

# Experiences of Pacific patients who have used Fanau Ola services

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**pacific** perspectives

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## Acknowledgements

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This report was prepared by Lisa Kitone and Debbie Ryan – Principal, Pacific Perspectives Limited.

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The primary author(s) are responsible for any omissions or errors of interpretation.

## Executive Summary

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As part of an internal evaluation of the Pacific Fanau Ola (FO) programme, Counties Manukau Health (CMH) have commissioned Pacific Perspectives Ltd (PPL) to independently capture the experiences of Pacific patients and families who have used FO services. The evidence provided in this research report should be considered along with the findings of the Fanau Ola programme evaluation conducted by CMH, rather than a stand-alone critique of the Fanau Ola service.

### Study method and design

To capture patient and family experiences of FO and provide demographic, clinical and socioeconomic context for the findings, the study design consisted of five main components:

- In depth interviews with individual participants or including their families.
- Qualitative interview analysis identifying key common themes and development of an overall thematic analysis.
- Hospital discharge summary analysis providing a clinical context to patient narratives
- Case studies for each participating patient or family made up of interview summaries and clinical history (included as a confidential part of the report, for senior CMH management only)
- FO document and targeted review of relevant health services literature.

### Participant characteristics

Some participants were not the only family member to have complex health needs. Most of the patients and families were affected by socio-economic issues and had specific transport, connectivity, communication and health literacy needs that create significant barriers to accessing quality and timely health care.

All participants suffered from multiple health conditions, including many chronic diseases, that were long-standing and/or had resulted in a rapid deterioration of health. Most participants were prescribed a large number of regular medications, required a complex management approach in hospital, frequently required input from a number of separate specialist services while inpatients and were discharged with outpatient follow-up.

### Experiences of Fanau Ola

In addressing the key research question: **How do patients and families experience CMH FO services?**, the research found:

- Many participants described positive experiences of FO staff.
- Initial interviews suggested that many participants were not clear about what FO was. Many others lacked an awareness of the FO service.
- Follow up interviews, referring to a FO advocate by name, showed an increased recollection, awareness and demonstrated understanding of the FO programme.
- Understanding of the FO Champion role varied amongst participants.
- Suggested improvements of the FO service centred on improving communication.
- Receiving ethnic specific support may not always be the preference for FO patients and families

### What matters to patients - a patient centred analysis

The interviews were designed to provide patients and their families with the opportunity to tell their stories, describe their experiences in their own voice and raise unprompted issues and concerns.

Findings from the patient and family interviews fell within four broad themes:

- *Support networks*: family as the main support network and associated financial and time costs
- *Health and social needs*: contact with multiple health and social services, housing issues and knowledge of social assistance entitlements

- *Understanding and experience of health, illness and treatment:* beliefs and attitudes of health and illness, self management of health conditions
- *Understanding and experience of health services:* previous experiences of primary and secondary care services

## **Patient centred findings - a synthesis of interviews and literature**

The research process highlighted three areas of particular relevance to the FO programme:

### *The role of family as main carers and supporters*

While the support and care provided by participating families highlights the considerable strengths of these family units, providing this support has time and financial costs and can create stressful, conflicting demands on family members. These issues are compounded when, as was the case in several of the interviews, multiple family members suffer from serious health conditions. Family support commonly extends to providing language and translation assistance in health settings, problematic when family members acting as informal translators may not have a strong knowledge of health issues themselves.

### *Understanding and navigating complex health and social systems*

The multiple health and social needs experienced by families necessitate contact with a range of social and health organisations, each with specific systems to understand. Many of the interviews showed a critical lack of knowledge about how to access certain services or assistance. These findings mirror a growing body of literature, describing the challenges of navigating a complex and often fragmented bureaucracy, systems and processes, particularly when combined with financial and time constraints.

Low health literacy, low English proficiency and cultural barriers have been called the “triple threat” to effective health communication for vulnerable, ethnic minority groups with complex conditions. Better understanding the differences between these barriers to communication can help with tailoring appropriate responses. Participants frequently felt information was hard to access from health professionals, suggesting that communication breakdowns were occurring at key times of need.

### *The impact of health beliefs and attitudes and previous experiences of health services*

Previous experiences, both positive and negative, influence ongoing expectations of services. The vast majority of the positive comments about FO made by participants, emphasised communication and relational aspects of care. Relational qualities (understanding, caring, personability, culturally respect, sensitivity) have been found to be fundamental to patient navigator/advocate roles. These qualities facilitate trust and compliance, making the patient-navigator relationship a ‘medium through which navigator tasks are completed, rather than a self contained function.’

## **Conclusion and Recommendations**

The size and scope of the project limit comment about what can be attributed to the FO programme in terms of improvements to health outcomes or changes to care experiences since FO’s establishment. What is also clear, is that patient and family experiences of FO cannot be viewed in isolation from their specific personal and clinical circumstances and their experiences of broader health and social systems. For all of the participating patients and families, FO represented a fraction of a multiplicity of presentations to health and allied professionals, teams with multidisciplinary members and a plethora of community and primary health care activity that contributes to the care of their significant and complex health and social needs.

While ethnicity is recognised as a significant risk factor for health (independent of socioeconomic status, and other health risk and demographic variables), more in-depth understanding is required of how ethnicity impacts on health. This research contributes to emerging NZ studies identifying the need for more in-depth understanding of the

linguistic, cultural and migrant factors which health interventions may be designed to address. A key message from the existing literature and a central finding of this research, is that poor, vulnerable and ethnic minority populations, such as those represented in this study, require a different model of care offering enhanced chronic care and coordination services to adequately address their needs.

### **Recommendations**

- Better understanding the specific circumstances and needs of families to develop meaningful and coordinated responses to support:
  - their role as primary carers of a family member or family members with chronic health needs,
  - their knowledge, understanding and ability to access and navigate multiple services and systems at key points of need.
- Better understanding of, and tailoring of appropriate responses to, the low English proficiency, health literacy and cultural communication barriers facing Pacific patients with chronic conditions and their families.
- Better understanding of the health trajectories of migrants, including research and analysis using a life course perspective, that explores the impact on health of factors such as place of birth.
- Further consideration of the concept of 'partners in care' from a patient centred perspective and development of tools to support an improved partnership approach.
- Consideration of care models that incorporate palliative care approaches and support for some high needs patients.
- Exploration of FO advocate, patient and family perceptions of relational aspects of care in future evaluations. Examination of the perceived importance of relational qualities, how they impact the advocate-patient and family relationship and subsequently contribute to the aims of FO, to provide insight for the ongoing development of the FO advocate role and programme as a whole.

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# PART A

## 1. Introduction

Counties Manukau Health (CMH) is undertaking an internal evaluation of the Pacific Fanau Ola (FO) programme. As part of the evaluation, Pacific Perspectives Ltd (PPL) was commissioned to independently capture the experiences of Pacific patients and families who have used FO services.

The key question to be addressed was: **How do patients and families experience CMH FO services?** This question was explored through broad themes regarding the participant's personal circumstances and how they understood their health, illness and treatment, and more specifically through exploring the following experiences of participants of the FO services:

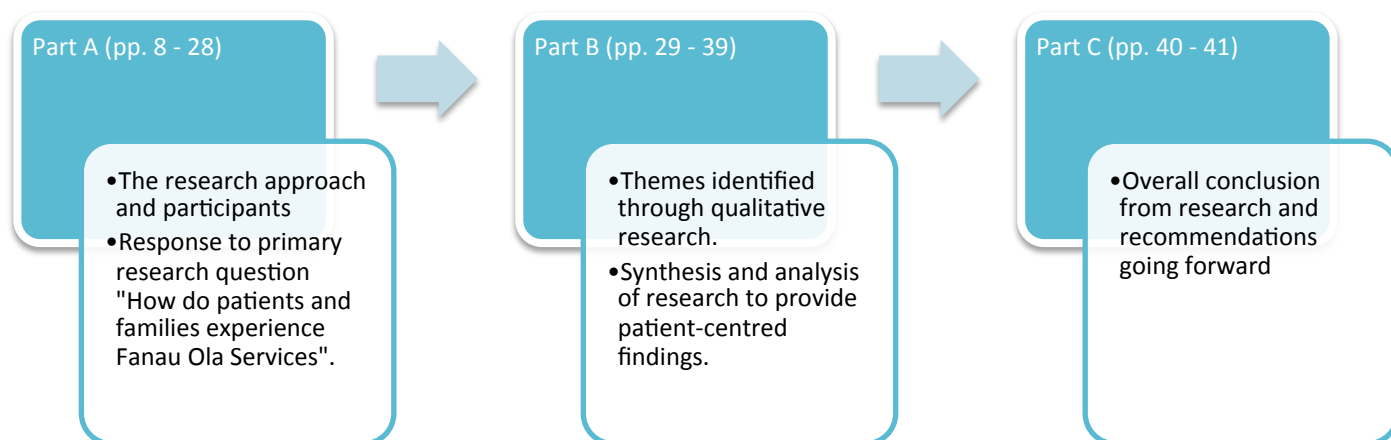
- participants' understanding of what the FO service was,
- contact participants had with the FO services (in hospital and after discharge),
- plans that are set and followed when participants are unwell, and
- the role of the FO champion and what that role is understood to be.

The evidence provided in this research report should be considered along with the findings of the Fanau Ola programme evaluation conducted by CMH, rather than a stand-alone critique of the Fanau Ola service. Patient and family experiences of FO cannot be viewed in isolation from their specific personal and clinical circumstances and their experience, so this report includes additional research to help build a broader evidence base of patient and family experiences that may be useful to build on over time for future evaluations by CMH.

This report is set out in three parts: A, B and C.

- Part A sets out the research methodology, builds a profile of the participants involved in the research and attempts to answer the research question posed.
- Part B is a patient-centred analysis that is provided with the view to helping CMH build an evidence base that will in time help to fully evaluate and build a FO service that is fit for purpose.
- Part C sets out high level recommendations for CMH to consider going forward.

Figure 1: The research report structure





## 2. Method

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This project was designed to capture the experiences of patients and their families of CMH Fanau Ola services and provide demographic, clinical and socioeconomic context for these findings.

### Study procedure

The number of interviews and the selection of patients for interview was determined by CMH as part of the overall plan for the evaluation of FO. The goal was to engage 10 patients for PPL to interview. All patients had received services from the FO team and the Pacific cultural support team (prior to 2012) and were representative of the FO patient mix in terms of ethnicity, gender and age.

CMH staff made the initial contact with all patients by phone to explain the project, and to seek their consent for participation and for passing on their personal information to the research team. PPL prepared an information sheet, a consent form and suggested dialogue for recruiters to use with potential participants. CMH were able to contact and gain consent of nine patients to participate in the research. Specific consent was sought from patients for researchers to access their clinical records.

Qualitative research methods using in-depth interviews with individual participants and/or including their families were chosen to capture the richness and depth of patient experience (Patton, 1990). Pacific cultural research methodologies using the process of talanoa (Southwick, 2012) provided the overarching framework for the research design. The talanoa is embedded in the context of ongoing relationships (or “va”) with communities, families and individuals.

Although a semi-structured interview schedule was developed to guide interviews, PPL’s approach was to facilitate a narrative or ‘story telling’ approach about **what mattered to the patient** (Appendix A). This enabled participants and their families to raise aspects of their experiences, that were important to them, in their own voice (Moekawa Barnes, 2000).

Each participant received a koha as recognition and reciprocity for their contribution of information to improving health services for the community.

The interviews were undertaken during December 2014 at a venue and in a language chosen by the participant. Interviews were undertaken face-to-face, in participant’s homes or at their local primary care providers’ facilities. Interviews were conducted in Cook Island Māori, Niuean, Tongan and English. Follow up interviews were conducted over the phone in April 2015. All interviews were recorded with a dictaphone, transcribed and where required, translated into English.

### Qualitative interview analysis

Analysis involved multiple readings of the transcribed interviews by two members of the research team. Data from each interview was sorted into key ideas and themes. Those common to all or several interviews were identified and presented as an overall thematic analysis.

