Patient 131.

While others attributed it to a perceived lack of ability to change their situation (a feeling of disillusionment).

“He needs to know about the sort of food he is eating but he doesn’t really want to know about it. Actually he does know what to do but he can’t put it into practice. He really is unmotivated and struggling I guess in the confines of his flat… We have been racking our brains how to help him to prepare his own food but a lot of it comes down to motivation to do that.” Family Member 125.

“I think young people… that we work with, they don’t have that long term view that they need to be careful about what I am eating now because in the future it might shave ten to fifteen years to twenty years off my life, they are not thinking ahead like that—so it is kind of what’s the point of doing anything differently now and what’s the point anyway. Because even if people try and lose weight the medication can make that more difficult so people don’t get the quick wind that you might do if you aren’t on medication that helps to kind of keep that momentum going.” Staff 015.

Barriers to attend the programme

Although a lack of motivation was considered the primary psychological barrier to improving health and attending a lifestyle programme, some programme-specific barriers emerged relating to anxiety, disinterest, and fear of failing.
“Cos it wouldn’t always necessarily always be to partake would it?...I guess if that was emphasised before the groups that it’s a teaching thing as well then maybe that would be broader for the people that—cos I mean if they’re coming along they obviously are showing an interest but just too anxious or too nervous to partake.” Patient 138.

“Maybe if someone has some sort of mental health crisis the last thing they probably would want to do is like drag them into a healthy eating class… it would be more like ‘I need help.’” Patient 133.

“Might say they don’t have the time to come in or maybe they’re just so used to others cooking for them and they just don’t really want to learn the skills.” Patient 137.

“I think it is also acknowledging that they fail a lot, and so not to make them feel guilty about that because it is a very hard thing to do…I would imagine it is the same with people coming to see the dietitian and not having actually succeeded, maybe they won’t come next time.” Staff 011.

It was also mentioned that physical barriers could be used as excuses to not attend, but that there could be simple solutions to overcome them.

“If it was a free service or not—if there was a cost involved I imagine that might be a barrier to some people.” Patient 135.

“Maybe work, cos some of the boys are looking for work so when they find work they might not be able to attend the groups…Transport could be another one, but I’m sure that Totara House could arrange for transport to get them here. Other than that I can’t see too many barriers.” Patient 133.

**Gender differences**

During the patient interviews there was an apparent distinction between the male and female responses indicating their different values placed on nutrition and health, and therefore different strategies would be required for engaging them.

“The females are harder to motivate, they’ve got different priorities. With the guys it is the gym… The big draw is the gym and [case manager], I would say, and the easy relationship he has with the guys…I don’t know whether they are intimidated by the male thing—I don’t know what it is...But getting the females interested has been a lot harder.” Staff 1110.

“I haven’t got any girls on my caseload so I am a bit out of touch, it’s coming back to your identity, I would challenge the female case managers to come up with something,
Females showed more of interest in what nutrition can provide for them in the wider context of their lifestyle and how they can use it to help others.

“I guess again for me it’s about wanting to learn healthy lifestyle habits so that I can model them for my family so that is a pretty big driving force for me.” Patient 135.

“Like I notice a lot of the people here are very young, teenage boys who probably don’t care about that type of thing [nutrition], but there is a whole big world of yummy things that if you could open their minds to it I am sure they would get excited about it because who doesn’t like nice food.” Patient 139.

Males however showed a narrower focus on nutrition, seeing it as a means of eating good food or as energy for achieving fitness goals (e.g. to gain muscle or lose weight).

“Just because I am a pretty serious ‘gymer’—I want to make as many gains as I can…Strength mainly, and maybe a better size, muscle.” Patient 136.

“Just getting healthy and staying fit.” Patient 134.

“For me it was all about participation like going to the gym group so I guess having a Totara House group we talk about nutritional things and maybe tying it in with the gym group. It’s just even the gym group it’s having a more active life around the diet as well. If you can’t exercise or don’t want to exercise it’s not the only thing you can do to stay active.” Patient 138.

5.3.3 Motivators

Motivators in this context refer to psychological and external influencers that can encourage the patients to achieve positive changes in their lives, particularly achieving better health and wellness.

Motivators to becoming healthier

The primary factor motivating patients to improve their health was to “feel better” and for those who had medication-related weight gain there was added motivation to return to their former weight.
“It’s not just good for them physically but mentally as well to eat healthily.” Family Member 126.

“I think just going through the process of cooking things for yourself is quite good for your mindfulness and your wellbeing. It is obvious there are health benefits from not having takeaways.” Family Member 127.

“...cos it sucks, but I don’t want to gain more weight, like I just lost four in the past month for the first time, every time it’s gone up like five, then I crammed and it went down four.” Patient 131.

“With my group of clients, the main concern for them is weight gain since they started on the medications, so I guess the main motivation for them to learn about nutrition is try and control that or to lose weight.” Staff 017.

**Intrinsic motivators**

Intrinsic motivators come from within oneself, so instead of doing an action to gain an external reward, doing the action becomes the reward itself. It involves building confidence and the feeling of achieving small but significant goals.

“I think the reward of it is enough eh, just knowing that you are going to benefit, a better wellbeing, better health, I think that should be enough really…I think knowing how to cook a good meal is very important, cos you feel rewarded afterwards. When you cook something nice it’s like ‘I made this’, that’s good.” Patient 133.

“…when you are feeling real crappy I found the best thing to do is actually to concentrate on something and be distracted from your thoughts was great.” Patient 139.

**Motivators to attend the programme**

There were two predominant incentives to attending a healthy eating programme: the prospect of having free food, and learning an important and valuable life skill. Gaining life skills could improve confidence and regain independence by enabling patients to take care of themselves rather than having to rely on others.

“If I wasn’t here he couldn’t survive, he couldn’t look after himself. If he can’t cook and can’t do things, it’s pretty hard on me to leave him in that situation.” Family Member 121.

“It would be bettering myself obviously cooking for myself and maybe for others…you
don’t have to rely on your mother or friend to cook for you all the time. It’s just a nice skill to have, everybody should learn it and it could be fun.” Patient 137.

This was accompanied by a sense of pride and accomplishment in being able to show others what they have learned.

“I guess because I have an interest in cooking and now that I have been learning some more about nutrition and wanting to feed my family healthy food, the idea of having a professional take a class is quite cool to me, to have an opportunity to learn some new skills would be an incentive for me.” Patient 135.

“Encouraging the idea that cooking isn’t just the thing you do to get food, but it is like a hobby and people do it for enjoyment and incorporate the social aspects of it like having friends round to cook a big meal, have a shared pot luck and things like that.” Staff 014.

There was a less prominent theme of having a sense of place and routine, providing somewhere to be and something meaningful to do for a few hours each day.

“I know when [patient] was quite unwell and not feeling particularly motivated it was really good to have the group session here, or an activity she was expected to be at so there was some incentive for her to get out of the house and be active and meet other people and things like that.” Family Member 127.

“…with [patient] and myself I was working quite a lot so it was nice to have him have somewhere safe to go to for a few days of the week.” Family Member 126.

5.3.4 Relationships

All participants, including patients themselves, considered relationships to be a critical component to engaging with patients. It was a large determinant of their willingness to participate in groups and activities that could aid in their recovery, and also helped to enhance their feelings of belonging, noting how isolating it can seem when experiencing mental illness. Although relationships with family members while recovering were important to some participants, this was not echoed throughout the sample.
**Therapeutic relationships**

Relationships were viewed as one of the most important factors for healing and recovery from a psychotic episode. Patients needed to feel that they could trust someone (who at the time was a complete stranger) in what is arguably their most vulnerable state.

“People come here who have had something horrific happen in their life and they need to build that trust. They need to know ‘who is this guy?’ So it takes a bit of time to build that trust and build that relationship…if you haven’t got engagement with someone then they’re not going to come, cos you don’t have any engagement with them. It’s also about building that trust, respect and stuff like that. Once they are there that natural relationship will just happen. They will talk about their common interests, do stuff that they enjoy, talk about things and that is what draws them back, comradery, social support.” Staff 119.

“…give them support and just chipping away at those different areas in that motivational way not going bull attack which might put people off completely.” Staff 015.

**Belonging and social accountability**

There was an underlying feeling amongst patients that there was a deep desire to “belong” somewhere, being understood and accepted by others around them. This was believed to reduce feelings of loneliness and isolation that can accompany mental illness, and through these relationships they could begin to create an understanding of what they had experienced, helping with acceptance and moving forward in their recovery.

“I guess also an opportunity to meet like-minded people, people who have had similar experiences. In a possible social setting which is funny though because that one is a very on the fence kind of—because on one hand it can be an incentive but on the other hand it would be a bit daunting if you are feeling a bit anxious.” Patient 135.

“That’s something I found really difficult that there was no one like me here at all, and like the young girls that were in the women’s groups, I had a better time talking to the staff…It’s nice to be in contact with people who are going through a similar thing, but
again there was no one here like me that I could connect with, so that was quite isolating.” Patient 139.

There was the sense that by belonging to a group that they could support each other to achieve their goals and ambitions, providing a peer-accountability that feels encouraging, rather than an ‘expectation’ from a health professional or family member.

“I suppose just like dedication and the social aspect of it too, when we are all getting together I’m accountable for them and they are accountable for me being there so it works both ways...So I think the social aspect of it, like keeping each other accountable as well. Cos I think we really take a bit of a holistic approach when it comes to wellbeing here. So obviously what you eat is a big part of it, but also the exercise and the social aspect as well.” Patient 133.

5.3.5 Relevance to me and my situation

Those with FEP could experience altered perceptions and worldviews of their environment; therefore it was considered critical that anything new they were exposed to had to fit within these existing worldviews if they are to be adopted into their lifestyle.

“That’s kind of down to me really, I have to want to. I don’t think anyone can make you want to…It just goes in one ear and out the other to be honest, especially with dietitians, I don’t know why, feels rude but...When it’s viable to what you are already doing [it works], new ideas you just shrug off.” Patient 131.

For patients who were able to live with family members while they recovered, there was little motivation to improve their skill-set or change their situation, as things were essentially done for them.

“I’m lucky that my parents do most of the cooking and I only cook one meal a week.” Patient 138

“I cook, I do the dishes, I do everything and because [patient] hasn’t got that energy or because he is on that medication he hasn’t got that motivation to do anything—washing, vacuuming the floor or whatever. You get sick of it. Don’t get me wrong though, I don’t mind doing it, but I’d like to have a bit of break away from it.” Family Member 121.
For patients who did not have the ‘luxury’ of living with family members, finances were seen as a large contributor to their confidence in being able to afford healthy foods and live the healthy lifestyle they desire.

“I’ve seen programmes on TV where they say someone can live on $80 a week, what they do is get a top chef in to show you how to do it and I think that’s the most ridiculous thing because the average person is not a chef and if they don’t know all the cooking stuff how can they do that?!...And they only do it for a week! Anyone can do anything for a week!!” Family Member 121.

