



# **Enigma on stigma in acute mental health wards: Staff and service user views of each other.**

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## **Abstract**

This study identifies and explores the types of stigma that are experienced and are evident on adult acute mental health wards in New Zealand. It delves into how stigma operates and what it looks like. This is a qualitative study conducting 85 semi-structured interviews of staff (42) and service users (43) on four different adult acute mental health wards in New Zealand. Interviews were thematically analysed with a theoretical approach. Key findings present were patient internalised stigma, stigma separating patient groups, and staff stigmatizing patients. Patients believed they were 'crazy' due to external stigma they experienced. Patients and staff both categorised service users into groups of underserving and deserving of treatment.

*Key words: Stigma, acute mental health wards, qualitative, service users, staff*

## **Background**

The majority of studies that came up in the literature search were looking at stigma against mental health in the community/general population rather than an acute mental health setting. The other studies that we did find which were conducted in an acute mental health setting tended to only assess either staff<sup>1</sup> or service user<sup>2, 3, 4, 5, 6, 7, 8</sup> perspectives, not both.

A literature search to find articles looking at both service users and staff perspectives of stigma in an acute mental health ward setting portrayed a lack of knowledge and research conducted in the field. There were articles looking at stigma against mental illness in the community, and in hospitals, but we only found four articles examining both staff and service user perspectives in an adult acute mental health setting. (9, 10, 11, 12).

We focused on the 4 primary research articles that examined stigma on the acute mental health ward. (9, 10, 11, 12). The research reported in these four peer reviewed journal articles was all qualitative, two papers were based on UK setting, one on the US and the other, Belgium. Sample sizes ranged from 9 patients and 7 nurses to 42 patients and 43

care providers. Two studies used semi-structured interviews, one used focus group interviews and one used open-ended phenomenological interviews. It is also important to note that three of the four studies conducted these interviews on the ward during the service user admission, the other was a mixture of one and off the ward. Three of these studies were published during or after 2015.

Sercu et al 2017, defined stigma and the theorists it used; mainly Goffman's definition of stigma and those that build on this, including one of the main theorists our study is using, Link and Phelan. (10, 13). This was the only study aiming to investigate stigma, the others were atheoretical and consequently found themes of stigma while looking at other aspects of the acute mental health setting; safety<sup>12</sup> and the nurses' station<sup>11</sup> being two of these.

All four studies commented on how service users felt that they were disrespected and treated as though they were untrustworthy. The studies also had either service users or staff members mentioning how the environment of the wards created an "us and them" dynamic. Three studies discussed that service users felt that they were being treated as criminals and likened their environment to that of a prison. (9, 11, 12). Please refer to **Table 1** in Results section for key data about these four articles.

This shows a gap in the literature and a need for our study. This study looks at both service users and staff perspectives on an acute mental health ward setting in New Zealand. Our study is unique as we aimed to assess the adult acute mental health ward design and how that influenced both staff and service user experiences. We did not intend on studying experiences of stigma but consequently found a high presence of stigma in our data.

We used three key theorists to define our understanding of stigma; Goffman<sup>14</sup>, Link and Phelan<sup>13</sup>, and Jones et al<sup>15</sup>.

Goffman describes the "stained identity" and specifically discusses how a person can have a deeply discrediting attribute which impacts on their social interactions and status.

Link and Phelan builds on Goffman by introducing five dimensions necessary to develop a stigma: labelling, stereotyping, separating, status loss and discrimination, and

power difference. Link and Phelan describes how labelling and individual leads to stigmatization and the effects/impacts of this.

Jones et al describes six different dimensions of stigma: concealability, course, disruptiveness, aesthetics, origin, and peril. In context for mental health this relates to how mental illness develops/is perceived to develop, if it can be hidden, and if it is seen as permanent or reversible etc.

## **Method**

This data was collected as a part of the four-year study 'Design of Acute Mental Health Wards: The New Zealand Experience'. Marsden Fast Start (UOO1623) funded this research. The research has been collected to examine the environment and design of New Zealand adult acute mental health wards and its therapeutic role.

### **Ethics, consultation, and locality approvals**

In coherence with University of Otago requirements, for research including Māori, consultation with Ngāi Tahu Research Consultation Committee occurred prior to funding of the research. The ethics application (17/CEN/94) was approved by the Central Health and Disability Ethics Committee. The four participating DHBs gave local consent. The studies protocol is available at <http://www.ANZCTR.org.au/ACTRN12617001469303.aspx>

### **Data Sources**

We received our data from previous research and the interviews undertaken with staff and service users in four different New Zealand adult acute mental health wards.

#### *Case selection*

We selected four of the twenty publicly funded adult inpatient acute mental health wards in New Zealand to partake in this study. They were selected based on their age,

representativeness, and diversity. (16). All four which we approached after gaining ethical approval agreed to take part.

### *Interviews*

GJ the Principal Investigator (PI) on the project interviewed all participants for this study between 2018-2019. The majority of these interviews were conducted on the wards, with a few over the phone. Interviews tended to last between 30 to 90 minutes and were professionally transcribed. These were semi structured interviews with overarching questions around interviewees perspective of the wards' physical environment, relationships between individuals in the wards, purpose of the wards and many other questions. There were no questions directly asked to find themes of stigma as this study was atheoretical and this was not the purpose of conducting this study. However, themes of stigma have coincidentally been found.

In an aim to collect generalisable and representative data from the wards many different staff members were invited and participated in this study; nurses, social workers, occupational therapists, psychiatrists/psychiatric registrars, pharmacists, clinical team leaders, and cultural or consumer engagement advisors.

### **Analysis of Data**

Of the 85 interviews for service users (43) and staff (42) we thematically analysed the transcripts using Nvivo technology and a theoretical approach. We analysed data theoretically looking at three different theories of stigma; Goffman 1963, Link and Phelan 2001, and Jones et al 1984. (13, 14, 15).

## **Results**

Stigma was very prevalent amongst our transcripts and in the adult acute mental health wards in New Zealand. We found many different themes of discrimination, beliefs of origin of stigma, and separating of individuals due to stigma. The three themes that I found

most interesting were internalised stigma of patients, stigma between different patient groups (separating) and then staff stigmatizing patients.

### Internalised Stigma

The internalised stigma found was of patients believing the stereotypes and labels that had been placed on them from different areas of life.

*Yeah I just think that like it's almost like you got  
mental...it's a horrible feeling...because I'm here going  
'Oh my God, is this where I'm at now I'm mental patient'  
and you just you feel like you've gone to some other zone.*

*Service user AMHFN006*

This example shows a service user depicting what the stereotype and stigma against mental health patients is like, and how they have now projected it on themselves. Another service user mentioned how service users have to:

*Stick together... Because we're all in it together, we're all  
crazy as fuck, we're insane.*

*Service User AMHFM009*

These were two separate service users both showing examples of internalised stigma. There were many more encounters of this present in the wards with other patients calling themselves losers, and inmates.

### Stigma Separating Patient Groups

Many patients also tended to label and separate themselves from other patient groups. It appeared that this occurred due to patients believing that there were some groups who were stigmatized more and were undeserving of the same treatment.

There were a lot of comments about those who suffered from “real mental illness” and those who had abused drugs. Many of our service users and staff mentioned that they

believed individuals which drug addiction should go to another unit not the mental health ward.

*Drug-related problems. But it wasn't that like staying in Palmerston North. There isn't a-- a hospital unit for people with drug and alcohol problems. They all ended up on the psych unit.*

*Service User CMHMNM0010*

*So I don't know why they don't have two stories and have upstairs the addicts and downstairs the people who need psychiatric care, you know, why mingle them together because it's just, yeah.*

*Service User AMHFM009*

*because some people, some of our clients with a true psychotic illness will try and take things like some of the recreation drugs to counterbalance the more sedating effects of the medications that (they've got).*

*Staff ASFM002*

There also seemed to be a lot of stigma against those who “hear voices” or may be experiencing an episode of psychosis.

*I reckon they should separate the people who hear voices from those who don't hear voices a lot more for our own safety.*

*Service User DMHMNM003*

*she's quite a big, solid lady. And she gets quite violent. She can be get quite violent, and she she's probably the worst one here...I think she's schizophrenic*

These quotes reinforce and highlight the stigma against mental illness in our society and that individuals are perceived as dangerous. This also shows lack of knowledge and education from staff and service users around drug addiction and other mental illnesses.

### Staff Stigmatizing Patients

The amount of labelling, separating, and discrimination amongst staff towards service users was immense. While some staff members did not discriminate and stigmatize, there were many who did. Some staff members stigmatized against specific groups of patients, while others generalised and discriminated against all service users.

*Yeah. It's like some patients have like an illness, like a schizophrenic illness, but most of their presentation is purely their chosen behaviour, and they may be aggressive to staff*

Staff BSMNM001

This shows the lack of knowledge around some mental illnesses by staff, commenting that it is their choice to hear voices or behave 'badly'. There was also a lot of staff commenting on the behaviour of service users:

*Well, I mean sometimes, sometimes it's not about people being mad, it's about people being bad*

Staff CSFNM0011

*Oh that's right – she'd been unwell. That gets used a lot. It's only true half the time. They've got a mental disorder, but it doesn't mean that have to (...) have bad behaviour."*

Staff ASFM001



Staff suggesting that service users were intentionally 'bad' reinforces the stereotyping of mental health patients and lack of knowledge around mental health illnesses.

Please see the coding book as **Appendix 1** of this article for more examples of quotes coded. Also see **Appendix 2** for a table containing the numbers of quotes we found for each code.

Title	Authors	Country	Population	Sample Size	Data Collection	Aim	Key Themes	Relation to our Research
A safe place? Service users' experiences of an acute mental health ward	Wood, Daniel Pistrang, Nancy	UK, England (London), 2004	Staff and service users of an acute mental health unit ward in London.	n=9 patients n= 7 nurses	Semi-structured interview around safety on wards. Developed by the authors. Seven areas the interview covered (listed in the method). Style of interview was 'directed conversation' to phrase questions openly.	"to provide a detailed description of the experience of being an inpatient on a mental health ward, specifically with regard to feelings of safety and threat." "construct a coherent narrative of participants' 'lived experience'."	1: patient interactions: assault and intimidation, sexual harassment, sharing bedrooms, supportive friendships, own and others' psychological functioning 2: staff behaviour and attitudes: ability of staff to protect patients, ability of staff to listen to and understand patients, boundary infringements 3: non-consensual treatment: seclusion and restraint, forcible administration of medication	Staff commenting on the fact it must be scary sharing a dorm with multiple psychiatric patients... stigma between patients and portrayal of some illnesses in the media can make new patients scared "Ability of staff to listen to and understand patients" – good quotes about how staff treated patients... patients not feeling like they have rights "them and us" attitude. "they made me feel as if I did something wrong, as if I was a criminal" in response to a suicide attempt

Title	Authors	Country	Population	Sample Size	Data Collection	Aim	Key Themes	Relation to our Research
Life in acute mental health settings: experiences and perceptions of service users and nurses	Rose, D Evans, J Laker, C Wykes, T	UK, England (London), 2015	Service users (in the last 2 years)  Nurses and healthcare assistants	n=37 patients n=48 nurses	"A topic guide was produced and piloted allowing for open-ended discussion of the experience of acute care from the perspective of both nurses and service users". Had four <i>focus groups</i> which met twice. Interviewed service users who had been on the ward in the last 2 years (not necessarily current).	To explore the perceptions and experiences of service users and nurses in an acute psychiatric ward setting.	Staff and service user's interactions on acute wards and how power manifests itself between and across them. Speaks about coercion and control. Service users' felt the ward environment was untherapeutic: "lack of available staff and helpful staff". Focused on control, restraint and forced medication under service users. The prison like environment "provoked extreme frustration and anger... responded to by nurses in a way they thought aggressive and unnecessary". Mentions both staff and service users felt there was an "us vs them" environment.	Talks about respect and dignity and communication issues with nurses and service users. Also shows the discrepancy between nurse and service user perspectives with the same issues. "But what happens when dignity and respect are lost? Arguably, a group of nurses cannot restrain a patient and forcibly inject him or her with 'dignity and respect'.". Issues of forced medication taking away dignity and respect...

Title	Authors	Country	Population	Sample Size	Data Collection	Aim	Key Themes	Relation to our Research
How Patients and Nurses Experience an Open Versus an Enclosed Nursing Station on an Inpatient Psychiatric Unit	Shattell, Mona Bartlett, Robin Beres, Kyle Southard, Kelly Bell, Claire Judge, Christine A Duke, Patricia	United States, 2015	Inpatient unit in south-eastern US. Patients who were admitted before and after the removal of the enclosed nurses station.	n=13 patients n=16 staff	Open-ended phenomenological interviews. Patients were interviewed during their time at the hospital. "Participants were asked, "Tell me about a time when you were aware of the open nursing station or enclosed nursing station."". Interviews took place ~2.5 years after nurses station was removed.	Wanted to "better understand the experience of those who spend time in and around the nursing station". "examined the experience of an open nurses' station from the perspective of both patients and nurses who have experienced the unit when the nursing station was enclosed".	Nurses' experiences: confidentiality, awareness, communication strengths and weaknesses.  Patients experiences: imprisonment and freedom, separation and togetherness.	Being open made nurses more responsive to patient needs. More aware of keeping confidentiality and not saying things about patients. Helped communication, being enclosed may have prevented patients from communicating openly with nurses (found this in some of our transcripts). But being open made it more frustrating for some nurses as they kept getting interrupted.  Barrier made patient feel like they were being punished and needed to be separated – added to perceived stigma. Mentions how they feel like they were in jail – mentioned in a lot of our transcripts. Form of judgement and separation due to their illness. Found staff more accessible when it was opened.

Title	Authors	Country	Population	Sample Size	Data Collection	Aim	Key Themes	Relation to our Research
Stigma, Social Structure, and the Biomedical Framework: Exploring the Stigma Experiences of Inpatient Service Users in Two Belgian Psychiatric Hospitals	Sercu, C. Bracke, P.	Ghent, Belgium, 2017	Two Belgian psychiatric hospitals	n=42 patients n=43 care providers	Semi-structured interviews with inpatient service users and service providers on wards. And participant observations. Service providers included nurses, psychiatrists, psychologists and social workers.	"Discusses the stigma experiences of service users in mental health care, within the debate on the role of the biomedical framework for mental health care and power relations in society."	<i>Findings offer insight into how stigma experiences are affected by social structure.</i> Looks at stigma experiences in relation to Health-related attitudes, Medical knowledge, position, and stigma, and The meaning of health literacy. Discusses how individuals from different backgrounds find different interactions to be stigmatizing and discriminatory. Those from a higher education background found it stigmatizing to be treated the same as those who did not have that education. Those who had less education found their interactions with the psychiatrist to be degrading as they did not understand the medical terminology they used.	"stigma seemed to be related to the relation between care providers and service users their social position"

**Table 1: Summary of Key Literature**

## Discussion

Stigma was seen in multiple ways in the four adult acute mental health wards in New Zealand which we researched. The most common and obvious forms of stigma were service users being separated into groups; of those deserving and undeserving of treatment, staff members not wanting to deal with a specific group of service users and classifying some mental illnesses as not 'true' mental illnesses. Stigma was also present in less obvious forms by service users labelling and stereotyping themselves due to accepting external stigma and discrimination.

Previous literature suggested that knowledge and education of mental illness would decrease stigma present. (8). This meant the way staff stigmatized patients was unexpected due to the expectation that staff would have knowledge and be educated around mental illness.

Our research supports and reinforces the other literature we found. Finding common themes of disrespect, discrediting and status loss of service users in acute mental health wards. (9, 10, 11, 12). Our research, however, delves more into both staff and service users perspectives and is unique in looking at stigma between different patient groups.

The strengths of our study include large sample size, semi-structured in-person interviews, and asking a wide variety of questions about the environment of the ward. These are strengths as it allows us to get a wide range of information for a sample representative of New Zealand acute mental health wards. It also helped to show that themes were reproduced and reinforced throughout all the wards.

Some limitations of our study are that we did not ask questions specifically about stigma. This meant we may have missed some experiences of direct stigma the service users and staff may have experienced. However, asking about the ward environment and relations between individuals present on the ward produced many experiences of subtle and prominent cases of stigma. If we had approached the interviews with a theoretical approach, we may have been too close minded about the questions we asked and data we extracted.

Applying Link and Phelan's theories of stigma to our data was very insightful. I found Link and Phelan's five dimensions of stigma useful to simplify stigma in a way that is easy to explain but also very difficult to code for as all five dimensions strongly interlink.

Coding for 'labelling' was simple as if a diagnosis was present, it could be coded into the labelling code. However, commonly attached to a diagnosis was a comment which could either have stereotyped, separated, or discriminated against that label; often more than one of these, so it would be coded into multiple sections.

Goffman's discrediting traits/attributes was also a simplified way to code. As Link and Phelan based their understanding of stigma from Goffman's definition the codes overlapped significantly. Link and Phelan resulted in more broad codes and found more of the subtle examples of stigma and so I believe this is a better theory to approach the data with.

Writing a journal article based on Link and Phelan or Jones et al stigma definitions will be two very different articles. The findings for Link and Phelan will look more at the results of stigma and the impacts on an individual's life. Whereas Jones et al comes from more of a background approach at why the stigma is present and how an individual with stigma is discredited.

The most difficult part about coding with these three theories of stigma was the vast amount of data collected and how stigma underlies such a large proportion of how we think. It was also difficult to remove internal biases that I may have had when interpreting and analysing the data. My internal bias may have resulted in me interpreting quotes differently to how the individual intended they be interpreted.

## **Conclusion**

Looking forward there needs to be more research on these groups and stigmas present in adult acute mental health wards and where the stigma originates. It will also be vital to look at the consequences of stigma on the recovery and rehabilitation of service users.

It will also be beneficial for us to look at if there were any differences in stigma seen between the four different acute mental health wards in New Zealand that we researched. If differences are found it would be important to assess and examine why there may be differences, due to ward environment, education of all individuals, or different therapies.

There is an enigma around stigma. Stigma is mysterious and while it comes to us all as we grow up there is no single root cause, therefore it will be harder to remove.



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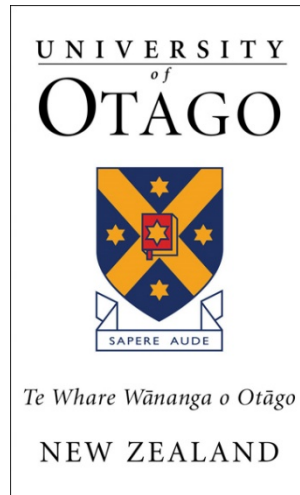
## **Conflicts of Interest**

No conflicts of interest were disclosed.

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# **Adolescent Idiopathic Scoliosis**

## **Awareness, perceptions and factors influencing decision-making among rangatahi and whānau**

**Summer Studentship 2020/2021**

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## **Abstract**

### **Introduction**

Adolescent Idiopathic Scoliosis (AIS) is a 3D spinal deformity of unknown aetiopathogenesis resulting in potentially detrimental long-term physical and psychological impacts. If left untreated, the progression of AIS may cause severe pain, cosmetic issues, limitations to physical function and mobility as well as cardiopulmonary complications. In addition to this, AIS is also associated with negative mental self-image and psychosocial functioning, impacting relationships and social interactions. Optimal therapeutic approaches remain controversial with current methods involving spinal fusion surgery and there is little variability in what is advised between orthopaedic specialists.

Very little research has been undertaken in New Zealand or internationally about perceptions, awareness and experiences of AIS by rangatahi (young people) and their whānau. Awareness from both rangatahi and whānau is essential, as it allows for early detection, and subsequent better treatment outcomes.

### **Methods**

This qualitative study was guided using Kaupapa Māori methodologies. Nine rangatahi (aged 12-23 years) diagnosed with AIS between 2015-2020 and their supportive whānau were recruited. Semi-structured interviews with rangatahi and whānau were undertaken allowing direction of the korero as well as open-ended discussion.

### **Results**

Thematic analysis was undertaken revealing seven main themes with respective sub-themes. The main themes identified were the shock of diagnosis for rangatahi and whānau, the extensive impact of AIS on daily activities, the varying concern between rangatahi and whānau, the importance of support systems, feeling let down by services and the lack of timeliness of the New Zealand health system.

### **Discussion**

Rangatahi and whānau affected by AIS identified several key themes highlighting the need for more research into rangatahi and whānau experiences of AIS.

## **Introduction**

Adolescent Idiopathic Scoliosis (AIS) is a three-dimensional spinal deformity of unknown aetiopathogenesis resulting in potentially detrimental long-term physical and psychological impacts on rangatahi(1). A diagnosis of AIS is made through the exclusion of all other causes of scoliosis, along with the estimation of a spinal curvature, with a Cobb Angle of 10 degrees or greater. The international prevalence of AIS remains around 0.5-5%, with spinal surgery being a common elective paediatric procedure for those with advanced curves(2, 3).

The progression of AIS may cause severe pain, limitations to physical function and mobility with cardiopulmonary complications(1). In addition to this, AIS has also been associated with negative mental self-image and psychosocial functioning, further impacting relationships and social interactions(4-7).

While there is clear evidence of a cosmetic deformity, current research lacks understanding of psychosocial effects of the deformity on diagnosis or treatment. Optimal therapeutic

approaches remain controversial, with current surgical methods involving spinal fusion surgery, an invasive procedure with long-term implications. Alternatively, non-surgical bracing is often chosen to prevent further curvature, however it is only effective for moderate curves when there is further growth expected. Bracing presents challenges with compliance, due to the lengthy hours the brace is required(8). Newer less invasive methods such as Vertebral Body Tethering (VBT) which is a method of using a polyethylene cord to straighten the vertebral bodies, are now being offered, but require optimal timing, to produce spinal alignment on completion of growth(9). Treatment decisions of bracing, tethering or surgery are complex and emotional for rangatahi and whānau(10). The emergence of this physical deformity during a fragile time of puberty and adolescence requires extensive consideration of individual patient perspectives for all treatment decisions(11).

There is very limited research on patient and whānau experiences of AIS and what there is, tends to focus on biomedical research aspects rather than qualitative biopsychosocial exploration(11). This paucity in qualitative research demonstrates the limited understanding of patient perspectives and experiences surrounding AIS diagnosis and treatment(12). Previous studies have found that qualitative research is extremely valuable, as it enables many perspectives to be shared without limitations(12).

Early detection is essential, as it allows for less invasive treatment procedures and increases the chance of better outcomes(13). Typically, whānau initiate seeking healthcare for rangatahi with suspected AIS, however little is known about when and how they decide to do this. Knowing this would provide further understanding of the factors contributing to AIS detection. Similarly, there is no published New Zealand research about perceptions, awareness and experiences of AIS in the rangatahi population.