### Discharge summary review

Hospital discharge summaries from the past two years for each participant were examined by the clinician/researchers in the team, to provide clinical context to the patient narratives. For each patient, analysis included the number and type of clinical conditions, current medications, and the reasons for hospital admissions over the previous two years. Each participant was assigned a Charlson Comorbidity score (see Appendix B) in an attempt to summarise their burden of disease (Charlson et al, 1987). The Charlson Comorbidity index is a weighted

scoring system that was developed in a cohort of general medical patients (Quan et al, 2011). It is the most extensively validated measure of the prognostic impact of chronic illnesses and it has been used more recently for predicting health care costs (Charlson et al, 2014).

### **Individual case studies**

Interview summaries for each participating patient have been presented in Part A of this report, together with a summary of their clinical history. We have retained the ethnicity of the patient in these case studies as the information is relevant to the issue of developing culturally appropriate services. Other aspects of the participants have been anonymised to reduce the risk of identification of the patients.

### **Documentary analysis and literature review**

CMH provided background documents about Fanau Ola (Appendix C). An iterative process of targeted review of the health services literature was conducted throughout the project. Relevant health services literature for Pacific people and similar migrant, minority populations with complex health and social needs due to multiple chronic conditions was reviewed and informs the discussion section in Part B.

### **Research team**

The PPL research team was led by Dr Debbie Ryan, who had overall responsibility for the research design and integrity of the data. Pacific researchers with appropriate health sector knowledge and experience were recruited to conduct the interviews. Two team members are also experienced medical practitioners.

For the interviews, a researcher information package was developed by PPL to provide background information and context about the project. All researchers were of the same major ethnicity as the families they were interviewing. Researchers were highly skilled in their specific Pacific language and culture and understood how to apply these skills in appropriate situations and according to the needs of each patient and family. Families had the opportunity to be interviewed in their Pacific language.

### **Ethics**

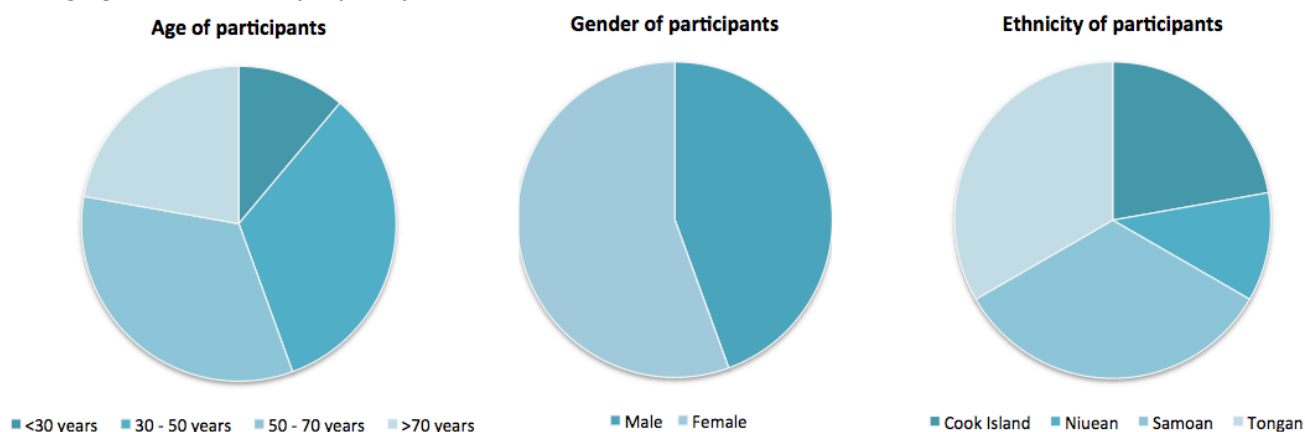
As the project is part of a programme evaluation for internal use by CMH at a senior management level, it fell outside the scope of ethical review and ethics approval was not sought. Measures were nonetheless taken to ensure the safe participation of patients and families and that culturally appropriate processes were employed. Particular care was taken to act consistently with National Ethics Approval Committee (NEAC) Guidelines (NEAC, 2012) and the Health Research Council (HRC) Pacific Guidelines (HRC, 2014).

We also asked two research leaders to review the final draft report to ensure patient confidentiality had been protected.

### 3. Participant characteristics

The age of the participants ranged from 27 years to 80 years, with an average age of 52 years. Five of the participants were female and four male. Four Pacific Island ethnicities were represented: Cook Island Māori (2), Niuean (1), Samoan (3) and Tongan (3) (figure 2 refers).

Figure 2: age, gender and ethnicity of participants



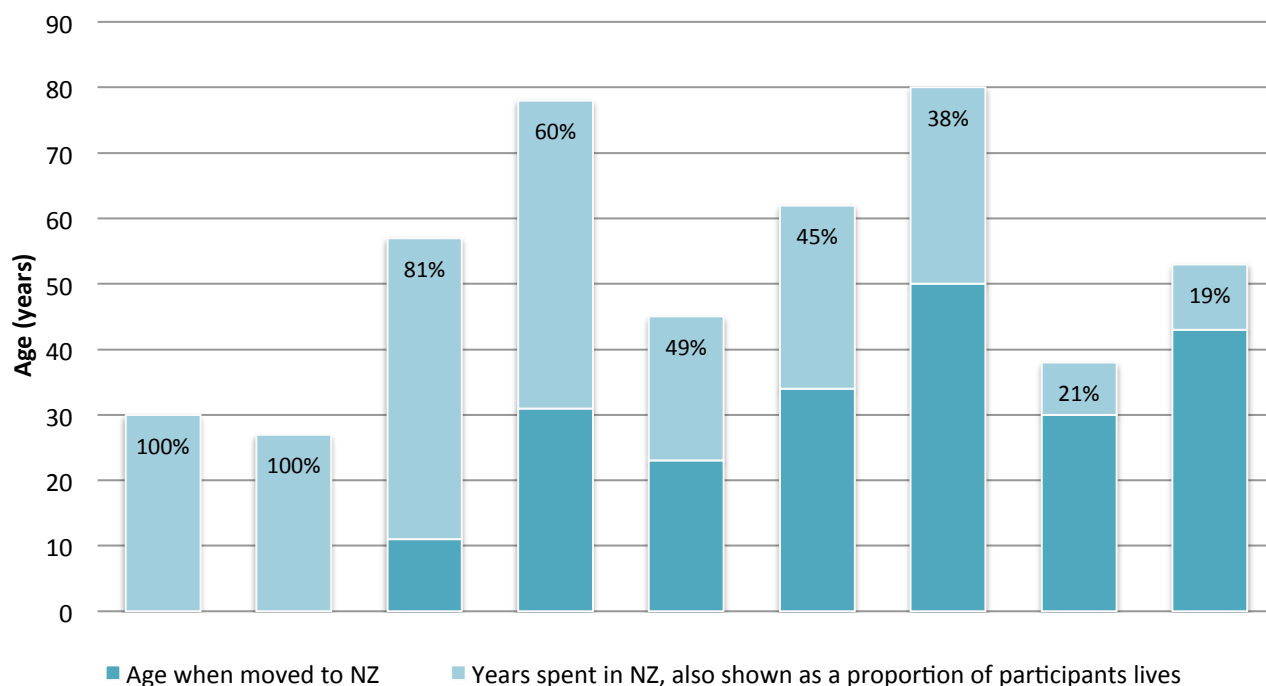
#### Personal circumstances

In some cases the participants were not the only family member to have complex health needs. Some of the patients and families were negatively affected by socio-economic issues relating to housing, income and employment, such as cold or inadequate housing and difficulty meeting expenses. They commonly experienced specific transport, connectivity, communication and health literacy needs that created significant barriers to accessing quality and timely health care.

#### Migrant population

Figure 3 shows the age of all participants and the percentage of time they have spent living in New Zealand. Two of the 9 participants were born in New Zealand. The other seven participants had migrated to New Zealand from the Pacific Islands. There are two recent migrants that have arrived in New Zealand in the last 10 years. 6 of the 7 migrants arrived in NZ when they were under 45 years old (ranging from 11 years to 43 years). The average age of those that migrated to New Zealand is now 59 years. Their average age at migration was 31 years old, meaning nearly half of their lives has been in NZ.

Figure 3: Column chart showing the age of participants, the age of migrants when they arrived in New Zealand and the percentage of their lives participants have lived in New Zealand.

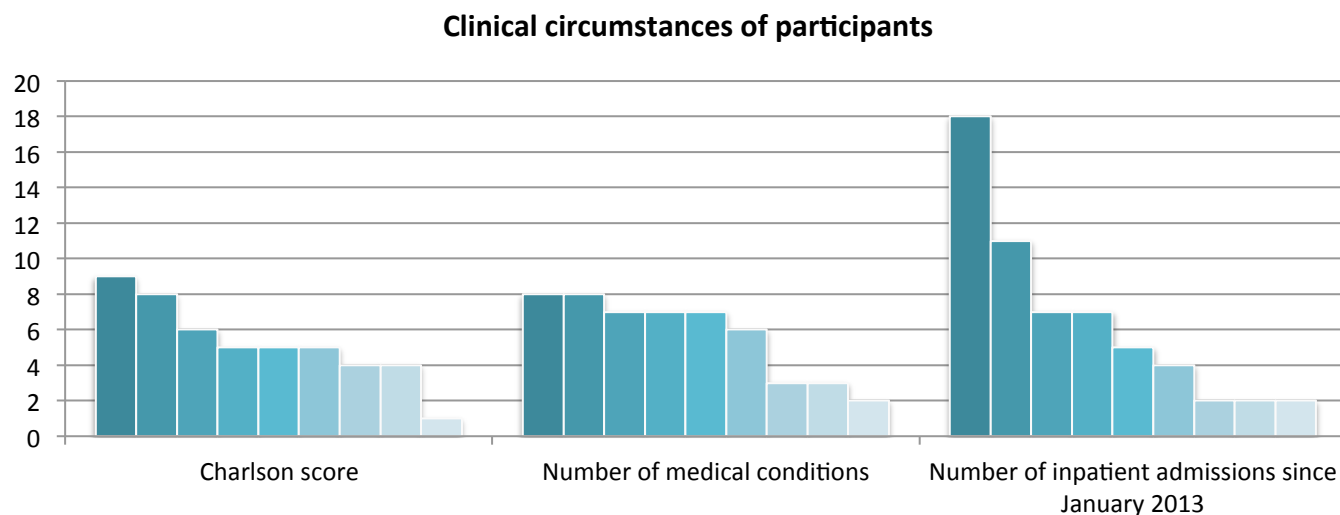


## Clinical circumstances

The participants all presented with multiple health conditions, including many chronic diseases such as type 2 diabetes, renal disease, chronic lung disease, gout and heart failure. In many cases, these conditions were long-standing and/or had rapidly resulted in a deterioration of health. Because of these multiple comorbidities, most participants were prescribed a large number (five or more, but frequently many more) of regular medications, and their management in hospital often involved engaging in a fine balancing act between normalising fluid status, controlling infection, monitoring blood glucose and carefully managing renal function. These participants were often known to more than one hospital service, frequently required input from a number of separate specialist services while inpatients, and discharged with outpatient follow-up.

Figure 4 shows the Charlson scores of participants which ranged from 9 down to 1 with a median score of 5. The number of medical conditions of participants (listed in their hospital discharge summaries) ranged from 8 to 2 with a median of 7. The number of inpatient admissions since January 2013 is also shown. Admissions range from 18 to 2 with an average of 6.4 admissions.

Figure 4: showing the Charlson score, number of medical conditions and number of inpatient admissions since January 2013 of participants.



\*The Charlson Comorbidity Index is a weighted scoring system that uses 19 categories of illness to summarise the burden of disease for a patient. It has been shown to be associated with a person’s risk of short-term and long-term mortality. A score of zero indicates no comorbidity, and higher scores indicate greater comorbidity, with scores of three or more generally thought to be “very severe” (Charlson et al, 1987).