“We are picking up food parcels from 0800 Hungry, for people who are hungry, and it is full of rubbish. Full of things like chips, biscuits and I try and give it to these guys who have got metabolic issues, who are hungry, so it just makes me [angry]...they are all on benefits, they’ve got no money and that’s more of a societal, policy, government level, it’s at a different level. However you can cook affordable food with a little bit of money with simple recipes, you don’t have to just go to dollar white bread, dollar this and dollar that...” Staff 119.

5.3.6 Summary

Personal values including cultural beliefs, motivators, barriers, relationships and perceived relevance were seen to shape the patients’ worldview and their belief of being able to make small but meaningful changes to their lifestyles to achieve greater health outcomes.

Māori and cultural values were considered to be critically important when engaging with Māori clients; however the holistic nature of these values showed applicability to the recovery from psychosis in patients from non-Māori (Pakeha) backgrounds. There was also an emphasis on food as being a unifier for people-acting as a social catalyst.

All participants acknowledged the importance of engaging with patients and maintaining quality social relationships while recovering from psychosis. This allowed feelings and opinions to be heard in a trusting environment and goals to be created
that aligned with what the patients felt was important to them. The feeling of belonging within these relationships was greatly valued by patients, but they acknowledged that although they may desire having social relationships, this is not always easy.

There was an underlying theme that anything (new) that is suggested to patients has to be seen as relevant to their current situation as new or foreign ideas could be dismissed as too hard or unachievable.
5.4 Knowledge and experiences of health and nutrition

This theme outlines the participants’ understandings of how their health can be affected by the medications they are prescribed and their experiences with trying to regain their health and wellbeing following medication treatment. This theme is summarised in Table 3.

Table 3. Summary of Themes and Sub-Themes - Knowledge and Experience of Health and Nutrition

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5.4.1 Understanding of medication side effects and health

**Influence on appetite**

All participants mentioned how after commencing the medications there were significant changes to appetite and eating habits. Patients freely talked about the struggles of coping with this artificially stimulated appetite, and how dominant it was within their daily lives.

“You’re always hungry, it’s like you can’t win. You could eat five bowls of cereal and still be hungry. You just have to ignore the hunger, I am hungry right now, you almost have to starve yourself. It’s just the injection I’m on. Makes you so hungry…I can’t stress that enough, like it must be hard for other people to interpret without ever trying the injection…I don’t know what it is but the hunger is unreal, like unreal.” Patient 131.
“It would make me feel as if I was starvingly hungry basically all day long. In fact there were some nights I actually couldn’t get to sleep because I was feeling that I hadn’t eaten even though I had eaten more than enough, way more than enough in the day and it was really hard to combat that feeling of hunger especially when I was really, really anxious and trying to deal with the psychosis symptoms at the same time. I didn’t have the fortitude of mind to really combat that enough and although I was warned I guess I didn’t really take it seriously enough, I just thought ‘oh it won’t be that bad I will be able to deal with it’, but actually it is really hard.” Patient 135.

“Obviously the weight comes from food not the tablets but I guess the tablets must alter your metabolism and alter the way you process those foods and hold on to fat and things like that but maybe part of it was not being as active and not quite doing the aerobic exercise that you might need to do to cope with that. It’s probably a combination of things, I don’t know how you would manage it because you still need to eat and if the medication is going to make you hold on to it and gain weight naturally it’s hard to imagine changing completely how you operate, exercise and things like that.” Family Member 127.

**Influence on mindset**

Participants indicated that while on the medications the patients’ thought patterns and mental state changed dramatically, making them feel very lethargic, unmotivated (as covered previously), and that things were harder to process cognitively.

“When I was on Olanzapine I found I did a lot of just sitting around, so I think it is a double edged sword that makes you gain weight and it makes you feel melancholy I guess.” Patient 138.

“You memory is all over the place so if you teach them things it is not going to penetrate—it will go in one ear and out the other, and you want it to be useful for them long term rather than just short term and sometimes there is no telling them ‘you’re full’ ‘you’re over full’ and ‘you’re still eating’ but he doesn’t listen.” Family Member 122.

“…I guess when you are having trouble with mental illness and trying to go through some sort of recovery you don’t want to overload yourself with all the stuff you feel you have to do to manage things but it’s probably a bit hard to focus on all that sort of stuff.” Family Member 127.
5.4.2 Awareness of relationship between mental health, physical health, nutrition and medications

This theme was felt by the researcher to be an indicator of the insight participants had into the interconnectedness that exists between facets of health. It was difficult to determine however whether an absence of insightful responses from a participant indicated a lack of awareness, or if it was simply not mentioned during the interview.

“I think if you put the right things in you get better energy, get more of a life I guess…I know when some of the boys are putting on weight it affects everything, like it affects their mood, so if we can put something into place to help prevent that as well as deal with it when it arises that will be very good.” Patient 133.

“…I think when you are in that state of mind the only pleasure you get is from food, nice food. That was the only thing that gave me joy to be honest. I think it is only natural to have a few caramel slices here and there, thinking I feel so bad I am going to have a treat, but that definitely dissipates after a while…Because to be honest when you are putting on weight that quickly that’s really depressing in itself. Like that makes you more upset and grumpy, especially for women. It’s like you aren’t in control of your body at all.” Patient 139.

“They can’t change the medication cos it works for what it’s used for. The positives outweigh the negatives and unfortunately weight gain is a big negative.” Patient 131.

5.4.3 Nutrition knowledge

This theme provides insight into how the participants viewed their nutrition and health knowledge; their understanding of nutrition recommendations, their sources of ‘trusted’ information and their confidence that their knowledge was true and accurate.

Self-reported knowledge

Patients and family members/carers showed a moderate confidence in their level of nutrition knowledge, indicating that they felt they knew some of the fundamentals but lacked knowledge or confidence on more specific components or topics.
“Cos I eat a lot of fruit and vegetables and stuff—that’s the main thing I know about nutrition, that fruit & vegetables are good for me.” Patient 134.

“If I ate healthy I probably wouldn’t gain weight. I don’t see me gaining weight if I sat there all day eating celery sticks…it’s common sense though, we all know what is good for us. It all comes down to our own choices in the world.” Patient 131.

“On a scale of 1-10 maybe 6? Pretty average. I think especially thinking about how much there is to know, it is one of those subjects where the more you learn the more you realise how much there is to learn.” Patient 135.

“Crap really—I think I’ve got the fundamentals. At school we would have been taught at cooking about the food triangle and I guess I’ve always made sure there are carbs, proteins and veges—maybe not quite the right proportions.” Family Member 126.

Staff members rated themselves as having a similar level of knowledge to the other groups, however showed a higher confidence in what they knew, indicating that they were doing their own research into nutrition topics and often chose to pass this information onto their clients.

“I would say pretty high, we have all these discussions about it and we have all tried different things so we are probably not your average. I would say we are quite educated about it…at least we are all thinking about it and we are doing our research and trying to look after ourselves and eat well, but our clients haven’t even got to that step and although we are not sure this research is exactly right yet, overall we are probably eating well but our clients haven’t even got to the point of deciding ‘do I even need to change what I am eating?’” Staff 011.

“Although still aware that there are a lot of different messages out there. I make food choices for me for personal and, in addition to health reasons but I don’t know what the evidence is about what the difference foods are, I hear about the ketone diet, Paleo diet, cutting this out and there’s still the high protein/low carb. There’s different things different people say different things it’s quite confusing.” Staff 015.

“So some of the things are like teaching the boys about having porridge for breakfast, looking at the labels, working out what’s good and what’s bad. It’s not about me trying to tell them you’ve got to do this, you’ve got to do that, it’s all about knowledge and education and wisdom to know what’s good for you and what’s bad for you. Everything in moderation and balance is important…” Staff 119.
Trusted sources of nutrition advice.

Participants indicated that there was a trust in health professionals such as dietitians and nutritionists (degree qualified) for healthy eating advice, and showed caution about what is posted around the internet and on television.

“Obviously a trained dietitian—I know there are a lot of ‘cowboys’ in the industry and I think there is a lot of information out there which I think is quite confusing to people—it’s just getting it straight.” Family Member 125.

“It would have to be some sort of registered medical professional for me to take it seriously, I wouldn’t just—you know. And I am cautious about what I read online as well because even then you know there is just so much psychobabble out there, you have to be careful about what information you take as gospel…” Patient 135.

However many indicated that their most trusted source of information was family members—mothers especially. This also extended to people who had recovered from their illness and lost weight, or staff members who had their own journey to health.

“My mum! Probably you as a nutritionist. Probably people that have sort of been there and done that I guess, someone experienced because I am probably not going to listen to uum. Just someone that knows I guess, that’s done the research and knows the information as opposed to the average guy on the street that are telling me ‘don’t eat this, don’t eat that.’” Patient 133.

“…I would like to say that maybe my mum and dad but they have not been the most healthiest, my dad is a little bit overweight.” Patient 137.

“[my Dietitian], my mum and my sister, and [my case manager]—I would talk to [him] quite a bit about his salads and stuff, that’s about it.” Patient 138.

5.4.4 Strategies to manage health

Participants spoke about methods and techniques they had used to try to improve their health and/or lose weight. A diet-focused approach was favoured by those who lacked the energy or motivation to attend physical activity groups or the gym, while the opposite was true of those who were dedicated to their exercise routines.
Altered eating habits

Most patients identified that variations of food restrictions and ignoring hunger cues were the most successful strategies to control their eating. There appeared to be a “dieter’s mentality” in those who were trying to restrict their eating, which could be viewed as either unhealthy or healthy behaviours surrounding food intake.

“Ignoring my hunger definitely…Sometimes you’ve got to eat things you don’t like, and that’s another thing you can do actually when you are really hungry is eat something you don’t like so then you will just stop when you are full, well not full but you know what I mean, you won’t eat as much if you don’t like it.” Patient 131.

“Counting macros and learning how to do that. I was using an app to track my calories though.” Patient 136.

“For me I just watch bread, sugars, carbs, potatoes and stuff like that. I probably keep it pretty simple but I think it is easier to stick to it that way…make sure you exert energy that you put in so I have to exercise and stuff.” Patient 133.

Some patients reported having had the assistance of a dietitian to help with their nutrition, and they all showed enthusiasm about their experiences. There appeared to be a willingness to adhere to dietetic recommendations as they were personalised to participants’ situations and felt achievable, while there was also the underlying motivation of not wanting to let the dietitian down by not succeeding at these goals.

“I learnt quite a bit because I had dietitians throughout my pregnancy [concurrent with FEP] so they kind of did the portion controls and better choices and stuff like that.” Patient 132.