Qualitative research will provide information from rangatahi and whānau about the experience of seeking assessment for AIS, receiving an AIS diagnosis, making treatment decisions and experiencing the intervention. The findings from this study will then aid in the development of information for future rangatahi and their whānau diagnosed with AIS. This could be through raising awareness and understanding of patient experiences, developing a comprehensive AIS research programme, enhancing the availability of AIS information resources or screening programmes.

This study aims to explore rangatahi and whānau awareness and treatment experiences of AIS as well as factors influencing decisions to seek care among whānau with rangatahi diagnosed with AIS.

## **Design and Methods**

This study uses qualitative methods in the form of semi-structured interviews with adolescents with AIS and respective whānau. Through the use of a qualitative methodology, the exploration of patient perspectives is unlimited, as it encourages patient participation and offers an open-ended format of discussion. This is especially necessary for AIS research, as existing studies enlist surveys or questionnaires, where responses are limited. Furthermore, semi-structured interviews allow issues to resurface, as survey responses

typically created by adults may lack the same perspective of adolescents as to what aspects are important and maybe overlooked(14).

### **Kaupapa Māori**

This project will be guided by Kaupapa Māori Research principles. Kaupapa Maori Research is related to Maori ownership of knowledge and validity of Maori practices while underpinning several key concepts(15). These include Rangatiratanga; allowing participants autonomy in their engagement with this study, Te Reo: upholding the mana of the language of the indigenous people of Aotearoa, Whakapapa; recognising the importance of genealogies of mankind as well as contextualising relationships between people, communities and participants, Tikanga Maori; upholding the correct procedures and appropriately navigate within Māori values and practices developed over time and Whānau: the responsibility of the researcher to include the extended family structure through whakawhanaungatanga and respecting relationships between all participants(15, 16). Kaupapa Maori stands on the foundations of Te Tiriti o Waitangi, ensuring research is undertaken in a bi-cultural manner that encourages Maori participation and increases rangatiratanga (self-determination)(17, 18).

### **Participants**

A purposive sample of 9 rangatahi (aged 12-23 years) diagnosed with AIS between 2015-2020 and at various points in their AIS journey was sought. Rangatahi were recruited via their whānau who also took part in the study. Whānau were alerted to the study through three mechanisms; researcher networks (Scoliosis Facebook Page), promotional flyers at the CCDHB and 'snowball' sampling where whānau were asked to inform other potential participants.

### **Informed Consent and Ethics Approval**

This study has been approved by the University of Otago Human Ethics Committee (Health) H20/151. Written informed consent was obtained from all participants. If rangatahi were under 16 years, a Rangatahi Assent form was completed as well as a Whānau Consent Form. Consent and assent were also checked verbally before the commencement of the interview. A study information sheet was also developed for all rangatahi and whānau. Rangatahi and whānau were also asked to provide some basic demographic and condition related information (age, gender, location, month/ year of diagnosis, treatment/s undertaken and hospital providing care).

### **Data Collection**

Semi-structured dyadic interviews (rangatahi and whānau) were undertaken using a method convenient for the participants. Most were done in-person, and a few by videoconference (Zoom). Interviews were beneficial as it allowed the opportunity to direct the korero (conversation) whilst giving participants the ability to spontaneously share information from their account and experiences(19). The general line of questioning involving rangatahi and whānau included the awareness, perceptions and experience of AIS before and after diagnosis, AIS information sources, factors influencing treatment-seeking and decision-making, experiences of healthcare services as well as beneficial experiences and areas of improvement along their journey. The research student piloted the question schedule with rangatahi and whānau observed by a qualitative researcher and received feedback on technique. In the interviews the research student took care to involve both rangatahi and

whānau, ensuring each had the opportunity to give their perspective and acknowledging rangatahi views may be different from whānau and that both were important.

### Thematic Analysis

Each interview was electronically recorded and transcribed by the research student. The transcripts were reviewed and coded supported by Nvivo software. Thematic analysis was undertaken using Braun & Clarke(20) methods where similar and different ideas in the dataset are categorised and formed into themes. Categories and emergent themes were discussed between the research student and supervisor. Consistencies and differences were discussed and resolved resulting in the final set of themes and subthemes. Quotes yielding the essence of each theme were identified in the data to incorporate in this paper.

## Results

Ten semi-structured interviews with rangatahi and respective whānau were undertaken. (See Table One).

For the purpose of the summer studentship, ten participants were included, as this was the data collected over this period. For further studies, twelve participants will be analysed and included into the results.

**Table One: Summary of participants and demographic data**

Rangatahi	Gender of rangatahi	Whānau	Age of rangatahi	Age at diagnosis	Treatment	Stage of treatment
Kiwi	F	Kauri	14	12	Brace	Post treatment observation
Kaka	F	Kahikatea	14	12	Brace	In brace
Takahe	F	(interviewed by herself)	19	12	Brace and spinal fusion surgery	Post treatment
Kea	F	Rimu	15	15	Waiting for spinal fusion surgery	Waiting for surgery
Moa	M	Tōtara	17	13	Brace	Post treatment observation
Pūriri	F	Kawakawa	15	11	VBT	Post treatment
Weka	F	Kōwhai	14	12	Brace	In brace
Ruru	F	Mānuka	15	14	Spinal fusion surgery	Waiting for surgery



<b>Pūkeko</b>	M	Pōhutakawa	13	12	Spinal fusion surgery	Waiting for surgery
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*Pseudonyms have been used.*

Through thematic analysis, seven themes and sub-themes originated from the data. These are shown in the table below.

**Table Two: Themes and subthemes**

<b>Theme</b>	<b>Sub-theme</b>
<b>The shock of diagnosis</b>	Lack of whānau awareness Perceived sensitivity of the health professional at the diagnosis
<b>Extensive impact of AIS on daily activities</b>	School Family and friends Sport Mental well-being Physical well-being
<b>The varying concerns between rangatahi and whānau</b>	Whānau concerns Rangatahi concerns
<b>Whānau feeling alone</b>	Perceived lack of support from health professionals Feeling uncertain
<b>Importance of support systems</b>	Facebook Group Others with AIS Website
<b>Feeling let down by services</b>	Lack of adequate understanding of AIS Ineffective communication Lack of clarity Unsatisfactory available information Preferring overseas treatment
<b>Timeliness of New Zealand System</b>	Lack of preventative action Delay to receiving healthcare

### **The shock of diagnosis**

Many rangatahi said receiving a diagnosis of an uncommon condition such as AIS can be devastating and life changing(21). Because of the limited knowledge of AIS in the community, receiving such a diagnosis was very unexpected and rangatahi and whānau described it as “a bit of a shock”. This shock often meant they did not ask the questions they needed to at the time.

*“I think I'd have asked more questions, and I would have sort of asked to see the X ray, and you know, just being a bit more. Also, I think it's a bit of a shock at the time. (...) Yeah, I think you think you do need time to come to terms. Because it was a lot to take on in a very short time.” (Rimu – Whānau)*

## **Lack of whānau awareness**

Whānau said their awareness and understanding of AIS was very limited. Many participants reported having none or minimal knowledge of what scoliosis was.

*“No, I didn’t know anybody or anyone who had scoliosis. Even though I have a nursing background I didn’t know anyone or anything about it”* (Kauri – whānau)

*“I knew absolutely nothing at the beginning”* (Kiwi - rangatahi)

*“I’d never heard of it (...) But yeah, I’d never heard of it before that. And I have some friends who had it at the same time as me, but I was like the first one to know, because I’m slightly older than them. So yeah, I never knew what it was.”* (Takahe - rangatahi)

## **Perceived sensitivity of health professionals at diagnosis**

Many rangatahi and whānau felt upset about how their diagnosis of AIS was communicated. Some whānau felt that the amount of information was overwhelming for a young person to hear at one time and perceived that the health professional was indifferent to how significant receiving this diagnosis was.

*“And then we had to go into this room, which was full of men from [the scoliosis clinic]? I didn’t know. Actually, I still don’t know who they all were, from the orthopedic, no, from the orthotic centre. A couple of medical people and then [specialist\*] on video and then he dropped the bombshell that actually it had progressed, and she should be braced. (...) you know, we both got a bit upset.”* (Kahikatea - whānau)

*“We had the misfortune of meeting a very young doctor who just regurgitated everything he ever learned and basically told her worst-case scenario; she’s going to die in her 40s or 50s. (...) It is terrible. How can you say that God, plus A, you can’t tell what she’s got based on first X ray. B, you don’t say this anyway, and see nobody dies of scoliosis anymore, you know,”* (Kawakawa - whānau)

*“He said, this is what you’ve got. Here’s an image of someone that’s had it with a spinal fusion. Your type of scoliosis is going to get worse so I can tell that. So, go away. Have a nice Christmas. Don’t worry about it. And we’ll be- we’ll see you after Christmas. Well, in about six months, I think it was we’ll check-up and we’ll see what’s happening.”* (Kōwhai – whānau)

*“We found him really rude actually, you know, to show a child who has just been told they’ve got scoliosis, spinal fusion X ray on a computer, I thought was a little bit much. I think he should have said Weka\* do you mind going out in the waiting room while I have a word with Mum and Dad. You know, and we all just walked out of there bawling our eyes out it was just horrible.”* (Kōwhai - whānau)

## **Extensive impact of AIS on daily activities**

It is evident that AIS had huge impacts on everyday life for rangatahi. These changes were described in biopsychosocial terms, with rangatahi and whānau acknowledging the broad

effects of AIS. Rangatahi described the mental and physical changes impacting on their everyday life at school and with family and friends.

## **School**

While the school systems were reported as generally supportive towards rangatahi with AIS, rangatahi still had difficulty with pain or wearing a brace at school.

*“probably worst at school just like with PE and stuff because you know in Year 9 and 10 PE is compulsory so it's something you can't hide that easily like everyone gets changed together so you can't really hide it”* (Takahe - rangatahi)

*“in school, like literally with everything like I'd sit in class and I couldn't focus because like I'd sit there for like five minutes and then just be in pain.”* (Pūriri - rangatahi)

## **Family and friends**

Wearing a brace impacted on family relationships, as whānau found it difficult to enforce wearing the brace for a significant number of hours, whilst maintaining a positive relationship with rangatahi.

*“Yeah, as a parent it's a hard one because you know that they need to be in it for as much of that, (...) But at the same time, you need them to stay sane and have some time. (...) As the parent it was quite hard trying to figure out what that balance is.”* (Kauri - whānau)

Most rangatahi found their friends to be very supportive.

*“They were all very supportive. That's for sure. No One... There's was nothing like negative really. Everyone was very supportive about it and trying to help I guess.”* (Moa - rangatahi)

## **Mental well-being**

Learning to live with AIS causes considerable difficulty on the mental well-being of rangatahi. This was described as anxiety surrounding potential surgery or feeling self-conscious of the physical deformity or having to wearing a brace.

*“sometimes I feel like self-conscious about it because I don't know, it sticks out at weird places”* (Kaka - rangatahi)

*“My shoulder would like stick out more and more. And because my shoulders were obviously lopsided, as well. So that kind of became a lot more noticeable. And people would pick up on that, but I just, I don't know, I wasn't really fussed, because I didn't look like overly crazy. It definitely wasn't noticeable. And I guess that'd be slightly self-conscious about it. But I wasn't too bothered. It was more my brace that I was self-conscious about.”* (Takahe - rangatahi)

*“I do think about it sometimes. (...) What would happen if the surgery went wrong?”* (Pūkeko - rangatahi)

*"We were at a colleague's house the other day going over some school stuff, and he took a book. She's got a lovely pool, so she offered him some togs. And yeah, she didn't have a like a rash shirt. And he wouldn't get in the pool because he'd have to take his top off. Yeah, that concerns me that he can't just be, like there was not even anybody else there that you know, would see." (Pōhutakawa - whānau)*

### **Physical well-being**

AIS caused immense strain on the physical well-being of some rangatahi. This was described as back pain, difficulty sleeping as well as generalised pain and skin rashes experienced by those using a brace.

*"I was starting to get in pain like I couldn't sit for too long I would just everything like hurt and I'd get like this big muscle tension on my back" (Pūriri - rangatahi)*

*"If I had any pain during periods, because I get pain in the brace from sitting down. Because it would, it rotates your spine when you sit down, and it pushes quite hard." (Moa - rangatahi)*

*"It's getting definitely more increased now. With like, like her sleeping a little bit you know, she will come and say her neck's sore or something like that. More than it used to, so it is increasing a little bit the pain." (Mānuka - whānau)*

*"it's always the worst for like the first week or two weeks. That's when your body's... because you also get quite bad skin rashes, I guess." (Moa - rangatahi)*

### **The varying concerns between rangatahi and whānau**

Whānau caring for rangatahi with AIS spoke of a variety of concerns relating to the well-being of rangatahi. Often these concerns exceeded far beyond the individual concerns of rangatahi and focused on long-term health and well-being of rangatahi. In contrast, rangatahi tended to focus on immediate areas of concerns often related to physical activities and friends.

### **Whānau concerns**

*"a lot of his focus also went into this big, long detail about back X-Rays and how bad they are and how much radiation a back X-Ray gives you compared to, say, a chest x ray or something else. And it's... and so I walked away going, OK, we're doing this once. And if it's fine, I never want to do another one because it's not good for my daughter." (Kahikatea - whānau)*

*"I remember when we were told that, like, when we went to the Auckland hospital, and we were just told, like, Oh, it's too late. Now you're gonna have fusion. And like, Mum started crying, and I didn't cry. I was like, fine with it. Like, I just remember being like, Oh, it's okay. Like, I was supporting her." (Kawakawa - whānau)*

*"For me, it's more long-term health. And what it's going to mean for him as an adult. So yeah, I've seen adults with scoliosis that hasn't been corrected, and see the pain and discomfort that they are in later in life. And I don't want that for Ethan." (Pōhutakawa - whānau)*

### **Rangatahi concerns**

*"I'm like, not excited about not being able to do as much as like activity. And so that's probably the main thing that I'm not excited about. But the actual, like surgery. I'm not that worried about." (Kea - rangatahi)*

*"not being able to go back to surf or kind of being like, I was worried that after surgery, I'd be like, a whole different person and never be able to do anything again. And like, I'd feel like get FOMO and stuff. And, you know, it's just like, just missing out on everything, I guess." (Takahe - rangatahi)*

*"Probably just not being able to see my friends. I'll see Terry\*, but not be able to see my friends for a while." (Ruru - rangatahi)*

### **Whānau feeling alone**

Whānau that disagreed or were uncertain about what the local services offered, or strongly wanted to avoid spinal fusion, often found themselves with huge responsibility, becoming the sole advocate for rangatahi with AIS. This lack of support for whānau promoted feelings of anxiety and uncertainty, despite whānau aspiring to do the best for their rangatahi.

### **Perceived lack of support from health professionals**

*"It didn't feel like there was a lot of support really, or not a lot of support because he did hook us up with that guy locally first of all who was in the clinic, but he didn't seem very convinced that it was going to work." (Kauri - whānau)*

*"[Specialist] wasn't overly helpful. Yeah, he wasn't supportive. You'd go away questioning, what you were doing, you'd feel pretty small? Yeah, it was really hard, actually. Because you're making a huge decision, that as an adult, as a parent you're making for your child, and you just hope you get it right. And you really want to know that you're doing the right thing. And he didn't make you feel like you were. He made you feel like you're a stupid little woman." (Tōtara - whānau)*

*"I felt really alone, like I did not trust the system around me. And every time I felt like I found the right person. I'm in good hands now. And then (...) you know, I have two more kids I'm a single parent, and they all have their dramas. And I feel okay, this is on track, we're safe now. And then I come back and I'm cheat, I can't trust you [specialist] as well. And I, I let the ball down. And then this crazy guilt of, you know, every six months, she's growing, it's getting worse (...) when we went to Auckland the last time and got this horrible news that actually they're not going to do what they said, it's not going to be a VBT and blah, blah,*

*blah. I literally spent two weeks in bed, crying and banging my head on the wall.”*  
(Kawakawa - whānau)

*“I just felt like it was not forthcoming thing, again, just a little bit standoffish with it, whereas the kind of would have been nice to have more support about it. And, and more sort of, you know, this is what we've got, this is what we need to deal with and how to deal with it.”* (Mānuka - whānau)

### **Feeling uncertain**

*“It's like, is this brace gonna work or isn't it? Yeah, you know, are we doing the right thing or not? I still don't know if we've done the right thing. Do you know what I mean?”* (Kōwhai - whānau)

*“You know as the parent you are quite vulnerable at that stage because you've got a kid with a new diagnosis of a condition you don't know anything about and you're reliant on their expertise”* (Kauri – whānau)

## **Importance of support systems**

Rangatahi and whānau reported support systems as pivotal to their successful journey through AIS. The most beneficial support systems identified by whānau and rangatahi were the use of social media groups, websites made by others with AIS and support through other similar families.

### **Social Media Groups**

*“You know that was just fantastic having that Facebook group. You know I would have obviously googled and done my research and questioned but knowing who to go to and find that support. (...) It was honestly that was a Godsend having that Facebook page. Because there was so much research, so much information and then you could link into overseas ones as well and just read everything and I suppose that's what got me on my little pathway, finding out who were the doctors in New Zealand.”* (Tōtara - whānau)

*“Once I found them that was the best thing. The Facebook, the New Zealand site and what they actually meet once a year or once every two years”* (Kōwhai - whānau)

### **Websites**

*“There was a lovely website that one of the mothers from Wellington did you're probably aware of, her name is Sarah\*. And she did a really nice website that is easy for kids and fathers.”* (Kawakawa - whānau)

*“The site was quite helpful because it had kind of every aspect. From like sleeping to tips and tricks, to like information.”* (Kaka - rangatahi)

### **Others with AIS**

Helpful support and coping mechanisms identified by rangatahi and whānau included other whānau who shared their experiences of living with the condition:

*“For me it was having Sally\* and Lucy\* in Wellington, without those two, God knows what I would have done. (...) And I think being able to talk to Sarah's daughter Sky about her operation and how that went.”* (Tōtara – whānau)

*“We flew down to Wellington to meet Lucy\* and Sally\*, so we went down there and meet them which was great because they just knew especially Lucy's daughter's kind of been through the same thing with the bracing, so they were great to actually talk to”* (Kōwhai - whānau)

*“I found somebody else who had it in Motueka, and we sat down together and just talk about what our experiences were so far”* (Mānuka - whānau)

## **Feeling let down by services**

Many whānau found their experiences with healthcare professionals variable particularly at the beginning of their journey relating to diagnosis and again when treatment was proposed. Some whānau felt that some health professionals had quite limited understanding of AIS or spoke of how they felt that the information was communicated ineffectively. This left whānau with a lack of clarity, driving them to seek information from other sources.

Some whānau that felt dissatisfied with the local services offered, decided to go overseas to receive treatment. This was mainly from those wanting to avoid spinal fusion, pursuing bracing as the preferred treatment. Whānau felt the most effective braces were available overseas, with some sacrificing substantial time and money to access this treatment for their child.

### **Limited understanding of AIS**

*“I was a bit annoyed about that. But I don't think that the I think people aren't educated. I mean, I hit Dr [GP] up about it and said, Hey, why don't you know, and he goes I don't know anything about it. And actually, having talked to, cause then I talked to my GP, our neighbour behind us was a GP and I sort of started going Why don't you guys know, you know, come on, you should know. And they said well, we don't we're not taught about it.”* (Tōtara - whānau)

One participant received extended treatment from a physiotherapist who did not notice his AIS:

*“But essentially, he noticed my spine was curved. Because I mean, he was you know, massaging my back and looking at it. But all he said was there was a small kink in the lower half my back. That's all he picked up on.”* (Moa - rangatahi)

### **Ineffective communication**

*"I found him really terrible, to be honest. I, I complained after that because we came away just going, we, you know, like we didn't know what to trust and know whether anything would work. He was really negative. I was just like my God; you've just come out of lockdown. You should be really positive, and you should be reassuring us. But he wasn't reassuring us that wasn't the role he was taking at all. It was awful."* (Kahikatea - whānau)

*"Sometimes it's hard when you ask the specialists questions, and they're like, 'oh, like, could be this could be that'. And they just, like, kind of blunt and then leave it. And it, like, kind of stresses you out?"* (Takahe - rangatahi)

*"I had to sort of find out whether physio was an option where I thought that should have come from them, you know, options to help us. Yeah, we had to like to suggest it and see if it was right. And I thought maybe it should have come from them."* (Mānuka - whānau)

*"[Specialist] told us that if we went to Australia to do bracing, we were wasting our time. And that he's seen it before. And a lot of people their marriages break up. And we were wasting our money, basically."* (Kōwhai - whānau)

### **Lack of clarity**

*"They kind of left us hanging a little bit. Like, we had to work out, you know, whether we wanted to get on the surgical list or whether we wanted to wait a little bit, but it was kind of like, Yeah, well, they were not really forthcoming I guess with wanting to help us more. But we had to kind of dig it out of them. It wasn't quite so... I yeah, it was a little bit of little tough. Yeah. Trying to get what we needed to do and how to do it."* (Mānuka - whānau)

*"You never get an actual straight answer of this is what's happening. Or this might happen or this, but if you go see this person, they might tell you a different thing. And then they'd tell you something else, who will tell you to refer to someone else."* (Pūkeko - rangatahi)

### **Unsatisfactory available information**

The process of receiving a diagnosis of AIS can come as a shock, and often whānau feel confused, requiring further information about the condition and consequent action. The available information provided for whānau was often inadequate, leaving whānau overwhelmed, confused and needing to search for information themselves.

*"I'd have liked more information. I think we got given a sheet. I'd like more information."* (Rimu - whānau)

*"the lack of... I mean, thank God for Sarah\* and Lucy\*, but there wasn't... the information that they were handing out at the hospital. You know, they weren't saying here's, here's a whole lot of information, or here's a website that we've set up. There was nothing."* (Tōtara - whānau)

*"Nobody's discussed options, like, yeah, we were the one to raise, you know, would a brace be suitable or not. No, no doctor suggested any exercises that would be useful or help with his development or recovery or anything like that."* (Pōhutakawa - whānau)



## **Preferring overseas treatment**

*"We would kind of feel everything's progressing and everything here seems so backward compared to overseas, when you look overseas, what everyone's doing, and you read all the research and the papers everyone writes and what they're offering and the great success stories." (Tōtara - whānau)*

*"It definitely works. And he told me the history behind him changing to using those braces and the results he was getting were unbelievable. And he still I mean, when I say to him, you know, my God, it's amazing what you've done with the brace" (Tōtara - whānau)*

*"Because we weren't happy that spinal fusion was the only answer. We felt that we needed to look into it a bit more. And went over there and yeah, and got a brace made. And we were back in another couple of weeks to have it fitted and shown Schroth exercises to help it. Yeah, so and then Ava's had her brace on for two years." (Kōwhai - whānau)*

*"They have a low dose radiation machine there which was also attractive because they end up having to have a lot of X-Rays. So, you want to keep the dose down where you can" (Kauri - whānau)*

One participant describes a brace made in Australia as:

*"Better quality, more experienced orthotist making it, and he was pretty awesome" (Kauri - whānau)*

One participant fundraised to afford VBT in Turkey.

