



Quantifying and understanding the impact of unmet need on New Zealand general practice

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1. KEY FINDINGS SUMMARY

This report details findings from quantitative and qualitative analyses of unmet secondary healthcare need (UMN) in New Zealand and the impact on general practice and primary care. The research presented in this report identified that, through the period from 2018-2022 covered by the quantitative study, the volume of referrals by general practitioners (GPs) to public hospital specialists has remained relatively stable. However, there has been a decline in access to referred specialist services. Results of the quantitative analyses show that the risk of being declined at prioritisation – following initial GP referral – significantly increased over time. There was a 5.2% increased risk of being declined per year. Females experienced significantly increased risk of being declined compared to males. In contrast, those in the younger age groups (0-9 years, 10-19 years) and in the oldest age group (80 years and over) had significantly lower risk of being declined. Māori and Pacific peoples also had significantly lower risk of being declined. These findings were all statistically significant. There were also important variations by former DHB region with some regions clearly in a more challenging situation than others. The findings have implications for equity and national consistency but also for the impact on managing the growing number of declined referrals in the general practice and primary care sector.

Based on insights from site visits to six general practices and a series of interviews, the research revealed that UMN through being declined access to necessary secondary services is having a significant detrimental effect not only on patients; it is also affecting the health professionals in the primary care sector involved in providing care for these patients, and impacting on the general practices they work for. The research identified that GPs, in particular, are being put at significant risk and under additional pressure managing patients with UMN. This is because GPs are increasingly working with patients who have needs that are not being met by the secondary sector. These patients have no alternative and are directed by the secondary sector when it is unable to deliver on patient needs to seek support from the primary care sector. There is no additional payment to the primary care sector for this work, no extra support from the secondary sector, no formal factoring into the workload of the primary sector, and it requires GPs to manage patients who have a genuine and clinically-determined need for specialist care. In some cases, GPs are not referring patients to secondary services as they know that there is time and administrative work involved in doing so and the referral ultimately will be rejected; in other cases, GPs are being required to work beyond their usual scope of practice and expectations.

These findings have multiple implications which demand a response. Some options are outlined in the Discussion.

2. BACKGROUND

In August 2022, GPNZ formed a planned care working group (WG) to support Dr Jeff Lowe with his appointment onto the national Planned Care Taskforce. The goal of the national taskforce was to ‘reset and restore’ planned care, as noted in its key report. The GPNZ WG was established following the taskforce establishment. The WG produced a proposal for Health NZ/Te Whatu Ora that addressed the Primary Care elements of the taskforce report. Alongside this proposal, the WG discussed the opportunity to commission a project that looked at unmet need (UMN) within Primary Care which was not covered by the taskforce. Initially, the WG discussed commissioning a literature review to understand UMN methodologies. After socialising this with University of Otago academics it was decided to commission a research project identifying UMN within General Practice as it was agreed the key methodologies had been adequately described elsewhere.

The project and research described in this report are the result of the commissioned research which was undertaken by the Centre for Health Systems and Technology (CHeST) at the University of Otago. The research was conducted in 2023-24 following a series of discussions between CHeST and GPNZ, the aim of which were to define the scope and aims of the research. It was agreed that UMN is a complex, multifaceted and distributed challenge that can be studied at different points in the health system with different aims using a variety of approaches and methods. This reflects the general complexity of healthcare systems and services organisation and provision. The methods section in this report describes how the CHeST research was undertaken, with a mix of quantitative and qualitative approaches.

The agreed scope of the research was to gain a solid understanding of the occurrence of UMN, its impact on general practices, and how it is being responded to, using a case study approach. Therefore, the focus was on generating data on the occurrence of UMN, and gathering in-depth insights into the phenomenon of patients presenting with UMN at practices, practice responses, and patient management patterns. In keeping with this, data were requested from Health NZ/Te Whatu Ora and analysed by the CHeST team. A range of questions were also investigated through six general practice case study sites in order to better understand and document the level of UMN being managed by practices. The goal was to include both mainstream and Kaupapa Māori practices as understanding the experience of Māori and non-Māori is essential to understanding and responding to identified inequities.

Some key assumptions underpinned the research, including:

- Māori patients are unfairly impacted by planned care systems. For example, they are likely to have longer wait times for planned care interventions;
- General practices are managing patients who are on hospital specialist waiting lists for significant periods of time before they are given the treatment they require;

- Therefore, patients on waiting lists are utilising general practice capacity (without additional resourcing) more than those who are not on waiting lists;
- Patients are presenting to general practice with a concern that the clinician believes requires hospital and specialist care but knows the patient does not meet the threshold for treatment and therefore do not get referred. Such patients are increasing GP workload.

Collecting data with potential to probe these assumptions was the intent of this project.

The CHeST team worked in close partnership with GPNZ throughout the research with regular meetings and assistance. This was critical to building a strong relationship with Te Whatu Ora in the process of accessing data in what was a large and complex data request, and to facilitate access to general practice case study and interview sites.

3. UNDERSTANDING UNMET NEED

UMN refers to the situation where people who need health care services do not receive these or receive inadequate or inappropriate care.¹⁻³ Unmet need can have negative consequences for individuals and society, such as poor health outcomes, high spending, productivity loss, and health inequalities in access, processes and outcomes. Measuring unmet need is important for monitoring the progress and performance of health systems and achieving universal health coverage (UHC), which is one of the targets of the Sustainable Development Goals (SDGs).² There is a well-documented history in the New Zealand public healthcare system of not measuring UMN despite widespread acknowledgement of its existence.⁴ The measurement question is important as UMN is highly likely to affect the less well-off and Māori and Pacific populations in particular. At the most basic level, these groups are more likely to be reliant on the public sector which is less likely than the private sector to be able to deliver on health care needs. It is well known that New Zealanders with private insurance or ability to pay are able to access care in the private sector.⁵ They will access the private sector often in the knowledge that they will face a significant wait time if they are referred for treatment in the public sector, or may not be offered treatment due to being considered low priority. The decision to go private is made at the point of referral and in discussion with the primary care provider. This is an unintended consequence of the institutional arrangements underpinning New Zealand's health system which date back to the origins in the Social Security Act 1938 and subsequently compromises on the system design.⁶

Defining and measuring UMN is not straightforward, as it depends on various factors, such as the availability, affordability, and quality of health services, as well as the social determinants of health, individual values, preferences, expectations, and health literacy. Different methods and sources of data can be used to assess UMN, such as surveys, administrative records, clinical guidelines, and expert opinions. Each method has advantages and limitations, and may capture different aspects of UMN.⁷