“I think definitely at the start that would be helpful to have some sessions with the dietitian…but I have only ever known that I could go to her at the very end, which was ‘this would have been very helpful a year ago!’ So definitely at the start to know that you have got that help would be great. That’s something I wasn’t really aware of. I think everyone here is just so focused on getting you better and medicating you that that’s a real after-thought.” Patient 139.

“I suppose we were lucky enough to go to [the dietitian], I don’t think that was the norm that everyone went to a dietitian or had that opportunity.” Family Member 126.
**Physical activity**

A number of patients interviewed had at some stage attended the Rec group at Totara House run by one of the staff members and found that was a safe and supportive way of being introduced to a gym environment (as they have private access to a facility in Christchurch a couple of times a week).

“When I first got out of hospital I started gyming once a week and then when I had my group that were gyming more I started going with them more, started feeling more comfortable around the gym.” Patient 136.

“Why do we go to the [private] gym? We do have other services that provide gym things but a lot of my guys are like 18 to early 20s, they don’t want to be spending time with 40 year old chronic patients…we can be ourselves.” Staff 119.

Other patients who had not attended this Rec group—or felt it was not the right fit, found alternative exercise solutions that would retain their interest and motivation.

“[patient] goes to yoga and the gym regularly…regular classes that she goes to, she’s not putting pressure on herself but is disappointed if she misses out on one of those nights and the opposite of that is that she feels really good if she has done all of the ones she plans to do during the week, or does an extra one.” Family Member 127.

5.4.5 **Attitude towards cooking**

Overall there was a positive attitude towards cooking from each group; however there were underlying factors that affected that attitude. Some participants reported that in their household it is the family members (mothers) who do all the regular cooking, as mentioned previously, those in this context showed little desire towards learning how to cook as there was no perceived need. This reflected a feeling that cooking was a chore they had to do in order to eat rather than as a pleasurable experience.

“All the time in the world [to cook], I usually can never be bothered, honestly. At the moment anyway; I used to cook all the time. I am really unmotivated after this episode.” Patient 131.
“At the moment he is flatting although he comes home for a couple of nights a week and at his flat the only thing he really cooks is rice, on its own and he does supplement it with the odd takeaway. Sometimes someone in the flat will cook a meal and he will join in with that. So not great, not regular. When he comes home we do try and fill those gaps.” Family Member 125.

“Well we actually help them cook their meals—they get to choose what they want to cook, but most of the time they are too lazy to think about what they want to cook so they leave it to the staff.” Carer 123.

Other participants showed high enthusiasm and passion for cooking, and this was irrespective of whether they had to rely on themselves for cooking each day, if they shared the role with others, or if they relied on someone else for the majority of meals.

“I love cooking! It’s a bit of a passion of mine, I’m always kinda looking for new recipes and new ways to cook things.” Patient 133.

“I talked to one of the boys last week…He said ‘I would actually be interested but I don’t cook, I live at home with my mother she cooks everything, I would actually quite like to cook.’” Staff 1110.

“Hardly a lot, I’m a bit lazy, but I’ve always wanted to try out cooking just by testing out random things…I’m good at following recipes, I should probably just download a few from the internet. Just follow them through.” Patient 137.

5.4.6 Summary

This theme explored the participants’ thoughts and beliefs about nutrition and health, and showed their insight into the effects of the illness and medications on their health.

Medications were reported by participants to be life-altering and the side effects difficult to manage. Hunger was considered to be the single most challenging side effect and when coupled with a new-found lethargy created the situation where weight gain could become inevitable.
Self-awareness of the inter-relatedness of health components was shown by some participants but not others. It highlighted that there is a holistic belief surrounding nutrition and mental health, but this may be more prominent in those who are further into their recovery. This needs to be encouraged in patients to motivate them to make healthy choices and changes for their intrinsic benefits (such as enjoyment of food, the pleasure of cooking, having more energy, and feeling better about themselves) as opposed to just for physical changes in their health.

Nutrition knowledge was reported to be quite average, however the confidence in what they knew differed amongst the groups, as did their sources of (trustworthy) nutrition information.

Past strategies employed by patients indicated the presence of a “dieter's mentality,” using food and exercise as a means to lose weight (or gain strength), and although there were holistic approaches taken toward each of these approaches, mental rigour is required to maintain adherence to dietary changes. Food and dietary approaches to reducing weight were favoured by those without motivation to exercise, whereas those with a focus on exercise used food as a means to further their fitness goals.

There was a dichotomy of attitudes towards cooking, with some viewing it as a chore in order to eat, while others saw it as a mental release and source of pleasure. Some patients had minimal exposure to cooking as their household had its meals catered for by another family member, whereas those on their own or in alternative living arrangements had to have a daily exposure—whether it was enjoyed or not.
5.5 Programme-specific details

This theme followed a slightly more content-analysis approach as it focussed specifically on things that the participants felt were important things to cover during the programme, or things that were needed in order to increase engagement and participation with the programme. This theme is summarised in Table 4.

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5.5.1 Programme design

This theme explores the logistics and structure for this proposed programme desired by participants to enable it to best meet the needs of the patients. This will take into consideration the cognitive capabilities and attention spans of the patients, while acknowledging the organisational challenges of organising a group activity in a facility where everyone is on different schedules.
**Intended Audience**

There was a divide amongst participants as to whether the patients would benefit most from this programme if they attended it immediately after beginning medications to help to prevent weight gain, or once they are more mentally stable but might now be in a position where weight loss is required.

“The weight gain is so drastic and so quick if this could be implemented at a start with a real focus on that—these drugs are going to make you put on weight, this is going to counterbalance that, I think that would be really helpful.” Patient 139.

“I think as far as some general information goes and some statistics or something, relatively early would be okay, but things like the actual cooking classes and stuff might be better later on when people feel able enough to actually go out and do things and be stable enough to retain the information.” Patient 135.

“I would say it probably when they are a wee bit mentally stable…we have had feedback that at that time they can’t take it in so I think they need to be…But I think the education on the eating, the medication and all that, I think it is very very important….so I think a week down the track might be a good idea, just until they are at the stage where, okay, they’ll take the information in. Cos you want them to retain the information to actually go out and use it.” Staff 1110.

Waiting until the patients were more stable was a slightly more favoured approach, but compromises were also suggested by some participants.

“I think obviously prevention would be a big part of it because it is not really healthy to bounce up and down your weight too much. Like I wish this [type of programme] had been available when I first started putting on weight. I think both as well so if someone is already down the track and they’ve come to terms with the fact they are putting on weight and they decide they want to lose it then it’s good for them but it is also good to try and get the prevention of their weight gain as well, so I think both.” Patient 133.

“…possibly you need it two or three times through the process because not everybody is going to want to do it initially but I guess there is a little bit of denial about all sorts of things so even though you may have been told you are going to put on weight you may think you are not going to put on weight etc. But yes I suppose as much education as the individual is going to be happy to have. Initially before the problem, is a lot better than after isn’t it?” Family Member 126.
**Patient Input**

There was an underlying sense that the patients would want some influence and input into what they were able to learn or cook each week, showing a desire to regain some control over what they were being exposed to while recovering from their illness. This also reinforces the theme that they prefer a more casual environment rather than a classroom (teacher/student) environment.

“You could maybe ask everyone for a vote on what they would like to do on that particular day, or maybe it is depending on the ingredients you have available at that time.” Patient 137.

“If they could choose some of the meals, or have input into the programme. They might say ‘how do you cook this specific dish’ It’s like taking back your power isn’t it?” Family Member 122.

“I think if you talk to them about what they want…what shall we cook next week?…it is no good us saying what we think they would want without actually talking to them about what they want.” Staff 1110.

**Session Length**

All groups indicated that there would be a time-limit for how long a session would be able to run before patients would lose interest or become restless. It was theorised that if a formal session included education, cooking and a shared meal then it would be best run around one to two hours maximum, however if patients chose to hang around afterward to socialise this wouldn’t be discouraged.

“If you put a time limit on it you might be rushing and then you are not going to enjoy it, so I would be flexible, but I would say an hour or an hour and a half maybe, cos that includes the whole presentation as well as the cooking and stuff. I would say don’t worry too much about time but obviously we don’t want to be here for three days!” Patient 133.

“[no] more than an hour but I guess you could open it up for people to hang around longer if they felt like it.” Family Member 127.
It was also noted that the time of day would be a critical consideration to match patient energy levels and motivation to attend.

“Too early they won’t get up, too late in the afternoon they’re too tired, so somewhere in the middle. So doing it for lunchtime maybe.” Carer 123.

**Session Frequency**

The majority of participants favoured a more structured, course-like programme held weekly so that they could build on their skills and knowledge, however acknowledged that this is a ‘roaming’ population and they might not be able to attend all of the sessions in the programme during its run, showing a desire that each session could be stand-alone within the wider scope of the course. This reflects the themed sessions design used in Senior Chef—if one topic is missed you would still benefit from the rest of the course and could catch up on it the ‘next time around.’

“…because sometimes for me to get out and about if I’m feeling really anxious or if I am suffering any symptoms, it makes me very housebound and so then I would feel really guilty about not being able to go to all of the classes. So a one off session every now and then would better and then if I missed one I wouldn’t feel so awful having missed one.” Patient 135.

“I would like to see like a continuing course cos the participation [in Rec Group] is pretty good—most of the boys who come here come every week so, I know I will be here every week, but I think it would be good to build on it because it keeps people’s interest that way and you know they want to come back. Then you could even do a bit of both, it just not follow on study that we are going to continue each week but a little bit just like hints and tips as well are probably quite handy—just things that they are going to remember, one thing at a time that might make a difference.” Patient 133.

“I think I would have to go with both. Like when I was at the end of my [psychosis] I would have liked the controlled course where we go through all the stuff, but a drop in course would work better for everybody because there are people who just come and go.” Patient 138.
5.5.2 Learning environment

This theme describes the environment the participants want while participating in the programme, including who to include as facilitators, how to communicate information to them most effectively, and how to retain interest by putting the newly learnt skills into practice. The desire was for a relaxed, fun, social setting where they could learn at their own pace and feel they can be free to be themselves.

Facilitators

Participants expressed a desire for the course to be run by someone who is knowledgeable in their field-such as a dietitian or a chef, but to allow sessions (or parts thereof) to be taught by guest speakers who were either peers or people who had “been there done that” to increase relatability and confidence in the patients.

“I think they would listen to a dietitian or a nutritionist, somebody with knowledge and I think perhaps someone younger would be quite suitable, and obviously somebody with an insight into their conditions.” Family Member 125.

“If you had a regular core group of people attending all the time maybe roster it with ‘you come and cook a meal this week and next week someone else will come in’, you and someone else could come in and cook the meal as well.” Staff 016.

“I feel that things you [as a parent] would tell them they wouldn’t always necessarily want to take in so if somebody else told them, not necessarily the same but similar, that would perhaps have more weight and I think perhaps as a parent you don’t always want to be nagging so it is good that somebody else is saying it for you.” Family Member 126.