## 4. Participant Case Studies

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Individual case studies of the participants are included in this section. A case study is made up of the information about the participant's personal circumstances, their clinical history (from the hospital discharge summaries) and a summary of their interview.

### Participant 1

*My wish is that all this pain and sickness will end and I can go back to being normal. I am getting older now...If it is God's will for me to be like this then who am I to question or try to stop his plan. However, I still hope that I can return to the time where I could do everything.*

#### Personal circumstances

Participant 1 is a female in her 60s who migrated to NZ over 20 years ago. She has four children and 20 grandchildren. Her children all attended school in New Zealand and are now working in NZ. [Pacific language] is her preferred language. Her grandchildren speak mainly English, but she encourages them to speak [Pacific language] at home.

For the past six years, she has lived in a Housing NZ home with 5 other family members. They moved into the house before she was diagnosed with her illness. Since becoming sick, she has lived downstairs and showered outside because she cannot climb the stairs to the bedrooms and main bathroom. She has contacted Housing NZ about this and is still waiting for response.

The family have a vehicle, home landline and internet access. She receives a WINZ benefit.

#### Clinical circumstances

Participant 1 has multiple severe chronic conditions, including chronic obstructive pulmonary disease (COPD, on 23-24 hours of home oxygen per day), congestive heart failure with severe pulmonary hypertension, type 2 diabetes, polyarticular gout (of which she has had multiple attacks), chronic renal impairment, obesity hypoventilation syndrome and cataracts. She also has a history of gastritis/peptic ulcer disease, keratitis and adrenal adenoma. Her Charlson Comorbidity Score is 8, indicating an extremely high degree of illness. Her most recent discharge summary lists 11 regular medications, two inhalers and home oxygen.

Since January 2013, participant 1 has been admitted to Middlemore Hospital as an inpatient seven times and been assessed, treated and discharged from the Emergency Department twice. The reasons for these admissions have included infective exacerbations of COPD (three times), worsening congestive heart failure (twice), flare-ups of gout (twice), diarrhoea (once) and nausea and vomiting (once). Three of these admissions have lasted five or more days, and the longest time period she has remained out of contact with acute services over the last two years has been seven months. She has been followed up in the rheumatology, respiratory and oxygen outpatient clinics.

#### Understanding of her health, illness and treatment

She was diagnosed with heart disease around eight years ago and in the last four years feels like she has gained a better understanding of her sickness.

She takes 14 tablets a day (before and after meals) for her heart, stomach and pain relief. She receives support and assistance from her family with transport, translations, medication to manage her illness.

*My daughter knows exactly how much medication I am taking*

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*My family supports me by taking me to the hospital and to see the family doctor. The medics explain my condition to my family and they tell me in my language.*

*When I feel sick and we have no petrol, we call the ambulance to come.*

The FO team, Super Clinic and [Pacific] primary health provider staff have explained the medications to her. She receives regular home visits from the Super Clinic and from [Pacific] primary health provider.

*I find the hospital very helpful to me. Not only that, but the Doctor from Super Clinic visits me every 2 weeks. He comes to check up on me and then follows up after that. I am very happy with my Doctor and I know him very well now.*

Language support, [Pacific] primary health provider was specifically mentioned, is a major help to her.

*I use the Hospital services which include the social worker there, Super clinic, [Pacific] primary health provider, and my own family doctor. I use [Pacific] primary health provider because I can understand what they are saying. Communication is a big part in why I use them.*

## Participant 2

*At this moment in time, I am 100% happy with my family's wellbeing. However, there's one thing I'm not entirely happy about and that is my health situation...my sickness is the only downfall in my life.*

### Personal Circumstances

The participant is a male in his 40s who migrated to NZ over 20 years ago. He met his wife, who had also immigrated from [Pacific Island], in NZ. He has four NZ born children - one high school student, one at intermediate and two at primary school. One child has epilepsy and needs to take medication daily. He speaks [Pacific language] at home with his wife and a mixture of [Pacific language] and English with his children.

His wife is working and he is unemployed due to sickness. He receives a WINZ benefit. He has lived in the same Housing NZ home for 7 years with his wife and children.

*...our biggest concern is the house during the winter. It gets very cold in this house for us...We have holes in the wall that have been there before we moved into the house. I did get in touch with [Housing NZ] regarding this issue and they said they were going to help make it better for us. But we haven't heard anything from them since.*

They have a family vehicle, home landline and internet. The family is financially strained.

*Financially, there are times when we struggle to make ends meet with all the bills to pay. My wife is our sole provider and whatever money we have, we try our best to work with it. My medical bills have been reviewed by WINZ and hopefully they grant me with assistance.*

### Clinical circumstances

Participant 2 is well known to haematology services at Middlemore Hospital. He was diagnosed with lymphoma in 2008, treated with chemotherapy and went into remission, only to relapse in 2010. He was then treated with chemotherapy and bone marrow transplant and again declared to be in remission. In 2012 he again relapsed and was commenced on both chemo- and radio-therapy. He is also under hepatology services due to chronic hepatitis B and for this he is on long-term medication for an indefinite period of time.

Participant 2 also has a history of benign biliary strictures and in March 2014 was admitted under general surgical services due to choledocholithiasis and an associated infection. At this time he was treated with intravenous fluids and antibiotics and underwent treatment for gallstones. The discharge summary at this time notes that he is booked for further surgical treatment, but there is no further paperwork from the hospital after this time.

### Understanding of his health, illness and treatment

He was diagnosed with cancer in 2008 and has undergone five major treatments since. He also takes medication for Hepatitis B once a day to manage and prevent other complications, including liver problems.

His health and the burden it places on the rest of his family is the greatest source of concern and worry for him.

*Overall if I were to rate out of 10 my current level of happiness in my life, I would say 7 because I'm not normal like before. Even though my health has improved over time, the doctors have told me that my condition is unpredictable...So right now I'm living on the edge. A lot of times I get paranoid because of this.*

He understands the things that he should do to manage his sickness, but some things - such as his housing situation - are challenging and difficult to control.



*...during the winter I have to take extra caution to keep warm, because if my body gets cold then I risk my life. I don't have a strong immune system to combat the cold...Or if a germ were to infect my body then my health would also be at risk...If I feel my body and health will be affected from something, I do my best to minimise it as soon as possible.*

He frequently uses ambulance services as a fast and convenient way to get to the hospital and to avoid queues and waiting times.

*The ambulance services are good. I use it a lot because it is fastest way to see the medical team at the hospital. If I were to go to the hospital in my own car, I would have to join the long waiting queue. The only problem is the cost of using it because of my financial situation. But when I can, I pay it off bit by bit...when it's urgent, I call the ambulance. Another reason I use the ambulance is so my wife can stay here and watch the kids. She can't take me to the hospital and leave our children here by themselves.*

*When the ambulance arrives at the hospital, the medics there are ready for me. They push me to the room and the nurses do their checkups on me until I see the doctor.*

He wanted to try traditional healing methods before chemotherapy.

*When I was diagnosed with cancer...I asked the doctor if he could put chemotherapy on hold for two or so months so I could try traditional healing methods. I wanted to see if there were other alternatives to cure my sickness. The doctor agreed and gave me 3 months to try [Pacific] traditional healing and if I had any problems then to return...I didn't get to the 3-month mark because I felt like I was going to die. So I went back to the doctor and asked if I could get chemo the next week and a few days later I was able to...it didn't work well for my body. But it was good to try anyways.*

He is happy with how hospital staff treat him and communicate with him. He can understand in English what they are trying to explain.

*The way they treat me is good overall and I feel welcomed using their services.*

*The doctors at the hospital are good. Sometimes they seem a little stressed because there are so many people there to see them but majority of their work is good.*

### Participant 3

*I don't like to think about my sickness because when I do, then I start to feel sick. I like to just enjoy my life without the worry.*

#### Personal circumstances

The participant is a female in her 50s who immigrated to NZ around 10 years ago. She and her husband have five children and three grandchildren.

[Pacific language] is the language spoken in the home, though the children and grandchildren also speak English. For the last two years she, her husband and their daughter, have rented a privately owned house for \$420 per week.

She and her husband receive benefits from WINZ and feel financially strained most of the time.

*We are just getting by with our benefit...when we get paid, our rent is deducted and we have \$200 left to budget for food, and other things. If we can't afford vegetables to eat then we will not buy it. Whatever we can afford is what we will get.*

They have a landline, but no internet connection. They do not have their own transport and rely on their children to provide transport for trips to the hospital and WINZ appointments.

#### Clinical circumstances

Participant 3 has had two inpatient admissions (both in April 2014) and five assessments in the emergency department in the last year. She has rheumatic heart disease (having previously had a valvular surgery in 1987) type 2 diabetes and paroxysmal atrial fibrillation (for which she is on warfarin). In 2004 she suffered a stroke. There are eight regular medications, as well as insulin, listed in her last discharge summary, including frusemide, suggesting that she has some degree of heart failure.

#### Understanding of her health, illness and treatment

Family members suffer from multiple chronic health conditions. The participant has had diabetes and heart problems for about 28 years, her husband has high blood pressure and diabetes, and one of her children has heart problems and asthma.

Her health and wellbeing is something that worries and burdens her.

*...At times I feel very weak and feel like I'm going to die...sometimes I don't know how to tell what is wrong with me...For example, I think there's something wrong with my heart, but then I find out later it's my diabetes. I feel worried with my health just in case something serious happens to me.*

She takes a large amount of medication each day and understands the importance of taking it correctly in order to manage her conditions.

*I take six pills in the morning and eight pills in the evening. It is blister packed ready for me to take. I take Warfarin to treat blood clots, and I take pills for my heart and also for high blood pressure...and Furosemide to prevent fluid build up around the heart. And I get insulin injections and take pills for my diabetes. I also get an injection for my heart once every month.*

She will use an ambulance to go to the hospital when she is in extreme pain, about four times a year. She would use it more often if it wasn't for the cost (\$77).

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*Sometimes we are behind in our ambulance bill and get a penalty fee on top of that. We think to ourselves that the money we use to pay the ambulance can be used elsewhere...for us to buy toilet paper, so we use the ambulance service wisely.*

However, as she explains, not using the ambulance service has costs for the family as a whole.

*Our children have to sacrifice their work time to take us to the hospital instead.*

She uses [Pacific primary care provider] services, particularly for language and communication reasons. Each year during the NZ winter she visits [Pacific island] and will take [Pacific] herbal medication.

## Participant 4

*It is better to ask the patient what they need before they are discharged from hospital before they go home. Provide appropriate information about what services are available. What help's available to help the patient when they are discharge from hospital to maintain good health. (Participant's family member)*

### Personal circumstances

The participant is a female in her 70s who immigrated to NZ over 40 years ago as an adult. [Pacific language] is her first language.

She rents a three bedroom house with two family members for \$480 per week. They have a family car, home landline and internet. She receives a pension from WINZ. It is sometimes a struggle to meet the rent and other costs.

Her niece is her main support, particularly as she is becoming less mobile.

*I rely on my niece 24hrs a day.*

*...before [I was able to] normally travel by bus to the GP. Now because the problem with my leg (she uses the walking stick but walk very slowly), I am no longer able to catch the bus.*

*I got [the participant] an alert alarm device. I did it myself. The plan is if I'm out of the house and if [the participant] feels sick, all she has to do is to press the alarm and help will come. (Niece)*

### Clinical circumstances

Discharge summaries from Middlemore Hospital for participant 4 were supplied for the year 2013. In 2014 she moved to another DHB catchment area and was seen in the renal, infectious diseases and diabetes outpatient clinics. In December 2014, she moved back into the Counties Manukau DHB region. She has had type 2 diabetes for 32 years, complicated by kidney disease, mild neuropathy and peripheral vascular disease (she had a toe amputated in 1998). She also has chronic thyroid disease (on thyroxine replacement), osteoarthritis, chronic gastritis and a precancerous skin condition. In September 2013 she was admitted to Middlemore Hospital for treatment of a compound fracture of her hand. According to her last clinic letter February 2015, she is currently on six regular medications, as well as insulin.