One common method is to use survey questions that ask people whether they had any unmet need for medical or dental care in a stated period (such as the past 12 months) due to cost, distance or waiting times. This method provides information on the self-reported barriers to health care access and the extent of UMN across different population groups. Such questions are included in the NZ Health Survey and surveys undertaken by the Commonwealth Fund international comparison studies and others.⁸ However, these methods do not capture other dimensions of UMN, such as quality issues, how patients with UMN are managed, the impact on services such as general practice, lack of awareness or diagnosis, or dissatisfaction with care received or which is inaccessible.⁹

According to survey methods, on average across 27 OECD countries with comparable data, only 2.6% of the population reported UMN for medical care in 2019. However, there was considerable variation across countries, with Estonia having the highest rate of UMN (15.4%)

and Spain having the lowest (0.2%).¹⁰ UMN was generally higher for dental care than for medical care, reflecting lower coverage and higher out-of-pocket payments for dental services in many countries. UMN was also higher among people with lower income, education, or health status, indicating significant socio-economic disparities in access to health care.¹⁰

The New Zealand Health Survey routinely reports cost, alongside other factors, posing a barrier to accessing GP services. The 2022/23 Survey indicated 12.9% of the general population cited a cost barrier; 21.4% of disabled adults faced a cost barrier, compared with 12% of non-disabled; and 15.1% of women experienced a cost barrier, compared with 10.5% of men. Māori and Pacific populations were more likely to face such cost barriers, at 16.9 and 17.6% respectively. Dental care poses a particular challenge, with 44% of the general population, 55.9% of Māori, 58% of Pacific, and 52.4% of disabled people reporting UMN.¹¹

The COVID-19 pandemic has exacerbated the problem of UMN in many countries, as health systems faced unprecedented challenges in delivering essential services while responding to the crisis.¹² Fear of infection, movement restrictions, financial constraints, and reduced availability of services were some of the factors that prevented people from seeking or receiving needed care. On average across 23 OECD countries with comparable data, more than one in five people reported having forgone a needed medical examination or treatment during the first 12 months of the pandemic.¹³

There are various options to address UMN and improve access to quality health care for all. This includes policy makers adopting a comprehensive and multi-dimensional approach that considers both demand and supply side factors. Some of the possible strategies include expanding health coverage and reducing financial barriers; increasing the availability and distribution of health workers and facilities; enhancing the quality and safety of health services; promoting health literacy and awareness; improving the systems of referral and patient management; and strengthening data collection and monitoring systems. Underlying this, of course, is the need for detailed information on where barriers to addressing UMN exist, where bottlenecks in the system are located, and where investments should be made.⁹

What is clear is that there is a need for more in-depth understanding of multiple aspects of UMN. This is outlined in a 2023 paper published in the BMJ produced by a multinational research group seeking a WHO resolution for member countries to commit to measuring UMN and to do so using consistent and comparable approaches.⁷

4. METHODOLOGY

A mixed-method quantitative and qualitative data collection was undertaken, through a case study approach. The focus was on calculating occurrence of UMN, and gathering in-depth insights into patients presenting with UMN at practices, practice responses, and management patterns. A range of questions were investigated through the case studies in order to better understand and document the level of UMN being managed in general practices. The research included mainstream and Kaupapa Māori practices. Understanding the experience of Māori and non-Māori within the research was considered essential to understanding inequities and the impact of UMN.

Ethical approval

Ethical approval for the study, covering the data request and analysis and case study site visits, was provided following review by the University of Otago Human Ethics Committee in August 2023 (reference number D23/222). The quantitative and qualitative methods employed in this study were carried out in accordance with the guidelines and regulations prescribed.

5. QUANTITATIVE STUDY

The aim of the quantitative study was to provide a high level national overview of referrals for first specialist assessments (FSA) in New Zealand cross-sectionally and over time. More specifically, we aimed to:

1. Quantify the number of first referrals for FSA by year from 2018 to 2022 overall, by sociodemographic sub-group, former District Health Board (DHB), and health specialty.
2. Examine prioritisation outcomes of those referred for an FSA, overall, by sociodemographic sub-group, DHB, health specialty, and over time.

METHODS

Study design, setting, and participant population

This was a repeated cross-sectional study of all individuals in New Zealand referred for an FSA over a five-year period from 2018 to 2022.

Data source: The National Patient Flow

The National Patient Flow (NPF) Collection is a national data collection that enables the monitoring, comparison, and reporting of key stages in a patient's journey through secondary and tertiary healthcare. It encompasses patient referrals to specialised services and records pertinent information regarding referral service engagements, offering a holistic perspective of the patient's secondary care trajectory. The NPF includes information pertaining to people referred from primary care, the outcomes of referrals, and the timeliness of care access. This includes data at local, regional, and national levels. The NPF is structured around patient journeys. The presenting referral is the first time a patient with a presenting problem is referred for specialist care.

Primary Outcomes

Presenting/first referrals

A presenting referral is the first referral in a patient's journey. Therefore, a presenting referral does not have a previous related referral.

Prioritisation outcomes

First referrals are triaged and a prioritisation outcome is determined by a clinician. The four prioritisation outcomes are: accepted, transferred, not decided, and declined. In addition, a

prioritisation outcome reason is also recorded. These include: transferred to another specialty; transferred to another organisation; pending test results; pending confirmation of eligibility for public funded care; insufficient information; service not required (the prioritising clinician determines that the patient does not require the referred service, can be offered an equivalent or more suitable service in Primary Care and/or is unlikely to benefit from the referred for service); below threshold (referral is appropriate and the patient would benefit from the service but the referral is below the hospital's capacity threshold which may be clinical or financial or a combination of both); not eligible for publicly funded care; and patient not medically fit for service.

Sociodemographic measures

Sociodemographic information were drawn from the NPF. These included sex (male/female), age in years (categorised as 0-9, 10-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80+ years), and prioritised ethnicity using Level 1 groups, collapsed into Māori, Pacific, and non-Māori/non-Pacific (NMNP). In addition, meshblocks associated with domicile information were used to link to area level deprivation measures using the New Zealand Index of Deprivation 2018 (NZDep). NZDep scores were collapsed into quintiles (1 reflecting the lowest levels of deprivation and 5 the highest).

Statistical Analysis

Counts of first referrals for FSA were tabulated by year, sociodemographic sub-groups, DHB, and the twelve highest volume health specialties. Among those referred for an FSA, annual rates of prioritisation outcomes were calculated, overall, by sociodemographic sub-group, DHB, and health specialty. In addition, among those declined, annual rates of the reasons for declined were also calculated.