Communication style

There was a distinct preference by patients for hands-on and practical content as they identified themselves as visual learners-wherein words could be ignored or misinterpreted, and endless reading of “boring” content would be off-putting. The
content has to be fun and engaging, but without coming across as instructing, condescending or overly simplified.

“I think from having psychosis myself taking part is more of a watching and learning kind of thing. Words can get easily misread, I know a lot of the time when I was hearing good advice I just wasn’t listening in the right way, so I guess at the end of the day the best thing is, for me, would be to learn by doing and watching.” Patient 138.

“Make it sound fun—I usually try and pay attention. Maybe not over exaggerating in some areas. I’m not really sure about that one.” Patient 137.

“I think if we are going to say ‘we are going to prepare a meal and I want you to do this, this and this’ that’s just not going to work, because to them it is an instruction, but if we say ‘this is awesome, let’s try this and that’ – it’s how you package that particular lesson is quite important.” Staff 012.

Incentives for continued attendance

It was expressed by participants that some kind of “homework” or in-between session tasks would help to retain interest in what was being taught, and to build confidence in the new skills they have learnt.

“If they were given one of the main ingredients to take home with them… something they may not have at home, a herb or a spice, not necessarily an expensive part. Also the actual recipe. And being hands on with the actual making of it too. Cos it is about confidence, you know someone else can make it look easy and you think ‘I couldn’t do that.’” Family Member 122.

“A cooking book so you’ve got the recipes you can take home and try. Maybe step by step instructions cos back in Intermediate [school] it was baking and we used to get our books at the end of the year. Do stuff like that.” Patient 136.

“Maybe things around kind of helping people to put some of those changes into practice outside of the group and the sessions…so I guess finding just really little achievable goals that people can set themselves between the sessions and ways of I guess helping keep that in peoples’ minds, so little reminders, you know pictures or shopping list-notebooks, and linking in with case managers to get them on board with what they are learning in the groups and what’s going to help them to kind of remind the client what to do in between.” Staff 015.
This was also viewed as an opportunity for informal accountability where they could check-in week to week to see how they were managing things, if they had met their goals or what the difficulties were in staying on track.

“Just general encouragement I guess, like having some positive reinforcements, like you guys could be texting, or some social media stuff would be quite fun, I think young people would enjoy that. Like a little private thing on Facebook where people can connect a little more with people who are also going through the same thing.”  
Patient 139.

“For me personally I guess some sort of loose accountability would be good. If there was somebody, like my case manager or someone, checked in to see how I was going with my eating or something like that. They already do but I do think that would be good if it is something that is refreshed every now and then in conversation. It would be good so you don’t forget or let it fall by the wayside. If you are encouraged regularly you are more likely to respond to it.”  
Patient 135.

“You could have a star chart thing that was like ‘how many meals you have cooked for yourself’ or the opposite of that being ‘you had a week where you didn’t have a particular type of bad food that you wanted to have’…they could go away and do a food diary for the week and look at what you were eating and then you could go through and see if it could be improved or find that it’s not too bad.”  
Family Member 127.

5.5.3 Educational content

This theme sought to explain what the participants felt the patients would benefit from learning more about to be able to make changes to their lifestyles. It also reflects the patients’ desire to have flexibility within sessions to ensure the content is most relevant to their specific situation and their needs at that time.

Nutrition-specific topics

There was desire from all groups that, in addition to basic nutrition information they wanted to know more about what goes into foods, the macro and micronutrient profiles of foods and how to decipher the ‘confusing and tricky’ labels on packages.
“What vegetables have certain vitamins and protein, stuff like that.” Patient 133.

“I guess the different nutritional values that are given to different foods within their groups.” Patient 138.

“I think the awareness of the tricky labelling we have now that it might be perceived that something is healthy but that it is actually going to have some hidden sugar in there, or something. I’ve been taught a couple of times of how to read those labels but it still perplexing me somewhat.” Family Member 126.

Patients specifically requested to learn more about appropriate portion sizes as they felt knowing this kind of information might help to stop their overeating and resulting weight-gain.

“Maybe some education around portion sizes like how much vegetable you should eat, how much meat you should have and stuff like that. I’ve seen these cool plates that have got sections on them to show you how much you should be having so something like that would be cool—[they] might think we’re allowed that much but we will stack it high!” Patient 133.

“…what I have in mind specifically is portion sizes. That is something that I struggled with for a long time as well and that led to a lot of weight gain as well as it was a lot more than I actually needed to. I didn’t realise just how much above what the recommended intake actually is.” Patient 135.

**Lifestyle information and practical content**

In addition to nutritional educational content and cooking sessions there was also an expressed desire for practical information during sessions to show how the theory comes together. Suggestions such as supermarket trips, coordination with other lifestyle groups such as garden club and Rec group, and how to navigate restaurant menus were thought to be ways of helping patients to “walk the walk.”

“I don’t know if you would want to go as far as say taking them to the supermarket, I guess it depends on the timeframe that was available to whoever was running it, how many kids you had, how many vehicles, it’s not that far from South City [mall] so that could be part of the exercise programme!” Family Member 126.
“With regards to fast-food is there a healthy fast-food, which of the fast-foods is the healthiest because I guess the reality is they are still going to want to eat fast-food so helping them to decide which is the healthiest is perhaps a wee bit of a help.” Family Member 126.

“There’s a lot of stuff you can get in the forest that is edible. So maybe getting someone who’s an expert in that field to take them out [foraging].” Carer 123.

5.5.4 Cooking/Recipe ideas

This theme specifically tapped into the high value that participants placed on food, exploring the cuisines and cooking methods that the participants wanted to learn how to make for themselves and what they felt they could confidently achieve in the kitchen.

Genre/style of cooking

The majority of responses indicated a desire for fast, simple, healthy, affordable meals that could help to meet their nutritional needs each day and alleviate their hunger, but that could also be adaptable to meet their individual needs (special diet, taste preferences, budget, access to cooking facilities or equipment etc).

“Talking to the guys about being adaptable, if you haven’t got this then think about trying this—it’s giving them different options. The choices are there you just need to think outside the square a wee bit.” Staff 1110.

“Affordable meals that are giving you all the necessities like the vitamins and everything that you need to be healthy.” Patient 133.

There were recurring requests to include recipes for healthier versions of their favourite takeaways, with the intention that if they craved the flavour rather than convenience they might choose to cook at home instead of going out.

“Healthy baking maybe cos you do crave a lot of baking so I think having some recipes that were like sweet but quite healthy would be quite good.” Patient 139.
“...like that food truck programme that used to be on. They would copy a takeaway style meal but make it a healthier option-looking at foods you might be into that aren't so good but try and replicate them in a healthier way.” Family Member 127.

**Specific dishes**

Dishes such as stir-fries that incorporate everything at once were the most popular choice amongst participants. This philosophy extended to dishes such as pastas, frittatas, slow-cooker meals, casseroles, soups, curries and salads where a large variety of ingredients can be included within a single meal—therefore making it easier to reach daily serving targets, without having to consciously think about adding them into a meal.

“Everything is in the stir-fry, the vegetables...I think that is pretty easy to do, just throw everything into a pan...pasta or frittata where everything is in one, with maybe a salad on the side” Patient 138.

“Salads and stuff in the summer, probably hotter foods in the winter” Patient 132.

“Frittata, he really enjoyed that and I thought it's got the protein, it's got the carb, you can put a few more vegies in there and hopefully have it with a salad” Family Member 126.

There was also a desire to use the programme as a means of introducing and exposing the patients to new foods and showing how they could incorporate them into their diets.

“I have a client who doesn’t know much about vegetables and what they taste like or look like.” Staff 017.

“So if...the clients are able to get for example some vegetables right there in front of them rather than them having to go and buy...The initial thing is to have it there and try it for themselves, because if you are going to go out and buy—you are not going to buy something which you have never cooked before, so initial part they get it for free and then they will start using and it and go ‘Oh this isn’t too bad.’” Staff 012.
5.5.5 Summary

Participants preferred a programme that would provide nutritional education as well as hand-on practical cooking classes and lifestyle tips and tricks. They sought a casual and social environment where they felt safe and free to be themselves.

Structurally, it was desired to have a programme that would provide weekly routine, but be flexible enough to meet the needs of a population that ‘come and go’ through the facility. This was thought to be through having sessions themed around a topic that would meet the needs of those attending on the day, but not disadvantage anyone that had missed it in future sessions. If this course was held cyclically like Senior Chef it would mean they could catch up on the missed session the next time around. The duration would be around one to two hours and would include a combination of education, cooking, and social time to eat the food they had prepared. It was predicted that those who were further into their recovery programmes would gain the most benefit from the more specific information taught in a programme like this, but to allow for those who were not at that stage to still attend as the information could still prove useful for preventing weight gain.

Participants requested that educational input be provided by qualified healthcare professionals such as dietitians, but showed desire for other people to assist such as those who had “been there done that” and to allow for peer-learning opportunities to increase confidence and self-esteem.

Educational content would need to be designed to accommodate visual learners, which could involve the use of videos or illustrations to convey the more “boring”
content. It was also suggested that providing small goals to achieve in between sessions would make patients more likely to try things out that they had learnt at home, helping to cement their new knowledge and skills and retain interest in the programme.

Participants wanted nutrition content that was specific to the patients’ situation, such as portion control and knowing what is really in the (processed) foods they are eating. There was also a desire for more practical skills and education, including supermarket tours, menu ‘hacking,’ and other novel approaches such as foraging in community forests. It was felt that this programme would benefit from linking with pre-existing groups, such as the Rec group, to increase interest and applicability.

Recipes that were quick, affordable, easy and nutritious were the most requested, with meals such as stir-fries that incorporated everything into one meal being very popular. It was suggested that this programme would be a good platform to introduce patients to new foods so that they might feel more confident in buying it for themselves later on.
5.6 Nutrition Knowledge Questionnaire

The Nutrition Knowledge Questionnaire was completed by all participants in the study (n=26). The average score across all groups was 11.8 (54%), with a range of 7-16. Family members/carers achieved the highest average score of 12.29/22 and also the highest individual score of 16/22, while the patients received the lowest average score of 11/22 (50%), and tied with the family members/carers for the lowest individual score of 7/22 (32%) (Table 5).

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Mean</th>
<th>Variance</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>10</td>
<td>12.20</td>
<td>2.18</td>
<td>10-15</td>
</tr>
<tr>
<td>patients</td>
<td>9</td>
<td>11.00</td>
<td>5.75</td>
<td>7-12</td>
</tr>
<tr>
<td>Family members/carers</td>
<td>7</td>
<td>12.29</td>
<td>10.57</td>
<td>7-16</td>
</tr>
</tbody>
</table>

A one-way ANOVA revealed no statistically significant differences between group scores (p=0.46) (Table 6).