### Understanding of her health, illness and treatment

She has had multiple health problems - diabetes, high blood pressure, liver disease, kidney failure, sore legs/bones - for about 33 years. Last year she was admitted five times to Middlemore Hospital for stays of about three to seven days.

She needs family and other support to understand medication and treatment. She is very satisfied with her GP because of the treatment and the clear communication she receives.

*I need an interpreter at the hospital because I can't speak English. [The hospital] provided me with a [Pacific language] interpreter.*

*I can sometimes understand what the person is saying but I need an interpreter. The [Pacific] family doctor is so good. He takes the time to explain things properly to make sure that [she and her niece] understand...His approach is so good, I feel comfortable to talk to him and my niece...He does not rush but takes the time to listen.*

She finds the waiting times very long at the hospital. She and her niece were also not impressed with other aspects of service.

*The hospital is okay but the waiting sometime is not good and so as the family doctor. Waiting time can be up to two hours.*

*I find Middlemore hospital service is not good. Did not get any help offered or support to know what is out in the community to meet the need of [the participant]. Coordination service is very poor...no social support. (Niece)*

She and her niece are proactive about looking for appropriate assistance

*I know about respite service from another [Pacific] woman...I have to look for help myself to get resources for [the participant]. I do not know what is available. There is a real need for a better coordination services, appropriate information, nappies, and resources..."Real slack", helping older people understand what they are entitled to...Services need to meet with the family to explain what is available...My experience if the old person don't understand [hospital staff] just leave them there. I found hospital doctors is very poor, poor communication to explain and inform us. Like when mum was admitted there was no follow up afterwards, no discharge plan given to us. I know because I have to do it myself. The health service don't offer anything apart from being in hospital and medicine. (Niece)*

## Participant 5

*When I'm sick, I'm sick no one tells me what to do - I'll get up when I'm ready...even though the right thing is to get attended to before you feel that bad or sometimes I just let it go and think it will go away, it'll get better, next thing I know I'm worse.*

### Personal circumstances

The participant is a male in his 20s. He is the second eldest of 5 children. He lives with his grandmother.

*...the house we are living at with grandma now its not a living environment...its too small, its not an easy place to live in...my nana says it will do because she has to get a place quick. If me and my nana were able to move into a nice flat, decent liveable that would help my health a lot I reckon.*

His grandmother and mother are his main supports. His family are an important part of his life.

*My great grandmother is my hero...she's 97 she's still strong, she doesn't need a walking stick, still goes to the casino, still strong as ever man, still got her own teeth, still hanging out her own washing...every now and again I go and see my nana just to let her know and give her some love...before when I'm that sick I don't want to live...that's how bad I feel, I just think of my nana, she's my strength.*

Culture and language are also important to him, even though he doesn't speak [Pacific language].

*I wish I knew the language use it, but in saying that its never too late, my culture plays a big part means more, its way up there, of course.*

### Clinical circumstances

Since July 2013, participant 5 has had 18 inpatient admissions to Middlemore Hospital, half of which were more than seven days in duration. In 2010 he developed endocarditis and subsequently developed severe heart failure, which is poorly controlled, as evidenced by 10 admissions between July 2013 and February 2015 for worsening heart failure. During these admissions, he was so fluid overloaded that losses of 10-20kg of weight over a period of 5-10 days were frequently recorded, and he was reviewed by the intensive care team on at least one occasion. At that time, ICU offered to support the patient's cardiac system if required.

Over the last two years he has also had frequent flare-ups of gout, asthma and eczema, necessitating multiple reviews from services including orthopaedics, dermatology and infectious diseases. In June, September and November 2014 he was admitted with severely infected eczema which required six weeks of intravenous antibiotic treatment each time. He was not considered eligible for home intravenous therapy, and instead discharged to a private hospital to finish treatment. His last discharge summary (dated February 2015) stated that he had been reviewed by NASC services, who had arranged permanent placement at this private hospital.

Participant 5 also has a history of type 2 diabetes (treated with oral medications) and congestive hepatopathy. He is listed as being on 11 regular medications, three topical eczema treatments and two inhalers.

### Understanding of his health, illness and treatment

He has a heart condition and type 2 diabetes. He feels as though he doesn't manage his health very well, particularly in terms of eating healthily.

*...could be better then, if I was up to it I wouldn't be back at the hospital all the time.*

*...being [Pacific] we love island food, we have not so good food which tends to not be the best for us but its the most tasty to us.*

He has developed a care plan with his FO advocate/social worker, but his commitment to managing his conditions is inconsistent.

*I can't exactly remember every single goal but well most probably, if I come up with them they either achievable or something I need to do.*

*I could also say that even the doctors wouldn't fully know [how to manage his conditions], no one fully knows everything eh, I know good enough to know what my condition, do's and don'ts how to keep it under control blah blah blah.*

He has placed other things, such as study or further training of some kind, on hold until his health is under control.

*I think most important is getting my health under control more than anything else, what I've gotten on to like a routine I've stayed out of hospital for a year, oh yep my starting to get on top of my medicines better, then I might think of some part time courses then, in the meantime remembering to take [medication] is the main thing on my mind to keep me alive, eating habits, all that stuff, yeah.*

## Participant 6

### Personal circumstances

The participant is a female in her 50s, who immigrated to NZ with her family at the age of 11 years. She speaks fluent [Pacific language] and English.

Her husband and her sister are her main supports.

*[my husband] is my main supporter he is the one that always takes me to the hospital and always be there as well as my family.*

*My husband bought a heat pump to make the house warm because he thought I needed it because of my migraine...he try to improve everything for the health.*

She also has a supportive and understanding employer.

*My job has been really good, they are really understanding...I've been in the hospital for the first time for 7 days and they were so good, they told me to take a couple of weeks off. Then when I went back to work they told me to work 3 days and 2 days off in between and that's every week until I [recovered]...*

She has contact with extended family and community and participates in cultural activities, but does not go to church.

### Clinical circumstances

Participant 6 is well known to the neurology team, having suffered from recurrent prolonged migraines for a number of years. These migraines have resulted in many presentations to hospital: four in 2010, six in 2011, five in 2012, five in 2013 and six in 2014, including four admissions that year lasting three or more days. Her migraines have been intractable to usual medication, and the associated vomiting is often so severe that treatment with intravenous fluids is necessary. During one hospital admission, she suffered a Mallory Weiss tear due to repeated vomiting. Related to this, she also has a history of reflux oesophagitis, duodenitis and gastric ulcer disease, and is on regular medication for this.

### Understanding of her health, illness and treatment

She suffers from frequent migraines and nausea that require her to take medication and oftentimes be admitted to hospital. She doesn't know for certain what causes the migraines.

*...[the migraines] come on with no reason, don't know what brings it on, could be many different things, sometimes it could be the food, could be going outside in the sun sometimes.*

She takes a lot of medication. It has been well explained to her by doctors at the hospital, but she is frustrated by the lack of improvement to her condition. She believes the hospital has not done enough to find out the cause of the migraines.

*...the hospital always say you've been here how many times a year and for them not to investigate deeper to actually find out and for them just to give me tablet all the time and to say take this, take that and they keep changing tablets all the time to see whether this will change anything [and] they keep increasing the dose. I think that's wrong...if they increase it more it shouldn't happen all the time.*



## Participant 7

### Personal circumstances

The participant is a female in her 30s, who immigrated to NZ eight years ago. She is unemployed and under some financial strain. However her family and extended family provide a lot of support, including transport to appointments.

*On the financial basis we are very good at budgeting. I do a lot of budgeting and when I get sick my mum helps me a lot and my sister also comes in and helps me, the family gathers around me and helps me out.*

As she has become less mobile, the bathroom has become an issue in her house.

*The only thing I find hard at home is our shower, because its over a bath and I find it really hard to get under the shower...the biggest support that would help me if we had a new shower put in, a shower that I could get into easily because when my legs get really sore I can't climb over the bath.*

### Clinical circumstances

Participant 7 has been admitted twice under general surgical services in the past two years with severe right leg cellulitis and sepsis. With a BMI of 78, her discharge summaries state that she is able to mobilise within her house only and needs assistance to wash and dress. She has severe obstructive sleep apnea, type 2 diabetes, gout and hypertension. During an admission in April 2013, she was reviewed by the intensive care team, but deemed not to be an ICU or surgical candidate due to her comorbidities. In February 2014, during an admission for cellulitis, she was admitted to the high dependency unit after failing to respond to intravenous fluid resuscitation. According to medical notes, she has received outpatient follow-up from the diabetes and infectious diseases teams, as well as the community dietician. She is listed as being on six regular medications for diabetes, gout and hypertension.

### Understanding of her health, illness and treatment

She likes her GP, who she sees at least every three months for repeat medication. However, she will go straight to hospital when she feels really bad.

Medication is explained well by her GP. If she gets new medication from the hospital, she takes it to her GP to explain.

She sleeps with two machines to aid her breathing.

## Participants 8

*I honestly believe its because I look for alternative treatment that I'm still alive today and also through praying. I don't always depend on the doctor's pills don't work, I believe they may work for a short while and then stops working, I think because I've had numerous operations, that's also has helped me stay alive, never cured just some relief.*

### Personal circumstances

The participants are a married couple, who immigrated together to NZ 50 years ago.

The husband, in his 80s, can speak English, but the wife not so well. For communication and translations, she is helped out by her husband and children.

*...sometimes the issue is around the language...Papa understands English so he helps out with the translation. Sometimes our daughter helps out, even our son in law. I always want to understand what's wrong with me so I ask the doctor and my family whoever is with me will translate.*

They have both been very involved in community activities throughout the years and now receive a lot of support and help from [Pacific] communities and churches.

*...we are still able to see the benefits of the help we have given our communities and churches...we get different help from different churches and communities. If there is a function they always remember us they always bring us food and they visit us...*

### Clinical circumstances

Discharge summaries were received for the husband only. He has had two admissions in the past two years: one for exacerbations of asthma and congestive heart failure, and the other for a lower respiratory tract infection. He suffers from heart failure, chronic obstructive pulmonary disease, obstructive sleep apnea, peripheral vascular disease, type 2 diabetes, gout and gastroesophageal reflux disease. He has previously had a total knee joint replacement. He is on seven regular medications and two inhalers, and has a total Charlson comorbidity score of six, which indicates a very high degree of comorbidity.

### Understanding of their health, illnesses and treatment

They suffer from multiple illnesses - cancer, leukaemia, gallstones, asthma and hernia - and are frequently admitted to hospital. The wife has had many operations for cancer and hernia.

They are open to trying and using a range of different alternative treatments, alongside conventional medicine.

*[Pacific] medicine or our potions from different people and places like Tahiti, Australia all over the place. Every time someone says this potion or medicine will help, we will try it, we do all this in combination with the doctor's medication and treatment. When the doctor asks are you feeling better? I don't know what's making me feel better so I just say yes.*

*From what I know some medicine works for certain ailments, we are always looking for alternative treatment for cancer. For 10 years I looked for our traditional medicine, [Pacific] medicine, I thought about our old people and how they treated cancer, not sure if our old people knew about cancer, I'm always looking for new treatment.*

*...if someone tells of a new medicine or treatment we buy the medicine or we try it out, we are always up to try anything...*

## Participant 9

*I just had to say to myself I can do it, have faith, no one else is going to take care of the medicine just you, that was my motto, live life for the kids and partner.*

### Personal circumstances

The participant is a male in his 30s. He is married and has two children. His partner is his main support person in relation to his health.

*...she pushes me and encourages me and sets me on the right pathway so I can be here for my kids and her.*

He has a family car and can transport himself to appointments and meetings. He receives WINZ support, but feels ongoing financial pressure.

### Clinical circumstances

Participant 9 has had 11 inpatient admissions since June 2013 under general medical, general surgical and orthopaedic services. He suffers from polyarticular gout, type 2 diabetes and chronic renal impairment, but most of his admissions have been due to recurrent soft tissue infections, including superficial abscesses in his knee, scalp, chest wall and face.