To analyse association between being declined at prioritisation and sociodemographic factors and to test if declined rates were changing over time, a generalised linear regression model with a log link and binomial distribution was estimated for the binary dependent variable of prioritisation outcome declined on year, sex, age, ethnicity, deprivation, and DHB. In addition, to test if prioritisation outcome declined rates were changing over time for specific sociodemographic groups, DHBs, and health specialties, models were estimated stratified by sex, age, ethnicity, deprivation, DHB, and health specialty.

QUANTITATIVE RESULTS

Table 1 shows annual counts of first referrals for FSA by year from 2018 to 2022. The data are disaggregated by sociodemographic, DHB, and the 12 highest volume health specialties. Table 1 shows that the annual count of referrals has stayed relatively stable at approximately 600,000 per year, with a slight increase in 2020 and 2021. There were more first referrals for females and, generally, referrals increased by increasing age. Referrals by ethnic group were fairly representative of the NZ population, with a slight over-representation of Māori in the referral data. First referrals also increased with increasing levels of deprivation. As expected, there was substantial variation in the number of first referrals by DHB which generally reflected their population size. Notably, the Wairarapa DHB did not report any data for 2018. The highest volume health specialties included orthopaedic surgery, general surgery, and ENT which combined for approximately 30% of total referrals.

Table 1 data are in the context of a NZ population that increased by approximately 7% over the study period while, in contrast, total referrals stayed relatively constant. However, due to potential data quality issues around data completeness, we cannot be fully confident in making statements about trends in total referrals over time.

Table 1: Annual counts of first referrals for first specialist assessments (FSA) by sociodemographic characteristics, district health board, and health specialty, 2018 to 2022

	2018		2019		2020		2021		2022	
	n	%	n	%	n	%	n	%	n	%
Overall	595,672		598,092		618,012		619,516		598,190	
<i>Sex</i>										
Male	272,632	45.8	274,738	45.9	282,695	45.7	281,464	45.4	273,774	45.8
Female	323,040	54.2	323,354	54.1	335,317	54.3	338,052	54.6	324,416	54.2
<i>Age (years)</i>										
0-9	49,131	8.2	48,908	8.2	47,036	7.6	46,800	7.6	46,569	7.8
10-19	39,821	6.7	40,958	6.8	41,828	6.8	41,120	6.6	40,607	6.8
20-29	51,950	8.7	52,697	8.8	54,966	8.9	54,642	8.8	50,640	8.5
30-39	60,938	10.2	62,399	10.4	68,411	11.1	69,453	11.2	66,259	11.1
40-49	71,312	12.0	70,436	11.8	72,024	11.7	72,127	11.6	68,296	11.4
50-59	89,397	15.0	88,749	14.8	90,899	14.7	90,367	14.6	85,765	14.3
60-69	94,830	15.9	95,820	16.0	98,838	16.0	99,077	16.0	96,422	16.1
70-79	84,853	14.2	85,090	14.2	88,730	14.4	89,104	14.4	87,592	14.6
80+	54,283	9.1	53,851	9.0	56,322	9.1	57,873	9.3	57,149	9.6
<i>Ethnicity</i>										
Māori	110,412	18.5	112,565	18.8	115,815	18.7	119,056	19.2	117,407	19.6
Pacific	45,809	7.7	45,022	7.5	46,356	7.5	46,697	7.5	47,363	7.9
NMNP	440,294	73.9	441,321	73.8	456,883	73.9	454,810	73.4	434,529	72.6
<i>Deprivation</i>										
1 (least deprived)	91,879	15.4	92,594	15.5	96,678	15.6	97,121	15.7	92,828	15.5
2	103,870	17.4	104,033	17.4	108,437	17.5	109,074	17.6	104,321	17.4
3	115,740	19.4	116,727	19.5	121,072	19.6	121,180	19.6	117,793	19.7
4	128,266	21.5	129,231	21.6	133,538	21.6	134,232	21.7	129,836	21.7
5 (most deprived)	138,408	23.2	138,268	23.1	141,551	22.9	142,122	22.9	138,935	23.2
<i>DHB</i>										

Auckland	73,997	12.4	80,035	13.4	81,037	13.1	75,425	12.2	73,914	12.4
BOP	34,435	5.8	35,218	5.9	34,742	5.6	38,701	6.2	40,752	6.8
Canterbury	25,566	4.3	16,432	2.7	33,648	5.4	31,112	5.0	28,122	4.7
Capital and Coast	42,058	7.1	41,918	7.0	40,218	6.5	42,553	6.9	42,021	7.0
Counties Manukau	69,360	11.6	61,788	10.3	57,507	9.3	60,251	9.7	61,817	10.3
Hawkes Bay	25,916	4.4	16,904	2.8	15,777	2.6	15,907	2.6	15,457	2.6
Hutt Valley	20,373	3.4	24,543	4.1	27,594	4.5	29,728	4.8	27,642	4.6
Lakes	4,054	0.7	10,103	1.7	9,620	1.6	12,071	1.9	10,699	1.8
Mid Central	22,925	3.8	23,232	3.9	21,585	3.5	24,408	3.9	24,036	4.0
Nelson Marlborough	13,578	2.3	18,163	3.0	27,269	4.4	31,467	5.1	31,598	5.3
Northland	38,891	6.5	39,480	6.6	41,109	6.7	44,039	7.1	44,022	7.4
South Canterbury	13,810	2.3	14,067	2.4	11,236	1.8	13,338	2.2	8,755	1.5
Southern	33,293	5.6	34,835	5.8	33,371	5.4	9,856	1.6	4,427	0.7
Tairāwhiti	8,071	1.4	8,654	1.4	8,751	1.4	9,829	1.6	9,737	1.6
Taranaki	28,877	4.8	27,300	4.6	27,944	4.5	29,406	4.7	27,947	4.7
Waikato	61,649	10.3	63,444	10.6	63,991	10.4	66,591	10.7	63,578	10.6
Wairarapa	0	0.0	2,414	0.4	5,023	0.8	5,202	0.8	5,009	0.8
Waitemata	63,840	10.7	63,779	10.7	62,451	10.1	64,542	10.4	65,140	10.9
West Coast	7,006	1.2	7,122	1.2	6,672	1.1	7,053	1.1	6,101	1.0
Whanganui	8,816	1.5	9,477	1.6	9,509	1.5	9,084	1.5	8,525	1.4
<i>Health Specialty</i>										
Orthopaedic surgery	61,948	10.4	64,454	10.8	63,027	10.2	63,074	10.2	61,249	10.2
General surgery	61,561	10.3	58,547	9.8	58,890	9.5	60,361	9.7	56,495	9.4
ENT	48,704	8.2	47,373	7.9	45,259	7.3	44,520	7.2	44,523	7.4
Ophthalmology	45,922	7.7	44,082	7.4	45,105	7.3	44,983	7.3	43,468	7.3
Cardiology	38,790	6.5	37,867	6.3	37,709	6.1	40,621	6.6	41,109	6.9
Gynaecology	34,196	5.7	32,818	5.5	33,977	5.5	34,384	5.6	31,612	5.3
Gastroenterology	30,951	5.2	32,240	5.4	32,824	5.3	31,167	5.0	30,896	5.2
Urology	25,008	4.2	23,855	4.0	25,609	4.1	25,901	4.2	25,090	4.2
Respiratory	25,349	4.3	23,898	4.0	23,806	3.9	24,087	3.9	24,444	4.1