<table>
<thead>
<tr>
<th>ANOVA. Sources of Variation</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>P-value</th>
<th>F crit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>9.01</td>
<td>2</td>
<td>4.5049</td>
<td>0.803</td>
<td>0.460</td>
<td>3.422</td>
</tr>
<tr>
<td>Within Groups</td>
<td>129.03</td>
<td>23</td>
<td>5.6099</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>138.04</td>
<td>25</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
The highest ranking questions: “Which one of the following types of rice has the highest nutrient value?” and “What method of cooking increases the intake of fat in the diet?” were each answered correctly by all but one of the participants. Whereas the question “What is the best guide for determining adequacy of energy intake for an individual?” was only correctly answered by two people (Table 7).

Table 7. Nutrition Knowledge Questionnaire Results by question

<table>
<thead>
<tr>
<th>Test Question</th>
<th>% correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brown rice has the highest nutrient value of all types of rice</td>
<td>96 (n=25)</td>
</tr>
<tr>
<td>Frying increases intake of fat in the diet</td>
<td>96 (n=25)</td>
</tr>
<tr>
<td>Reaction to stress affects appetite</td>
<td>85 (n=22)</td>
</tr>
<tr>
<td>Dried beans are a meat alternative</td>
<td>81 (n=21)</td>
</tr>
<tr>
<td>Saturated fat is more likely to raise cholesterol levels in the blood</td>
<td>81 (n=21)</td>
</tr>
<tr>
<td>Correct identification of menu appropriate for prevention of heart disease</td>
<td>77 (n=20)</td>
</tr>
<tr>
<td>Of the following cereals, toasted muesli has highest proportion of calories from fat</td>
<td>69 (n=18)</td>
</tr>
<tr>
<td>B vitamin deficiency may occur with habitual high alcohol intake</td>
<td>69 (n=18)</td>
</tr>
<tr>
<td>Many women in low-income households tend to be overweight</td>
<td>65 (n=17)</td>
</tr>
<tr>
<td>Correct identification of the formula for calculating BMI</td>
<td>62 (n=16)</td>
</tr>
<tr>
<td>Recommended daily intake of fibre for adults is 30 g</td>
<td>54 (n=14)</td>
</tr>
<tr>
<td>Four major food groups correctly identified</td>
<td>46 (n=12)</td>
</tr>
<tr>
<td>Legislatively, ingredients must be listed in descending order of proportion on food packaging</td>
<td>42 (n=11)</td>
</tr>
<tr>
<td>Per 100 g column on nutrition information panel is used to compare different brands of food</td>
<td>42 (n=11)</td>
</tr>
<tr>
<td>Centrally distributed excess fat carries a greater risk of metabolic disease</td>
<td>38 (n=10)</td>
</tr>
<tr>
<td>Beef sandwich, cottage cheese, baked custard and skim milk is not a balanced meal</td>
<td>35 (n=9)</td>
</tr>
<tr>
<td>Of the following foods, one slice of wholemeal bread has the highest fibre content</td>
<td>35 (n=9)</td>
</tr>
<tr>
<td>HDL cholesterol not a risk factor for cardiovascular disease</td>
<td>27 (n=7)</td>
</tr>
<tr>
<td>Requirement for food calories increases when physical activity increases</td>
<td>27 (n=7)</td>
</tr>
<tr>
<td>Milk powder is the best buy on a cost per nutrient basis</td>
<td>27 (n=7)</td>
</tr>
<tr>
<td>Of the following foods, Peanuts have a high saturated fat content</td>
<td>19 (n=5)</td>
</tr>
<tr>
<td>Maintenance of desirable weight is the best guide for determining adequacy of energy intake</td>
<td>8 (n=2)</td>
</tr>
<tr>
<td><strong>Average score</strong></td>
<td>54% [11.8/22]</td>
</tr>
</tbody>
</table>
6. Discussion

This chapter discusses the major findings of the present study within the context of the existing literature about lifestyle interventions for those with FEP, discussing similarities and differences within the literature and providing implications and direction for future research.

6.1 Main findings

The results showed that staff, family members/carers and patients involved with Totara House want a healthy eating programme to be implemented. Participants indicated that there were unique challenges in motivating and engaging this population, but if they could contribute to the programme design and have an ongoing role in the delivery of the programme (increasing motivation and reducing barriers) the improvements in health and wellbeing could be promising (84). Patients sought a programme that provided a relaxed social setting where they could interact with their peers and learn valuable life skills, nutrition education and improve their health. The programme would ideally be delivered by someone with a nutrition background, with an insight into mental illness, conveying relevant content requested by the patients in a practical/visual manner, and include recipes that they could easily make at home. Patients sought routine in the programme structure that would also accommodate their needs as a ‘roaming’ population-acknowledging they might not be able to attend all the sessions but did not want to feel discouraged or hindered if one is missed. The nutrition knowledge questionnaire showed an average understanding of nutrition in all groups, which was intriguing given that some participants indicated they trusted those
in the other groups as sources of information (i.e. patients trusting family or staff for nutrition advice (85)). This finding supports the need for someone qualified in nutrition to develop and/or deliver the educational component of the programme.

6.1.1 Nutrition Knowledge Questionnaire

The results of the nutrition knowledge questionnaire were consistent with previous studies that showed average scores of 60.2% and 50% in nursing populations (78, 79) respectively. At face value the staff’s average score of 55% would be consistent with these findings. However the majority of patients and family members admitted to guessing a number of the answers which would have resulted in lower scores if they had left the question blank. Seven participants in this study (27%) scored less than 50% on the questionnaire (four patients, three family members/carers and one staff member), compared to 19.4% in the Schaller study (78) and 33% in the Forsyth study (79). The two most correctly answered-and the least correctly answered questions (Table 7) were the same in the present study as in the Forsyth study. The answering patterns reflected the nutrition information promoted through public health initiatives and general New Zealand healthy eating guidelines. It is important to note from these results that less than half of participants correctly identified the four food groups.

6.1.2 Adaptability of Senior Chef

The participants’ responses indicated that the Senior Chef model could be successfully adapted into Totara House. Senior Chef involves eight independently themed sessions that address various nutrition topics. In this context that could allow for teaching pre-planned educational content, while still allowing freedom and
flexibility within the theme to meet patient requests such as cooking seasonal recipes, and adapting the content to the skills and level of knowledge of that specific group. The current educational content used in Senior Chef could be used at Totara, but it would have to be adapted to meet the nutritional needs of a younger clientele, and allow for cognitive impairments that can accompany mental illness. The Senior Chef session structure intersperses education content with cooking tasks, which would be very suitable for Totara House patients as they felt that if the education part was too long they might tune out or get restless. Sessions concluded with a shared meal which addresses the patients’ desire for social contact and creating a Whānau-like environment. Senior Chef is held cyclically throughout the year to meet high participation numbers. This model would also be suitable for Totara House as it would accommodate those who are able to attend a full eight week course, and also to those who prefer to ‘drop in’ as they are able (or those wanting a ‘refresher’ session). Senior Chef provides each attendee with a cookbook that covers all of the recipes in the course. This was highly valued by participants in the present study as it provided a visual reminder of what they had learned. However because of the patients’ desired flexibility for content and recipes, a pre-printed book might not be suitable. Instead, patients could be given a blank notebook into which they could include the recipes and handouts from the session, and have space to write notes.

6.2 Similarities

The results of this study support themes described in the literature around health interventions in mental health services. The majority of participants in the present study confirmed observable changes in the patients’ appetites and dietary habits as a
result of commencing antipsychotic treatment, reflecting what was found in the literature (4, 12, 15, 29, 31, 54, 86-88). The patients in the present study considered this increased appetite to be the leading cause of their weight gain, as the hunger cravings were so intense and constant that they felt helpless to fight them, especially during the peak of psychosis where the weight gain is most rapid but nutrition is the last thing on their mind (15, 20-22). This feedback from the patients indicated how unprepared they were for these oncoming changes (12), and how this warning must be made abundantly clear at the beginning of treatment. The motivators and barriers expressed by the patients in the present study reflected what was found in the literature: social inclusion was a prominent motivator, which was considered a critical component in previous behavioural interventions to maintain enthusiasm for lifestyle changes (6, 7, 44, 70, 89, 90), and illness/medication factors were the prominent barriers identified to not achieving health related goals (71, 90). Involving patients within the creation of interventions allows for the content to reflect their needs and accommodate their motivators and barriers (91-93), which can also establish a sense of pride and control in their recovery journey (94, 95). The observed differences in attitudes towards health and cooking between male and female patients in the present study was supported by the literature showing that cooking behaviours are very gender specific; with females having better cooking skills, engaging in cooking more frequently and requiring less motivation than males (58, 96).

6.3 Differences

The literature review indicated that the preferred method for lifestyle interventions was to use individualised sessions as the primary source of information, with group
activities such as cooking classes seen as supplementary (47-49, 51, 65-67, 97). This approach was not favoured by participants in the present study as many of the patients already had access to a dietitian or nutritionist (or had declined their services), preferring instead to learn these new skills and information in a fun group setting with their peers rather than talking to another health professional. Although the literature recommended that interventions be started in those with FEP as soon as possible after commencing antipsychotic medications—specifically within the first month to six weeks when the weight gain is the most pronounced (12, 22, 40, 48, 51), the majority of participants in the present study felt that cognitively the patients were not ready to take in new information at the peak of their psychosis. Their key priority was re-establishing their mental wellbeing—nutrition was at the bottom of the list. They acknowledged that preventing weight gain was easier than losing weight but felt that for long term retention of the advice and skills learned in the programme, waiting until the patient themselves felt they were ready was considered the best approach.

6.4 Strengths

The greatest strength of the present study is that it fills a gap in the literature by not only including patient input in creating intervention initiatives but also involving those who are critically involved with the patients’ recovery journey: the outpatient facility staff and the family members/carers, to provide an all-encompassing view of what would be of the most benefit for the patient. The present study allowed each group to have an equal voice and opinion about what was “best” for the patient to help them achieve their health and nutrition goals, rather than assuming that one group would be more knowledgeable over another based on their experiences with mental illness.
The multiple methods used in this study (a focus group and individual interviews) ensured that participant feedback was able to be collected in an environment that they felt most comfortable in, allowing for more in-depth responses to be expressed.

6.5 Limitations

Working with a vulnerable population such as this includes a set of challenges that requires a flexible and adaptable approach to conducting research. The initial study design planned to run three focus groups (one for each group). However it became apparent that each group had differing needs, and adaptations had to be made as the study progressed. It was revealed during the data collection phase by one of the patients that the prospect of having to conduct multiple interviews and phone calls (that were implied from the flyer) was too intimidating, which explained the slow uptake of non-staff participants. Family members expressed they had very busy schedules, juggling the needs of the patient, their jobs, and the rest of the family, so finding time to do an interview was problematic and often occurred with short notice when time became available.