*"The surgeon we went to see now has a whole new department in the hospital, they build a whole building for that. And they are doing braces as well as the hospital. And then the only place that they know of that the doctors are completely working hand in hand with the people who do the rest because usually it's two different scenarios and they don't overlap. And so, they create such amazing braces that they're having less and less surgeries, they have such high success rate now with the braces (...) They just make you feel at home, and you know, a little bit about their personal life and there's eye contact and there's, you know, physical touch. There is just, we felt so safe. And you know, with some of them this language barrier, we had a translator, but really, I think that it made a massive difference. But as well, of course, the good results, you know, so nice if everybody's nice, but if they're not good at what they're doing." (Kawakawa - whānau)*

## **Timeliness of New Zealand System**

Whānau found that the healthcare of rangatahi with AIS was often compromised due to the lack of timeliness of available services. The lack of preventative action and delay in between appointments was often found frustrating by whānau, as it could potentially result in curve progression which meant that bracing was no longer possible.

### **Lack of preventative action**

Many whānau instead wished for earlier interventions to be put in place, such as exercises or bracing. Some even suggested potential screening programmes to identify AIS at an earlier, more treatable stage.

*“the biggest short, like for in New Zealand is that they just say we'll just monitor and they're monitoring in the stage that it's just progressing rapidly. And this is, this is just stupid. I mean, you need to monitor but there's no intervention. It's just monitor, monitor, monitor, monitor surgery. Yeah. It's a waste of their time.”* (Kawakawa - whānau)

*“if we could diagnose it earlier and get kids into bracing, then the expense on the health system would be a lot less. It's like, that's a no brainer, but it's like, we've just got the ambulance at the bottom of the cliff rather than on top”* (Tōtara - whānau)

*“It'd be nice if she'd had some sort of checkup. Like when she left primary school. And they, you know, I just feel that in England, I think they always check up every child at that age. And I don't think that happens over here. And I think if that had happened, they might have noticed at that point, and we could have done something about it earlier. Like a brace and that would have negated the need for surgery.”* (Rimu - whānau)

### **Delay to receiving healthcare**

The delay to receiving healthcare was another negative component highlighted by several whānau. The waiting times for rangatahi with AIS to see a specialist ranged from two-four months. Consequently, rangatahi needing spinal fusion surgery were often waiting for over a year. As AIS is a progressive condition, whānau expressed concern over curves increasing in this time.

*“Wait. And you wait, and you wait. It probably took about 4 months to get in I think”* (Kauri - whānau)

*“They would then refer us to the scoliosis clinic. And he said that would take about four months.”* (Kahikatea - whānau)

When asked when this participant's spinal fusion surgery would be the participant responded:

*“They said about a year.”* (Rimu - whānau)

Participant Tōtara and Moa discussed how luckily, they decided to get treatment overseas, as the New Zealand public system took over a year and a half to provide him with a brace.

*“Because I think the brace that I was applying for here took over a year.”* (Moa – rangatahi)

*“It was a year and a half before they got in touch with me. The orthotics.”* (Tōtara - whānau)

*“So, by then my back would have gone. Pretty gone.”* (Moa - rangatahi)

## **Discussion**

Previous research into AIS largely focuses on biomedical perspectives, drawing attention to potential pathogenesis or outcomes of surgical procedures. There are few publications identifying the perceptions and experiences of those affected with AIS. Although this study

highlights several key themes from the perspectives of patients and whānau only, it is worth acknowledging these suggested areas of improvement.

Similarly to an international study, rangatahi discussed the extensive holistic impact AIS has on everyday activities, affecting mental well-being as well as physical, changes to school-life and relationships with family and friends(14). Rangatahi and whānau reported support from other whānau who have experience dealing with AIS as being very beneficial. A strong support system is vital to combat the challenges that living with AIS can bring. Having a positive social support system, eases the emotional impact of AIS and can aid the success of treatment(22). Support systems are imperative for whānau as well as rangatahi, as parenting a young person with scoliosis presents with several challenges(23). Promoting support groups for rangatahi and whānau with AIS lead by others with AIS may be a helpful initiative, to help affected rangatahi feel understood and supported.

The method of giving the diagnosis of AIS is facilitated was often reported negatively by whānau and rangatahi. Hearing the diagnosis and receiving information about treatment options within the same consultation was overwhelming and did not allow whānau time to come to terms with the diagnosis. This was often further negatively influenced by the perceived lack of sensitivity by health professionals, and lack of available information. For health professionals, imparting any life-limiting diagnosis is difficult, but must be done with sensitivity and transparency. This is important, as it has implications for future doctor-patient relationships and gives the patient better understanding of their diagnosis(24, 25). An option for patients to return back for a discussion about treatment options may be an effective solution, to allow whānau time to reflect on the diagnosis and understand the information communicated.

Participants felt that there were several potential improvements that needed to be made to the AIS healthcare. Many whānau felt that better information about treatment options was needed so they could compare local services to advanced overseas approaches. Whilst this acting on these suggestions is not an easy or inexpensive adjustment, identifying potential improvements is a positive step. In a small country like New Zealand, offering choices is difficult as AIS is an uncommon condition with low numbers in each sector. However, for other rare conditions like child cancer, national working parties (i.e. National Child Cancer Network Working Group) or managed clinical networks have been developed, where sectors are able to work in a collaborative manner, enhancing service delivery of child cancer care(26).

Improving local services is also important to reduce potential health inequalities from some patients obtaining overseas care. Many whānau sacrificed substantial time and money to obtain treatment overseas. Other whānau may not have the resources to receive this treatment, so the perceived better treatment opportunities are exclusively given to whānau with financial means. This could result in potential health inequalities.

In this study participants reported delays in receiving healthcare is another detrimental aspect of the healthcare system highlighted by participants. Many whānau reported extensive wait times before seeing a specialist or receiving surgery. Some whānau with financial means were able to be treated quickly by the private sector, further contributing to health inequalities, as early treatment could potentially prevent or reduce further curve progression.

Two participants were based on rural locations, distanced from hospitals where scoliosis care is centred. This presented further barriers to receiving treatment, with extensive transport required. One participant raised the possibility of Zoom appointments, as often the specialist did not require a physical examination during the consultation. The possible establishment of Zoom appointments could improve efficiency for both patient and specialist, allowing quicker appointments with less travel required.

Participants in some locations felt that the specialists in the public system monitored curvatures rather than offering preventative bracing. Once the curvature progressed to an appropriate degree, they offered to perform spinal fusion. Spinal fusion is a costly procedure, with lengthy recovery times(27, 28). It is unclear why this approach was adopted however shifting this focus to offering the bracing approach would be less invasive with possibly better outcomes long-term.

Early diagnosis of AIS is important and this study highlights the need to consider establishing a screening or awareness programme, and the early implementation of treatments (29, 30). A potential cost-effective initiative could be adding the forward bending test, to an existing service, such the administration of Tdap vaccination in Year seven(31). Furthermore, improving the New Zealand bracing services to equal the quality of overseas services would improve treatment experience and outcomes locally. In addition, ensuring contemporary on AIS treatment (bracing, VBT, surgery) is included in local clinical guidelines or pathways would reduce treatment variability.

This is a unique exploratory study into AIS from the New Zealand perspective. It is evident that there is an essential need for further research into the perceptions and experiences of young people with AIS and their whānau. Future studies focusing on the perspectives of AIS from health professionals would be beneficial, in order to improve current awareness and improve services further.

## **Strengths and Limitations**

This study was guided using Kaupapa Maori Research. The use of the Hui process in each semi-structured interview allowed each participant (rangatahi and whānau) to feel comfortable and encouraged open discussion. Another key strength was the use of thematic analysis, allowing emergent themes to be discussed. Our sample size encompassed a range of patients from different ages, with a range of different treatment regimes, to create a holistic view of AIS experiences. There was an imbalance of females to males, however this is justified as AIS is more common in females than males(1). Furthermore, the experiences shared from each participant are very valuable, as it is the foundation for future studies on this matter. This study is the first of its kind in New Zealand focusing on people's experience with AIS, an issue currently underrepresented in research. From this, recommendations can be systemically developed.

Despite these strengths, the sample size for this study was relatively small. In addition to this, rangatahi do not always present rich descriptions and were often hard to encourage discussion. Focus groups of rangatahi be another tactic to facilitate this, as rangatahi may be more inclined to share experiences with their peers(32).

## Conclusion

Adolescent Idiopathic Scoliosis is a condition that has immense impact on the lives of rangatahi and whānau. There is a substantial lack of qualitative research exploring the awareness and perceptions of people affected by AIS especially in the New Zealand study. This exploratory study has highlighted several matters that need to be discussed to improve the experiences of rangatahi with AIS. Future research into this area as well as exploring the perspectives of health professionals will be beneficial to explore this subject further.

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# Young Adult Diabetes Service CCDHB: How are we doing and what improvements can we make?

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## Abstract

Diabetes can lead to significant morbidity and mortality if chronically poorly managed. Young adulthood can prove quite a risky time for people with diabetes, due to significant physiological and psychosocial changes occurring during that stage of life. As such, it is essential that health services pay particular attention to this group of people, and ensure effective support and education is given throughout early adulthood. Within the Wellington region, the Capital & Coast District Health Board has formulated a service specific for this 18 to 25 year old age group, with significant changes to the service made at the end of 2018. This report aims to examine the impact of these changes on patient wellbeing, as well as auditing how well these changes have been put into practice.

## Introduction

Diabetes mellitus is a chronic condition associated with a wide variety of potential complications, and requiring lifelong vigilance and monitoring of glycaemic control. Young adults with diabetes are a particularly vulnerable group for multiple reasons. Firstly, transition into adulthood is often accompanied by a range of other physical, physiological, and psychosocial changes which may impact on the ability to consistently and effectively maintain glycaemic control.<sup>1-5</sup> Secondly, due to the increased life expectancy in recent years, particularly of individuals with Type 1 diabetes (T1DM), there is a focus on prevention of morbidity in later life.<sup>6-8</sup> The habits that are put in place during adolescence are also often those which follow-through into adulthood.<sup>14-15</sup> Accordingly, it is paramount that adequate education, support, and reinforcement is provided to this group to secure them the best chance at a complication-free adulthood.<sup>6-9</sup>

Many international organisations have acknowledged the importance of supporting young adults through this difficult life transition, and have hence developed guidelines outlining the specific recommendations for support and education in this age group.<sup>10-12</sup> These guidelines acknowledge the importance of a holistic approach to diabetes care, including input from psychological and dietetic services. Furthermore, the value of discussions around alcohol, other drugs, contraception, and other social factors are also emphasised.

Within the NZ context, the Paediatric Society of New Zealand Clinical Network, Children and Young People's Diabetes Services released a 'Consensus Statement on Transition' in 2017, which includes national recommendations for those who have transitioned out of the paediatric service.<sup>13</sup> Consequently, at the end of 2018, large changes were made to the Capital and Coast District Health Board (CCDHB) Young Adult Diabetes (YAD) service in an attempt to provide a service which is more congruent with national guidelines.

This study examined the YAD service by two modalities. Firstly, a quantitative retrospective audit was completed to assess the YAD service at Wellington and Kenepuru hospitals since changes were made to the

service at the end of 2018. This was then compared against features of the service during 2017/18, before the service change, with the aim of determining the impact of the changes as well as identifying areas where improvements can still be made. Secondly, a mixed qualitative and quantitative questionnaire was created and distributed to collect the opinions of patients currently enrolled in the service, in a further attempt to identify areas of success and potential improvement within the YAD service.

## Methods

### 1. YAD Audit

A quantitative retrospective audit was completed to examine the YAD service at Wellington and Kenepuru hospitals within the CCDHB from 2019 and 2020. Data was collected for all 169 patients aged 18-25 years, who attended at least one outpatient clinic appointment for management of diabetes between January 2019 and December 2020, and compared against 139 patients who met the same criteria from January 2017 to December 2018. Those that may have been part of the service, but did not attend a clinic during the investigated time were not captured in this audit.

Data was collected through patient records on the CCDHB Concerto database, alongside notes from physical patient files, and collated in Microsoft Excel. Collected variables included baseline and diabetes-specific characteristics; number of attended and 'did not attend' (DNA) clinics; the presence of a range of comorbidities; interactions with psychological, dietetic and nursing services; screening tests and checks; and a variety of discussion points during consultations. All HbA1c values for the relevant time period were also recorded alongside the corresponding date of collection.

All baseline characteristics were collected at the last time point for each individual, and included DOB; gender; ethnicity; NZ Dep score as determined by the address documented on the last clinic letter using the Environmental Health Indicators NZ website<sup>14</sup>; type of diabetes (T1DM, T2DM, monogenic diabetes); insulin regime (basal-bolus, continuous subcutaneous, none); and type of glucose monitoring (finger pricking, continuous sensing). It was also noted whether patients had had a trial of a continuous sensing system (e.g. Freestyle Libre) at any stage during the relevant time period. Age at diagnosis, entry pathway into the YAD service (paediatric, other YAD, new diagnosis), date of first YAD clinic, and transition time (if transitioning from the paediatric service) were also recorded. Clinic location was recorded as either Wellington or Kenepuru; wherever the majority of clinic appointments occurred.

Comorbidities identified included the presence of albuminuria (micro or macro); a psychological disorder (anxiety or depression); an eating disorder; peripheral neuropathy; gastroparesis; a thyroid condition; or coeliac disease. The degree of maculopathy (0-4) and diabetic retinopathy (non-proliferative: none, minimal, mild, moderate, severe; or proliferative) were also recorded for those that had a retinal screening test result within the time period or where it was noted on clinic letters. The presence of macrovascular complications, including; ischaemic heart disease; cerebrovascular disease; and peripheral vascular disease were also noted. The number of diabetes-related Emergency Department (ED) and hospital admissions were also collected, with a further breakdown as to the primary diagnosis from the admission. This breakdown included diabetic ketoacidosis (DKA); hypoglycaemia; hyperglycaemia; soft tissue infection; need for insulin supplies (in the ED admissions only); or microvascular complications.

Service interactions were documented for mental health, dietetics and nursing services. Mental health engagement included Mental Health, Addictions and Intellectual Disability Service (MHAIDS), Central Region Eating Disorder Services (CREDS), or Wellington Psychological Associates (WelPA). Referrals to WelPA were also noted separately. For dietetics, the number of attended and DNA appointments was further specified, as well as

whether patients had been referred to, or completed, the Matching Insulin To Carbs, Health And Lifestyle (MITCHAL) carbohydrate-counting course. It was also recorded whether any phone or face-to-face interaction with either a diabetes nurse or nurse practitioner was documented during the relevant time period.

The frequency of a number of diabetes screening tests was also recorded. In terms of biochemical tests, this included albumin creatinine ratio (ACR); lipids; coeliac antibodies; TSH; and B12. The occurrence of injection site checks; foot checks; blood pressure and weight measurements were also noted using information within clinic letters and notes. Furthermore, the most recent recording, within the relevant time period, for weight and blood pressure was collected. Retinal screening was also examined, and recorded as either 'up to date (UTD)' or 'due' at the end of the time period.

Clinic letters were further used, in conjunction with dietitian and nursing notes, to determine the occurrence of a range of discussion points. This included discussions around diet; physical activity (including the effects of exercise on insulin sensitivity); goals and targets; psychological health; support networks; drugs; alcohol (including alcohol safety with insulin); smoking; driving safety; contraception; pre-pregnancy planning; hypoglycaemia management; sick day management and ketone testing; immunisations; and dental care. Variables unique to the 2019/20 cohort included discussions around the impact of COVID-19 as a person with diabetes, and the completion and scoring of the diabetes-related psychological distress questionnaire.

Alongside all HbA1c values within the relevant time period, up to two baseline HbA1c values were recorded. The first baseline value was taken as the last HbA1c recording before entering the CCDHB YAD service (or as near to this date as possible). The second baseline was taken as the last HbA1c recording before the change of service (i.e. as near to the end of 2018 as possible). For those that were not involved in the service during this time period, no second baseline HbA1c value was recorded.

Assessment of 'loss to follow-up' was determined by if a patient was discharged from the service due to DNA, a re-referral was required for them to access the service, or if a patient stopped engaging with the service after the normal follow-up period had elapsed and no further interaction was documented.

It was also determined how many months, out of a maximum two year time period, each patient was active within the service. This could have been truncated for a variety of reasons, including; a referral to the service after the allotted start date, being outside of the 18-25 year age bracket for some of the time, or being discharged from the service due to DNA or moving away from the area.

Data analysis was then completed with guidance and assistance from Professor Mark Weatherall and Dr Brian Corley. Simple descriptive tables were generated using Excel software. A more complex generalized linear mixed model analysis was also completed using SAS software for mean HbA1c and loss to follow-up measurements to generate a statistical comparison.

## 2. YAD Questionnaire

An online questionnaire was created and distributed using REDCap software, to capture the experiences of patients currently enrolled in the YAD service at Wellington and Kenepuru hospitals. Questions for the questionnaire were previously written by Dr Patricia Whitfield, with the intention of investigating different aspects of the service, covering themes identified as important aspects of a YAD service.<sup>10-13</sup> A range of question types were used, including 5-point scales, short answer boxes, and yes/no questions. The full consent form and list of questions can be found in Appendix 1. The survey was distributed via email to all 106 patients. Two follow-up emails were also sent to promote further engagement; one week and six weeks after the original email was distributed. All participants had to complete the online consent form before participating in the survey.

Results of the completed surveys could then be exported to Microsoft Excel software for further analysis. Quantitative data has been illustrated through bar graphs, while the qualitative data collected will be interpreted at a later date.

## Results

### 1. YAD Audit

A total of 169 patients attended at least one endocrine clinic for their diabetes management at Wellington or Kenepuru hospitals during 2019/20; 133 in Wellington hospital, and 36 at Kenepuru. Comparatively, 139 patients were seen during 2018/17; 109 in Wellington, and 30 at Kenepuru. Key differences in baseline characteristics between both Wellington and Kenepuru; and 2019/20 ('post') and 2017/18 ('pre') cohorts, are outlined in Table 1.1. NZ European was the primary ethnicity for both Wellington and Kenepuru services in both the pre and post cohorts. However, the Kenepuru service was formed by a much higher percentage of Māori and Pacific Islanders, compared with the Wellington service. The Kenepuru service also had a greater number of patients living in the most deprived (9-10) regions of NZ, accounting for 33.3% of the post cohort, compared with only 6% of the Wellington cohort.

Expectedly, the most common form of diabetes in both cohorts was type 1 diabetes mellitus (T1DM); composing 89% of Wellington's service, and 78% of Kenepuru's service during 2019/20. There was a higher prevalence of type 2 diabetics (T2DM) among the Kenepuru cohort, constituting 19.4% of the Kenepuru cohort in 2019/20. The most common entry pathway into the CCDHB YAD service was through referral from another YAD service for the Wellington cohort, but through referral from paediatrics in the Kenepuru cohort.

In terms of diabetes management, basal-bolus dosing was the most common method for insulin administration and finger pricking the most common method of glucose monitoring. In 2019/20, flash glucose monitoring was used by 35% of the Wellington cohort, and 28% of the Kenepuru cohort; with 41% and 50% having had a trial of the freestyle libre system at some point for Wellington and Kenepuru, respectively. For insulin administration in 2019/20, 20.3% of the Wellington cohort was using continuous subcutaneous infusion, compared with 17.9% of the Kenepuru cohort.

Mean age of diagnosis ranged from 12.1 to 14.3 years, depending on the location and time of the service. For those transitioning from the paediatric service, the transition time remained fairly stable across groups, and averaged around four and a half months. Mean baseline HbA1c readings were higher for the Kenepuru service in both the pre and post cohorts ( $81 \pm 26$  vs.  $76 \pm 23$  mmol/mol for the pre cohort;  $85 \pm 26$  vs.  $75 \pm 24$  for the post cohort). However, the standard deviation illustrates marked variation in mean HbA1c readings across all cohorts.

**Table 1.1: Baseline characteristics of Young Adult Diabetes Service patients**

	Wellington				Kenepuru			
	PRE (n= 109)		POST (n=133)		PRE (n=30)		POST (n=36)	
	n	%	n	%	n	%	n	%
<b><u>Gender</u></b>								
Male	56	51.4	68	51.1	18	60.0	17	47.2
Female	53	48.6	65	48.9	12	40.0	19	52.8
<b><u>Ethnicity</u></b>								
Māori	10	9.2	17	12.8	9	30.0	8	22.2
NZ European	74	67.9	84	63.2	13	43.3	17	47.2
Pacific Islander	4	3.7	8	6.0	4	13.3	6	16.7
Asian	7	6.4	8	6.0	1	3.3	0	0.0
Other European	14	12.8	14	10.5	2	6.7	3	8.3
Other	0	0.0	2	1.5	1	3.3	2	5.6
<b><u>NZ Dep score</u></b>								
1-2	28	25.7	35	26.3	9	30.0	10	27.8
3-4	23	21.1	33	24.8	5	16.7	3	8.3
5-6	29	26.6	34	25.6	4	13.3	3	8.3
7-8	20	18.3	23	17.3	4	13.3	8	22.2
9-10	9	8.3	8	6.0	8	26.7	12	33.3
<b><u>Type of diabetes</u></b>								
Type 1	101	92.7	118	88.7	25	83.3	28	77.8
Type 2	8	7.3	15	11.3	4	13.3	7	19.4
Monogenic diabetes (MODY)	0	0.0	0	0.0	1	3.3	1	2.8
<b><u>Entry pathway</u></b>								
New diagnosis	24	22.0	29	21.8	10	33.3	14	38.9
Other YAD service	47	43.1	63	47.4	3	10.0	5	13.9
Paediatrics	38	34.9	40	30.1	17	56.7	17	47.2
<b><u>Insulin Regime for T1DM</u></b>								
Basal-bolus	84	83.2	92	78.0	19	76.0	23	82.1
Continuous subcutaneous infusion	17	16.8	24	20.3	6	24.0	5	17.9
<b><u>Glucose monitoring</u></b>								
Finger prick	75	68.8	84	63.2	20	66.7	25	69.4
Flash glucose monitoring (e.g. Freestyle Libre)	31	28.4	46	34.6	9	30.0	10	27.8
None	3	2.8	3	2.3	0	0.0	1	2.8
Trial of Freestyle Libre	34	31.2	54	40.6	14	46.7	18	50.0

**Table 1.1: Baseline characteristics of Young Adult Diabetes Service patients (cont.)**

	Wellington		Kenepuru	
	PRE (mean±SD)	POST (mean±SD)	PRE (mean±SD)	POST (mean±SD)
Mean age of diagnosis (years)	12.1±6.0	13.6±5.9	12.1±6.1	14.3±6.7
Mean transition time from paediatrics (months)	4.4±2.5	4.6±2.4	4.6±3.0	4.5±2.6
Mean baseline HbA1c (mmol/mol)	76±23	75±24	81±26	85±26

A summary of HbA1c measurements collected can be found in Table 1.2 and has also been illustrated using a box-and-whisker plot in Figure 1.1. It was found that the pre group had a mean HbA1c of 74.0±20.7, compared with 70.2±19.2 in the post group. However, this difference was found to not be significantly different, with a p-value of 0.25.