General medicine	21,024	3.5	21,978	3.7	22,345	3.6	23,335	3.8	21,975	3.7
Paediatric medicine	17,941	3.0	19,133	3.2	18,806	3.0	19,651	3.2	20,413	3.4
Neurology	18,503	3.1	19,397	3.2	19,332	3.1	18,331	3.0	16,919	2.8

Prioritisation outcomes

The following set of Figures (Figure 1 to Figure 12) show observed prioritisation outcome rates of first referrals, and prioritisation outcome declined reasons, for 2018 and 2022, by sex, age, ethnicity, deprivation, DHB, and health specialty.

Figure 1 and 2 show that declined rates were higher for females compared to males, and that declined rates for both groups increased from 2018 to 2022.

Figure 1: Prioritisation outcomes rates, overall and by sex, 2018 and 2022

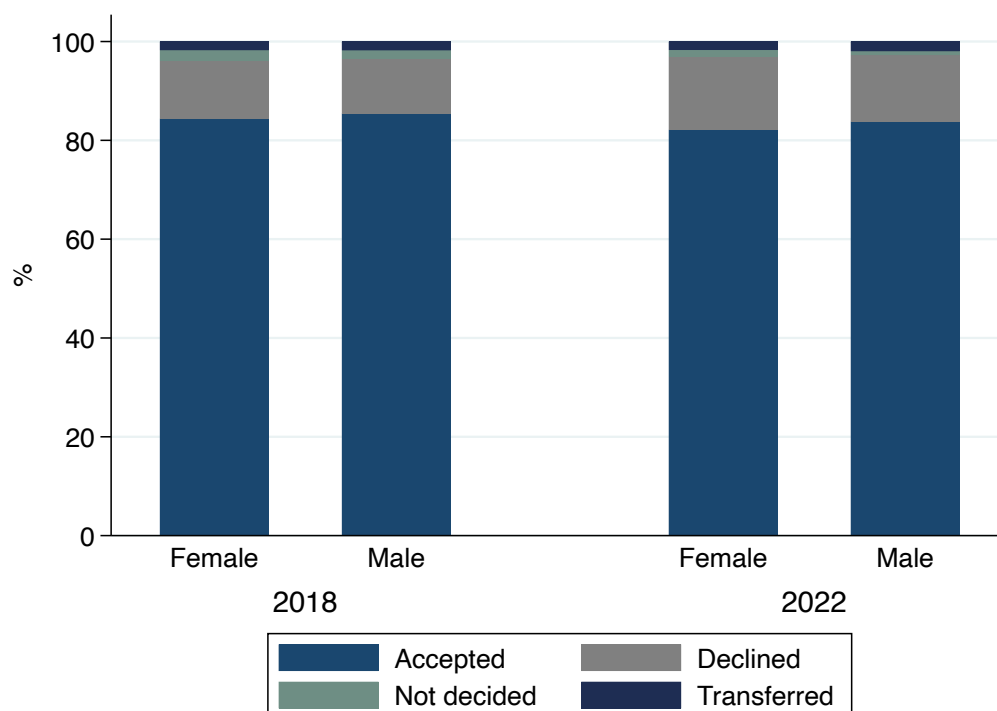
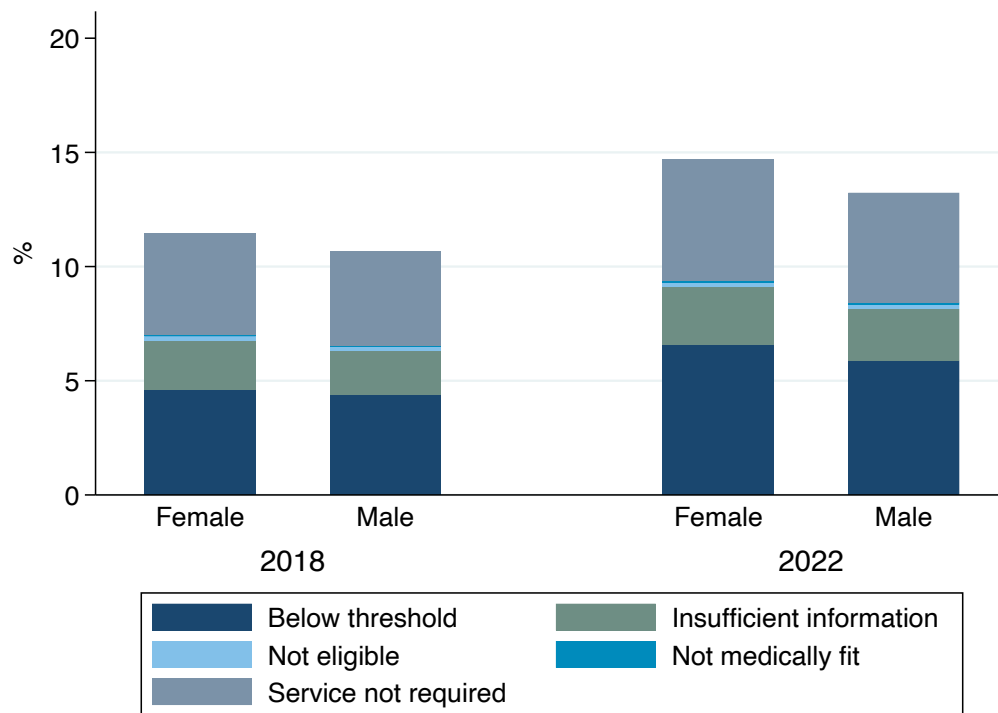


Figure 2: Prioritisation reason declined, overall and by sex, 2018 and 2022



Figures 3 and 4 show variation in observed declined rates by age and over time. Declined rates increased from 2018 to 2022 across all age groups, but substantially less so among the youngest age group.