6.6 Implications for future research

Future research at Totara House could build on the present study results by: designing the programme, undertaking a financial and practicality analysis and conducting a pilot study with evaluation measures and patient feedback. Evaluation studies could assess changes in health parameters or eating behaviours as a result of attending the programme. The present study was based at only one outpatient facility, and included only a small subset of the available population. For this reason
the findings cannot be generalised to other facilities or age-groups and may not be appropriate in other settings. These questions warrant further research.

It was noted during the course of the study that there is a high prevalence of Māori who use Totara House. The present study however, was not designed to address the specific needs of Maori with the depth and careful consideration that it would require. As mentioned previously, the (Pakeha) researcher did not feel confident in presenting Māori concepts or philosophies beyond what was reported in this thesis as there are many deeper meanings that could be easily misinterpreted. Future research should involve collaboration with Māori and ensure that their needs are appropriately represented.

6.7 Conclusions

The present study showed that a healthy eating programme adapted from the Senior Chef model, would work at Totara House. However specific attention would need to be paid to patients’ values and their cognitive functioning to ensure they get the maximum benefit from the programme, and the needs of both the facility and each group of patients coming through the system would have to be considered. Incorporating patient feedback and requests throughout the sessions would be a good way of giving patients control and ownership of the programme and ensuring that the environment feels more “casual” than “classroom” is critical. The questionnaire results highlight the need for registered dietitians or nutritionists to be involved with the programme delivery and design to ensure that accurate, evidence-based information is provided to patients.
7. Application to Dietetic Practice

This research opportunity has provided insight into how people whose lives involve mental illness perceive facets of health and nutrition, and how dietetic involvement with this population needs to be specific, flexible and personalised.

The interviews indicated that prior to commencing treatment not all patients were aware of the metabolic complications and side effects that accompany antipsychotic medications. Participants commented that information on the severity of these side-effects, or tips on how to manage them would have been beneficial when they first started treatment. However many patients were unaware they had access to dietetic support through the CDHB’s Specialist Mental Health Service (SMHS) during that time, which could have helped manage the side effects experienced. It is unclear why these patients were unaware of this service, as the (small) dietetic team is very prominent throughout the SMHS, seeing a wide range of both inpatients and outpatients on a daily basis. It is acknowledged that there is very limited funding for dietetics and the dietitians are often in the position of not being able to see as many patients as they feel need their input. If a healthy lifestyle programme was implemented at Totara House it could reach a wider range of patients, who might otherwise not meet the criteria for one-on-one dietetic interventions (and those who might not have otherwise sought help). This would also free up the dietitians to work more intensively with complex patients who require additional help and support.

It became apparent during the course of this study that there is a recreation and health group being run by a Totara House staff member, who felt that the (primarily
male) clients were not responding to dietetic input (no further explanations provided), so wanted to do something to help by taking them to a local gym and providing some basic nutrition advice. It is great to see that nutrition is regarded so highly by the staff members and there have been some positive outcomes for the patients with regards to improved self-esteem, reduced bodyweight/increased muscle and a feeling of belonging to a group. However the staff member does not hold any nutrition or exercise physiology qualifications-and the nutrition advice is based on their own personal view and comprehension of how nutrition works. Given that Totara House has ready-access to a dietitian; it is surprising that no dietetic input has been sought about nutrition information or to provide clarification, instead feeling like they know what they are doing because it has ‘worked so far’. I believe this echoes what some members of the public feel when they encounter an evidence-based (and accountable) health professional that they feel they cannot relate to-instead seeking out someone that “knows better” hoping for an answer that is closer to their own beliefs—much like what dietitians experience when the public take advice from ‘naturopaths’ and ‘health coaches.’

Although not discussed clearly within the thesis, I personally found there was a prominent theme within the patient group that they found it very difficult to articulate to an ‘outsider’ what they were experiencing while recovering from their psychosis, which I would not attribute to a cognitive impairment or altered functioning. Once the patients felt more comfortable talking to me as the interview progressed-(sensing that it was nothing more than a casual conversation about things), they spoke more freely of their struggles they faced during recovery, but you distinctly sensed that they could
not convey just how severe those struggles were, and without having been on those medications or having experienced psychosis you cannot truly understand their situation in the way that they need you to. As health professionals, we can read all of the literature and extensively research phenomena in an attempt to understand exactly what is going on, but it is only the patient that can convey how it feels. I find this is best likened to a Cantabrian trying to explain to an Aucklander what it’s like to live through thousands of aftershocks following severe earthquakes: you can mention living in constant anxiety and ongoing stress, convey the raw emotions that resurface with each and every rumble, and explain the physical sensations you experience, but if you have never felt the ground move beneath your feet and the absolute helplessness that accompanies it, that barrier to achieving mutual understanding will always remain. Acknowledging a mutual-understanding barrier allows the patient to feel that you respect their input and experiences, allowing their trust to grow and a therapeutic relationship to develop. They have experienced helplessness and by reaching out they are asking you not to help them specifically, but to help them to help themselves-to regain control and independence in their lives, seeing you as someone in their corner rather than just another person “telling them what to do.”
7. References


38. Correll CU, Frederickson AM, Kane JM, Manu P. Does antipsychotic polypharmacy increase the risk for metabolic syndrome? Schizophr Res. 2007;89(1-3):91-100.


68. Clark A, Bezyak J, Testerman N. Individuals with severe mental illnesses have improved eating behaviors and cooking skills after attending a 6-week nutrition cooking class. Psychiatr Rehabil J. 2015;38(3):276-8.
84. International Physical Health in Youth (iphYs) working group. Healthy Active Lives (HEAL) consensus statement—Keeping the Body in Mind in Youth with Psychosis. 2013.
91. Davis LA, Morgan SE, Mobley AR. The utility of the measurable messages framework as an intermediary evaluation tool for fruit and vegetable consumption in a nutrition education program. Health Educ Behav. 2015.
Appendix A. Nutrition Knowledge Questionnaire

The questionnaire has a total of 22 questions. Please answer them all. Each question has only one correct answer. Circle the letter in the column on the left which corresponds with the answer you think is correct.

**Nutrition Questions.**

1) Which one of the following foods has the highest proportion of calories coming from fat?
   a) Cornflakes
   b) Weetbix
   c) Rolled oats
   d) Toasted muesli

2) Which one of the following combinations would not be a balanced meal?
   a) Pepperoni and mushroom pizza, cantaloupe/rockmelon, and milk
   b) Baked beans, wholemeal roll, margarine, coleslaw and low fat milk
   c) Sliced chicken, tossed green salad, muffin, yoghurt and orange juice
   d) Hot roast beef sandwich, cottage cheese, baked custard and skim milk

3) Which one of the following lists foods from the four major food groups?
   a) Meat and meat alternatives, milk and milk products, fruits and vegetables, snack foods
   b) Meat and meat alternatives, bread and cereals, fats and oils, fruits and vegetables
   c) Meat and meat alternatives, bread and cereals, green and yellow vegetables, fruits and desserts
   d) Meat and meat alternatives, milk and milk products, bread and cereals, fruits and vegetables

4) Which one of the following is considered to be a meat alternative in the Ministry of Health Food & Nutrition Guidelines?
   a) Vegetables such as peas and carrots
   b) Whole grain cereals
   c) Avocados
   d) Dried beans

5) Which nutrient deficiency or deficiencies may occur with habitual high intake of alcohol even if food intake is normal?
   a) Calcium and phosphorus
   b) Vitamin E
   c) B vitamins
   d) Dietary fibre

6) Which one of the following is not considered to be a risk factor for cardiovascular disease?
   a) High serum triglycerides
   b) High serum levels of HDL cholesterol (High Density Lipoproteins)
   c) High serum levels of LDL cholesterol (Low Density Lipoproteins)
   d) Elevated diastolic blood pressure

7) Which nutrient requirement is increased for an adult who increases his physical activity?
   a) Protein
   b) Calcium
   c) Food calories
   d) Vitamin E

8) What is the best guide for determining adequacy of energy intake for an individual?
   a) The recommended daily intake for energy from the recommended daily dietary allowances for one’s size, age and activity
   b) Maintenance of desirable weight for the individual
   c) The food pattern from the healthy diet pyramid
   d) Feeling full after eating meals

9) Which one of the following meals would be recommended to someone concerned with preventing heart disease?
   a) Half grapefruit, fried eggs, bacon, buttered toast and coffee with cream
   b) orange juice, toast with peanut butter, and low fat milk
   c) grapefruit juice, sausage and bacon, croissant and low fat milk
   d) orange juice, homemade roll (meat filling), cheddar cheese, coffee

10) What is one way in which mental health and nutrition are related?
    a) A deficiency of vitamin D often causes schizophrenia
    b) A high intake of lecithin increases brain efficiency
    c) Reaction to stress affects appetite
    d) The brain is stimulated by food additives
11) Many women in the low income category tend to be one of the following
   a) Underweight
   b) Overweight
   c) Lacking in protein
   d) Lacking in vitamin D

12) Which one of the following types of rice has the highest nutrient value?
   a) Par boiled rice
   b) Long grain white rice
   c) Short grain white rice
   d) Brown rice

13) On a cost per nutrient basis, which one is usually the best buy?
   a) Whole cows milk
   b) Milk powder
   c) Flavoured cows milk
   d) Trim milk

14) Which method of cooking increases the intake of fat in the diet?
   a) Frying
   b) Boiling
   c) Barbequing
   d) Grilling

15) Government legislation requires that food labels include which one of the following?
   a) Nutrients listed in descending order according to their weight in the product
   b) Only the name of the food and the company which packages it
   c) Ingredients listed in descending order of proportion of the packaged product
   d) As much information as the packaging company wants the consumer to know

16) What is the formula for calculating Body Mass Index (BMI)?
   a) weight (kg) ÷ height (m2)
   b) height (m2) ÷ weight (kg)
   c) waist circumference (cm) ÷ height (cm)
   d) waist circumference (cm) ÷ weight (kg)

17) Which do you think carries a greater risk of metabolic disease?
   a) centrally distributed excess fat
   b) peripherally distributed excess fat
   c) excess fat carries the same risk regardless of body distribution
   d) BMI greater than 30

18) Which of these foods do you consider to have a high saturated fat content?
   a) peanuts
   b) instant noodles
   c) bananas
   d) avocado

19) Which of the following foods has the highest fibre content? Circle only one.
   a) one slice of wholemeal bread
   b) one small apple
   c) two slices of white bread
   d) one weetbix

20) What is the recommended daily intake of fibre for adults?
   a) 20 grams
   b) 24 grams
   c) 30 grams
   d) 33 grams

21) On the nutrition information panel below, which column would you use to compare different brands of food?