In August 2014 he was admitted with an infection, which necessitated prolonged treatment with intravenous vancomycin. He was discharged on this treatment, but unfortunately developed antibiotic toxicity and was readmitted shortly after with nausea, vomiting and a probable Mallory Weiss tear. The discharge summary also notes an acute kidney injury from vancomycin at this time.

He also has a history of long-standing diarrhoea (of more than three years duration) and lower gastrointestinal bleeding, the cause of which is not clear. In November 2014 he was admitted with an anal fissure. In December 2014, during an admission for a facial abscess, participant 9's haemoglobin was noted to have dropped from 143 to 72, and he was given a blood transfusion. Further investigations are planned to instigate the dramatic drop in haemoglobin, the surgeons organised for an outpatient colonoscopy, which they have said they will review in clinic.

He is on insulin for diabetes and allopurinol for gout. A discharge summary in May 2014 noted that he had been seen by the liaison psychiatry team and started on medication, but no further details were given and subsequent discharge summaries do not list this as a regular medication.

### Understanding of his health, illness and treatment

He has been a diabetic for the last ten years and suffers from gout regularly. He feels like he doesn't manage his illnesses very well and during the past year has been in and out of hospital.

He had a previous bad experience with his medication. Although a pharmacist came to the ward to discuss medication, he doesn't understand what he has been prescribed.

*Not too sure what they are giving me when I'm in pain because I tend to vomit and get nausea, then I ask them if the pills are too strong and sometimes the doctors don't tell me.*

*I'm a person that doesn't like to take medicine, [but] I guess there's more important things in life just not about myself, the only reason why I do it is for my kids.*

*I didn't take any of my meds I've only just started doing it last year and this year and its been a big improvement.*

## 5. Experiences of Fanau Ola

The primary research question to be addressed was: **How do patients and families experience CMH FO services?**

The size and scope of the project limit detailed comment of what can be attributed to the FO programme in terms of improvements to health outcomes or changes to care experiences since FO's establishment. However, the research found:

- Many participants described positive experiences of FO staff.
- Initial interviews suggested that many participants were not clear about what FO was. Many others lacked an awareness of the FO service.
- Follow up interviews, referring to a FO advocate by name, showed an increased recollection, awareness and demonstrated understanding of the FO programme.
- Understanding of the FO Champion role varied amongst participants.
- Suggested improvements of the FO service centred on improving communication.
- Receiving ethnic specific support may not always be the preference for FO patients and families.

Most patients and families recalled meeting with a Fanau Ola worker while in hospital and after discharge, however many did not fully understand what the role of a FO champion was.

**Table 1: Participants recollection of meeting with FO workers and the role of the FO champion.**

In Hospital	After Discharge	FO Champion
Recalls meeting a FO worker in the hospital	Was contacted by FO worker after discharge	Knows who the FO champion is and understands their role
7 out of 9	7 out of 9	2 out of 9

### Understanding and experience of Fanau Ola services

#### Fanau Ola positives

There were many comments made about positive experiences with FO staff. Participants spoke about communication and language assistance, being listened to, receiving explanations about treatment and medication provided, and the relationships, trust and connections they and other family members were able to develop with FO advocates.

*I am very happy with the Fanau Ola services especially because they can speak to me in my language and I am able to understand them.*

*There is definitely a difference with the Fanau Ola service. I am very satisfied when they explain to me what is going on with my health and it makes me happy that I can understand. They are very helpful in explaining to me what my medication is and how often I am supposed to take them.*

*It is like I have known him for a long time. He's open with me when we talk and tells me why he is there. He also told me to feel free to ask him any questions I have or wants I may have. We speak to each other in the [Pacific language].*

*FO help me, they always encourage me to look after myself and health. They make sure I am ok and offer help when I want. I feel that I am satisfied with them as they help me very much to understand my health.*

*I was very happy about it. I don't understand what the doctor is saying in English, so it's good to have help from someone who can speak [Pacific language] to help explain to you what is going on. (Husband of participant)*

*[The FO advocate] helped me best...like finding easier ways [to] remember to take medicine maybe have signs up on the fridge, little reminders that I found helpful for a while.*

*They come in and check on how am I doing. If I need any help with anything else, they would always be there if I needed anything.*

*Me and [FO advocate] spoke in English at first, then in our native tongue. He talked about help that was available for me to use and was interested to know why I was in hospital. He asked questions about housing conditions. I told him it wasn't so much the environment or the place I was living in, I've struggled with my health ever since I was little and they couldn't find out what happened to me. He asked about the foods I was eating and stuff like that. (Response from follow up interview)*

Furthermore, some participants spoke about specific instances of receiving support from their FO advocate, that had helped them both in and out of hospital. These included arranging nurse visits to the home, development of care plans, liaison with medical staff on the participant's behalf and contacting social workers.

*...they did say if the house is cold they can easily look into if we are qualified for any heating with putting up applying for insulation and all that...We didn't even know what you could ask for and any of the stuff.*

*[FO advocate] was really good...listens to patients, follows up to what is happening and pushes nurses or doctors towards what I needed to know and get more information.*

*[FO advocate] went the extra mile to see social workers about my benefit and staff and to see the pharmacist were keeping track of my kidneys if the medication I was taking was right for myself.*

*I needed a lot of help when I came home and there were some times when I just couldn't go to the doctors because I was too sore, so [FO advocate] had a nurse staff sent out and she still sees me when I'm sick.*

*...when I come home I tend to do things my own way...instead of bringing my own medication in the bottles [FO advocate] went out of his way and made blister packs to make it easier for me.*

## **Awareness and understanding of Fanau Ola**

Initial interviews suggested that many participants were not clear about what FO was and there was sometimes a mismatch between FO processes as described by staff and the participant experiences. Many participants seemed not to realise that they had agreed to be part of the programme or had a FO advocate. Some participants were uncertain whether they had seen a FO advocate or a social worker.

This could be explained by the fact that participants are usually very sick when they are admitted to hospital and not fully aware of what is happening around them. Family members are not always present when FO advocates make ward visits and do not get to meet them. In addition, participants and families are in contact with many different people as a result of their conditions and simply do not understand what each person's function is.

In a number of follow up interviews, conducted to investigate these responses further, the name of the relevant FO advocate was provided to participants. Follow up interviews and referring to the FO advocate by name showed that,

although still slightly varied, there was an increased recollection, awareness and demonstrated understanding of the FO programme.

*I remember someone who came but I'm not sure if that's who you're talking about. They came and explained to me about their service but they never really asked any questions.*

*...to be honest I don't know how extra they could've helped, I had all the nurses and doctors to help...the people that know me best the nurses that could help me the best.*

*...in hospital there are so many different faces, people I don't even know, people I've never seen before, they come in and say hello I'm blah blah, you can't expect me to remember every tom dick and harry that comes in.*

[Response from the same participant in follow up interview] *If it's the same [person] you're talking about, she did an interview kind of thing...She just asked general questions, like do I need help, everything, stuff like that. She spoke to me in English.*

*...they came [to the hospital] and said how are you and then they left, no one actually did any explanation around who they are if they are Fanau Ola or not.*

*She was talking about health and everything to do with getting help when you go to the hospital. She was useful because she spoke in [Pacific language] and my Auntie was able to speak to her about wanting help. She answered all our questions to help us.* [Response in follow up interview after initial unawareness of FO]

In addition, some of the participants who were unaware of FO, nonetheless liked the concept of the service. The availability of language support when family members were not present in hospital and the translation of medical information to a Pacific language, were specifically mentioned.

*I personally would prefer to have a nurse or person [of the same ethnicity] to look after my Mum when we cannot be at the hospital due to work commitments...now that I know [about FO], I would really want to use that service for our Mother. A lot of times we want some help but we don't know about it. There are times when the doctor tells us we can't go into the operation with our Mum so we wish there was a translator there to explain to her what is going on. (Family member)*

*It's ok for us when the doctor explains to us in English about what is going on with my Mum, but when it's time to explain it to her in [her first language] in a way that she can understand, it is difficult. It's better to have a...person translate for my Mum so she can tell them exactly what she is feeling and they can then communicate it to the Doctor. (Family member)*

*I now think with Fanau Ola's help we may not need to be admitted so often. We do get support at home from the Pacific Home Care Service...Fanau Ola will help us understand why we get admitted and why we get admitted so frequently.*

Understanding of the FO Champion role varied amongst participants.

*Whenever [I get sick] then [the FO Champion] is always there to help and put me first before his own stuff and all that. He gladly gives up his stuff to be there and goes the distance and all that. He's always in the hospital with me. When the doctor told me go home I was still throwing up and stuff, but my husband turned*

*around and told them that they might as well dig a hole for me, because I was unwell. So they let me stay in the hospital. [Follow up interview]*

*My understanding is that when I go to the hospital and the hospital needs to come and see you at home...It's like helping or when you go to the hospital for a visit and you're discharged, you make sure things are up to date or something like that for when they come and see you at home. [Follow up interview]*

### **Suggested improvements**

The home visits and support offered by FO were rated less favourably by some participants. In one case, this was from a participant who had felt very positive about support provided in hospital.

*He wanted me to fill out some forms. He said he was going to come over to talk with my wife and me, but he didn't come by...if he was to contact me and couldn't reach me, I would like it if he kept trying to get hold of me...if he came and I wasn't home, but he should call me to tell me if he came so we could reschedule another visit for him to come see me. Also, it would be nice for him to set a time for him to come see me so I know when to expect him. So right now, the agreement we had to fill forms to help me and wife is on hold.*

*It was never explained to me what Fanau Ola is...the lady that came to see me didn't actually explain, she came and she said she will come back and see me but she never came back...Because it wasn't explained to me I don't really understand and I don't know if I have a Fanau Ola advocate. I do remember she came to our house and brought a couple of papers and she said I had to sign them. I read the paper and it said it was saying what help do I need in the home...I needed the shower to be fixed so I could get into it, that was a long time ago and I never heard back.*

One participant suggested other process improvements.

*It is better to ask the patient what they need before they are discharged from hospital before they go home. Provide appropriate information about what services are available. What help available to help the patient when they are discharge from hospital to maintain good health. (Family member)*

Receiving ethnic specific support may not always be the preference for FO patients and families.

*...there are [people] who don't feel comfortable with other [people of the same ethnicity] helping them out...So I really think that...you need to ask if they want [someone of that ethnicity] to help them, especially in terms of Fanau Ola, or would they prefer someone from another ethnic group to help them. I think that is one of the reasons why we don't...access Fanau Ola because we don't want a [specific ethnicity] Fanau Ola worker.*

### **Advocating on behalf of patients in a hospital setting**

Some participants wanted their FO to talk to hospital staff about their treatment or medication. A range of factors, such workplace dynamics, staff seniority and capacity of FO team members, may limit FO ability to do this effectively.

*...they should be able to say I think you should be able to do more for her to investigate more because it's happening all the time because she's coming to the hospital often and yet you are increasing her tablets all the time and it's not doing her any favours because if you increase her tablets all the time then her migraine cease, should be less.*

## PART B

### 6. What matters to the patients

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#### Key themes

The interviews aimed to provide an increased understanding and insight into the care experiences and patient journeys of people with multiple presentations to secondary care. The interviews were designed to allow the patients and their families to discuss the issues that “mattered to them”. Rich information was collected by providing patients with the opportunity to tell their stories and describe their experiences in their own voice and raise unprompted issues and concerns.

#### Capturing Patient Experience

The Health Quality and Safety Commission (NZHQSC) have identified patient experience as a priority for health quality improvement. The focus on patient and family experiences reflects an increasing recognition, in NZ and internationally, of the central role of patient voices and stories in the design and delivery of informed and compassionate health services. (Robert G et al, 2011).

Proponents of experienced based approaches have argued that patients and families, when recounting their interactions with the health system, will focus on the emotional responses or experiential factors (eg, trust, respect, support and empathy) that marked their care journey (Baxter, H et al, 2009). Experiences can provide a valuable insight into the expectations and motivations of patients and families. Using patient and family experience as a basis for service design and improvement recognises that, even though they may not always correlate with clinical priorities, experiential factors can have a significant impact on the quality of care received (Parsons S et al, 2010).