Figure 3: Prioritisation outcomes rates, by age, 2018 and 2022

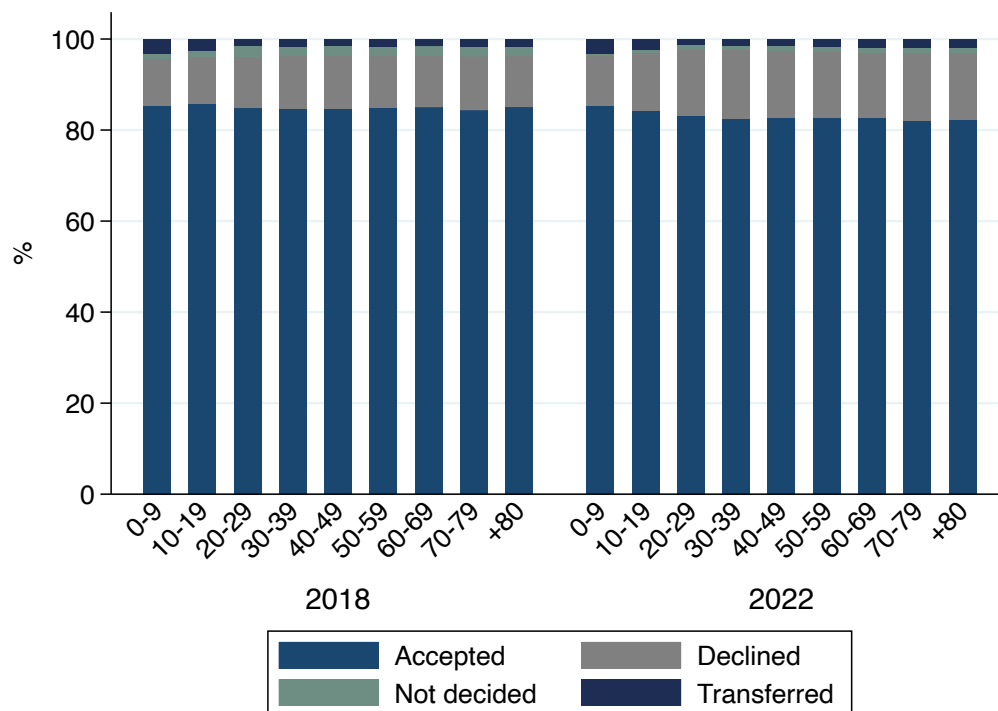
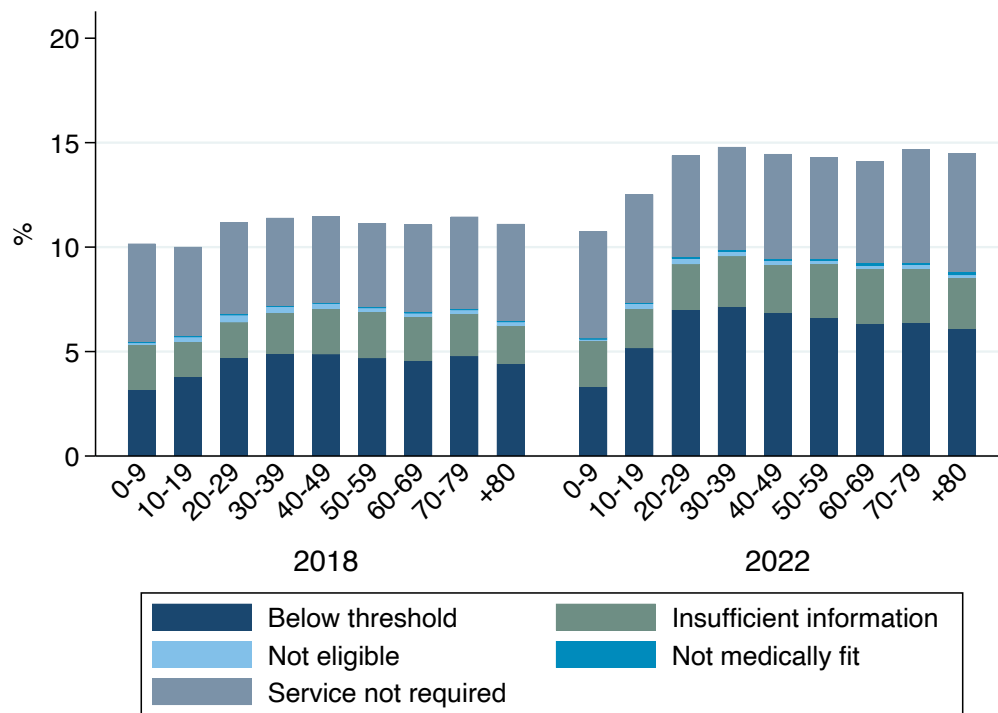


Figure 4: Prioritisation reason declined, by age, 2018 and 2022



Figures 5 and 6 show observed declined rates are lowest among Pacific and highest among NMNP. Declined rates increased from 2018 to 2022 across all ethnic groups with the highest increase being among NMNP.