<table>
<thead>
<tr>
<th>Energy (kcal)</th>
<th>Avg per serve</th>
<th>Avg per 100g</th>
<th>% RDI</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>201</td>
<td>402</td>
<td>8.7</td>
</tr>
<tr>
<td>Protein (g)</td>
<td>5.3</td>
<td>10.6</td>
<td>10.6</td>
</tr>
<tr>
<td>Fat - total (g)</td>
<td>5.4</td>
<td>10.8</td>
<td>7.7</td>
</tr>
<tr>
<td>- saturated (g)</td>
<td>0.9</td>
<td>1.8</td>
<td>3.6</td>
</tr>
<tr>
<td>Carbohydrate - total (g)</td>
<td>29.6</td>
<td>59.2</td>
<td>9.6</td>
</tr>
<tr>
<td>- sugars (g)</td>
<td>8</td>
<td>16</td>
<td>8.9</td>
</tr>
<tr>
<td>Fibre (g)</td>
<td>5.8</td>
<td>11.6</td>
<td>19.3</td>
</tr>
<tr>
<td>Sodium (mg)</td>
<td>4</td>
<td>8</td>
<td>0.2</td>
</tr>
</tbody>
</table>

   a) per serve column
   b) per 100g column
   c) %RDI column
   d) both a) and b) could be used

22) Which one of these is more likely to raise cholesterol levels in the blood?
   a) Mono unsaturated fat
   b) Polyunsaturated fat
   c) saturated fat
   d) cholesterol in food
Appendix B. Ethics Application documents

1. Ethical Approval

Dr J Elmslie
Department of Psychological Medicine (ChCh)
Terrace House, 4 Oxford Terrace
University of Otago, Christchurch
University of Otago Medical School

1 June 2016

Dear Dr Elmslie,

I am again writing to you concerning your proposal entitled “Totara House Healthy Eating Study”, Ethics Committee reference number H19/063.

Thank you for your email of 31st May 2016, with letter and revised documentation attached addressing the issues raised by the Committee.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

1. Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

2. Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committee Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office.

   http://www.otago.ac.nz/healthandsafety/index.html

3. Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:

gary.witte@otago.ac.nz

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

The Human Ethics Committee (Health) asks for a Final Report to be provided upon completion of the study. The Final Report template can be found on the Human Ethics Web Page http://www.otago.ac.nz/committees/committees/HealthEthicsCommittee.html

Yours sincerely,

Gary Witte
Manager, Academic Committees
Tel: 419.9200
Email: gary.witte@otago.ac.nz

c.c. Professor R Porter Head, Department of Psychological Medicine (ChCh)
2. Māori Consultation.

19 May 2016

Dr Jane Emslie
Department of Psychological Medicine
University of Otago, Christchurch

Mā te rangahau Hauora e tautoko te whakapiki ake te Hauora Māori. All health research in Aotearoa New Zealand benefits the Hauora (health and wellbeing) of tangata whenua.

Tēna koe Jane,

Thank you for taking the time to meet with me at my office at the University of Otago, Christchurch on the 16th May 2016, to discuss your research study titled:

Totara House Healthy Eating Study

I note that you are the identified Principal Investigator for this project and that this is a collaborative study involving the University of Otago (UOC), Christchurch and Totara House, Specialist Mental Health Services, Canterbury District Health Board. Ms Aimee Borich, a Master’s student with your department will be involved in the study. This study has received funding from the Dietetic Training Programme.

Commentary on Proposed Research Projects

Totara House is an outpatient service for young people with first episode psychosis and is part of the Specialist Mental Health Services, Canterbury District Health Board (CDHB), Christchurch. Nutrition related physical conditions such as obesity, metabolic syndrome and type 2 diabetes are common in young people with first episode psychosis. Medications used to treat psychosis can contribute to overeating and lack of activity and this can cause weight gain. Healthy food and eating behaviours can reduce the risk of weight gain, but there is currently no dedicated healthy eating programme for Totara House young people. The Senior Chef Programme is a highly successful healthy eating and cooking programme which was initially developed by CDHB dieticians to help elderly eat well and reduce their risk of nutrition related illness. The aim of this study is to investigate whether the Senior Chef Programme can be adapted to meet the needs of Totara House patients. It is anticipated that study participants for this study will be recruited from Totara House and include patients, staff, whānau/family and caregivers. Focus groups will also be held at Totara House.

Māori Health Gain

In Canterbury, Māori were nearly 40% more likely than non-Māori to be admitted to hospital for a mental disorder during 2011-2013. Further, mental disorders for Māori are more common in those aged 16-24 and 25-44. Unfortunately, contact with health services for mental health need is low for Māori relative to need.

Research Office, Department of the Dean
University of Otago, Christchurch
PO Box 4345, Christchurch Mail Centre, Christchurch 8140, New Zealand
Tel +64 3 363 0237 • Fax +64 3 364 1490 • Email research.uoc@otago.ac.nz
www.uoc.otago.ac.nz
The project has potential to improve the quality of life and physical wellbeing of patients with serious mental illness, by contributing to the development of a tailored intervention to improve dietary intake and reduce the development of nutrition related illness such as obesity and diabetes in Totara House patients. This provides the appropriate context to the importance of this research topic to improving Māori health and health outcomes for this population.

Consent
Issues regarding informed consent for Māori participants who are recruited to this study were discussed. With this in mind, you must ensure that Māori participants are explicitly aware that consent is for this project only.

Ethnicity
While this research does not specifically target Māori, you have indicated that it is possible Māori will have a presence within the recruitment population. Ideally your study cohort should be reflective of the Māori population currently utilizing Totara House mental health services. You will also need to consider how ethnicity data will be collected for this study. It is recommended that ethnicity data is collected in accordance with the Ministry of Health guidelines, which involves the use of the Census 2013 question. If a participant identifies as Māori, but this is not recorded in their records, this should be rectified. This may be likely to occur given the poor ethnicity data collection in hospital protocols and databases.

Partnership
As you are aware Hauora Māori involvement for this study would ensure that Tikanga Māori frameworks are considered and integrated throughout this project. With regard to Māori involvement in your study, I suggest that further consultation be undertaken with Ms Leslie Dixon, Pukenga Aotahi (Māori Mental Health Worker), Totara House. I understand that you will also be meeting with members of Te Korowai Atawhai (the Māori Mental Health Unit), at Specialist Mental Health Services, CDHB. It is anticipated that this group will provide cultural input and advisory for this study. As discussed, you would need to consider how Hauora Māori staff will be supported to participate and assist with this study. Therefore, there will need to be discussion with the Pukenga Atawhai Māori staff directly, and also between yourself (the Primary Investigator) and the appropriate General/Service Manager (Mr Richard Grist) for Totara House. This will help you to identify the availability of Māori capacity for this project and ensure that the current patient workload for Māori staff is not compromised. I have also suggested that Leslie Dixon, be involved in this study and assist with healthy eating programme delivery, that she is acknowledged for her input as a co-author in the publication for this study.

Potential Further Support Resources
Further resources that you might want to access to strengthen your responsiveness to Māori within your research are: 1. HRC’s Noa Pū Rangahau Hauora Kia Whakasipiko Ake Te Hauora Māori 2003–2006. 2. The Health Research Strategy to Improve Māori Health and Well-Being 2004–2006. For regional data relating to Māori in each District Health Board (DHB) region, the District Health Board (DHB) Māori Health Profiles (2015) published by the Ministry of Health New Zealand will help to create a picture of the health status of a DHB’s population at a given time. The other reference that is available is 3. Hauora Māori Standards of Health IV: A Study of the Years 2000-2005 by Bridget Robson and Ricci Harris, Māori Health Research Unit, Wellington School of Medicine, University of Otago, Wellington. All provide Māori specific information on a range of health issues. The recent publication Tikau Kākahu: Māori Health Chart Book 2010, Ministry of Health, 2010 (3rd edition) is an update relating to the socio-economic determinants of health, health status and service utilisation of the Māori population. Further references are available from the HRC’s Guidelines for Researchers on Health Research Involving Māori.

Dissemination of Results
The HRC’s Guidelines for Researchers on Health Research Involving Māori, is important in terms of how your research results may contribute to Māori health gain. Therefore, it will be necessary that appropriate Māori organisations/services and participants are aware of your findings. This should occur not only in an academic forum, but also within the community from where data is drawn. You inform that study participants will be invited to a formal presentation of study findings at Totara House and that there will be opportunity to disseminate your findings back to Te Korowai Atawhai. As such these pathways will allow an opportunity for the consideration of Māori feedback into any discussion going forward with regard to your study.

No rāiraka mai tanu ngā mihia,

Karen Keelan
Māori Research Advisor/Kaitohutohu Rangahau Māori

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3. Amendment to Ethics Proposal

UNIVERSITY OF OTAGO HUMAN ETHICS COMMITTEE AND
UNIVERSITY OF OTAGO HUMAN ETHICS COMMITTEE (HEALTH)

REQUEST FOR EXTENSION OR AMENDMENT TO A PREVIOUSLY APPROVED STUDY

If the nature, content, location, procedure (including recruitment of participants) or personnel (including student investigators) of an application approved by the University of Otago Human Ethics Committee or University if Otago Human Ethics Committee (Health) changes, applicants are responsible for informing the Committee of those changes.

<table>
<thead>
<tr>
<th>Application Reference number (e.g H13/011, 13/131, D13/001):</th>
<th>H16/063</th>
<th>Name of University of Otago staff member responsible for the project:</th>
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Title of Project: Totara House Healthy Eating Study

Please detail the amendment(s) you would like to make to your approved proposal, the reasons for the change(s), and any additional ethical considerations:

We would like to collect information about patient participants’ medication and diagnoses. As psychotropic medications and diagnoses affect eating behaviours, the information will help us to understand and interpret the final data more accurately. The information will be collected in a de-identified format to protect study participants’ anonymity which is extremely important in all studies but more so in this study as the patients belong to a vulnerable population. Please find our revised Information Sheet and Consent form attached.

Please email your completed form, together with your amended Information Sheet(s), Consent Form(s), Survey(s)/Questionnaires, or any other relevant documents, as appropriate, to:
Gary Witte (Manager, Academic Committees) gary.witte@otago.ac.nz or
Jane Hinkley (Academic Committees Administrator), jane.hinkley@otago.ac.nz or
Jo Farron de Diaz (Research Ethics Administrator), jo.farrondieza@otago.ac.nz.

Researchers can normally expect a response within a week of submitting their request.
Dr J Elmslie
Department of Psychological Medicine (ChCh)
Terrace House, 4 Oxford Terrace
University of Otago, Christchurch
University of Otago Medical School

18 July 2016

Dear Dr Elmslie,

I am again writing to you concerning your proposal entitled “Totara House Healthy Eating Study”. Ethics Committee reference number H16/063.