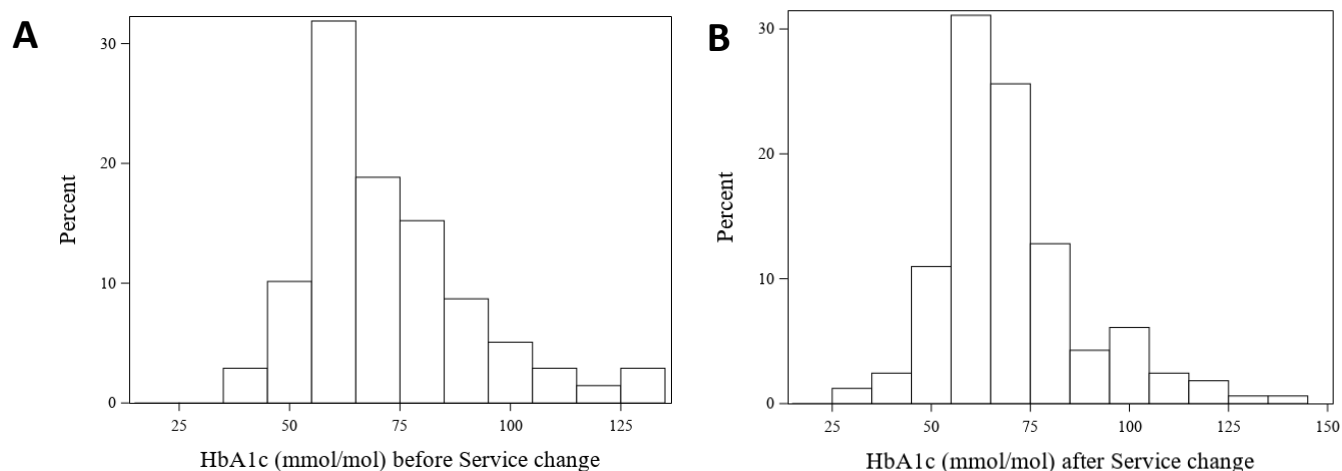
**Table 1.2: HbA1c measurements**

	Pre (n=423)	Post (n=649)
Mean (SD)	74.0 (20.7)	70.2 (19.2)
Median (IQR)	69 (60 to 84)	66 (78 to 59)
Min to Max	30 to 142	30 to 157



**Figure 1.1: Box plot of mean (by patient) HbA1c in relation to service change.** Horizontal lines represent the 25<sup>th</sup>, 50<sup>th</sup> (median), and 75<sup>th</sup> percentiles; the whiskers extend from the minimum to maximum values, and the circle represents the mean. Difference between groups = -2.5 mmol/mol (95% CI -6.7 to 1.8), P=0.25.

Histograms depicting the range of mean HbA1c values for both pre and post cohorts are present in Figure 1.2. Overall, similar trends can be seen in the distribution of mean values for both the pre and post cohorts. Both have just over 30% of the cohort within the 55-64mmol/mol range. The post cohort also has a further 25% in the 65-74mmol/mol range, compared with less than 20% in the pre cohort. Overall, the post cohort also appears to have a smaller percentage of patients with a mean HbA1c of greater than 75mmol/mol, compared with the pre cohort, suggesting a leftward shift of values.



**Figure 1.2: Frequency histogram of mean HbA1c (by patient) for both pre- and post-service changes. A) Pre-service change. B) Post-service change.**

Lost to follow up was designated to 17 patients in both the pre and post groups (12.2% and 10.1%, respectively), as shown in Table 1.3. Using a generalized linear mixed (proc glimmix in SAS) model, an odds ratio of 0.8 (0.28 to 1.67) was determined, with a p-value of 0.54. Therefore there was no significant difference in loss to follow-up rates between the two cohorts.

**Table 1.3: Lost to follow-up**

	Pre (n=139)		Post (n=169)	
	n	%	n	%
Lost to follow-up	17	12.2	17	10.1

Descriptive analyses tables have been used to outline features of the pre and post cohorts, although no direct statistical analysis has been made between groups at this stage. Table 1.4 illustrates differences in clinic attendances between the two cohorts. The 2019/20 service had an average of three clinics per person per year that were attended, with a DNA rate of 13.0%. The 2017/18 cohort had a slightly lower DNA rate of 11.7%, but also had fewer attended clinics with an average of just under two clinics per person per year.

**Table 1.4: Frequency of DNA and attended YAD clinics**

	Pre (n=139)	Post (n=169)
	mean # per person per year	mean # per person per year
DNA	0.33	0.60
Attended	1.92	3.00
Total	2.26	3.60

	Pre (n=139)	Post (n=169)
	mean %	mean %
DNA rate	11.7	13.0

Data pertaining to patients' involvement with dietetic service is outlined in Table 1.5. In the pre cohort, people attended an average of 0.35 appointments per year (one appointment every three years), and 0.14 recorded DNA appointments per year (one in seven people had a DNA each year). Comparatively, the post group attended 0.69 appointments per person per year (one appointment every year and a half), and 0.10 DNA appointments per year (one in ten people had a DNA each year). The MITCHAL carb-counting course was completed during the time period by eight people in the pre cohort (5.8%), and 15 people (8.9%) in the post cohort. A greater number of people had been referred for, but not yet attended, a MITCHAL course; 19 people (13.7%) in the pre group, and 24 people (14.2%) in the post group.

**Table 1.5: Involvement with dietetic services**

	Pre (n=139)	Post (n=169)
	mean # per person per year	mean # per person per year
Appointments attended	0.35	0.69
Appointments DNA	0.14	0.10

	Pre (n=139)		Post (n=169)	
	Yes	% of cohort	Yes	% of cohort
MITCHAL referral	19	13.7	24	14.2
MITCHAL course completed	8	5.8	15	8.9

Involvement with mental health services is another important aspect of the YAD service (Table 1.6). There was a greater use of MHAIDS and WelPA services in the post cohort compared to the pre cohort, with 10.1% vs. 8.6% involved with MHAIDS; and 8.3% vs. 2.2% having attended WelPA consults. The number of WelPA referrals was also greater in the post cohort (16.0% vs. 2.2%). CREDS were involved in the care of two patients within the pre group, but no patients in the post cohort.

**Table 1.6: Involvement with mental health services**

	Pre (n=139)		Post (n=169)	
	Yes	% of cohort	Yes	% of cohort
MHAIDS	12	8.6	17	10.1
CREDS	2	1.4	0	0.0
WelPA referral	3	2.2	27	16.0
WelPA attendance	3	2.2	14	8.3

Both cohorts were assessed for a variety of diabetes-related complications and comorbidities, as outlined in Table 1.7. For diabetes-related ED admissions, this was 0.3 admissions per person per year in the pre cohort, and 0.21 in the post cohort; translating to an admission approximately every three years and five years, respectively. Hospital admissions were slightly lower, at 0.24 and 0.15 admissions per person per year for the pre and post cohorts, respectively. Furthermore, ED admissions were experienced by 21.6% of the pre cohort compared with only 12.4% of the post cohort. Similarly, hospital admissions were experienced by 17.3% of the pre cohort compared with 9.5% of the post cohort. In terms of DKA-specific admissions, this was also reduced within the post cohort, with a mean frequency of 0.06 (down from 0.17) ED admissions per person per year, and 0.07 (down from 0.17) hospital admissions per person per year. DKA admissions also accounted for a smaller percentage of both the ED and hospital level admissions in the post cohort; accounting for 30% vs. 60% of ED admissions, and 45% vs. 72% of hospital admissions. This means that the frequency of DKA admissions dropped more significantly than the overall decrease in admission for the post-group.



In terms of comorbidities, higher rates of retinopathy (25% vs. 21%), anxiety or depression (17% vs. 14%) and eating disorders (4% vs. 3%) were recorded in the post group. Comparatively, the post cohort had lower rates of albuminuria (13% vs. 21%) and peripheral neuropathy (2% vs. 4%).

**Table 1.7: Frequency of complications and prevalence of comorbidities**

	Pre (n=139)	Post (n=169)
	mean # per person per year	mean # per person per year
ED admissions	0.30	0.21
DKA	0.17	0.06
Hospital admissions	0.24	0.15
DKA	0.17	0.07

	Pre (n=139)	Post (n=169)
	mean %	mean %
Rate of ED admissions related to DKA	58%	30%
Rate of hospital admissions related to DKA	72%	45%

	Pre (n=139)		Post (n=169)	
	Yes	% of cohort	Yes	% of cohort
Albuminuria	29	20.9	22	13.0
Retinopathy	31	22.3	43	25.4
Peripheral neuropathy	5	3.6	4	2.4
Anxiety / Depression	20	14.4	29	17.2
Eating disorder	4	2.9	6	3.6
ED admission	30	21.6	21	12.4
DKA	15	10.8	8	4.7
Hospital admission	24	17.3	16	9.5
DKA	15	10.8	8	4.7

The frequency of a variety of screening checks and tests were collected as detailed in Table 1.8. All laboratory tests occurred more frequently in the post group, including albumin creatinine ratio (ACR) (1.83 vs. 1.53 times per person per year); lipids (1.81 vs. 1.24); coeliac antibodies (0.49 vs. 0.19); TSH (0.71 vs. 0.35); vitamin B12 (0.46 vs. 0.18); and HbA1c (2.90 vs. 2.24). Injection site checks occurred more frequently in the post group (0.29 vs. 0.17 times per person per year), however foot checks occurred slightly less frequently (0.21 vs. 0.23). At least one HbA1c reading was taken for almost every person in both cohorts, with the exception of one person (0.7%) in the pre cohort, and five people (3%) in the post cohort. Retinal screening was deemed as up to date at the end time point for 76 people (55%) in the pre cohort, and 97 people (57%) in the post cohort. Conversely, retinal screening was due or overdue for 36 people (26%) in the pre cohort, and 37 people (22%) in the post cohort. The remaining people did not have any record or mention of their retinal screening status.

**Table 1.8: Frequency of screening for diabetes-related complications**

	Pre (n=139)	Post (n=169)
	mean # per person per year	mean # per person per year
<b><u>Clinical examinations</u></b>		
Injection sites	0.17	0.29
Foot check	0.23	0.21
<b><u>Laboratory</u></b>		
Albumin creatinine ratio (ACR)	1.53	1.83
Lipids	1.24	1.81
Coeliac antibodies	0.19	0.49
TSH	0.35	0.71
Vitamin B12	0.18	0.46
HbA1c	2.24	2.90

	Pre (n=139)		Post (n=169)	
	Yes	% of cohort	Yes	% of cohort
At least one HbA1c recording	138	99.3	164	97.0
<b><u>Retinal screening</u></b>				
Up to date	76	54.7	97	57.4
Due	36	25.9	37	21.9

A few key discussion points were counted across documentation of clinic appointments, dietetic appointments, and nursing notes, as shown in Table 1.9. Discussions around drugs, alcohol, and contraception were all reported as occurring less than once a year per person, in both the pre and post cohorts. However, discussions of all three occurred more frequently in the post cohort.

**Table 1.9: Frequency of discussion topics during documented interactions with YAD patients**

	Pre (n=139)	Post (n=169)
	mean # discussions per person per year	mean # discussions per person per year
Drugs	0.07	0.12
Alcohol	0.36	0.68
Contraception	0.16	0.42

## 2. YAD Questionnaire

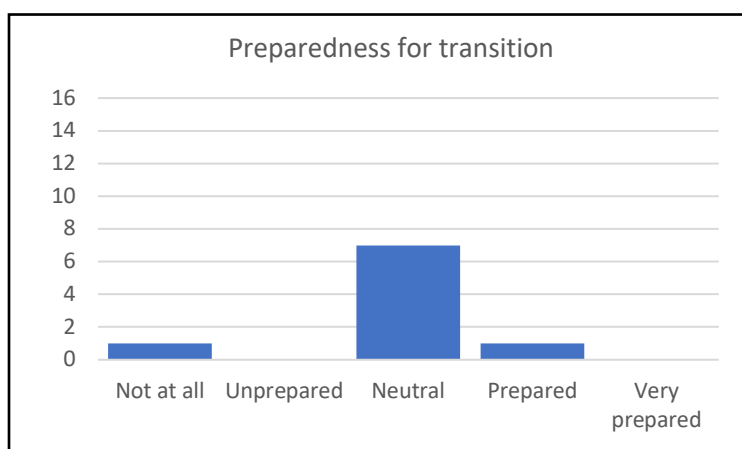
All 106 patients currently enrolled in the Young Adult Diabetes service at either Wellington or Kenepuru hospitals were asked to complete an online questionnaire regarding the service. Twenty one patients completed the survey, with their responses shown below. The basic demographics of those that completed the questionnaire are outlined in Table 2.1. Of note, the majority of responders were female (86%), identified as NZ European (95%), and attended Wellington clinics (91%).

**Table 2.1 : Baseline Characteristics of Questionnaire Participants**

	(n = 21)	% of cohort
<b><u>Gender</u></b>		
Male	3	14.3
Female	18	85.7
<b><u>Ethnicity (1 or more)</u></b>		
NZ European / Pākehā	20	95.2
Māori	1	4.8
Pacific	1	4.8
Other European	2	9.5
<b><u>Clinic Location</u></b>		
Wellington	19	90.5
Kenepuru	2	9.5
<b><u>Entry pathway</u></b>		
Paediatrics CCDHB	7	33.3
Paediatrics elsewhere	2	9.5
YAD elsewhere	5	23.8
Only seen in YAD here	7	33.3

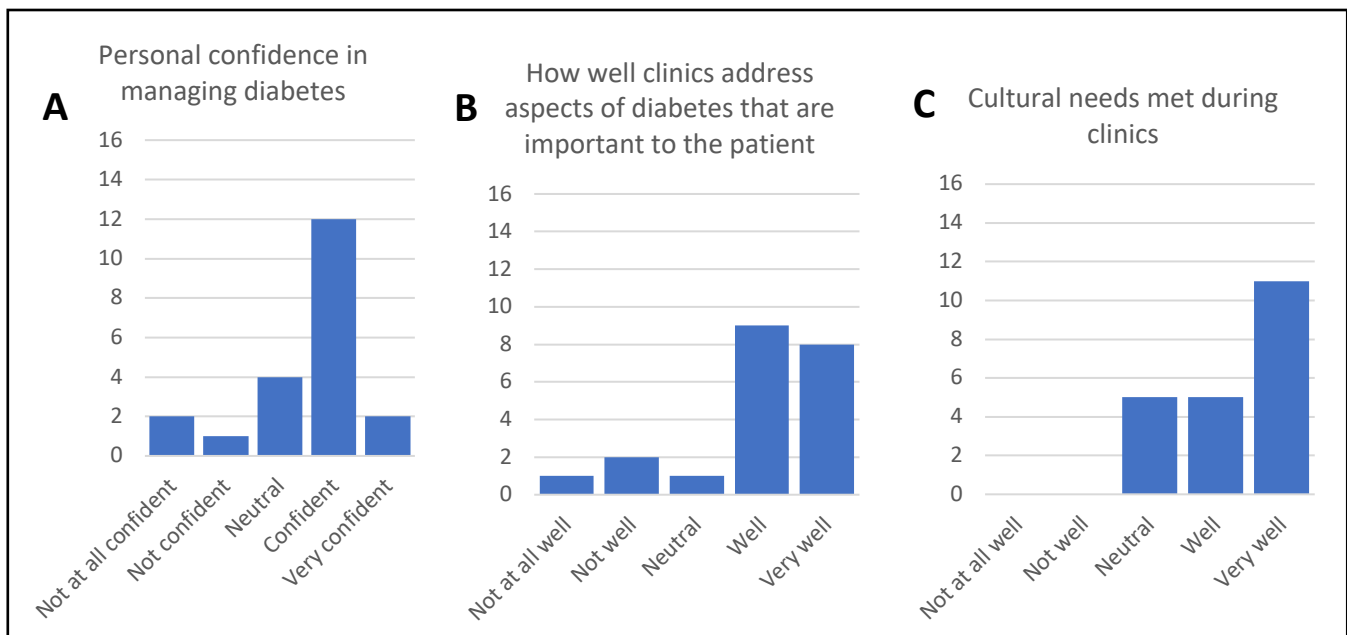
	Mean (SD)	Median(IQR)
<b><u>Age</u></b> (years)	22.7(2.2)	23(3)

Responses to questions around transition from the diabetes paediatric service to the YAD service are highlighted in Figure 2.1. Nine patients (43%) had transitioned from the paediatric service; of which only one (11%) felt not at all prepared for the transition. One (11%) felt prepared, and the other seven (78%) felt neutrally about the transition.



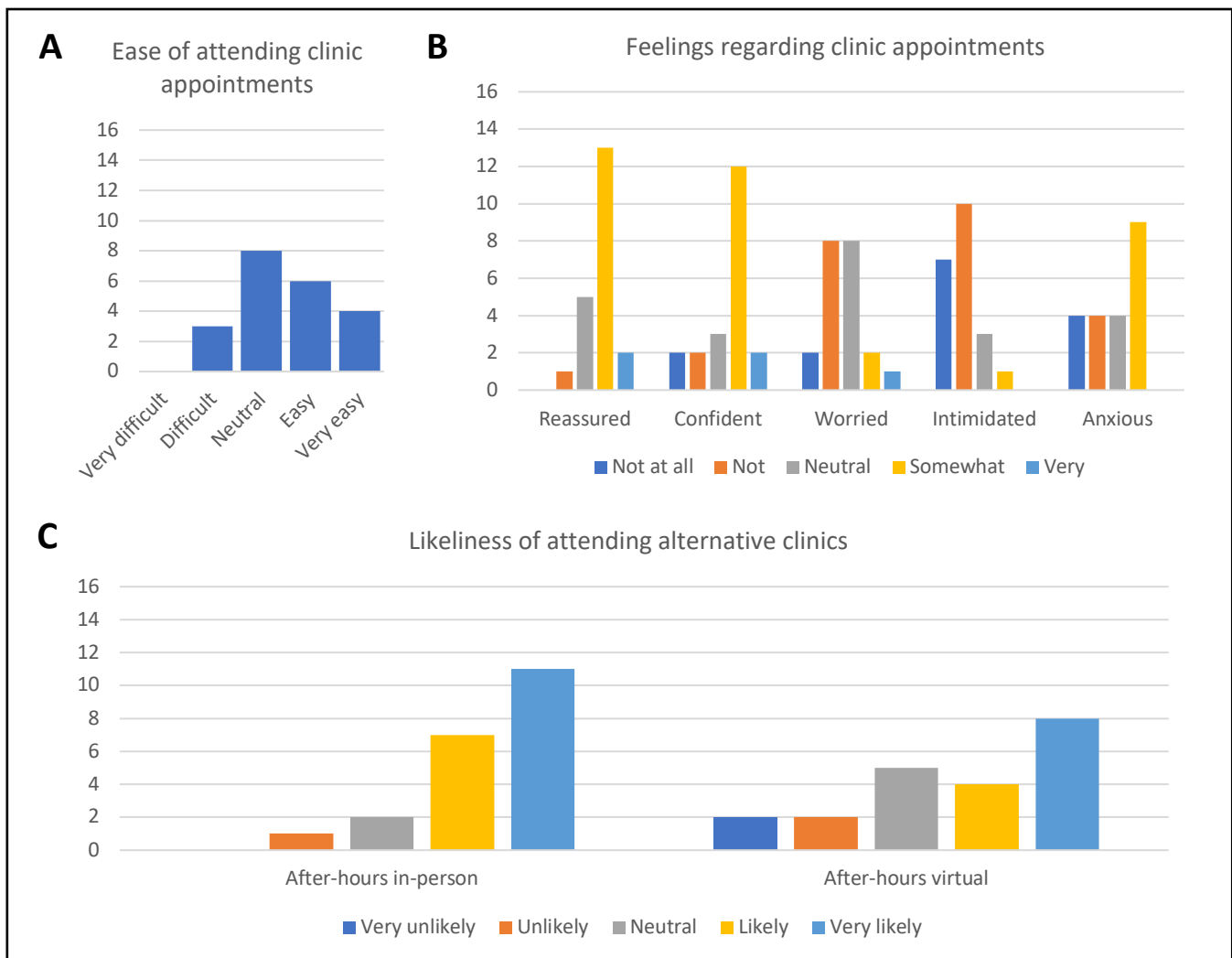
**Figure 2.1: Views on the transition from the paediatric diabetes service to the YAD service.** Bar graph showing how prepared participants felt about the transition from paediatric to young adult services, for the nine participants that underwent this transition.

Fourteen participants (67%) felt confident or very confident in managing their diabetes, while two (10%) felt not at all confident, and one (5%) not confident (Figure 2.2). In terms of clinic appointments, 17 participants (81%) felt these appointments addressed aspects of their diabetes that were important to them well or very well. All participants felt that the clinics met their cultural needs to a neutral or greater degree, with 11 (52%) rating this as 'very well'.