This is even more important for populations like Pacific with high health and social needs. The voice of Pacific patients and families, experts in their own use and experience of health services, has been a largely untapped resource in the health sector. Very little is known about the underlying beliefs, values and other factors that impact Pacific people’s choice and behaviours in seeking care; or effective methods for engaging Pacific patients and their families as partners in healthcare. In order to develop better strategies for Pacific populations, more research needs to be undertaken to determine baseline levels of knowledge that exist in these communities (Southwick M et al, 2012). For regions with significant Pacific populations in particular, creating a place for Pacific patients and families in evaluation, design and improvement processes may help ensure that services better reflect and respond to their needs.

As a methodological approach for research, the capturing of patient and family experiences through unstructured interviews, narratives and storytelling, aligns with Pacific cultural methodologies and frameworks, such as Talatalaga A Aiga (talking with families) and talanoa (telling stories without concealment), that promote the open discussion of participants’ stories and experiences. Southwick et al (2012) describe the use of life-stories or narratives as a way of understanding how individuals and communities make sense of their world. They enable cultural communities to maintain the essence of their stories and traditions and apply them to modern contexts. Used in this way, narratives allow the flexibility to respond to the preferences of diverse Pacific groups.



**Table 2: Summary of common themes identified from analysis of individual participant and family interviews**

Theme	Subtheme
Support networks	<ul style="list-style-type: none"> <li>Participants identify family members as their main source of support.</li> <li>Providing support places financial and time costs on families.</li> <li>Other support networks include workplaces, community groups and churches.</li> </ul>
Health and Social Needs	<ul style="list-style-type: none"> <li>Many participants are in frequent contact with multiple health and social services.</li> <li>Crowding and quality issues are common with rental properties.</li> <li>Participants often lack of knowledge in regards to social assistance entitlements.</li> <li>Many participants receive financial support from WINZ and experience constant financial pressure regarding living and medical expenses.</li> </ul>
Understanding of health, illness and treatment	<ul style="list-style-type: none"> <li>Many feel overwhelmed and burdened by their health conditions.</li> <li>Participants felt that managing their health condition was a challenge.</li> <li>Care plan development and implementation varied amongst participants.</li> <li>Ambulance services were often used to get to hospital.</li> <li>Use of traditional medicines was seen as beneficial by some.</li> </ul>
Understanding and experience of health services	<ul style="list-style-type: none"> <li>Primary care providers were generally viewed positively.</li> <li>Many participants described past negative hospital experiences.</li> </ul>

### Support networks

All participants identified family members as their main source of support for managing their health conditions. Spouses, children, grandchildren, nieces and nephews provided help with transport, language and translations, medication, cooking and shopping. Most participants were very reliant on this support and could not manage without it.

*My family supports me by taking me to the hospital and to see the family doctor. The medics explain my condition to my family and they tell me in my language.*

*[My husband] is my main supporter. He is the one that always takes me to the hospital and always be there as well as my family.*

*Papa understands English so he helps out with the translation. Sometimes our daughter helps out, even our son-in-law. I always want to understand what's wrong with me, so I ask the doctor and my family whoever is with me will translate.*

*...[my partner] pushes me and encourages me and sets me on the right pathway so I can be here for my kids and her.*

Participants understood that providing this support placed financial and time costs on family members.

Other support networks included workplaces, community groups and churches.

*My job has been really good, they are really understanding...I've been in the hospital for the first time for 7 days and they were so good, they told me to take a couple of weeks off. Then when I went back to work they told me to work 3 days and 2 days off in between and that's every week until I [recovered].*

*...we get different help from different churches and communities. If there is a function they always remember us they always bring us food and they visit us...*

### Health and social needs

Many participants have contact with multiple health and social services on a regular basis, such as their primary health care provider (often a Pacific provider), hospital services, Housing NZ and Work and Income NZ (WINZ).

Most participants rent their homes. Some felt that crowding and quality issues with their rental properties were impacting negatively on their health or a family member's health.

*...the house we are living at with grandma now it's not a living environment...it's too small, it's not an easy place to live in...my nana says it will do because she has to get a place quick. If me and my nana were able to move into a nice flat, decent liveable that would help my health a lot I reckon.*

*The only thing I find hard at home is our shower, because it's over a bath...the biggest support that would help me if we had a new shower put in, a shower that I could get into easily because when my legs get really sore I can't climb over the bath.*

Many participants and families, living either in Housing NZ or privately rented dwellings, were waiting for a response from their landlord after making complaints or requesting help about a quality issue in their home.

*...our biggest concern is the house during the winter. It gets very cold in this house for us...We have holes in the wall that have been there before we moved into the house. I did get in touch with [Housing NZ] regarding this issue and they said they were going to help make it better for us. But we haven't heard anything from them since.*

*The downfall about this house is that all the rooms are upstairs and ever since I have been sick, I have not been able to climb the stairs. Therefore, I live downstairs and am forced to shower outside because that is the only way I have access to water. I have contacted Housing New Zealand about this problem but I am still waiting for their response.*

Participants often did not know what social assistance they were entitled to, and did not feel well informed by health or social organisations about where and how to access assistance.

*I have to look for help myself to get resources for [the participant]. I do not know what is available. There is a real need for a better coordination services, appropriate information, nappies, and resources..."Real slack", helping older people understand what they are entitled to...Services need to meet with the family to explain what is available... (Family member)*

*...some of the nurses in the hospital said that social workers in the hospital could help set us patients with getting houses and that. Maybe if I knew the key people to go to everytime I go to the hospital. I'm well known in the hospital, you know when the doctors say to me you are eligible for a nice place through your social workers, it's just knowing who to go to.*

*...when I called WINZ to see if I can get on a [Housing NZ] house and I told them I was a sick person, they said the first priority for me will be renting and I said why is that and they only saw in the system that I had diabetes, and they won't take me on board.*

A number of participants were no longer able to work due to their health conditions. Many participants receive financial support from WINZ, such as a pension or sickness benefit. Most families felt that they were under constant financial pressure to pay rent, bills, hospital and medical expenses.

*Financially, there are times when we struggle to make ends meet with all the bills to pay. My wife is our sole provider and whatever money we have, we try our best to work with it. My medical bills have been reviewed by WINZ and hopefully they grant me with assistance.*

*We are just getting by with our benefit...when we get paid, our rent is deducted and we have \$200 left to budget for food, and other things. If we can't afford vegetables to eat then we will not buy it. Whatever we can afford is what we will get.*

Many times families were proactively seeking solutions to their own issues and looking for ways to improve their homes and living situations.

*I got [the participant] an alert alarm device. I did it myself. The plan is if I'm out of the house and if [the participant] feels sick, all she have to do is to press the alarm and help will come. (Family member)*

*My husband bought a heat pump to make the house warm because he thought I needed it because of my migraine....he try to improve everything for the health.*

## Understanding of health, illness and treatment

### Attitudes and beliefs about their illnesses

Many of the participants feel worried, overwhelmed and burdened by their health conditions.

*My wish is that all this pain and sickness will end and I can go back to being normal. I am getting older now...If it is God's will for me to be like this then who am I to question or try to stop his plan. However, I still hope that I can return to the time where I could do everything.*

*Overall if I were to rate out of 10 my current level of happiness in my life, I would say 7 because I'm not normal like before. Even though my health has improved over time, the doctors have told me that my condition is unpredictable...So right now I'm living on the edge. A lot of times I get paranoid because of this.*

*I don't like to think about my sickness because when I do, then I start to feel sick. I like to just enjoy my life without the worry.*

Some participants talked about the difficulty of knowing what is wrong with them and how to anticipate when they will become sick.

*...At times I feel very weak and feel like I'm going to die...sometimes I don't know how to tell what is wrong with me...For example, I think there's something wrong with my heart, but then I find out later it's my diabetes. I feel worried with my health just in case something serious happens to me.*

*...[the migraines] come on with no reason, don't know what brings it on, could be many different things, sometimes it could be the food, could be going outside in the sun sometimes.*

Some participants acknowledged the challenges of managing their health and conditions.

*When I'm sick, I'm sick no one tells me what to do - I'll get up when I'm ready...even though the right thing is to get attended to before you feel that bad or sometimes I just let it go and think it will go away, it'll get better, next thing I know I'm worse.*

*...being a [ethnicity omitted] we love island food, we have not so good food which tends to not be the best for us but it's the most tasty to us.*

*I'm a person that doesn't like to take medicine, [but] I guess there's more important things in life just not about myself, the only reason why I do it is for my kids.*

Some participants had developed care plans, but the degree to which they were implemented varied.

*I can't exactly remember every single goal but well most probably, if I come up with them they either achievable or something I need to do.*

### Use of ambulance services

Several participants noted their use of ambulance services to get to the hospital when they were very sick and in a lot of pain. Participants continued to do this even though it had ongoing and significant financial costs.

*The only problem is the cost of using [an ambulance] because of my financial situation. But when I can, I pay it off bit by bit...when it's urgent, I call the ambulance.*

*Sometimes we are behind in our ambulance bill and get a penalty fee on top of that. We think to ourselves that the money we use to pay the ambulance can be used elsewhere, so we use the ambulance service wisely.*

Participants gave a range of reasons for their use of ambulances. Some were transport related. However even when participants had a family vehicle, other factors (such as being out of petrol or family members being unable to drive because of work or child care), could lead people to call an ambulance.

*When I feel sick and we have no petrol, we call the ambulance to come.*

*Another reason I use the ambulance is so my wife can stay here and watch the kids. She can't take me to the hospital and leave our children here by themselves.*

*Our children have to sacrifice their work time to take us to the hospital instead.*

One participant used ambulance services because arrivals are treated by hospital staff with urgency and receive immediate attention.

*The ambulance services are good. I use it a lot because it is fastest way to see the medical team at the hospital. If I were to go to the hospital in my own car, I would have to join the long waiting queue.*

### Use of traditional and 'complementary' medicines and treatments

Most participants were taking a range of prescribed medication. However, the use of traditional medicines, usually alongside 'conventional' medication and treatments, was something that participants were open to or believed were beneficial.

*When I was diagnosed with cancer...I asked the doctor if he could put chemotherapy on hold for two or so months so I could try traditional healing methods...The doctor agreed and gave me 3 months to try [ethnicity omitted] traditional healing and if I had any problems then to return...I didn't get to the 3-month mark because I felt like I was going to die. So I went back to the doctor and asked if I could get chemo the next week and a few days later I was able to...It didn't work well for my body, but it was good to try anyways.*

*... medicine or our potions from different people and places...all over the place. Every time someone says this potion or medicine will help, we will try it, we do all this in combination with the doctor's medication and*

*treatment. When the doctor asks are you feeling better? I don't know what's making me feel better so I just say yes.*

*...if someone tells of a new medicine or treatment we buy the medicine or we try it out, we are always up to try anything...I honestly believe it's because I look for alternative treatment that I'm still alive today and also through praying. I don't always depend on the doctor's pills don't work, I believe they may work for a short while and then stops working, I think because I've had numerous operations, that's also has helped me stay alive, never cured just some relief.*

## Understanding and experience of health services

### Community, primary and secondary health care context

Most participants spoke about their health care experiences in the broader context of community, primary and secondary health care systems.

GP's and primary health care provider services were viewed positively by a number of participants. Pacific primary health care providers were specifically mentioned, particularly for language and communication reasons. Well coordinated health and social services were also mentioned by one participant.

*I can sometime understand what the person is saying but I need an interpreter. The [ethnicity omitted] family doctor is so good. He takes the time to explain things properly to make sure that [my niece and I] understand...His approach is so good, I feel comfortable to talk to him...He does not rush but takes the time to listen.*

*I use [Pacific health provider] because I can understand what they are saying. Communication is a big part in why I use them.*

*Yes, whenever I go and see my doctor and I need to go and see the physiotherapist or the social worker, they are in the same area and that is the same in the hospital.*

On the other hand, at least one participant had not visited a primary health provider in a long time, choosing instead to go directly to hospital when feeling unwell.