Figure 5: Prioritisation outcomes rates, by ethnicity, 2018 and 2022

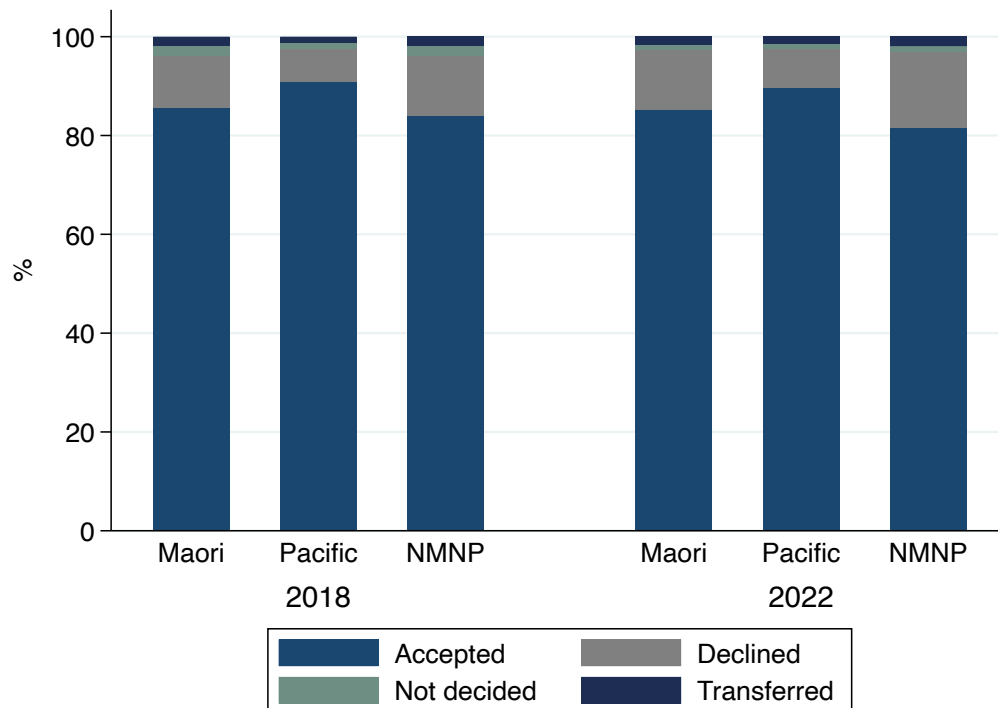
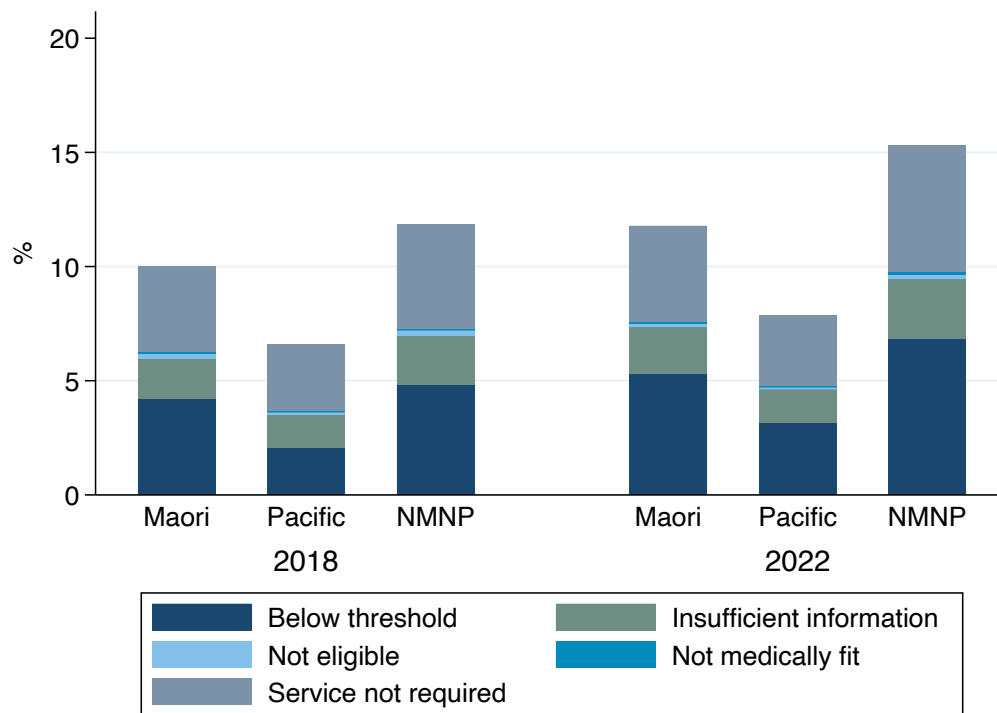


Figure 6: Prioritisation reason declined, by ethnicity, 2018 and 2022



Figures 7 and 8 show observed declined rates were fairly constant across all levels of deprivation except for those living in the highest level of deprivation who experienced lower declined rates. Declined rates increased from 2018 to 2022 across all levels of deprivation although the magnitude of this increase was highest among those living in the least deprived areas, and lowest among those in the most deprived areas.

Figure 7: Prioritisation outcomes rates, by deprivation, 2018 and 2022

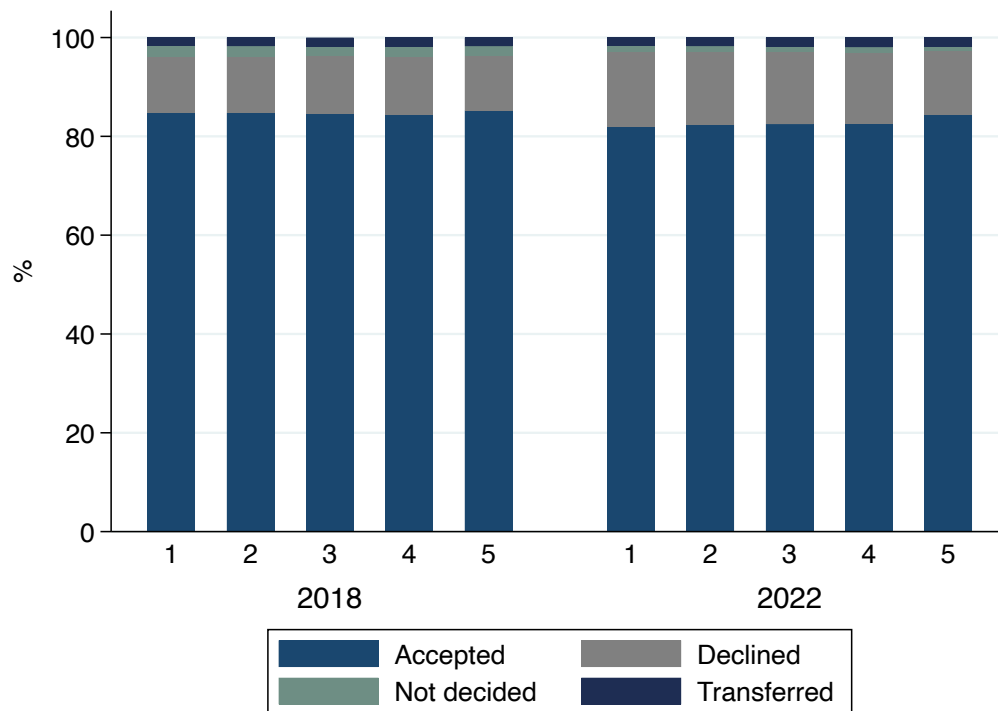
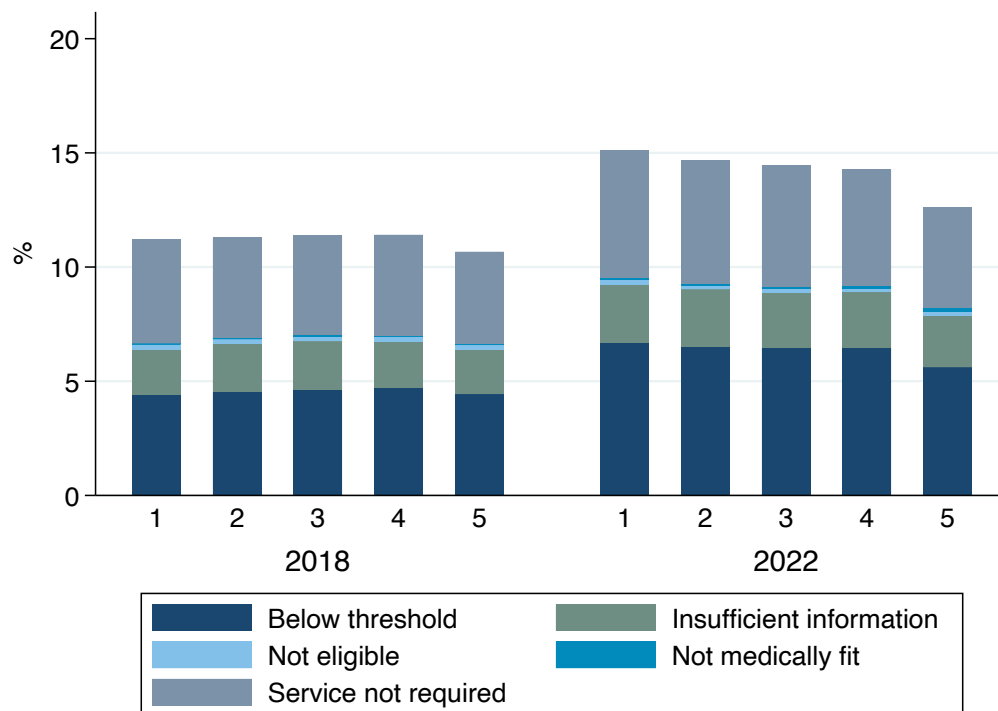