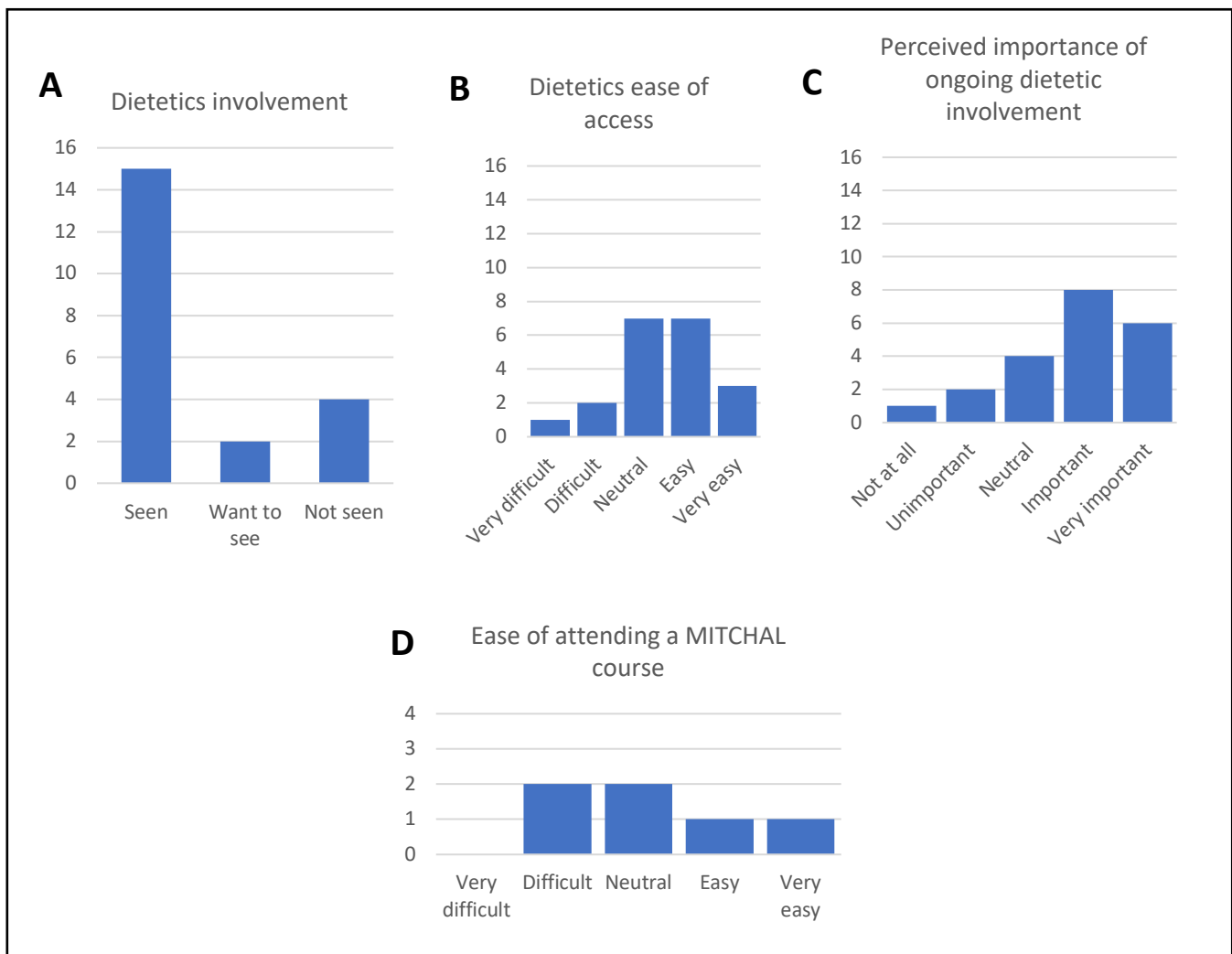
**Figure 2.2: Satisfaction of clinics and personal confidence in diabetes management.** A) Participants' overall confidence in managing their diabetes. B) Perceived satisfaction of clinic appointments meeting participants' needs. C) Perceived satisfaction of clinic appointments meeting participants' cultural needs.

Responses to questions regarding the current YAD service are illustrated in Figure 2.3. Most felt the clinics were at least neutrally easy to attend, with only three participants finding it difficult to attend clinics. In regards to participants' feelings surrounding clinic appointments, 15 (71%) felt reassured, 14 (67%) felt confident, and nine (43%) felt anxious to a somewhat or greater degree. Conversely, ten (48%) identified as not being worried, and 17 (81%) did not feel intimidated at clinic appointments. Eighteen participants (86%) were likely or very likely to attend in-person after-hours clinics, while 12 (57%) were likely or very likely to attend virtual after-hours clinics.



**Figure 2.3: Views on the current YAD clinics.** A) Perceived ease of attending clinic appointments at Wellington or Kenepuru hospitals. B) Feelings around attending clinic appointments, including degree of; reassurance, confidence, worry, intimidation, and anxiousness. C) Likelihood of participants attending other clinics, if offered, namely; after hours in-person or after-hours virtual clinics.

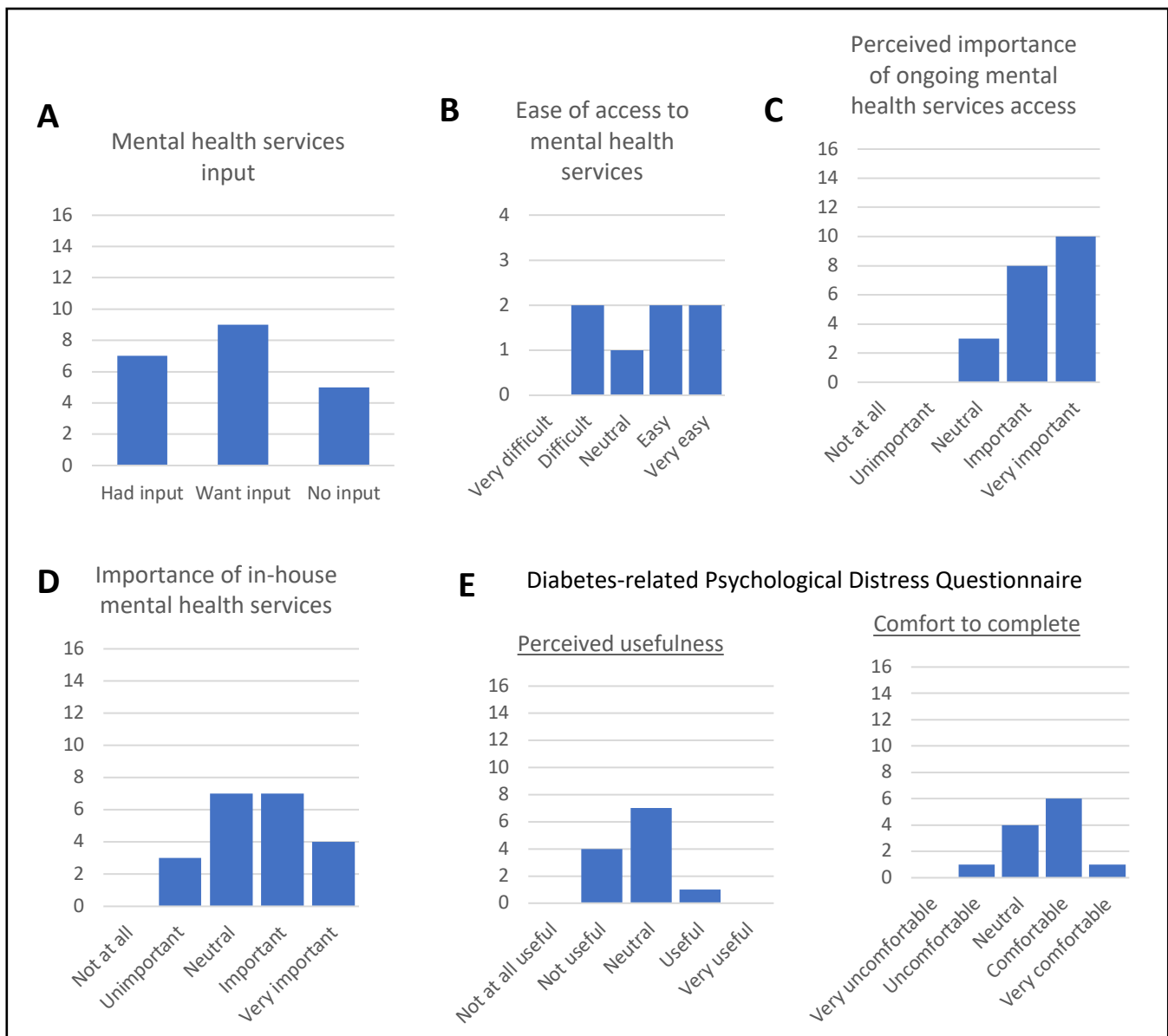
Responses to questions about dietetic input can be found in Figure 2.4. In terms of dietetic involvement, 15 participants (81%) had seen a dietitian, with only two people (10%) wanting to see a dietitian but had not yet. Only three people (14%) found dietetic appointments difficult to access, while ten (48%) found it easy or very easy to access services. Overall, dietetic involvement was perceived to be important or very important to fourteen people (67%) people. For the six participants that had attended a MITCHAL carbohydrate-counting course, two (33%) found it difficult to attend, while two (33%) found it easy or very easy to attend.



**Figure 2.4: Views on the dietetic service.** A) Participants' involvement in the dietetic service. B) Perceived ease of access to dietetic services. C) Perceived importance of ongoing dietetic involvement. D) Ease of attending a MITCHAL (carbohydrate-counting) course, for the six participants that had attended a course.

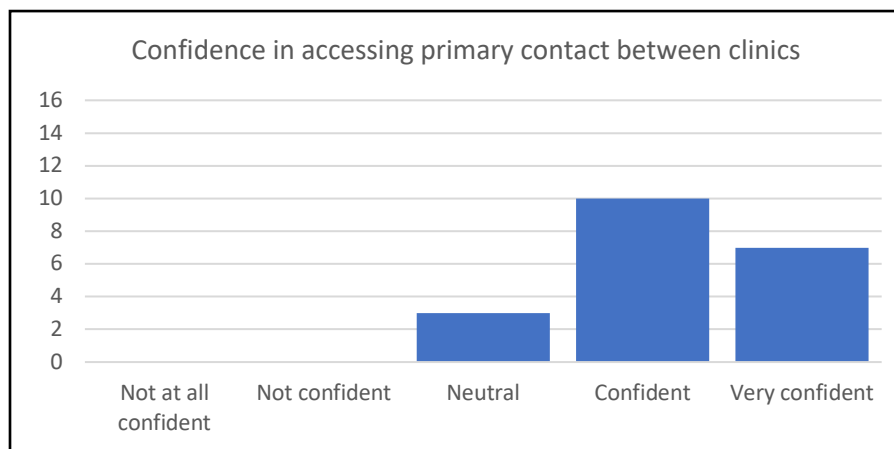
Responses to questions about mental health services input can be found in Figure 2.5. Nine people (43%) indicated that they wanted, but had not yet received mental health input, while another seven (33%) had already received input. For those that had accessed mental health services, four (57%) found it easy or very easy to attend, while two (29%) found it difficult. All participants rated ongoing access to mental health services as neutral or greater, with ten (48%) rating this as very important. Having access to in-house mental health services was rated as important or very important by 11 people (52%), while the other ten people (48%) thought this was either unimportant or were neutral on the matter.

Another aspect of mental health consideration within the YAD service is the introduction of a diabetes-related psychological distress questionnaire that patients may be asked to complete in the waiting room before attending their clinic appointment. For the twelve participants that had been asked to complete a questionnaire at some stage, four (33%) did not think the questionnaire was useful, while seven (58%) were neutral on the matter. Only one person (8%) acknowledged the questionnaire as useful. In terms of participants' comfort in completing the questionnaire within the waiting room, only one person (8%) felt uncomfortable, while the other 11 (92%) felt neutrally, comfortable or greater.



**Figure 2.5: Views on mental health input and consideration within the YAD service.** A) Participants' involvement with mental health services. B) Perceived access to mental health services, for the seven people that have had input. C) Perceived importance of ongoing access to mental health input. D) Perceived importance of having an in-house mental health service. E) Perceived usefulness, and comfort of completing, a diabetes-related psychological distress questionnaire in the waiting room before a clinic appointment, for the twelve participants that had completed a questionnaire.

A final question analysed was participants' confidence in accessing help with their diabetes in between clinic appointments; by whomever they considered their primary contact for this. Figure 2.6 demonstrates that 17 participants (81%) felt either confident or very confident in accessing this person, three people (14%) felt neutrally, and one participant (5%) did not answer the question.



**Figure 2.6: Participants' confidence in accessing help with their diabetes in between clinic appointments.** Bar graph illustrating participants' confidence in accessing help with their diabetes management, by whomever they considered their primary contact, in between clinic appointments.

## Discussion

### YAD Audit

This study has highlighted improvements to the CCDHB YAD service since changes were made at the end of 2018, although there is still room for further improvement. Small reductions in mean HbA1c levels and LTFU rates were identified following the service change, however these were not statistically significant. The mean HbA1c in the 2019/20 cohort of 70mmol/mol is still far from the recommended 55mmol/mol<sup>13</sup>; and conjunctively, a LTFU rate of 10% also illustrates the continued challenges of working with this age group.

Other variables were analysed on a descriptive basis, and therefore no conclusions can be made about statistical significance in these areas of the service. However, trends can still be noted on improvements to the frequency of a variety of screening points and discussions of relevant topics. This demonstrates a service with increased patient education, and also surveillance for early detection of potential comorbidities; both of which have been associated with improved outcomes for diabetics.<sup>6-9</sup>

There has been a larger attendance at clinic appointments, dietetic appointments, and involvement with mental health services; but DNA rates to clinics remained similar. The increased involvement in other healthcare services is particularly promising, given the importance of holistic care for effective diabetes management, particularly in the adolescent age.<sup>13</sup> Looking at mental health specifically, there appeared to be a greater need for the service, with an increase in rates of anxiety and depression, as well as an increase in rates of referral to the WelPA service. This increase in referrals may also have been a function of increasing acknowledgment of the significance of mental health for a disease like diabetes. These conversations were also prompted with the introduction of a diabetes-related psychological distress questionnaire as part of the service changes, which may initiate a referral to WelPA that would not have otherwise been identified as important. Reductions in frequencies of ED and hospital admissions were also seen in the post-service change group, suggesting that there may have been better diabetes control and therefore less diabetic emergencies in this cohort.

One of the major limitations of this study was the method of data collection. For all discussion points, and some of the screening measures, documentation in patient files or electronic records was relied upon. Anecdotally, health professionals have commented on the potential for under-documenting conversations,



particularly if they do not yield any significant concerns or conversely if there is questions about patient confidentiality in documenting this information. Therefore, one would expect that the true occurrence of these conversations has been underestimated in this study. However, the extent of this difference is difficult to ascertain.

The rates of LTFU in particular are likely also underestimated in this study, due to an element of selection bias. Patients were only included in this audit if they had attended at least one outpatient diabetes clinic during the relevant time period. Therefore, any patients that were part of the service, but not seen within this time, could not be captured.

A further limitation in this study is the effects that the occurrence of COVID-19 within the community had on the way that clinics were run during 2020; where all clinic appointments were run virtually for several months. This could have had several different impacts on the service. For example, screening rates may have decreased due to the lack of physical patient interaction and patient hesitancy at getting blood tests completed in the community. Point of care HbA1c tests could also not be completed at the time of clinic visits, which are often done if blood tests have not been completed. Conversely, there may have been increased documentation during consultations, as physicians could write notes while speaking with patients without the need for eye-contact. Degree of accessibility may also have been affected by COVID-19. Accessibility may have increased for those that struggle to attend clinics due to transportation and timing, however it may have decreased for those without access to the technology required for virtual clinics (i.e. access to a phone). There is therefore potential that the increased attendance seen in the post cohort may in part be due to the increase in virtual clinics within the service. The increased trends in screening examinations and HbA1c measurements may also therefore be an under-estimate of the improvements of the service, as this was stunted by the COVID-19 lockdown.

Overall, this audit has demonstrated the gains the CCDHB YAD service has made in recent years, and provides encouragement for continuing work to ensure the best outcomes for the future lives of our young adults living with diabetes.

### YAD Questionnaire

This questionnaire captured the opinions of 21 patients currently enrolled in the CCDHB YAD service, and were primarily NZ European females attending Wellington Hospital clinics who did not lack confidence in managing their diabetes. Their feedback was generally positive around aspect of the clinics, identifying them as meeting cultural needs and covering aspects of diabetes management that were important to them. Generally, participants felt reassured and confident at clinics, and didn't have difficulty attending.

In terms of areas of improvement to the service, both dietetic and mental health input were identified as being important, with a particular emphasis on the importance of ongoing support by mental health services. Surprisingly, little value was placed on the newly-implemented diabetes-related psychological distress questionnaire, with only one out of twelve people finding it useful.

Overall, this feedback was valuable in identifying the positive environment that the YAD clinics provide, although it should be noted that the range of demographics attending YAD clinics was not fairly represented in those that completed the questionnaire.

## Acknowledgements

Thank you first and foremost to the Maurice and Phyllis Paykel Trust for funding this valuable project. Many thanks also to the amazing diabetes team at Wellington hospital. In particular, thanks to Prof Mark Weatherall for your exquisite statistical knowledge and time, and to Dr Brian Corley also for your expert statistical knowledge and skills. To Tessa Clarke and Professor Jeremy Krebs for your enthusiasm and input. And to Dr Patricia Whitfield for your generosity of time, optimism, and continual encouragement – thank you.

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## Appendix

### Appendix 1: Consent form and YAD Questionnaire.

#### CCDHB Young Adult Diabetes Service: How are we doing and how can we improve.

*Please read the following information sheet and complete the consent form before continuing with this questionnaire.*



#### CCDHB Young Adult Diabetes Service: How are we doing and how can we improve?

#### Participant Information Sheet

##### **Investigators:**

Georgia MacKenzie, Medical Student  
Lorna Bingham, Diabetes Nurse Practitioner  
Tess Clark, Diabetes CNS  
Debbie Hughes, Diabetes Nurse  
Lindsay McTavish, Diabetes CNS  
Misty Ngatai, Diabetes CNS  
Professor Jeremy Krebs, Endocrinologist  
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You have been invited to take part in the above study. Participation is by your choice. It will not affect any future care or treatment. You may wish to discuss participation in this study with family/whānau. We are happy to provide further information to you or your whānau, either in person or via telephone. If you agree to take part in the study, you are free to withdraw from the study at any time. You do not need to give a reason for withdrawing, and this will in no way affect your current or future health care.

##### **What is the purpose of the study?**

The CCDHB Hospital Young Adult Diabetes Project is a study designed to look at:

- How successful recent changes to our YAD service have been
- What currently happens when teens leave the paediatric diabetes clinic and 'transition' to the Young Adult Diabetes (YAD) Clinic *and*
- How well the YAD clinic is meeting the needs of our patients, families and health-care providers

The methods of the study will be:

- Interviews or questionnaires with young adults attending the YAD clinic; whānau members; GPs and nurses looking after YAD patients
- Review of hospital clinic notes to check clinic attendance rates, HbA1c results of young adults who have left the paediatric diabetes clinic and now attend the Wellington or Kenepuru YAD clinic

Young adults and health professionals will be invited to participate in a survey looking at your experiences in the YAD clinic. It is expected that the time required will be between 15-20 minutes. Your responses will be anonymous and we will not be able to know your identity. You do not have to answer all the questions and you may stop the questionnaire at any time.

The online survey will be sent to you as an email link. The survey will be stored on a secure online database with password access. You may be invited to follow-up your answers with a brief telephone conversation with one of our health professionals.

### **What will happen to the information collected in this study?**

Data will be stored as digital files on the CCDHB computer system, and will be accessible only by user ID and password. Only study investigators will be able to access it. Files will be kept in our secure system for 15 years and then destroyed, as per CCDHB policy.

### **Cultural considerations**

You are very welcome to answer your questionnaire with the support of a whānau member/other support person, or meet with members of our Whānau or Pacific Support services.

For Māori health support, you are welcome to contact:

*Whānau Care Services at Wellington Hospital on (04) 806 0948*

For Pacific health support, you are welcome to contact:

*Pacific Health Unit at Wellington Hospital on (04) 385 5999 ext 4720*

### **Ethics Approval**

This research study has been assessed as minimal risk by the New Zealand Health and Disability Ethics Committee, and has been awarded Locality Approval by the CCDHB Research Office. The study design has been reviewed by the CCDHB Māori consultation committee.

### **Your rights**

If you have any questions, you can ask any member of the research team at any time. You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *Decline to answer any particular question;*
- *Withdraw from the study at any time without having to give a reason*
- *Ask any questions about the study at any time during participation*

If you choose not to take part, or if you withdraw during the study, this will not affect your future health care or treatment in any way.

If you have any queries regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability advocate:

*Free phone: 0800 555 050*

*Free fax: 0800 2 SUPPORT (0800 2787 7678)*

*Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)*

**Who may I contact for further information?**

If you would like more information about the research either before or after agreeing to participate, please contact:

Dr Patricia Whitfield, Endocrinologist

Signed, THE INVESTIGATORS

Georgia MacKenzie,

Lorna Bingham

Tess Clarke

Debbie Hughes

Lindsay McTavish

Misty Ngatai

Professor Jeremy Krebs

Dr Patricia Whitfield

Please answer the following statements before continuing:

I have read and I understand the information sheet (version 2, 23/09/2020) for volunteers taking part in this study designed to look at how our CCDHB Young Adult service is run and how we can improve it. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.	Y	N
I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.	Y	N
I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care or continuing healthcare.	Y	N
I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.	Y	N
I have had time to consider whether to take part in the study.	Y	
I know who to contact if I have any questions about the study in general.	Y	

*If yes to all of the above, the following will appear:*

I hereby consent to take part in this study (Y/N)

Date:

*If no to any of the above, the following will appear:*

You have opted to not take part in this study.

Ngā mihi nui for your time.

### **YAD Audit: Questions for patients enrolled in the YAD Clinic.**

Thank you again for taking the time to answer these questions.

It is important that we understand your experiences in the Young Adult Diabetes clinic, so we can find out what we are doing well and what improvements we can make to our service.

This questionnaire will take approximately 15-20 minutes to complete and will cover a range of topics.

#### **Section 1: Transition**

This section will explore your experiences moving into the Young Adult Clinic at CCDHB from other services.

1. What year did you join the CCDHB YAD service?
2. What best describes your situation:

- Transitioned from Paediatric service at CCDHB
- Transitioned from Paediatric service at a different DHB
- Transitioned from a Young Adult Service at a different DHB
- Have only attended the Young Adult Clinics at CCDHB

*The following questions will only populate for those who have transitioned from a Paediatric service.*

3. There are some differences between the Paediatric and YAD clinic services. Thinking back to your transition from the paediatric service, were these differences explained to you prior to transition? (Y/N)
4. How prepared did you feel for your transition to the YAD Clinic?  
(1. Not at all prepared, 2. Unprepared, 3. Neutral, 4. Prepared, 5. Very prepared)
5. How could this be improved?
6. If we were to develop a 'transition package' to introduce you to the YAD service, what do you think would be important to include?
7. When you attended your first YAD clinic appointment, did you know any of the health professionals at the appointment?  
(Y/N)
8. If you didn't, did that matter to you?  
(1. Not at all, 2. Hardly mattered, 3. Neutral, 4. Mattered somewhat, 5. Significantly mattered)
9. Once you turn 25, you will transition from the YAD clinic to the Adult Clinic at CCDHB. In the adult clinic, there is greater emphasis on self-management - you will be seen formally in clinic a little less frequently and in between visits, your GP/practice will be your first port of call for prescriptions/trouble shooting. Thinking forward to when you transition to the 'Adult Clinic' from the YAD clinic, what would you find helpful to assist with this transition?