Many participants spoke of previous negative hospital experiences. These experiences were often caused from a lack of communication from hospital staff to families or were examples of insufficient information given to patients and families. Participants felt that they had not been treated appropriately or respectfully, made to feel embarrassed or were not listened to. These experiences may have been significant in influencing ongoing expectations and interactions with health services.

*One incident - no one called to say that [the participant] had been discharged from hospital. She was told to go home and went and sat at the waiting room until I went to visit at the visiting time. She could be sitting all day waiting. I was not happy. (Family member)*

*My experience if the old person don't understand [hospital staff] just leave them there. I found hospital doctors is very poor, poor communication to explain and inform us. Like when mum was admitted there was no follow up afterwards, no discharge plan given to us. I know because I have to do it myself. The health service don't offer anything apart from being in hospital and medicine. (Family member)*

*...the hospital always say you've been here how many times a year and for them not to investigate deeper to actually find out and for them just to give me tablet all the time and to say take this, take that and they keep changing tablets all the time to see whether this will change anything [and] they keep increasing the dose. I think that's wrong...if they increase it more it shouldn't happen all the time.*

*...another time after my operation at Middlemore hospital, I was told I had [illness omitted]. The lady who deliver the meal just brought my food and left it too far from where I was lying in bed. The lady refused to come into the room because I had [illness omitted], so I had to use my walking stick to try to pull the food over and it went onto the floor. One of the doctor came in and this doctor was so good and tell them to get me another plate. I felt embarrassed and ashamed that everyone is looking at me... I felt the woman who brought my lunch should not work at hospital.*

## 7. Discussion

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The research design aimed to provide a patient and family perspective of FO within the broader context of their social circumstances, health and wellbeing and care journey. We have synthesised the information we collected and analysed from the patient and family interviews and the hospital discharge summaries, with findings from the research literature in this section.

Pacific Fanau Ola services are provided to a group of patients of Pacific ethnicity, many with migrant backgrounds, suffering from multiple chronic conditions at a relatively young age. The underlying premise of the service is that health workers with cultural and or linguistic competence can support Pacific patients with complex health and social needs, presenting frequently to secondary services, to overcome the barriers they face in accessing and effectively utilising the range of services they require meet their needs.

The CMH Pacific Health Development Annual Plan 2013/14 states that the aim is to provide a holistic and comprehensive framework that supports Pacific family capacity building to transform their lives. Trained Fanau Ola Advocates use the CMH FO framework with Pacific patients who frequently return to hospital for specialised care. The aim is to help people transition back to home life and to keep well at home alongside their fanau, working with primary health to facilitate that journey. Fanau are supported to be well informed about health systems and encouraged to be 'partners in care', actively sharing in decision making processes and fully understanding their care options .

The achievement of these ambitious aims is considered in the light of the limited evidence base for effective models of care that address the needs of populations with similar characteristics, that is , migrant, low English proficiency, low socioeconomic status, with complex and multiple co-morbidities. Reviews in New Zealand and internationally show that although poor, vulnerable and ethnic minority populations are most likely to require enhanced chronic care and coordination services, the needs of these groups are inadequately addressed in current health systems and research programmes (Ovretveit, 2011; Sheridan, 2011).

Our review of FO from a patient perspective has identified the following three main areas that are particularly relevant to the FO programme:

- the role of family members as main carers and supporters
- understanding and navigating complex health and social systems, and
- the impact of health beliefs and attitudes and previous experiences of health services.

### **The role of family as main carers and supporters**

The experiences and circumstances of individual patients could not be viewed independently of the (extended) family. The significance of the central role of families within a Pacific context is well understood in NZ policy and research. Family connections for Pacific people underpin a sense of holistic health and wellbeing (Southwick et al, 2012). The level of support and care provided by participating families highlights the cohesion and considerable strengths of these family units.

However, crucially, the interviews also clearly showed that providing this support has practical time and financial costs for families, particularly in terms of managing time taken from work, transport and childcare costs. The literature notes similar strains these responsibilities place on Pacific families. In a study of child hospitalisation due to injury, researchers reported that while the support of extended family was perceived to be very important, providing care while also managing other daily responsibilities, work and child care, created stressful, conflicting demands on family members (Arlidge B. et al, 2009). Southwick et al (2012) further noted that 'health' is only one of many competing commitments and that other things often need to take precedence. This is consistent with participant responses about the use of ambulance services when their usual mode of transport was not available.

These issues are compounded when, as was the case in several of the interviews, multiple family members suffer from serious health conditions. Family members are in the position of requiring care and support, but also providing it. These specific circumstances should be better understood in order to develop meaningful and coordinated responses that recognise the needs of the family unit as a whole.

Family support commonly extends to being present at hospital admissions and health appointments to provide language and translation assistance. As other studies have noted, this can be problematic when family members assuming the role of informal translators may not have a strong knowledge of health issues themselves (Southwick et al, 2012). At least one participant acknowledged that they were limited in this sense and welcomed assistance.

### **Understanding and navigating complex health and social systems**

The multiple health and social needs experienced by patients and families were accompanied by necessary contact with a range of social and health organisations, each with specific systems and procedures to understand. As noted in the interview analysis, many families were making multiple presentations to primary health care providers, hospital services (involving care from multiple health and allied professionals and teams) and were in frequent contact with agencies such as Housing NZ and WINZ. A growing body of literature describes the challenges of navigating a complex and often fragmented bureaucracy, systems and processes, particularly when combined with existing financial and time constraints (Sheridan NF et al, 2012. Southwick M et al, 2012).

While some participants gave positive accounts of integrated services that they understood how to navigate, many of the interviews showed a critical lack of knowledge and understanding about how to access certain services or assistance. In a home context, participants were generally well informed about the benefits of 'healthy housing', but uncertain about the availability of assistance for housing improvements or how to access this assistance.

Research with minority populations in the USA suggests the need for more in depth understanding of the health communication barriers experienced by migrant and minority populations. Low health literacy, low English proficiency and cultural barriers have been called the "triple threat" to effective health communication. While the concepts overlap, understanding the differences between them can help with tailoring appropriate responses (Schyve, 2007). Similar findings are reported in a large scale longitudinal study of older people in NZ. The Health Work and retirement (HWR) study included specific analysis of 108 Pacific respondents (out of 6,653 study participants) (Lotoala et al, 2014). The authors found that ethnicity was a significant factor associated with poor health, after controlling for a range of socioeconomic, health risk and demographic variables and that NZ born Pacific people had better health than those born outside NZ. The authors identified the 3 social categories: Pacific /non-Pacific, NZ born/non-NZ born, high English proficiency/low-English proficiency as '*intersecting but non-overlapping*' factors impacting on health that required further research.

Low English proficiency was demonstrated by many interview participants who were not born in New Zealand (although may have been resident in New Zealand for most of their adult lives) who preferred that the interview was conducted in their first language. Many participants also reported that they valued communicating with FO workers in a Pacific language. However, the reliance of some participants on family members in the hospital and primary care settings for translation and language assistance indicates that CMH must address access to interpreters across the spectrum of care – a wider system quality issue .

Furthermore, proficiency in English does not necessarily equate with health literacy. From the patient's perspective, health information which is complicated and full of jargon is not improved by translation. For example, we noted that the inpatient Discharge Summaries ( used by Fanau Ola workers to assist patients with understanding their conditions and instructions for care after discharge) used complex medical jargon and abbreviations and were sometimes difficult even for our experienced clinical/research team members to understand. This underlines the importance of organisational approaches to health literacy as a two sided concept, with professional health literacy



as important as patient health literacy. In these cases, improved professional health literacy by clinicians would assist FO workers in their roles.

In a hospital context, the interviews support previous research describing hospitals as a foreign environment for many Pacific patients and families (Arlidge et al, 2009) and suggest the need for enhanced cultural competence in communication. That many participants felt information or explanations were difficult to access from health professionals suggests that communication breakdowns (or miscommunications) were occurring at key times of need. The difference between linguistic proficiency and cultural competence was demonstrated by one participant who described a positive relationship with her family doctor who was of a different Pacific ethnic group. Although a family member was required to assist with translation, she had excellent rapport with the doctor who listened to her concerns and helped her understand her condition.

Practical challenges can confront Pacific families with high health needs at any number of stages during their journey through the health system. For example, the achievement of 'partnership in care', a central objective of the FO programme (and a concept increasingly used across the health sector), is challenging given the multiple health conditions experienced and range of services accessed by families. The interviews clearly illustrate that for patients and families, it was often not easy to identify a lead 'partner' to connect with. Connected to this, findings show that the concept of Fanau Champion, as a lead on the patient and families side, was not well understood or used by many participants. In addition, that only a few patients understood or used their care plan, presumably the basis of a 'partnership approach' suggests that the tools supporting a partnership approach need to be further developed to be useful to patients. Analysis of participant's clinical information shows that for many patients, during repeated hospital admissions, participants are stabilised, have physical needs met, but are far from achieving well being. FO advocates are effective in improving relational aspects of patient and family experience of secondary care, but what further they can be expected to achieve within this complicated context needs to be assessed.

How decision making is affected within circumstances that are constrained on many levels, is an important factor when considering these issues. Patient responses, such as use of ambulances or frequent presentations to hospitals after hours, which may be attributed to a lack of understanding or a failure of self-management, were in fact rational choices made by patients based on their specific family and socio-economic context. Reviewing this information, in the context of their prognosis using the Charlson Co-morbidity score suggests that some high needs patients require a different model of care, perhaps incorporating the principles of a palliative care approach and support.

### **The impact of health beliefs and attitudes and previous experiences of health services**

The interviews captured participant attitudes about both health and illness that provide insight into how they manage their conditions, seek or delay treatment and access services. Southwick et al (2012) suggests that Pacific people view health as a functional well being, in a holistic sense, and illness as an interruption to such function. Health services, it follows, are for fixing illness, not maintaining function or even preventing illness. Many participants felt overwhelmed and disorientated about their health conditions and also recognised that management of their conditions was not always optimal. However, participants equally showed an engagement (albeit at differing levels) in bettering their health, such as committed adherence to medication schedules or trying to improve living environments. Indeed even participant use of traditional medicines could be seen as a certain form of engagement in their health, though with different motivations. Evidence suggests that use of traditional healers/medicines is a form of self medication that enables patients to feel like they are taking control of their health or reducing dependency of health professionals, perhaps after disillusionment (CBG, 2008 unpublished).

In addition, previous experiences can influence ongoing expectations and interactions with services. As described in the interview analysis, several participants recounted both positive and negative experiences with health services. Of particular note, the number of specific and positive mentions of Pacific health workers and services, both GP and

community based, suggest that a Pacific workforce in hospital , primary and community settings are working with patients with high and complex needs.

Arlidge (2009), has reported that amongst Māori and Pacific families, expectations of health services and professionals were often based on negative previous experiences. The research notes that this appeared to undermine their confidence and curtail their ability to challenge hospital processes where necessary. Other research has suggested that experiencing a perceived lack of respect or previous attendance with an unresponsive or unsympathetic doctor may discourage future attendance (CBG, 2008 unpublished).

The vast majority of the positive comments made about FO had communication and relational themes - being able to speak in a first language, receiving clear and understandable information and explanations about treatment and medication, feeling listened to, feeling encouraged and developing trust. The value of relational aspects of care was noted in a recent study of a community based patient navigator programme. Interviews with patient navigators found that they perceived relational qualities - the ability to be understanding, caring, personable and culturally respectful and sensitive - to be fundamental to their roles and of greater importance than knowledge and skills. The study argued that these qualities facilitate trust and compliance, making the patient-navigator relationship a 'medium through which navigator tasks are completed, rather than a self contained function.' (Phillips, S. et al., 2014).

Families, even those not aware of FO, wanted hospitalised family members to be 'looked after' by someone who could provide language assistance and clear information when they could not be present. When considered alongside the three areas discussed above, further exploration of the relational aspects of care within the FO advocate role, it's relative importance in the context of the broader FO programme and the potential it may hold to fill a gap in the support systems for Pacific patients and families, may be useful.