Thank you for your request for amendment received on 15 July 2018. We note that you would like to collect information about patient participants’ medication and diagnoses. The information will be collected in a de-identified way to protect participants’ anonymity. Thank you for providing the revised Information Sheet and Consent Form for the study. We confirm the amendment is approved.

Your proposal continues to be fully approved by the Human Ethics Committee. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing. I hope all goes well for you with your upcoming research.

Yours sincerely,

[Signature]

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor R Porter Head Department of Psychological Medicine (ChCh)
4. Information sheet for participants

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

We would like to invite you to take part in our study, which will investigate the feasibility of adapting the Senior Chef Programme (a healthy eating and cooking programme) to meet the needs of Totara House patients by investigating your ideas of what an ideal healthy eating and cooking programme might look like. This study is being conducted by Dr Jane Elmslie and Professor Roger Mulder (Dept. of Psychological Medicine) and Ms Aimee Borich (Dietetic Training Programme, Department of Human Nutrition)

What is the aim of this research project?

Nutrition related physical conditions such as obesity, the metabolic syndrome and type 2 diabetes are common in people with first episode psychosis. Medications used to treat psychosis can contribute to overeating and lack of activity; this can cause weight gain. Healthy food and eating behaviours can reduce the risk of weight gain but there is currently no dedicated healthy eating programme for people who are Totara House clients. The Senior Chef Programme is a highly successful healthy eating and cooking programme developed by CDHB dietitians to help elderly...
people eat well and reduce their risk of nutrition related illness. The purpose of this study is to investigate whether the Senior Chef Programme could be adapted to meet the needs of Totara House clients.

**Who is funding this project?**

This project is funded by the Dietetic Training Programme, Department of Human Nutrition University of Otago.

**Who are we seeking to participate in the project?**

We are inviting 12 people aged over 18 years who are clients attending Totara House and 12 family members/caregivers of Totara House clients who have heard about the study through advertisements or their case manager to take part in this study. We are also inviting 12 Totara House staff to participate in the study. All participants will need to be fluent in English.

**Where will the study be held?**

The study will be held at Totara House.

**How many visits will there be during the study?**

There will be two visits and three phone calls during the study.

**If you participate, what will you be asked to do?**

Participate in one 1 hour individual interview. We will ask you to contribute your ideas about what an ideal healthy eating and cooking programme would be like and what would make learning about healthy eating and cooking interesting and useful. After the interview we will ask you to complete a pen and paper format Nutrition Knowledge Questionnaire. This will take about 30 minutes.

**Is there any risk of discomfort or harm from participation?**

There is no risk of discomfort or harm from any procedures in this study.
What data or information will be collected, and how will they be used?

Each interview will be audio-recorded and transcribed. Once transcribed, the audio-recordings will be erased. During the interview your first name will be used in conversation but will replaced with an ID number on all written materials relating to the study, including the transcripts. Information about your diagnosis and the medication you are taking will be obtained from your clinical file by a Totara House staff member and provided to the study researchers. To ensure that details of your condition remain strictly confidential, this information will not contain your name or any other information that could identify you. Upon the completion of the study, all data will be sent to Dr Jane Elmslie at the Department of Psychological Medicine, University of Otago Christchurch, where it will be held securely for 10 years after which it will be destroyed. Data generated in the study might be made available for use in future research. If data is used for this purpose, you will be asked for your consent. The results of the study will be published in a nutrition journal and used to inform the adaptation of the Senior Chef Programme to meet Totara House clients’ needs.

What about anonymity and confidentiality?

Each study participant will have a numerical ID number. This will be allocated upon entry to the study and used in all written and electronic forms of data. During the study, all data (participant names and code numbers, audio-recordings and transcripts) will be stored in a locked filing cabinet at the Dietetic Training Programme Office, University of Otago Christchurch. The study researcher, Aimee Borich, will hold the key. A separate list of participants’ names and code numbers will be stored securely for the duration of the data collection and write-up phase of the study and be accessible only to the study researcher (Aimee Borich). Once the study is completed and participants have been notified of the study results, this list will be destroyed. Each interview will be transcribed by a typist who will know your first name only. When the recording has been transcribed your name will be replaced with your ID number. During the study, only Aimee Borich will have access to the audio-recordings and transcripts, and Nutrition Knowledge Questionnaires. Dr Elmslie and Professor Mulder will have access to the de-identified transcripts and the Nutrition Knowledge Questionnaires. Publication of our results will be done in such a way that the individuals and families involved in the study cannot be identified.

Will my GP know that I am in the study?

Your GP will be not be informed about your participation in the study.
Will being in the study cost me anything and will I receive payment or reimbursement for expenses?

There will be no cost to you as a result of taking part in this study. You will not be paid for your involvement in the study.

If you agree to participate, can you withdraw later?

Your participation in this study is entirely voluntary (your choice). You do not have to take part in this study and if you choose not to do so you or your family members will continue to receive treatment as before. If you or your family members do agree to take part you are free to withdraw at any time, without having to give a reason and this will in no way affect your or your family members’ future health care or continuing health care.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Department</th>
<th>Contact phone number:</th>
</tr>
</thead>
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<tr>
<td>Aimee Borich</td>
<td>Research Student</td>
<td>Dietetic Training Programme</td>
<td>#######</td>
</tr>
<tr>
<td>Dr Jane Elmslie</td>
<td>Principal Investigator</td>
<td>Psychological Medicine</td>
<td>#######</td>
</tr>
<tr>
<td>Prof Roger Mulder</td>
<td>Co- Investigator</td>
<td>Psychological Medicine</td>
<td>####### Ext. ####</td>
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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
5. Consent form for participants

The Christchurch School of Medicine and Health Sciences
DEPARTMENT OF PSYCHOLOGICAL MEDICINE

Totara House Healthy Eating Study

Principle Investigator  Dr Jane Elmslie
Co-investigator  Prof Roger Mulder
Student Researcher  Aimee Borich

CONSENT FORM (Interview)

Name of participant: ………………………………………………………………………

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that as a participant I will be asked to participate in an interview and complete a questionnaire.
7. I know that the interview will explore my ideas about what an ideal healthy eating and cooking programme would look like and I will be asked to complete a nutrition knowledge questionnaire. I know that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and /or may withdraw from the project without disadvantage of any kind.
8. I know that information about my diagnosis and the medication I am taking will be obtained from my clinical file by a Totara House staff member and provided to the study researchers. I know that my name and any identifying features will be omitted from this information to ensure that details of my condition remain strictly confidential.

9. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.

10. I acknowledge that the interview is being audio-recorded.

11. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.

12. I understand that if data generated in the study is to be made available for use in any future research I will be asked for my consent for this.

13. I understand that the results of the project may be published and be available in the University of Otago Library, but I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant: 

Date: 

Name of person taking consent: 

Date: 

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Appendix C. Recruitment Flyer

CHRISTCHURCH SCHOOL OF MEDICINE & HEALTH SCIENCES
DEPARTMENT OF PSYCHOLOGICAL MEDICINE

Totara House Healthy Eating Study

Medications used to treat mental illness can contribute to overeating and lack of activity, causing weight gain. Healthy food and eating behaviours can reduce the risk of weight gain but there is currently no dedicated healthy eating programme for clients at Totara House. This research study will investigate what would be needed to adapt an existing healthy eating programme to meet the needs of Totara House clients.

Totara House clients, their family members (aged over 18 years) and staff, who are fluent in English will be eligible to participate in the study. You will be able to make suggestions about what would make a difference, what the content would be and how the programme could be delivered.

By taking part in the study you will contribute to the development of a healthy eating programme designed especially for Totara House clients.

There will be 3 visits and 3 phone-calls during the study. These will take 3-4 hours in total.

Contact Details:

Principle Investigator: Dr Jane Elmslie, Department of Psychological Medicine, University of Otago Christchurch, mobile: #########, email: jane.elmslie@otago.ac.nz
Student Researcher: Ms Aimee Borich, Dietetic Training Programme University of Otago, mobile: #########, email: borai405@student.otago.ac.nz.
Appendix D. Focus Group Questions

1. Do you think nutrition is something your clients need to be concerned about?

2. Why do you think that it’s important/ not important?

3. What nutrition topics do you think your clients would need or want to know about?

4. What would be the best way of communicating food and nutrition information to your clients to plan and prepare healthy meals?

5. Can you suggest anything else that would make the programme more useful for your clients?

6. What do you think would help your clients to lose weight e.g. knowing what and how much to eat, healthy cooking techniques, modifying recipes, a menu plan, shopping advice, ongoing support and encouragement, physical activity etc.

7. What cooking/ recipe style that would be more suitable or popular e.g. one pot wonders, 5 ingredient recipes, slow cooker/dump set & forget, how to make favourite dishes healthier etc.

8. Where does cooking fit into your client’s life? What time and/or energy is there for it?

9. What role do you think that nutrition plays in medication-related weight gain?

10. How would you rate your own food and nutrition knowledge at present?
Appendix E. Letter of Acknowledgement to Participants.

DEPARTMENT OF PSYCHOLOGICAL MEDICINE

CHRISTCHURCH SCHOOL OF MEDICINE & HEALTH SCIENCES
UNIVERSITY OF OTAGO

Dear [participant],

Thank you again for participating in Totara House Healthy Eating Study. Your contribution was invaluable and has helped to provide the data needed to begin development of a healthy eating programme for Totara House based on the Senior Chef cooking programme.

Further research next year will help to refine and develop this programme that will aim to incorporate all the excellent suggestions expressed by study participants and complement the holistic approach that Totara House takes towards mental health.

This study revealed that establishing a healthy eating programme was felt to be important by all participants, with a combination of education and hands-on cooking to be the best approach— including practical content and lifestyle advice that can help put the theory into practice. Learning simple, quick, affordable healthy meals was considered the most useful by participants, with recipes/cookbook provided so that they can have a compendium of all they have learnt from the course and can try out the meals at home. The impression from the interviews was that patients valued social connectedness and a feeling of belonging—and being supported by strong relationships, therefore establishing a Whānau environment will be a top priority when conducting the programme. Study participants felt there should be some input from qualified health professionals (such as dietitians), but expressed that learning from people who had “been there done that” or allowing for peer to peer learning opportunities was highly valued and would help to make the programme more meaningful and relevant for those attending. There was a preference for regularly scheduled sessions, but allowing for flexibility within each session to meet the unique needs of group members, there was also suggestion of holding the programme multiple times in a year so that if a patient missed a session they could catch it the next time around without hindering their progress in the current cycle, and would accommodate those who wouldn’t feel up to doing an entire course but might benefit from one or two sessions.

Your score on the nutrition knowledge questionnaire was [#]/22 ( [#]%), the average score across all participants was 11.8/22 (54%).

We are planning on providing a presentation of the results at Totara House, of which you are most welcome to attend, date and time TBC.

If you have any further questions as a result of completing this study please feel free to contact me.

Regards,

Aimee Borich.