## **Section 2: Clinic set-up**

These next questions will focus on the structure of the YAD clinics currently

10. Thinking about the formal clinic appointments, how easy is it for you to attend these appointments?  
(1. Very difficult, 2. Difficult, 3. Neutral, 4. Easy, 5. Very easy)
11. What are some of the barriers to attending the appointments?
12. How could we improve this?
13. Thinking about the formal clinic appointments, the following are some description of feelings you might experience when you have a clinic. Please indicate how well these describe your experience.
  - Reassured – (1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)
  - Confident – (1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)
  - Worried – (1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)
  - Intimidated – (1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)

- Anxious – (1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)
14. During lock-down this year, did you attend any clinic appointments via zoom or over the phone?  
(Y/N)
  15. How did you find these virtual clinics?
  16. If there was an option to continue using virtual clinics moving forward, would this be a service you would use?  
(Y/N)
  17. How would you like this to look for you?
  18. If we were to offer after hours **in person** appointments (for example after 4pm), how likely would you attend this?  
(1. Very unlikely, 2. Unlikely, 3. Neutral, 4. Likely, 5. Very likely)
  19. If we were to offer after hours **virtual** appointments, how likely would you attend this?  
(1. Very unlikely, 2. Unlikely, 3. Neutral, 4. Likely, 5. Very likely)
  20. How well do you feel your clinic appointments meet your cultural needs?  
(1. Very unlikely, 2. Unlikely, 3. Neutral, 4. Likely, 5. Very likely)

### Section 3:

#### Clinic staff and services

This next section will focus on the services provided by our clinic team

21. Where do you attend your clinic appointments?
  - Wellington Hospital
  - Kenepuru Hospital
22. Thinking about your clinic appointments every three months, how well do you feel that these address the aspects of diabetes management that are important to you?  
(1. Not at all well, 2. Not well, 3. Neutral, 4. Well, 5. Very well)
23. How could we improve this?

(Dietitian Services)

24. A major difference between the paediatric and Young Adult Clinics involves the degree of access to dietetic support. How important do you think it is to have ongoing involvement with a dietitian?  
(1. Not at all important, 2. Not important, 3. Neutral, 4. Important, 5. Very important)
25. Have you seen a dietitian or wanted to see a dietitian since attending the YAD service?
  - Yes, I have seen a dietitian
  - Yes, I want to see a dietitian, but have not yet seen one
  - No



26. How easy has it been for you to access the dietitian?  
(1. Very difficult, 2. Difficult, 3. Neutral, 4. Easy, 5. Very easy)
27. Have you attended a MITCHAL (carb counting course)?  
(Y/N)
28. If yes, how easy was it to attend?  
(1. Very difficult, 2. Difficult, 3. Neutral, 4. Easy, 5. Very easy)

29. How could this be improved?

(Mental Health Services)

30. Living with diabetes is not easy. Some young people receive psychological support for this. Since attending the YAD service, have you had, or wanted to have, psychological input.
- Yes, I have had psychological input
  - Yes, I want psychological input, but have not yet had any
  - No
31. If yes, how easy was this to access?  
(1. Very difficult, 2. Difficult, 3. Neutral, 4. Easy, 5. Very easy)
32. How important to you is it to have ongoing access to a psychologist?  
(1. Not at all important, 2. Unimportant, 3. Neutral, 4. Important, 5. Very important)
33. If important, how important would it be to have access to a psychologist 'in-house' (ie inside the hospital setting).  
(1. Not at all important, 2. Unimportant, 3. Neutral, 4. Important, 5. Very important)
34. We have recently commenced using a 'pre-clinic questionnaire' exploring diabetes related psychological distress. Have you been asked to fill out one of these questionnaires in the waiting room before your appointment?  
(Y/N)
35. Did you find filling out the questionnaire/discussing results useful?  
(1. Not at all useful, 2. Not useful, 3. Neutral, 4. Useful, 5. Very useful)
36. How might this be improved?
37. Overall, how comfortable were you filling out this questionnaire?  
(1. Very uncomfortable, 2. Uncomfortable, 3. Neutral, 4. Comfortable, 5. Very comfortable)

(Other services)

38. Thinking of the services provided in the YAD clinic, what additional services might you find useful? (for example in house psychologist; social worker; access to Drug and Alcohol support services; other forms of education)
39. Who do you consider is now the primary point of contact between clinic appointments for managing your diabetes?

40. How confident do you feel in contacting this person?  
(1. Not at all confident, 2. Not confident, 3. Neutral, 4. Confident, 5. Very confident)
41. Who would you contact for other issues in between appointments? (e.g. running out of prescriptions)
42. Is your family GP involved in your diabetes management?  
(Y/N)

(Nurse services)

43. Have you had any input from a community diabetes nurse or practice nurse?
- No
  - Yes, community nurse
  - Yes, practice nurse
  - Yes, both
44. If so, what level of input have you had?
45. Do you prefer to have input from a hospital diabetes nurse or a community diabetes nurse?
- Hospital
  - Community
46. How confident do you feel in managing your diabetes?  
(1. Not at all confident, 2. Not confident, 3. Neutral, 4. Confident, 5. Very confident)

(Final Question)

47. Can you think of any other ways we might be able to improve our service?

#### **Section 4:**

##### **Your details**

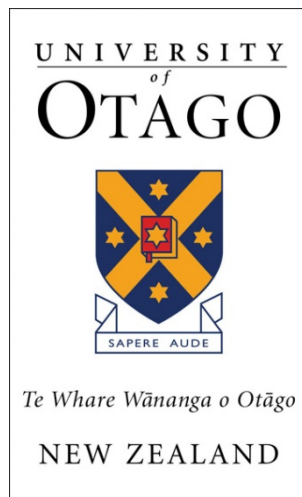
In order to ensure our service is as equitable as possible, we would like to know a few more details about you.

48. How old are you?
49. To which gender identity do you most identify?
50. What ethnic group(s) do you identify with?
- NZ European
  - Māori
  - Pacific peoples
  - Asian
  - Middle Eastern / Latin American / African
  - Other European
  - Other (please specify)

If you would like to discuss your answers further with one of our team, please provide some additional contact information:

- Email:
- Phone:

Ngā mihi nui for your time and involvement in our study!



# **Identifying Molecular Predictors of Response for Treatment of Early Stage Endometrial Cancer with the LNG-IUS**

Molly Dore

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## **Abstract**

**Introduction:** Endometrial Cancer (EC) is the most common gynaecologic malignancy in the developed world, and incidence is increasing in premenopausal women. The Levonorgestrel Intrauterine System (LNG-IUS) is gaining traction as an alternative treatment for hyperplasia and early-stage EC for women who are unable to undergo surgery. 30 to 50% of women do not respond to this treatment, making the unknown mechanisms of Levonorgestrel (LNG) resistance a critical obstacle for the conservative management of EC.

**Aim:** Isolate human endometrial cancer cells from cancer associated stromal cells and identify differentially expressed genes in LNG resistant cells compared to LNG sensitive primary human endometrial cancer cells.

**Method:** Human primary endometrial cancer cells were isolated from cancer associated stromal cells collected at the time of surgery (GB#52, GB#56, GB#60). Isolation of pure cultures was confirmed through western blotting using stromal and epithelial cell markers (CD10 and CK7 respectively) in GB#52 cells. LNG resistant cultures from three early stage endometrial cancer patients (GB#52, GB#56, GB#60) were developed. RT-qPCR was used to analyse the relative mRNA expression of 10 candidate biomarkers from GB#52 and GB#60.

**Results:** Western blot shows that CD10 protein expression is high in the cancer associated stromal cell culture and low in the human primary endometrial cancer cell culture and CK7 protein expression is high in the human primary endometrial cancer cell culture and low in the cancer associated stromal cell culture. This indicated that the isolation of the human primary endometrial cancer cells was successful. mRNA expression of MDR1 was significantly upregulated in both GB#52<sup>R</sup> MDR1: ( $p=0.0474$ ) and GB#60<sup>R</sup> MDR1: ( $p=0.0311$ ) cells lines compared to LNG sensitive controls.

**Conclusion:** Results identify that isolation of the human primary endometrial cancer cells was successful. Relative expression of MDR1 was significantly upregulated in GB#52R and GB#60R cell lines. This study suggests that MDR1 may serve as a predictive biomarker for response to the LNG-IUS and could be used to guide the treatment paradigm.

## Introduction

Endometrial cancer (EC) is the most common gynaecologic malignancy globally contributing to 3.9% of total cancers in women<sup>1</sup>. EC is generally diagnosed at earlier stages, with 75% of EC cases being classed as low-grade endometrioid EC (EEC) histological subtypes<sup>2</sup>. Currently, the standardised treatment of EEC is a hysterectomy<sup>3</sup>. However, a shift in global demographics has led to the rising prevalence of both ageing populations and obesity<sup>4, 5, 6</sup>; causing an increase in the incidence of EEC in inoperable groups. Up to 25% of EEC patients are premenopausal women who may wish to preserve their fertility<sup>7</sup> and despite women with a high BMI being more likely to be diagnosed with EEC<sup>8</sup>, up to 10% of these women in this group are deemed inoperable<sup>9</sup>. This shift is increasing the demand for conservative management of EEC.

Systemic progestogen therapy is efficacious in the treatment of hormone-sensitive tumours in inoperable women<sup>10</sup>. However, new evidence is shifting the conservative management of EC towards a long-acting reversible contraceptive device, the Levonorgestrel Intra-Uterine System (LNG-IUS). The LNG-IUS is currently used to treat women with abnormal and heavy bleeding (menorrhagia) as levonorgestrel (LNG) (a synthetic form of progesterone) suppresses endometrial proliferation through counteracting the effect of oestrogen<sup>11</sup>. The evidence base for the use of the LNG-IUS when treating EEC appears promising, with treatment in this setting yielding response rates between 52% and 67%<sup>12-14</sup>. Compared with oral progestogens, the LNG-IUS has a similar disease regression rate and is associated with fewer systemic adverse effects due to being placed locally in the uterus<sup>15</sup>. Still, the evidence appears that there is recalcitrance in LNG-IUS response for early stage EC in some women making the unknown mechanisms of LNG resistance a critical obstacle for the conservative management of EC.

Currently, the absence of predictive biomarkers for LNG-IUS treatment of early-stage EC limits the certainty of recommendation<sup>16, 17</sup>, with both response and monitoring of treatment depending on invasive biopsies every 3-6 months<sup>3</sup>. While research has been conducted, few papers investigate predictive biomarkers involved in LNG-IUS resistance explicitly, with only 3 looking at the effects of the LNG-IUS in women with EC. My previous research identified CRISPLD1, KLF4, SATB2, SOX17, ANO1 and HE4 as potential predictive biomarkers for LNG-IUS response when treating endometrial cancer. These genes alongside MSX1<sup>18</sup> and MDR1<sup>19</sup> were investigated further in primary endometrial cancer cell cultures in the current study.

This study aimed to isolate human endometrial cancer cells from cancer associated stromal cells and identify differentially expressed genes in LNG resistant cells compared to LNG sensitive primary endometrial cancer cells.

## **Method:**

### *Primary Cell lines and Ethics*

The current study used Primary cells derived from tissue samples of early-stage EC cultures donated by women as part of the gynaecological cancer tissue bank at Wellington hospital (*HDEC 15/CEN/143 and Otago H20/002*). A small section of endometrial cancer tissue was dissociated for 1 hour using collagenase type I (Sigma-Aldrich) (10mg/mg) in TESCA buffer (50 $\mu$ M TES; 0.36 $\mu$ M CaCl) (Sigma-Aldrich) diluted to 0.5mg/ml in PBS and DNase 1 from bovine pancreas (Sigma-Aldrich) diluted to 0.1mg/ml in PBS. Cell solution was passed first through a 100  $\mu$ m cell strainer then the flow through was again passed through a 40 $\mu$ m cell strainer to separate cancer-associated stromal cells from human primary EC cells. Cells were centrifuged and resuspended separately in Dulbecco's Modified Eagle Medium (DMEM/F12) (Gibco; Thermo Fisher Scientific) medium containing 10% FBS and supplemented with 100U/ml penicillin/ streptomycin. The human primary EC cells were used in the current study. Cells were grown in 5% CO<sub>2</sub> at 37 °C. Cells were passaged at 80% confluence up to four times (P4).

### *Development of resistant cell lines*

GB#52, GB#56, GB#60 cell lines were trypsinised, counted, and seeded on to a 96 well plate at a concentration of  $3 \times 10^5$  cells/ml. Following a 24h incubation, cells were treated with escalating LNG (Sigma-Aldrich # 797-63-7) dissolved in Dimethyl sulfoxide (DMSO, final concentration no greater than 0.001%) (Sigma-Aldrich) concentrations from 0-400 $\mu$ M and incubated for a further 24h. Plates were then analysed using the Cell Counting Kit-8 (CCK8) (Dojindo #CK04-11) according to manufacturer's instructions. Readings at 450 nm were obtained after 3 hours using the Thermo Scientific <sup>TM</sup> Multiskan GO <sup>TM</sup> Microplate Spectrophotometer (Thermo Fisher Scientific). An increase in absorbance indicated an increase in cell density. LNG treatment concentration for resistant clone development was identified as the point of 30% cell viability for each cell line.

LNG-resistant GB#52, GB#56, GB#60 cell lines were obtained from parental cells via continuous exposure to 150 $\mu$ M LNG dissolved in 0.001% DMSO. A DMSO control was created for each cell line at a dose of 0.001% dissolved in respective culture media.

### *Western blot*

Protein lysates were separated on a 4 to 20%, Tris-Glycine, 1.0 mm, Mini Protein Gel (Thermofisher Scientific) for 90 minutes. Following this gels were transferred onto a membrane and blocked in 5% non-fat dairy milk (NFDM) for 1 hour. Membranes were then incubated overnight at 4°C in primary antibodies anti-CD10 (Abcam #256494) and anti-CK7 (Abcam #68459). Membranes were then washed and incubated in secondary antibody goat Anti-Rabbit IgG H&L (HRP) (Abcam #205718) at room temperature for 1 hour. Membranes were visualized using chemiluminescence ECL solutions and quantified using the iBright western blot imaging system (Thermofisher Scientific).

### *RNA extraction*

RNA extraction was carried out as previously described <sup>20</sup>. LNG resistant cells and LNG sensitive controls for GB#52, GB#56 and GB#60 cells were harvested, pelleted, and the RNA from these cells extracted using the zymo *Quick-RNA* kit (Zymo cat# R1057) according to the manufacturer's instructions. RNA quantification (in ng/μL) and purity was assessed using the NanoDrop spectrophotometer (Thermo Fisher Scientific). A 260/280 and 260/230 ratio of ~ 2 was considered optimal.

### *RT-qPCR*

Conversion of RNA (1μg) to double-stranded cDNA was carried out using the QuantiTect® RT kit following the manufacturer's instructions (Qiagen #205311). RT-qPCR analysis was carried out as previously described <sup>20</sup>. 25 ng of cDNA, 100 nM of primers and 12.5μL SYBRGreen master mix (Qiagen # 204143) was used in each reaction. RT-qPCR cycling conditions were 95°C for 10mins, (95°C for 15 seconds, 60°C for 30 seconds, 72°C for 40 seconds) for a total of 40 cycles and then 95°C for 60 seconds, followed by melt curve analysis. C<sub>t</sub> values were analysed using the Vandesompele normalisation method <sup>21</sup> against three housekeeping genes Succinate Dehydrogenase Complex Subunit (SDHA), 90 kDa Heat Shock Protein 1 Beta (HSPCB) and 60S Ribosomal ProteinL13a (RPL13A).

### *Statistical analysis*

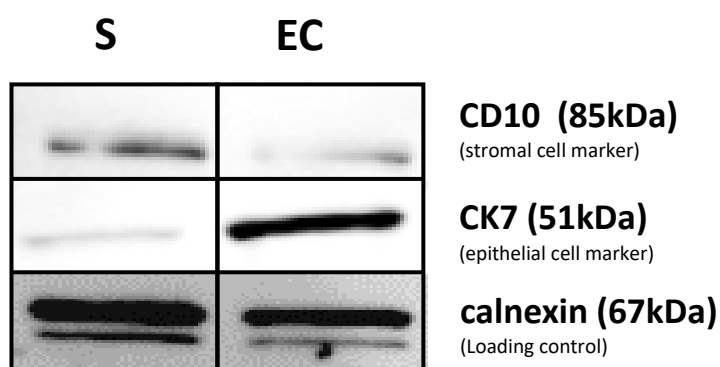
An unpaired student's t Test was carried out for comparison of differentially expressed genes (DEGs) between LNG resistant and LNG sensitive GB#52 and GB#60 cell lines. A p value of ≤ 0.05 was considered statistically significant. Technical triplicates (n=3) were carried out for each RT-qPCR experiment.



## Results:

### *Purification of human endometrial epithelial cells*

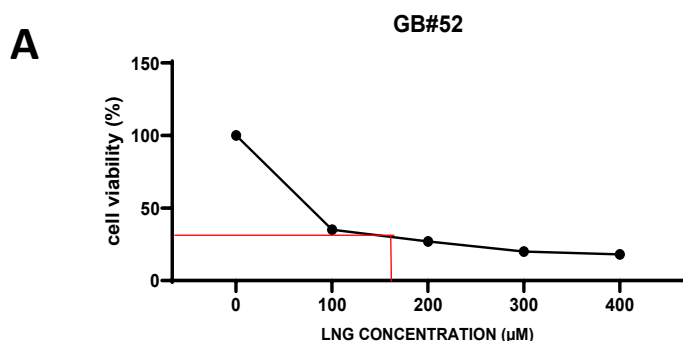
Following optimisation of cell isolation protocol, human EC cell cultures and cancer associated stromal cell cultures were evaluated for their purity. Western blotting was carried out on GB#56 isolated cell cultures. Results showed that CD10 protein expression is high in the cancer associated stromal cell culture and low in the human primary EC cell culture and CK7 protein expression is high in the human primary endometrial cancer cell culture and low in the cancer associated stromal cell culture (**Figure 1**). The calnexin (loading control) band was slightly thicker in the cancer associated stromal cells than the human primary EC cells (**Figure 1**).

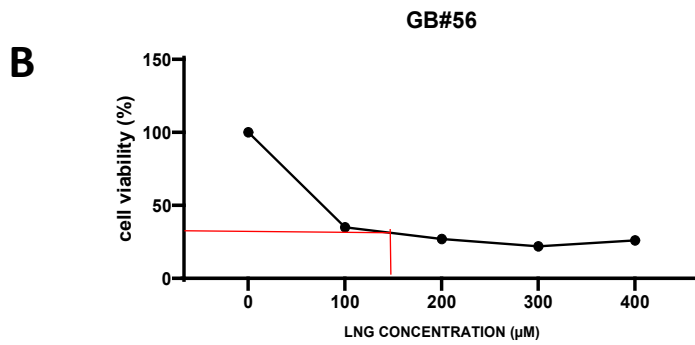


**Figure 1: Western blot of GB#56 primary human EC cells and cancer associated stromal cell cultures.** Western blot shows that CD10 protein expression is high in the cancer associated stromal cell culture and low in the human primary endometrial cancer cell culture and CK7 protein expression is high in the human primary endometrial cancer cell culture and low in the cancer associated stromal cell culture. This indicates that the isolation of the human primary endometrial cancer cells was successful.

### *Development of resistant cell lines*

To determine the concentration of LNG the cells were constantly exposed to in order to develop resistance, a kill curve was carried out. CCK8 was used to observe cell viability across increasing LNG concentrations from 0 $\mu$ M to 400 $\mu$ M. The point at which 30% viability was observed was chosen as the LNG concentration for long term treatment. This point was 150 $\mu$ M LNG for GB#52 (**Figure 2A**) and for GB#56 cell lines (**Figure 2B**).





**Figure 2: Determination of LNG treatment concentrations**

Human primary EC cell lines respectively after increasing LNG doses of 0μM, 100μM, 200μM, 300μM and 400μM. **A)** In the **GB#52** cell line, 30% cell viability observed at 150μM, represented on the graph by the red line. **B)** In the **GB#56** cell line, 30% cell viability observed at 150μM, represented on the graph by the red line.

*LNG resistant cells express different levels of mRNA to LNG sensitive cells in human prima endometrial cancer cells*

RT-qPCR was preformed to identify DEG's between LNG resistant and LNG sensitive GB#52 and GB#56 cell lines. mRNA expression of 10 genes selected from the literature was measured using RT-qPCR. Expression is displayed as relative to sensitive cell controls. Using  $\alpha = 0.05$  as cut-off criteria for statistical significance, five DEGs were identified in the GB#52 cell line and five DEGs were identified in the GB#60 cell line. Expression of MDR1 was significantly upregulated in both cell lines.