Figure 8: Prioritisation reason declined, by deprivation, 2018 and 2022



Figures 9 and 10 show observed declined rates varied substantially across DHBs and over time. Notably, Southern had the highest declined rate in 2022, substantially higher than all other DHBs.

Figure 9: Prioritisation outcomes rates, by DHB, 2018 and 2022

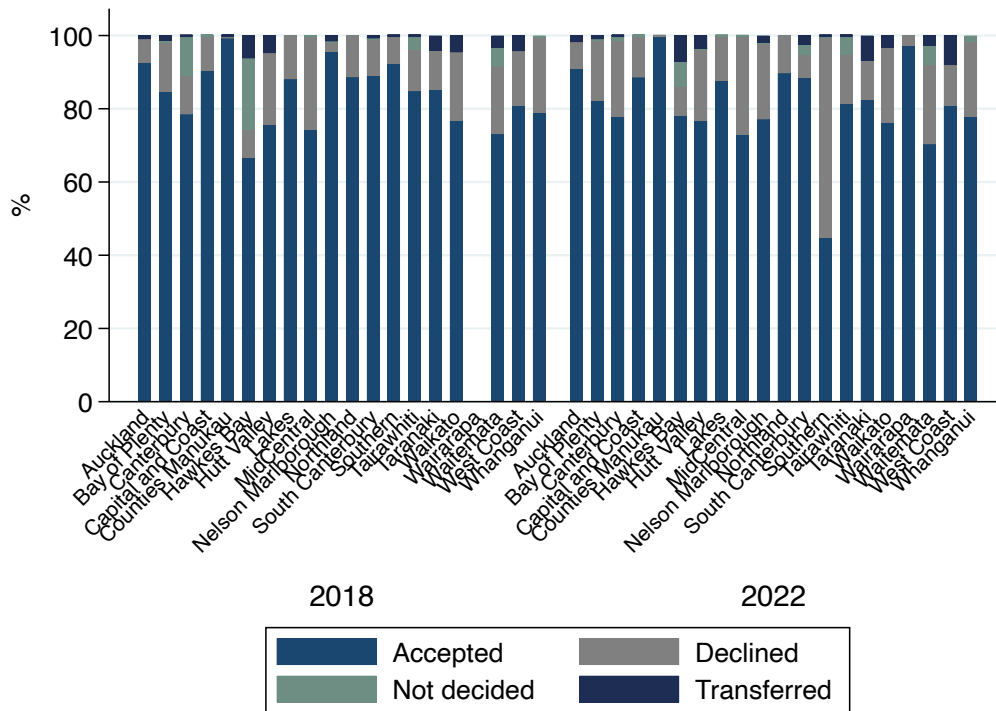
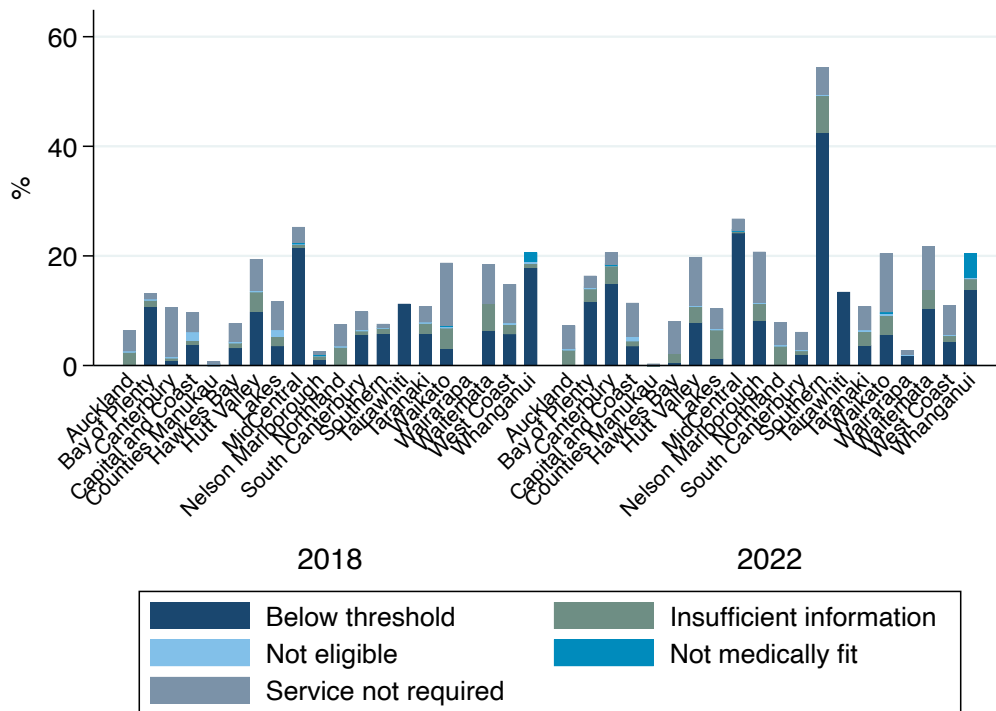


Figure 10: Prioritisation reason declined, by DHB, 2018 and 2022



Figures 11 and 12 show observed declined rates varied substantially by health specialty and over time. ENT had the highest declined rates in both 2018 and 2022 while respiratory had

the lowest. The majority of health specialties observed increased observed rates of declined over time, except for gastroenterology and ophthalmology which declined.