## PART C

### 8. Conclusion and recommendations

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The size and scope of the project limit comment about what can be attributed to the FO programme in terms of improvements to health outcomes or changes to care experiences since FO's establishment. However, as stated at the beginning of this report, use of a patient centred analysis initiates the building of an evidence base to assist future evaluations and further development of a fit for purpose FO.

What is also clear, is that patient and family experiences of FO cannot be viewed in isolation from their specific personal and clinical circumstances and their experiences of broader health and social systems. For all of the participating patients and families, FO represented a fraction of a multiplicity of presentations to health and allied professionals, teams with multidisciplinary members and a plethora of community and primary health care activity that contributes to the care of their significant and complex health and social needs.

For some participants, specific examples of assistance from FO advocates such as housing advice, coordination with hospital staff, pharmacists and social workers, helping with medication and arranging home visits by a nurse, clearly provided support and had a positive impact.

This must be balanced however by the existence of a range of issues, including ongoing support needs for families, system access and navigation barriers, unmet communication needs and, in terms of FO specifically, a lack of understanding about key programme functions and components. Patient and family experiences, viewed alongside clinical histories, present a picture that patients are repeatedly admitted to hospital intensely unwell, families are stretched in their ability to manage these frequent admissions alongside competing demands on their time and resources and there is confusion about the systems and processes they are faced with. Any assessment about the effectiveness of the FO programme, must be made within the context of CMH systems and broader health and social settings to enable a more meaningful analysis.

The aims of FO are ambitious and challenging. What the programme can be expected to achieve, and the degree of influence FO can have, within this context needs to be assessed. Questions surrounding how FO staff fit into broader ward schedule, how much time they get with families, capacity issues, resourcing constraints, the factors that impact advocating on behalf of patients to clinical staff, may be of value. The research clearly shows that FO advocates are effective in improving relational aspects of patient and family experience of secondary care. Furthermore, similar positive references to Pacific health services in hospital, primary and community settings suggests that there is a visible Pacific health and social service workforce performing a valuable function for Pacific patients and families with high needs.

The limited evidence base for effective models of care for migrant populations with low English proficiency, low socio-economic status, with complex and multiple co-morbidities illustrates critical knowledge gaps that need to be addressed in research programmes. While ethnicity is recognised as a significant risk factor for health (independent of socioeconomic status, and other health risk and demographic variables), more in-depth understanding is required of how ethnicity impacts on health. This research contributes to emerging NZ studies identifying the need for more in-depth understanding of the linguistic, cultural and migrant factors which health interventions may be designed to address. A key message from the existing literature and a central finding of this research, is that poor, vulnerable and ethnic minority populations, such as those represented in this study, require a different model of care offering enhanced chronic care and coordination services to adequately address their needs.

## Recommendations

- Better understanding the specific circumstances and needs of families to develop meaningful and coordinated responses to support:
  - their role as primary carers of a family member or family members with chronic health needs,
  - their knowledge, understanding and ability to access and navigate multiple services and systems at key points of need.
- Better understanding of, and tailoring of appropriate responses to, the low English proficiency, health literacy and cultural communication barriers facing Pacific patients with chronic conditions and their families.
- Better understanding of the health trajectories of migrants, including research and analysis using a life course perspective, that explores the impact on health of factors such as place of birth.
- Further consideration of the concept of 'partners in care' from a patient centred perspective and development of tools to support an improved partnership approach.
- Consideration of care models that incorporate palliative care approaches and support for some high needs patients.
- Exploration of FO advocate, patient and family perceptions of relational aspects of care in future evaluations. Examination of the perceived importance of relational qualities, how they impact the advocate-patient and family relationship and subsequently contribute to the aims of FO, to provide insight for the ongoing development of the FO advocate role and programme as a whole.

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## Appendix A: Patient interview guide

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How do Pacific peoples experience the CMH Fanau Ola services?

### Personal Circumstances

- What are you and your family's personal circumstances – NZ born/migrant – how long? Preferred language, education, employment, home ownership – length of time at current address; access to car/transport, phone, internet; access to benefits if required, family context – number in household etc
- How would you rate your current level of happiness/ concern with your (and or your families) health/well being/housing/finances?

### Understanding of health, illness and treatment

- In general, how would you describe your own health?
- What levels of understanding do you have about your health conditions and the management of those conditions? How long have you had these condition(s)?
- Overall, how well do you think you manage your health?
- What medications and therapies are you using currently? Is this what you were given when you were discharged from hospital? How well do you understand the treatments you have been prescribed? What are the reasons for adherence, non-adherence? How well do you understand your medications now?
- What health and social care needs do you have, what are their preferences for health services to meet these needs? Are these needs met?
- What secondary health care, primary health care, community and social services do you use regularly; why and how? Document visits to PHC, pharmacy, allied health, ambulance use, secondary care services, alternative health or traditional medicines use over the past 2 years.
- If you are using health services, what worked well, if not what were the barriers? Explore cost, transport, communication – language, understanding, rapport.
  - What factors enabled effective access to and use of the services you required to meet their health needs? What are the barriers?
  - How well integrated are the services you have used? What issues arise with co-ordination and how can co-ordination be improved? How well do services work for family-centred approaches?
- What gaps exist in service delivery?

### Understanding and experience of *Fanau Ola*

- What is your understanding of *Fanau Ola*?
- What contact(s) have you had with the *Fanau Ola* service? Who was the *Fanau Ola* Advocate? Were you of the same ethnic group? Did you see more than one? How did the contact occur – eg referred while an inpatient etc? What was the nature of the contact?
- What is their experience of how *Fanau Ola* has been delivered? Questions include: How did the *Fanau Ola* Advocate assist you in hospital - Prompts: eg that the *Fanau Ola* Advocate could speak your language, explain systems, connect you with other health or community services, assist with transport access to benefits etc.
- Have you had contact after discharge? Prompts – did the *Fanau Ola* Advocate discuss with you what help you could get at home? Your family doctor? Other services your family may require? Whether you understood why you were in hospital? Where you could go for help if you needed it?

## Experiences of Pacific patients who have used Fanau Ola services

- Did the Fanau Ola service make any difference to your experience of care – explore understanding of health condition, treatment and therapies, use of medication, hospital processes, access to things they needed eg translation, transport, benefits, other services?
- What if any difference was there between the approach used by *Fanau Ola* advocates and other hospital staff who provided care for you? How well do you think your *Fanau Ola* Advocate understood your health needs in hospital? How would you describe your relationship with your *Fanau Ola* Advocate?
- Explore if the use of *Fanau Ola* service contributed to empowering them to deal with their illness and improve health. Other prompts: Did your *Fanau Ola* Advocate help you to have greater input to decisions about your illness and health care? If so to what extent? Did this experience help you to have greater input to decisions about family illness and care?
- How can *Fanau Ola* delivery be improved?

## Explore patient's current plan when unwell

- Prompts: how do you decide what to do when you are unwell? Has this planning change since your last admission? Has anything changed because of the service you received through *Fanau Ola* service?
  - Do you have a wellness/*Fanau Ola* plan? Is this helpful – if so to what extent? If not why not? If you have used it please describe when and how.
  - Who sets the goals for your wellness plan? Do you agree with them? If not why not?
  - What are the outcomes you are seeking?

## Role of Fanau Ola champion

- What is the role of the Fanau Ola champion? How has this worked (or not) for you?

## Questions for follow up interviews

- Can you remember meeting with [Fanau Ola advocate name] during your admissions to Middlemore Hospital over the past 2 years?
- Can you tell me what you recall about meeting with [FO advocate name]?
- Here are the questions and prompts we used initially – for those who did not know what a fanau ola advocate was – if we use the name above – do they have anything to add to the questions below that we asked?
  - How did the Fanau Ola Advocate assist you in hospital? - Prompts: eg that the Fanau Ola Advocate could speak your language, explain how things worked, connect you with other health or community services, assist with transport access to benefits, explain what was happening when you were discharged from hospital, assist with understanding medications, outpatient clinic appointment,s anything else?
  - Have you had contact after discharge? Prompts – did the Fanau Ola Advocate discuss with you what help you could get at home? Your family doctor? Other services your family may require? Whether you understood why you were in hospital? Where you could go for help if you needed it?
  - Did the Fanau Ola service make any difference to your experience of care – explore understanding of health condition, treatment and therapies, use of medication, hospital processes, access to things they needed eg translation, transport, benefits, other services?
  - What if any difference was there between the approach used by Fanau Ola advocates and other hospital staff who provided care for you? How well do you think your Fanau Ola Advocate understood your health needs in hospital? How would you describe your relationship with your Fanau Ola Advocate?
  - Explore if the use of Fanau Ola service contributed to helping them them to deal with their illness and improve health and well being. Other prompts: Did your Fanau Ola Advocate help you to have



greater input to decisions about your illness and health care? If so to what extent? Did this experience help you to have greater input to decisions about family illness and care?

- If there was a relationship with the FO advocate- what aspect of the contact was most important to you- their skill and knowledge, helping with getting things done or advocacy, or the relationship and trust and empathy? All or none of the above or something else?
- Can we ask again specifically about the FO champion. The question previously was: What is the role of the Fanau Ola champion? Suggest now prompt with: Do you (and your family member) understand what the fanau Ola champion is meant to do. Please describe. Has this been helpful to you? Why or why not.

## Appendix B: Charlson Comorbidity Index

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### The Charlson Comorbidity Index

Comorbidity or multimorbidity is the co-occurrence of multiple acute and chronic medical conditions in one person. It results in an increased risk of hospitalisation, adverse effects of treatment, multiple competing demands on both patients and healthcare professionals, and increased mortality.<sup>1,2</sup> A comorbidity index reduces all coexistent illnesses and the severity of those illnesses to a single numeric score, allowing comparison with scores from other patients. The score indicates the overall severity of a patient's medical burden.<sup>3</sup>

One of the most widely used comorbidity measures is the Charlson Comorbidity Index.<sup>4,5</sup> This scoring system was developed in 1987 in a cohort of 559 patients admitted to a general medical service with a variety of medical conditions. It was then tested for its ability to predict the risk of death in a second cohort of 685 patients. With each increased level of the comorbidity index, there were stepwise increases in the cumulative mortality attributable to comorbid disease.<sup>4</sup> The Charlson Comorbidity Index includes 19 diseases selected and weighted on the basis of the strength of their association with one-year mortality. It assigns one point to: myocardial infarction, heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic lung disease, connective tissue disease, peptic ulcer disease, mild liver disease and diabetes without end-organ damage. Two points are assigned to: diabetes with end-organ damage, hemiplegia, moderate to severe renal disease, malignant neoplasm, leukaemia and lymphoma. Three points are assigned to moderate to severe liver disease and six points to metastatic cancer and AIDS.

Since development, the Charlson Comorbidity Index has been adapted for use with administrative databases,<sup>6-9</sup> and been validated in a range of different patient populations, including critically ill patients<sup>10</sup> and those with cancer,<sup>11</sup> renal disease,<sup>12</sup> stroke,<sup>13</sup> liver disease,<sup>14</sup> and coronary disease.<sup>15-17</sup> These studies have consistently demonstrated that the Charlson Comorbidity index is a valid prognostic indicator for mortality.

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## Appendix C: List of documents on Fanau Ola

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- An Evaluation of Fanau Ola: Evaluation of Fanau Ola practices applied to Pacific patients who present frequently to Middlemore Emergency Department. First and Second drafts, December 2014.
- Evaluating the effectiveness of the Pacific Health Cultural Support Team at Middlemore Hospital. 2006.
- Fanau Ola symposium: Moving Fanau Ola from a ‘Great Idea’ to “Business as Usual”. June 2014.
- Pacific Health Development Annual Plan 2013/14
- Pacific Health Development: Pasifika Fanau Ola forms: Initial Fanau Ola Assessment and Fanau Assessment and Reflection
- Patient Interview Schedule. Draft 2014.