#### GB#52

mRNA expression of HE4, MSX1 and MDR1 were all significantly upregulated the GB#52<sup>R</sup> cells compared to GB#52<sup>S</sup> cells. (HE4: (p= 0.0224), MSX1: (p=0.0263), MDR1: (p=0.0474). mRNA expression of ANO1 and HE4 was significantly downregulated in GB#52<sup>R</sup> cells compared to GB#52<sup>S</sup> cells. ANO1: (p=0.0108), ER: (p=0.000177). **(Figure 3A).**

#### GB#60

mRNA expression of ANO1 and MDR1 was significantly upregulated the GB#60<sup>R</sup> cells compared to GB#60<sup>S</sup> cells. ANO1: (p=0.000351), MDR1: (p=0.0311). mRNA expression of KLF4, SATB2 and PR were all significantly downregulated in the GB#60<sup>R</sup> cells compared to GB#60<sup>S</sup> cells. KLF4: (p=0.0135), SATB2: (p=0.004), PR: (p=0.0214). **(Figure 3B).**

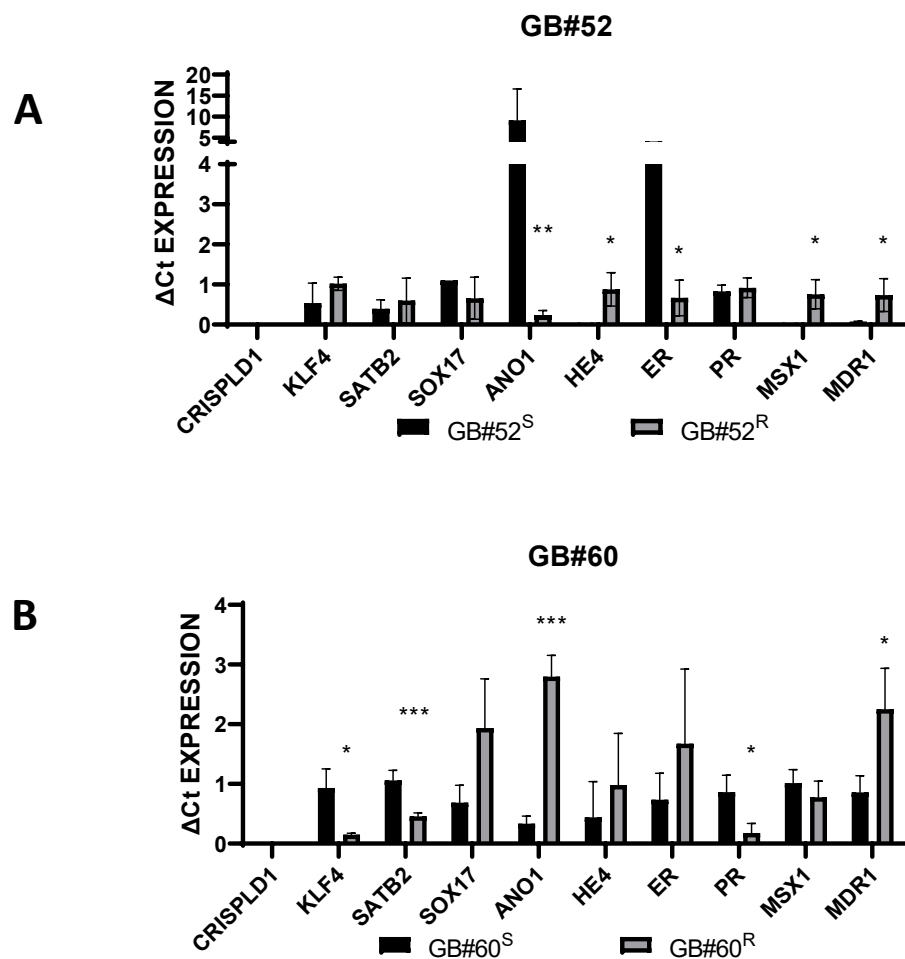


Figure 3A-B: LNG treated cells express different levels of mRNA to controls.

RT-qPCR was performed in technical triplicates and  $C_t$  values were normalised to three different housekeeping genes (SDHA, HSPCB, and RPL13A) **A)**  $\Delta C_t$  mRNA expression of key genes in the **GB#52<sup>R</sup>** and **GB#52<sup>S</sup>** cell lines. **B)**  $\Delta C_t$  mRNA expression of key genes in the **GB#60<sup>R</sup>** and **GB#60<sup>S</sup>** cell lines. Results are expressed as mean  $\pm$  SD. Individual groups were analysed using T-test.  $\alpha = 0.05$  is used as the minimum requirement to recognise statistical significance. Significance is shown via (\*). \*  $P < 0.05$ , \*\*  $P < 0.01$ , \*\*\*  $P < 0.001$ .

## Discussion

The aim of the current study was to isolate human endometrial cancer cells from cancer associated stromal cells and identify differentially expressed genes in LNG resistant cells compared to LNG sensitive EC cells. These DEGs could go on to serve as potential biomarkers to predict response to the LNG-IUS. Results identify that isolation of human primary endometrial cancer cells was successful. The stronger calnexin band in the cancer associated stromal cell culture could be down to incorrect loading of the sample into the gel or faults made during the BCA assay for protein concentration determination. If this protocol were to be done again it would be beneficial to use a more consistent loading controls such as GAPDH<sup>22</sup> or  $\beta$ -tubulin<sup>23</sup> which are both widely used and described as the most accurate loading controls. Interestingly, gross morphology of the cells indicated that isolation has not been successful, due to the accepted understanding that epithelial cells in the endometrium are columnar or cuboid shaped and develop in honeycomb patterns with little variation in size or shape and stromal cells are spindle shaped and form in cohesive groups. In the current study, both cancer associated stromal and primary EC cell cultures appeared spindle shaped and formed in cohesive groups. Only further investigation with western blotting confirmed that isolation had been achieved.

Ten potential biomarkers were identified in the literature and mRNA expression was investigated in LNG<sup>R</sup> and LNG<sup>S</sup> cell lines. Expression of multidrug resistance gene 1 (MDR1) was significantly upregulated in resistant cell lines (GB#52<sup>R</sup> and GB#60<sup>R</sup>) compared to LNG<sup>S</sup> controls. P-glycoprotein (P-GP) is a drug efflux pump that is coded by the MDR1 gene, both of which has been shown independently to be associated the multidrug resistance in cultured cell lines<sup>24</sup>. P-GP has also been shown to play an important role in carcinogen distribution and is connected with cell differentiation and apoptotic processes leading to endometrial carcinogenesis<sup>25</sup>. This could be an indication that the LNG resistant cells have a stronger oncogenic potential than LNG-sensitive cells. Terek *et al.*, has shown that premenopausal endometrial cancer patients have a significantly higher P-GP expression than post-menopausal patients and that P-GP immunoreactivity decreases with age<sup>19</sup>. Interestingly, progesterone has been proven to inhibit P-GP<sup>26</sup>, meaning conventionally, progesterone would be a successful treatment for EC as it inhibits the constant efflux of the drug, so the potential mechanism of resistance could be through an upregulation of MDR1, and therefore P-GP, which cannot be inhibited by progesterone treatment.

Overall, this study suggests that MDR1 has the potential to serve as a predictive biomarker for response to the LNG-IUS. The  $\Delta$ Ct mRNA expression of MDR1 and all other investigated genes in this study should be further analysed to determine if they can serve as predictive biomarkers that can be used clinically.

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## **Conflicts of interest**

The authors state they have no conflict of interest

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# UNDERSTANDING COMMUNITY HEALTH WORKER INFORMATION NEEDS IN A PANDEMIC

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## UNDERSTANDING COMMUNITY HEALTH WORKER INFORMATION NEEDS IN A PANDEMIC

The need for clear communication in a crisis is being demonstrated on a global scale as the world continues to manage the outbreak of COVID-19. Countries around the world are facing the challenges that come with large scale crisis and risk communication to the public (1). The management of this task has been directed by major organisations, including the World Health Organisation (2), and has been investigated in research around the world. The communication to health workers on the front-line of the pandemic effort, in comparison, has been less researched. However, for these workers, having a complete understanding of COVID-19 is essential to their ability to carry out their essential work (3). Health workers have been faced with not only the uncertainty felt by everyone in these unprecedented times, but also the constantly changing expectations for their practice and their own safety (3). This study will look at how New Zealand, as a country praised for its crisis communication to the public (4), understood the information needs of its health workforce in the community during these extraordinary times. This will identify the necessary changes that need to be made to ensure that New Zealand continues its success in outbreak management through effective communication across all levels of the population and workforce.

### Objective

This study should identify some of the strengths and weaknesses in COVID-19 communication to community health workers. It will have a focus on examining the information output from the Ministry of Health (MoH) website, which was one of the primary government outlets of information to the health workforce.

The short time frame of this research will limit this study to a small sample size of no larger than 10 participants. This may limit the generalisability of the results as a larger study pool would be required for the formation of more robust conclusions. However, this study proposes a starting point to highlight areas for improvement in communication to health workers on the frontline.

The study will investigate COVID-19 communication to health workers between the dates of New Zealand's first COVID-19 case in February 2020, to when they are interviewed in January 2021.

### Research Questions

#### **Primary:**

How effective have general practitioners, nurses, midwives and primary health organisation's found communication about COVID-19 to be while working in the community during New Zealand's management of the pandemic?

#### **Secondary:**

What **sources** of information did these health workers access and, if they utilised the **Ministry of Health website**, what did they use it for and how useful did they find it?

## **Rapid Literature Review**

### **Rapid literature review of existing international research investigating COVID-19 communication to health workers**

**Question:** How effective have health workers found communication about COVID-19 to be while working in the COVID-19 pandemic?

#### **What does the research tell us?**

2020 studies completed in Australia/New Zealand (5), Japan (6) and New York (7) all had health workers comment on their struggle with the infrequency of COVID-19 updates. Participants in the New York study also commented on how the frequency and content of updates were substantially different between health workers that were working in hospitals and home health care workers. Health care workers who provided care in the homes of patients felt invisible to help from their respective agencies. This led them to seek out information for themselves from sources such as workers' unions, government briefings and social media. The Australia and New Zealand study focused on PPE training programmes. These studies similarly found that, since the COVID-19 outbreak, health workers have not received sufficiently regular updates surrounding this safety information.

The Japanese study focused on the attitudes of health workers in the H1N1 pandemic in Japan, to predict work behaviours in the COVID-19 pandemic. This study links trust as a key factor for the willingness of health workers to work in a pandemic. It found that the frequent provision of information was one of the best ways to promote trust in the workforce, "regular and timely information was useful for alleviating anxiety to some degree".

These three studies highlight the importance of timely updates as part of effective communication to health care workers. Therefore, this will be an important element of the New Zealand Ministry of Health's communication to assess in this research.

A rapid systematic review published in the International Journal of Health (8) also highlighted concerns about timely information, as well as the complications that come with contradictory information. This study comments on the psychological wellbeing of health workers on the frontline of the pandemic and it highlighted "organisational aspects" as a main factor affecting the psychological health of workers. These organisational aspects include the provision of timely and accurate information. It observed how major organisations, such as the World Health Organisation (WHO), have to be very clear in communication to reduce the 'fear and sense of inadequacy' in health workers. This points out the impact that poor communication could have on health outcomes if health care workers are experiencing these psychological effects.

Another major issue that the previous study emphasised was the impact of the large quantities of 'fake news' that spreads in the media. The mass amount of information available to the public and health workers creates the opportunity for information sources to contradict each other. This was also referenced in a Pakistan cross-sectional survey of health care workers as, 'The pandemic of misinformation' (9). This study found that Pakistani health care workers used social media as their main source of information. This led the researchers to conclude that health workers need to start following guidelines from reliable sources such as WHO. It will be important to assess what kinds of sources of information New Zealand health workers are relying on and whether the information that is available from New Zealand's own Ministry of Health is found to be useful.

An Italian study published while Italy was experiencing the peak of its COVID-19 outbreak in March 2020 (10), specifically points out the importance of cohesive information to health care workers. It comments on how, when there are multiple sources of information providing practicing guidelines it is, 'of fundamental importance to be able to effectively analyse and rationalise all these inputs.' It will be of interest to assess how New Zealand health care workers felt about their ability to sort and analyse the information sources they were receiving.

A rapid qualitative literature review published by Cochrane Library (3), analysed the barriers of health workers adhering to infection prevention and control (IPC) guidelines. This study highlighted the importance of how the information was presented for it to be followed. It stated that health workers were more likely to adhere

to guidelines when they weren't too lengthy or ambiguous. Reviewing the presentation of information to New Zealand health workers will be an important aspect of communication to examine.

Like the previously mentioned studies, these workers also stated that they would feel overwhelmed with constantly changing guidelines. Another point mentioned in this study was that workers were more likely to follow guidelines when they saw the value of them. This is an important part of information communication, where an understanding of the importance of information promotes adherence.

A UK study looking specifically at how health workers viewed policy formation in COVID-19 reflected many of the same viewpoints as health workers in these other studies (11). It comments on how 'rapidly changing operational instructions' due to scientific uncertainty had negative impacts on the trust of health workers. Interviewees from this study also said that this trust could have been improved if there was transparency, even when situations were uncertain. It will be interesting to see if New Zealand health workers make similar comments about the transparency of information. An important feature of this review that was not highlighted in other studies was the need for the information to be appropriately targeted to the level that the health workers required it.

**The insights from these international studies were used to guide the formation of interview questions in this research to target areas where communication could be improved from New Zealand health care workers.**

### **Hypothesis**

Key points highlighted from health workers in international research included issues with clarity of information, frequency of updates (5,6,3), contradictions between information sources (9) as well as information that was not 'sufficiently or appropriately targeted to healthcare professionals' (6). Due to the ever-changing nature of COVID-19 information, health workers in New Zealand would have likely been dealing with similar issues.

New Zealand health workers have been exposed to various sources, including government sources: the Ministry of Health (MoH) website, Āwhina app (a dedicated app to inform health workers in New Zealand about COVID-19) and media stand-ups, as well as information from their respective practices, practicing councils and colleagues. Large numbers of information sources create the opportunity for confusion and contradicting advice. Community health workers who were faced with differing sources of information during New Zealand's experience of the pandemic may have found their trust in certain sources was reduced as a result of this.

Furthermore, it is likely that the timing of the information from official sources may have been ineffective. In a time where social media is so prominent, non-official sources would have likely reported new COVID-19 information to health care workers long before they received official information regarding any changes to their practice.

In terms of the utilisation of the MoH website, it can be assumed that the majority of health workers that are part of an organised practice would follow their practices specific guidelines, while health workers that work independently would be much more likely to go directly to the MoH website for advice. This was reflected in research completed in New York City which found that health workers working outside of major institutions received reduced amounts of information (7).

Poor communication could have a range of effects on health outcomes for patients. These could seem minor, such as slight variation as to how guidelines are followed, however, this could potentially have a significant impact on New Zealand's response to the COVID-19 outbreak.

## **Method**

### **The need for research on the success of the Ministry of Health (MoH) website as an information source and other information sources specific to New Zealand health care workers was proposed**

The MoH has been working throughout the COVID-19 outbreak to keep the public and health care workers updated. However, with information and guidelines changing so quickly, the MoH intelligence and surveillance team is interested in assessing how effective health care workers have found Ministry of Health communication to be. Additionally, they are interested in what other information sources health workers have been accessing and whether all these sources of information have met the needs of our health care workers.

#### **1. A rapid literature review of overseas studies investigating COVID-19 communication to health care workers was completed**

This allowed for a brief analysis of how health care workers internationally have found communication about COVID-19 from their respective governments and other higher authorities. The results of these studies gave direction to the kinds of questions that need to be asked of New Zealand health care workers. They also directed the creation of a conceptual framework that was used to collate the interview questions and responses into different elements of what 'effective communication' was to these workers. These elements included 'content', 'time' and 'trust.'

#### **2. Research questions were formulated**

The research questions were formulated by combining the research requests of the MoH, the gaps of knowledge in current New Zealand research about health worker communication and with the aim to be able to compare the results of this research to similar international research that has already been completed.

The focus on the MoH website aims to provide direct insights into how the MoH can improve its communication as the foundation of New Zealand COVID-19 information.

#### **3. The target population was determined**

The target population was selected based on which groups of health workers would have likely experienced the most pronounced changes to their practice due to COVID-19. These workers would have consequently had the heaviest reliance on communications from higher organisations.

##### **Target population:**

Eight-to-twelve interviewees will be selected in total - comprising of midwives, community-based nurses, general practitioners and members of primary health organisations (PHOs).

##### **Inclusion criteria:**

- Midwife or GP or nurse working in the community; or
- Member of a PHO involved in the dissemination of COVID-19 information; and
- Worked between February 28<sup>th</sup> (date of first New Zealand COVID case) – date of interview.

GPs, community nurses and midwives make up most of the community workforce. Therefore, their information needs will be important to assess. Working in the community is a key part of the inclusion criteria. This is because community health workers are more likely to have been managing the information about changing guidelines to their practice independently. So their experience with communication regarding COVID-19 is likely to have been more varied.

The fourth group that will be interviewed are members of PHOs. While members of PHOs were not part of the health workforce working directly in the community, their insights will be valuable to this research, as a large part of their role during the management of the pandemic was the dissemination of COVID-19 information to health care workers.

Time for research completion is the most limiting factor for carrying out a larger number of interviews, however, these results should still allow for the formation of a comprehensive thematic analysis.

#### 4. The methodology of data collection and analysis was determined

The data collection was determined to be in the form of semi-scripted interviews. This generated qualitative data from which a thematic analysis was completed. The thematic analysis, which involves harvesting common themes from the data, encompassed the shared insights of these health professionals and will allow for valuable answers to research questions.

##### Measuring outcomes:

'How effective' communication has been will be based on how these health care workers have found the **content** of the information to be, its **timing** and how **trustworthy** they have found it.

**Content:** How did health care workers find the quality of information content to be:

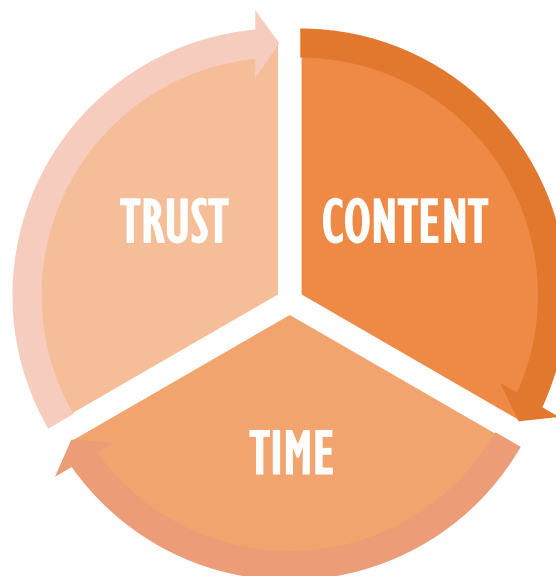
- Was there an adequate amount of information?
- Was the communication of some information excessive?
- Was it at the right level of complexity?

**Timing:** How did health care workers find the timing of information to be:

- Was the information received at a quick enough rate to be useful to these health workers?
- Did they have time themselves to utilise it?
- How frequently did they access the Ministry of Health website?

**Trust:** How trustworthy did health care workers find the information to be:

- Did the health workers have confidence in the information being correct and up-to-date?
- Did they have a sense of being well-informed?
- Did they find information sources would contradict each other?
- Did they think that access to different health workers was equal?



#### 5. Interview questions are scripted in order to answer the target questions

The interview questions are framed around the conceptual framework - trust, content and time. The questions allowed for insightful answers to the research questions.

#### Appendix 1: Interview Questions

### **6. Interview participants are located**

Emails were sent directly to the New Zealand College of GPs, New Zealand College of Midwives, New Zealand College of Nurses and primary health organisations (PHOs) around New Zealand. All of those who responded as being willing to take part in the research were interviewed.

### **7. Interviews are arranged and carried out**

Eight interviews were carried out. This allowed for a range of data to be collected while still keeping within the time frame of research completion. This group consisted of a midwife, a nurse, four general practitioners and two members of primary health organisations who had key roles in disseminating information about COVID-19 to the practices that worked with them.

### **8. Interview responses are collated and analysed**

Once all the interview responses were collated, the common themes between interviews were extracted.

### **9. Findings are summarised in a qualitative report**

The indications for improving communication that were highlighted in the thematic analysis are stated in the discussion of this report.

## **Summary of Findings**

These interviews provided rich insights into how these health workers managed, and continue to manage, the COVID-19 outbreak for their own practices and the safety of their patients. The key themes that were highlighted by these interviews are discussed below. The themes are divided into those regarding the Ministry of Health website as an information source and those regarding all other sources of information.

### **Ministry of Health website themes**

Strengths of the Ministry of Health website

- A. Uses of the website
- B. Frequency of website use
- C. Usefulness of the website
- D. Trustworthy information

## Shortcomings of the website

- E. Relevance of the information
- F. Delayed rate of updates
- G. Accessibility of the website
- H. Difficulty contacting the MoH
- I. Lack of supportive messaging

## Strengths of the Ministry of Health website

### A. Uses of the website

The primary reason health workers used the Ministry of Health website were to review case numbers, case definitions and testing criteria.

“It was useful looking at the cases and it was great having daily updates on where the cases were, as, at that initial point, we were monitoring where patients were and how close they were to us and all that sort of thing.”

“Testing criteria. The criteria got more and more complicated and so we’re always looking that up.”

Other useful aspects of the website that were highlighted by health workers were:

“The patient-facing information [was useful] for PHO community health workers and outreach nurses who needed communications for them to give to their patients.”

“They had good criteria and sort of checklists for receptionists.”

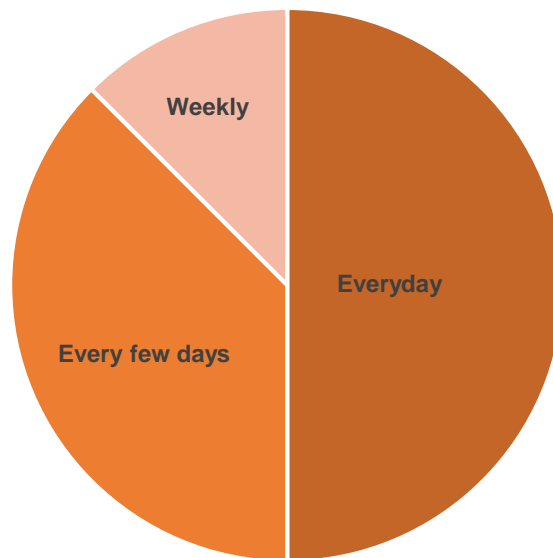
### B. Frequency of website use

Participants were asked about how often they utilised the Ministry of Health website also on a scale of 1-5:

- 1- Never
- 2- Less than weekly
- 3- Weekly
- 4- Every few days
- 5- Everyday

The graph below shows that ‘everyday’ was the most common answer, and no user accessed the website less than weekly. It is clear the Ministry of Health website is heavily relied upon as an information source.

### Frequency that health workers utilised the Ministry of Health website



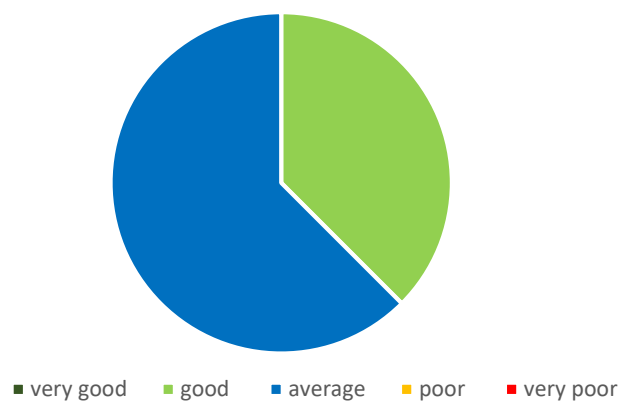
### C. Usefulness of the website

How useful did health workers find the Ministry of Health website

This question was answered on a scale of 1-5

- 1- Very poor
- 2- Poor
- 3- Average
- 4- Good
- 5- Very good

### Rank for usefulness of the Ministry of Health Website





Despite the issues health workers described with the Ministry of Health website, no health worker rated it as below 'average' usefulness.

#### D. Trustworthy information

Health workers reported the Ministry of Health website as the place they would go for information that they trust. This reputation of the website is reflected in the high frequency that all users were accessing the website.

"It's a source of truth, so you know what you're reading [was true]."

"It was always a place that I would go to. I tried to ensure that everywhere I went was an essential source of information, so it's one of my most commonly accessed sources of information."

The consistency of the messages coming from the website was another feature that reinforced this.

"The messages from the MoH were clear and in-line with what GPNZ were saying."

"The messages we got from the Director-General of Health matched what was on the website. Consistent and clear."

### Shortcomings of the website

#### E. Relevance of the information

Issues with the relevance and specificity of the website were mentioned by various roles of health workers. This was in relation to its relevance to those actually working with patients and its applicability to rural and Māori health providers.

"[The Royal New Zealand College of GPs] are much more practically based, you know, they know what it's like for us in face-to-face consultation so you know, it's just a lot more practical and relevant [compared to the MOH website]."

"Sometimes, it was not that relevant to rural areas or to Māori and I work in a Māori rural area. So, it didn't really include those types of specifics."

Recommendations for midwives from the Ministry of Health were reportedly written by an obstetrician. This had repercussions of decreasing the trust midwives had in subsequent MoH information.

"They put up a whole lot of stuff about midwifery, but it was written by an obstetrician... another profession thinks that they have something to say about how I work. It was pretty insulting that the Ministry let that happen. I think the Ministry let the midwives down by doing that and in the middle of all of this they had to rescind it and say sorry."

"I have no idea why midwives would trust the Ministry of Health. But we have to work with them, and we do, and we have an ongoing relationship with them, and so it would be great if that improves."

#### F. Delayed rate of updates

Many of the participants stated that their main use of the MoH website was to check for up-to-date information. However, there were also many comments suggesting that these updates would tend to lag.

“Generally, I found as the time went on, the MoH advice was just slightly behind what would have been prudent practice based on what was happening in other countries.”

“I thought the MoH was slightly behind in terms of dissemination of up-to-date information to general practitioners.”

“But the stuff about advice for medical professionals, it seemed to lag behind a bit, and it was sometimes contrary to what we were getting (from other sources).”

## G. Accessibility of the website

Issues with the accessibility of the information on the website was also mentioned by multiple participants. Similarly, the volume of information on the website was mentioned by these health workers in addition to this problem of accessibility.

“The information is there but sometimes it’s hard to find the right information. I actually went looking yesterday to find the current swabbing number in New Zealand, and I found it eventually, but it just took a few various tabs to find it.”

“Screens and screens of information and nothing very succinct. The other day I tried to look up how many tests have been done the previous date in the country and I couldn’t find it.”

“Very wordy and hard to navigate – a lot of info there that you have to wade through.”

“It has improved but maybe because now I know where to go. I think if I was a frontline health professional finding out where to go, I think I would find it harder than somebody who’s been using it pretty much every day for the last six months.”

## H. Difficulty contacting the MoH

Another aspect of communication difficulty with the MoH arose when health workers attempted to contact the Ministry of Health for more information.

“Trying to deal with the Ministry directly is very difficult, it’s hard to know who’s wearing a particular hat, they change hats fairly frequently, their job titles are so obscure you don’t really know if it’s the person you need to speak with.”

“We were having difficulty getting to talk to people in the Ministry about stuff. I understand that it was a busy time, we all know that”.

## I. Lack of supportive messaging

A final aspect of Ministry communication that was mentioned was the unsupportive nature of the messages that were coming to health workers:

“[RNZCGP] engaged and they actually were very supportive from that point of view. Whereas the Ministry of Health was very clinical, and they just send out a definition of what you do... I don’t feel particularly supported by the Ministry; they’re just spitting out the information just like any government bureaucracy would do, you know?”

## Common themes related to other information sources

- J. Excessive number of information sources
- K. Increased workload
- L. Inadequate complexity of information
- M. Use of Facebook as an information source
- N. The impact of incorrect information
- O. Contradictory information in the media
- P. The relationship between higher organisations and individual health workers
- Q. Underappreciation of work
- R. Frequency of updates (from all sources – not just the Ministry of Health)
- S. Understanding of unprecedented times
- T. Health worker suggestions for communication improvement

### J. Excessive number of information sources

Upon asking the participants about what sources they were receiving and accessing, the most common response from nearly every health worker was a comment on the sheer volume of information they were dealing with. Some workers did comment that more information was better:

“Sometimes people want to be over-communicated with in times of uncertainty.”

“We were hungry for information – I was one of the ones collating all the info, so I was happy to have more. Initially, it was a bit bombarding, but once I sorted out the good sources it made it easier.”

But the most common comments regarded the extra work and confusion that came with this information overload. There was a need made clear by these health workers for organisations to collate these updates into coming from a single source.

“There was definitely an overload of info, like getting the same email sent to you by 10 people, which I understand because they’re wanting to get the information out. And we’re connected to the Ministry and DHBS, and College of GPs, PHOs.”

“Some of it was very repetitive but some of it wasn’t, so you kind of almost had to read every email all the time... Rather than just forward one email on each of those three organizations kind of put their own slant on and so you had to read it in its entirety.”

“I think it was just that it kept coming via multiple sources. You would get the same email three times but then you wouldn’t get the one email that was really important.”

### K. Increased workload

All this extra information came with more work for health professionals on top of their already busy work days. This differed between roles, as well as between general practices, and whether they had the responsibility of relaying COVID-19 information to their community’s.

“Yeah, definitely, at the beginning it was daily where I was Googling, looking, searching, reading – it was a very big part of what we did here. I just really didn’t [have time in the working day]. A lot of it was after hours, all hours.”

“It was an incredibly busy time, but I make the time to read the information. Because people are asking me, ‘did read it that?’ and ‘what’s your opinion?’”

“I’ve never been so stressed in my whole life.”

“Just had to do it – 7 days a week with prolonged hours earning no money.”

#### L. Inadequate complexity of information

While the health workers repeatedly stated that they were being overloaded with information, there was still a call for the specific information they needed at the level of detailed they required it. This was mentioned by one health worker in relation to the building of CBACs (community-based assessment centres), which they had reportedly received no information on how to build and manage.

“Just a general lack of all information to be able to do these sorts of big things that we've never done before.”

“We needed a lot more detail than that for some things, but I don't think the information has really evolved much, the information as far as I know is the same now as it was six months ago.”

#### M. Use of Facebook as an information source

In previously mentioned international research, officials have raised concerns about the use of social media as an information source for health professionals. This research did not raise this question specifically, but the use of Facebook groups was a common information source pointed out by participants. These participants noted the extra support they felt due to getting information from others in their role across the country.

“The GPs for GPs Facebook website... I actually found that the most useful to be honest.”

“I belong to a couple of Facebook groups, so midwives all over the country were putting up stuff about how they were planning on running their practice. We just didn't know what we were doing, so that was really helpful, giving us ideas about what other people had come up with.”

“The practicalities of how to do stuff did come from the College of Midwives, but initially it was the Facebook groups.”

One GP working in a rural area also said that their practice used Facebook as a method of outputting information:

“We became the providers of info that people were looking to, so we were doing Facebook, you know videos and things so that our local community understood what was happening. Because a lot of the info that was coming out nationally wasn't relevant.”

#### N. The impact of incorrect information

The midwife interviewed in this research reported many instances where incorrect information delivered to the midwifery community had damaged their trust in higher organisations. Regarding information put out on the Ministry of Health website by an obstetrician that was incorrect to midwifery practice, she stated that it was:

“Actually, derogatory to midwifery.”

And she also mentioned the impact it then had on her trust:

“That was really incorrect and every time there's an incorrect piece of information or something that's really off, then it makes you doubt the rest of the information, you see what I mean? When something

is a little bit off, that's sort of understandable but when it's really off then you're like well what do they know anyway?"

## O. Contradictory information in the media

Other health workers discussed their frustration with contradictory information with reference to what was coming out in the media.

"It annoying when in mainstream media it's made out that everything's fine."

"Every day was a learning curve and every week brought a fresh insult that made us angry about something."

"[A lot] of meaningless information that was really about managing the media rather than managing the response. It was really frustrating, and I can understand it but it made it much harder for us to do our jobs."

## P. The relationship between higher organisations and individual health workers

The consequences of the disconnect between higher organisations including the MoH, DHBs, PHOs, the New Zealand College of GPs and New Zealand College of Midwives on the information flow to individual workers was emphasised by five out of the eight participants. Some of the main consequences mentioned included increasing contradictions between these sources, resulting in a decreased trust of the information. Furthermore, this was also apparent in the reverse direction, where health workers also couldn't get their requests heard by these higher organisations.

"The DHBs clearly weren't communicating to the Ministry or if they were, the Ministry was choosing not to listen. So, there were difficulties in communication between those levels."

"Our access to getting heard at different levels up the ladder was poor. Ministry and DHBs level, it was very hard for us – I wrote a lot of letters to them, mostly just got pat replies."

"I think if the Ministry and the College could coordinate next time, I think that would be much more respectful and much more useful."

"The DHBs needed much more direction sooner from the Ministry to say support your LMCs [lead maternity carers], support your community-based midwives in every way possible."

"Bad blood between us [GPs], DHBs and the Ministry because everyone's been on a different page."

"Sometimes the Ministry would get something to the DHB, so it would be a bit slower to get to us, and then by the time it came to us we would have less time to respond."

Two health workers did comment that while this disconnect between the levels was occurring, there was also some relationship building occurring between these entities.

"General Practice has been divided for many decades, so one of the positive things that's come out of this, is trying to reunify General Practice as a single voice, because we know what we need, it's trying to get the funders and politicians to try to understand that."

"I think we've learned a lot and there's certainly been a huge amount more collaboration across the sector – with us, and DHBs, and the Ministry."

One of the PHO workers also had positive comments about building a positive relationship with their DHB and how this made them feel more supported.

On feeling well-informed; “But I think maybe that might be somewhat more to do with our relationship with our DHB. We were really brought in and seen as partners within the response. Stuff that they would receive they would share with us.”

#### Q. Underappreciation of work

Some health workers expressed a sense of feeling underappreciated by both the public and higher organisations.

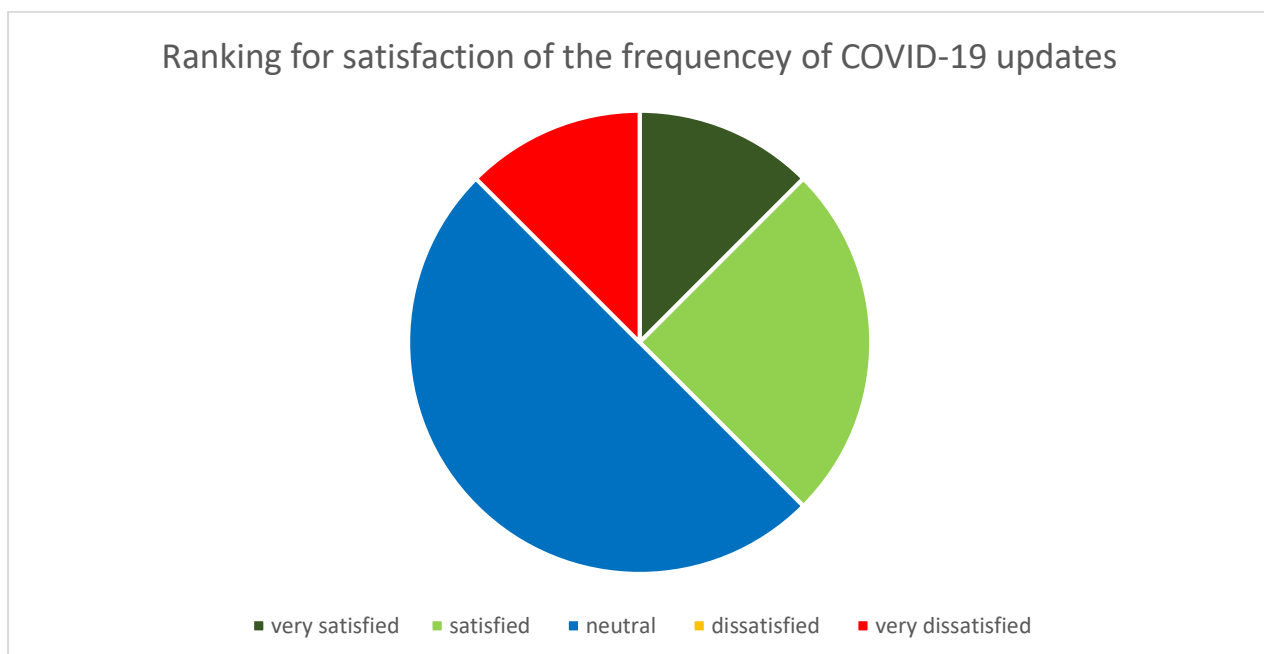
“It was interesting 'cause people started coming out of lockdown and they all had a month holiday... they all made bread and went on the treadmill... but I come out, and the midwives come out of it, absolutely shattered.”

“I don’t think the general public appreciated what it required to keep general practices functioning, the hospitals were shut but we had to stay open.”

#### R. Frequency of updates (from all sources – not just the Ministry of Health)

Participants were asked how satisfied they were with the frequency of COVID-19 updates out of 5.

- 1- Very dissatisfied
- 2- Dissatisfied
- 3- Neutral
- 4- satisfied
- 5- Very satisfied



Most participants found this question difficult to answer, as the rate of updates was so varied over the time of their pandemic management. This makes these results less reliable to draw conclusions from.

Those who answered with a range (e.g. 3-4), had their answers scaled down to the lowest value in order to get the most conservative estimates of satisfaction.

## S. Understanding of unprecedented times

Despite the frustration expressed in the interviews, seven of the eight participants expressed an understanding of the stress, pressure and constantly changing nature of the information that higher organisations were faced with.

In reference to contradicting info; “It was only coming from people trying to do the best job and we're all learning pretty fast, and things were changing really quickly”.

“It's easy to complain because we've never had to deal with something like this before.”

“You've got to appreciate that in the early days, it was the same for them as it was for us. Things were changing day-to-day and so they were pretty good”.

“It was probably really hard for the poor people who were making the testing guidelines and flow charts to keep up themselves.”

## T. Health worker suggestions for communication improvement

The main issue that workers wanted resolved was the multiple sources of information they would receive that delivered the same information. They raised the idea of having organisations improving their communication between themselves so that there could be one cohesive set of guidelines or advice delivered to health workers in the same role.

“If we had a one port of call, a group of public health physicians that sat somewhere and they spat out info that we could rely on, and also if we had a question, we could put it into an expert group and they could spit back an answer – that would have been my most useful.”

“If the three organizations that I said could have coordinated their emails, that would have been better.”

“There's never been one bible we can go read... we just need a one-page poster with bullet point of what we should be doing in terms of infection control and clinic management.”

Other suggestions included improving Māori and rural specific information, especially representation in the media.

“There was never a Māori in sight. I think it would have really helped to have Māori and Pacific input into the press releases.”

## Discussion and Recommendations

These interviews have highlighted several aspects of miscommunication about COVID-19 to health workers in New Zealand. Many of these aspects were predicted to be areas of difficulty due to the rapidly-evolving nature of the situation the world has found itself in since the beginning of 2020. One of the main themes to come out of this research was the acknowledgement from health workers that organisations were working with information that was changing as quickly as it was distributed. Recommendations and improvements in the communication of information will be focused on aspects that are fixable, even in such fast-changing situations.

Minor changes could be made to the manner in which information is delivered in order to have a large impact on how it is received by health care workers. The idea of making some of the Ministry of Health messages to health workers supportive as well as informative is something an interviewed health worker stated that the New Zealand College of GPs did well. While it is important for such critical messages to maintain a professional and authoritative tone, the addition of supportive

messages could have the potential to encourage health workers to persevere with reading information when they are inundated with emails and have limited time.

On a similar note, multiple health workers mentioned feeling under-acknowledged for the work they did throughout the COVID-19 outbreak. Increased recognition from the Ministry of the resilience of these workers could help to strengthen their relationship with health workers.

Furthermore, one health worker commented on the, 'relentlessly positive', nature of the Ministry's messaging. While acknowledging the importance of public reassurance, they discussed that this could be frustrating when some aspects of the response being discussed were incorrect. The trust and respect that is to be gained from health workers by admitting mistakes in communication, may have the potential to outweigh the benefits of keeping up an ever-positive front to the public.

The Ministry of Health website does have many references for Māori and Pacific people's specific guidelines and information. However, a health worker did still comment on the lack of this information available. It is likely that the accessibility of the website is hindering this information from being readily available to those who need it. Accessibility was also an issue for other health workers attempting to locate info from the website. This health worker also commented on the lack of Māori representation at the COVID-19 press conferences. As our Māori population are some of the most vulnerable people to be affected by COVID-19 (12), it is essential that they have representation in the press conferences that are so widely watched by the public.

The huge role Te Rōpu Whakakaupapa Uruta played in the communication of COVID-19 information to Māori was also pointed out in these interviews. The Ministry of Health could demonstrate their support for this group by providing contact information for the Te Rōpu Whakakaupapa Uruta group on their website. It will also show their recognition for the importance of Māori specific COVID-19 information.

The negative attitude towards social networking sites as information sources is something that this research shows needs to be reconsidered. While the 'pandemic of misinformation' is a very real factor to consider for both the public and health workers, this research shows that, regardless, Facebook has been a helpful, if not an essential, resource for many of our health workers. There are definite and clear benefits, including the ability of health workers to communicate rapidly directly from one colleague to another. Furthermore, the fact that it is likely frequented by many health workers for uses other than work, means that it is likely that on these occasions, they would view COVID-19 updates upon scrolling on their regular newsfeed. This would theoretically make it a great place to update health workers, if not for the ability for false information to spread so proficiently. However, if workers are going to go to sites such as these for support and information in times of crisis, the false information should just be addressed rather than completely ignoring Facebook as an information source. There could potentially be Ministry of Health 'fact-checkers' within these Facebook groups such as 'GPs for GPs' or 'New Zealand midwives'. This means that information that is posted can be shared rapidly while also ensuring that it is in-line with the Ministry of Health guidelines.

The suggestion that was mentioned by many of the health workers themselves was the need for a single source of information. Much of the 'excessive information' mentioned was the same information but from the Ministry of Health, DHBs, as well sometimes PHOs, or the Colleges of Midwives, nurses or GPs. The idea was raised by one health worker to have representatives from different groups all come together so that one output of information could then be disseminated whilst including all of these perspectives. This would improve the chance that these updates would be checked by health workers and would decrease the workload of health workers. Co-ordination between these different entities would not only be beneficial for the dissemination of information but



also for showing a general front of cohesive support for health workers in these unprecedented times.

The Ministry of Health website received many negative comments regarding its accessibility, the specificity of information for different roles and its tendency for updates to lag. However, it was still accessed very frequently by nearly all of the participants. This highlights the trust the source still maintains and the importance that its communication difficulties are resolved. There are many opportunities, as outlined in this discussion, for small changes to be made that could have a large positive effect on how information is received by New Zealand's health workforce.

While this study samples size was limited, the rich insights that were gained indicate the potential in extending this research to a larger sample size, in order to increase the understanding of health worker communication needs.

### **Ethical consideration**

Study accepted by University of Otago ethics committee

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## APPENDIX 1: INTERVIEW QUESTIONS

### Introduction

Hello [name], My name is Phoebe van Boheemen and I will be conducting the interview today.

Thank you so much for taking the time out of your day to talk to me.

As you will know, we are carrying out this research to investigate how effective health workers in the community have found communication to them about COVID-19 to be, throughout New Zealand's ongoing experience of the pandemic.

All the questions will be open to discussion with no right or wrong answers, so please describe everything in as much detail as possible, as everything you say is extremely useful information.

Do you have any questions?

I'll start recording the interview now as was mentioned in the consent form and we can get started.

1. What area of health do you work in?

### Source:

2. Since the beginning of New Zealand's management of the COVID-19 outbreak, what **sources** of information have you **received** to communicate details of COVID-19 to you as a health care worker?
3. Can you describe a time where you had to independently seek for more information other than what you received from your practice or practicing council to inform you?

**If yes** to having to independently seek information:

What sources of information have you used the most when independently seeking COVID-19 information to inform your practice?

4. What information sources did you find were the **most useful** for communicating details of COVID-19 to you as a health care worker?

What made these information sources the most useful?

5. Are you aware of the Ministry of Health's COVID-19 information app called Āwhina?

**If yes:**

Have you downloaded it?

**If yes:**

Can you describe a time where you used the Āwhina app over other information sources?

6. Did you use the **Ministry of Health website** as an information source for any information regarding COVID-19?

**If yes:**

What situation prompted you to seek information from the Ministry of Health website?

What type of COVID-19 information did you access from the **Ministry of Health website**?

Rate the usefulness of the **Ministry of Health website** out of five:

- 1- Very poor
- 2- Poor
- 3- Average
- 4- Good
- 5- Very good

What were your reasons for choosing this answer?

## Content:

7. From all official information sources aimed at you as a health care worker: What were some **categories** of information regarding COVID-19 that you thought were **inadequately and/or ineffectively communicated** to you?

What do you think was the **impact** of this on your practice?

8. From all official information sources aimed at you as health care worker: What were some **categories** of information regarding COVID-19 that you thought were **excessively communicated** to you?

What do you think was the **impact** of this on your practice?

9. From all the official information sources aimed at you as a health care worker: How did you think the level of **complexity** of the information matched what you needed to use it for?

How did that **impact** your ability to do your job?

10. How **relevant** did you find the COVID-19 information you received for guiding your practice or knowledge as a health care worker?

## Time/frequency

11. From all the official information sources aimed at you as a health care worker: How satisfied were you with the rate that COVID-19 information and guidelines were **updated** as the situation evolved?

- 1- Very dissatisfied
- 2- Dissatisfied
- 3- Neutral
- 4- Satisfied
- 5- Very satisfied

What were your reasons for choosing this answer?

12. What was your experience with finding **time** in your working day to read and understand new updates regarding the COVID-19 outbreak and its' management?

13. How often did you access the MOH website?

- 1- Never
- 2- Less than weekly
- 3- Weekly
- 4- Every few days
- 5- Everyday

What were your reasons for choosing this answer?

## Trust

14. Did you have confidence in the information being provided to you as being **consistently correct**?

15. Did you have confidence in the information being provided to you as being up to date?

16. From all the official information sources aimed at you as health care worker: Did you have a sense of being **well informed** on the situation throughout the management of the outbreak?

Can you tell me more about that?

17. From all the official information sources aimed at you as health care worker: Can you tell me about a time where different sources of information regarding COVID-19 **contradicted** each other?

What do you think was the **impact** of this on your practice?

18. What did you think the **equality of access to** information was like between different kinds of healthcare workers?

Can you tell me more about that?

## Conclusion

Thank you, that is everything I wanted to ask. Do you have anything else you want to add, or do you have any questions for me?

Thank you so much for all your time today, your insights from working in the community this year will be extremely helpful in looking at how we can improve communication to health workers in the future.