Figure 11: Prioritisation outcomes rates, by health specialty, 2018 and 2022

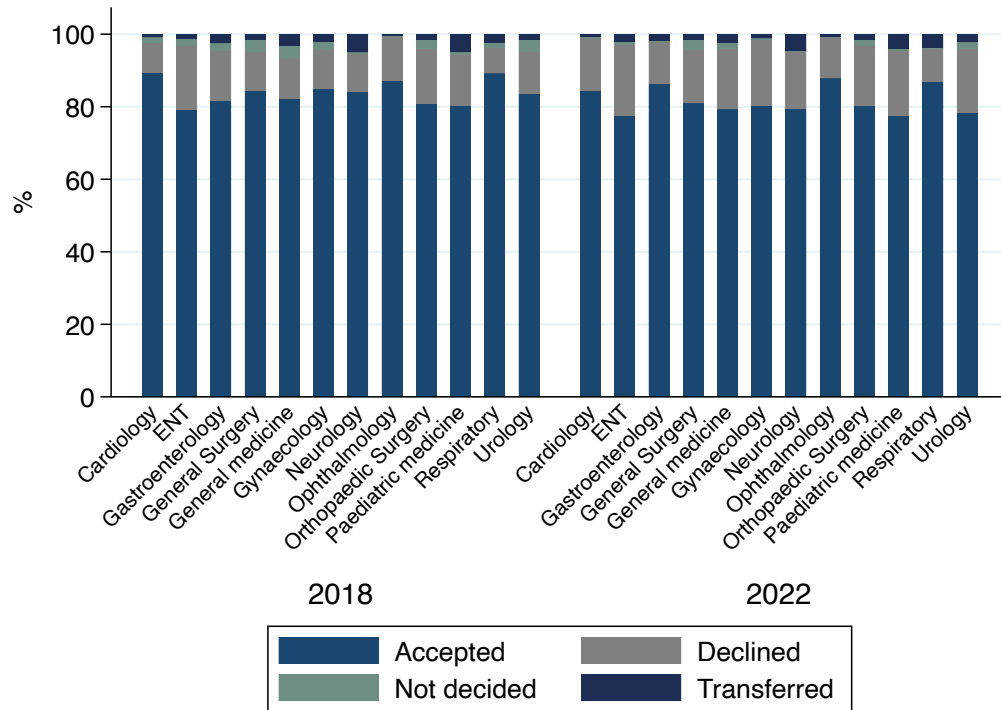


Figure 12: Prioritisation reason declined, by health specialty, 2018 and 2022

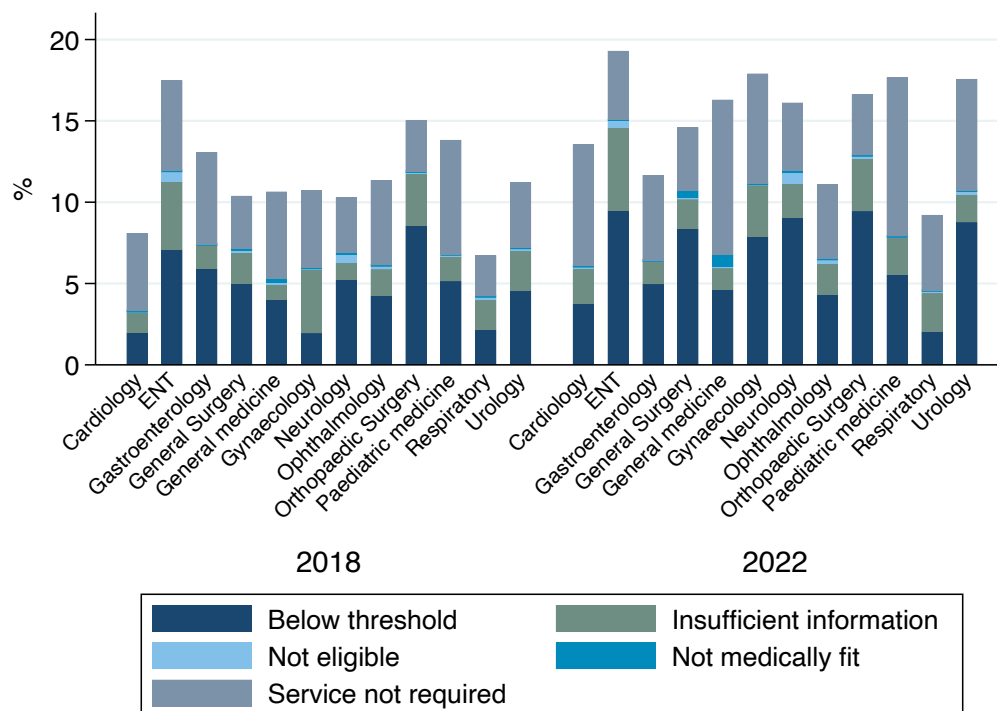


Figure 13 presents regression results for pooled prioritisation outcomes data (N=2,938,810) from 2018 to 2022 and shows the estimated associations (risk ratios) and corresponding 95% confidence intervals (CIs) between being declined at prioritisation and year, sex, age, ethnicity, and deprivation. The analysis also controlled for referring DHB. In the figure, the solid dot represents the estimated risk ratio corresponding to the variable indicated on the y-axis, and the error bars adjacent to risk ratio estimates represent the 95% CIs for those estimates. Any point estimate that lies to the right for the dashed line through 1 on the x-axis represents increased risk of being declined at prioritisation, and any point to the left represents decreased risk of being declined. When the error bars (95% CIs) also lie completely to one side of the dashed line through one, those estimates are statistically significant.

For the overall model, results show that the risk of being declined at prioritisation significantly increased over time. More specifically, there was a 5.2% increased risk of being declined per year (RR, 1.052; 95% CI, 1.050-1.055). In addition, females experienced significantly increased risk of being declined compared to males (RR, 1.070; 95% CI, 1.063-1.076). In contrast, those in the younger age groups (0-9 years [RR, 0.840; 95% CI, 0.829-0.852], 10-19 years [RR, 0.886; 95% CI, 0.874-0.898]) and in the oldest age group (80 years and over [RR, 0.949; 95% CI, 0.937-0.960]) all had significantly lower risk of being declined. Māori (RR, 0.816; 95% CI, 0.809-0.822) and Pacific peoples (RR, 0.704; 95% CI, 0.694-0.715) also had significantly lower risk of being declined.

Figure 13: Generalised linear regression of prioritisation declined on year and sociodemographic characteristics

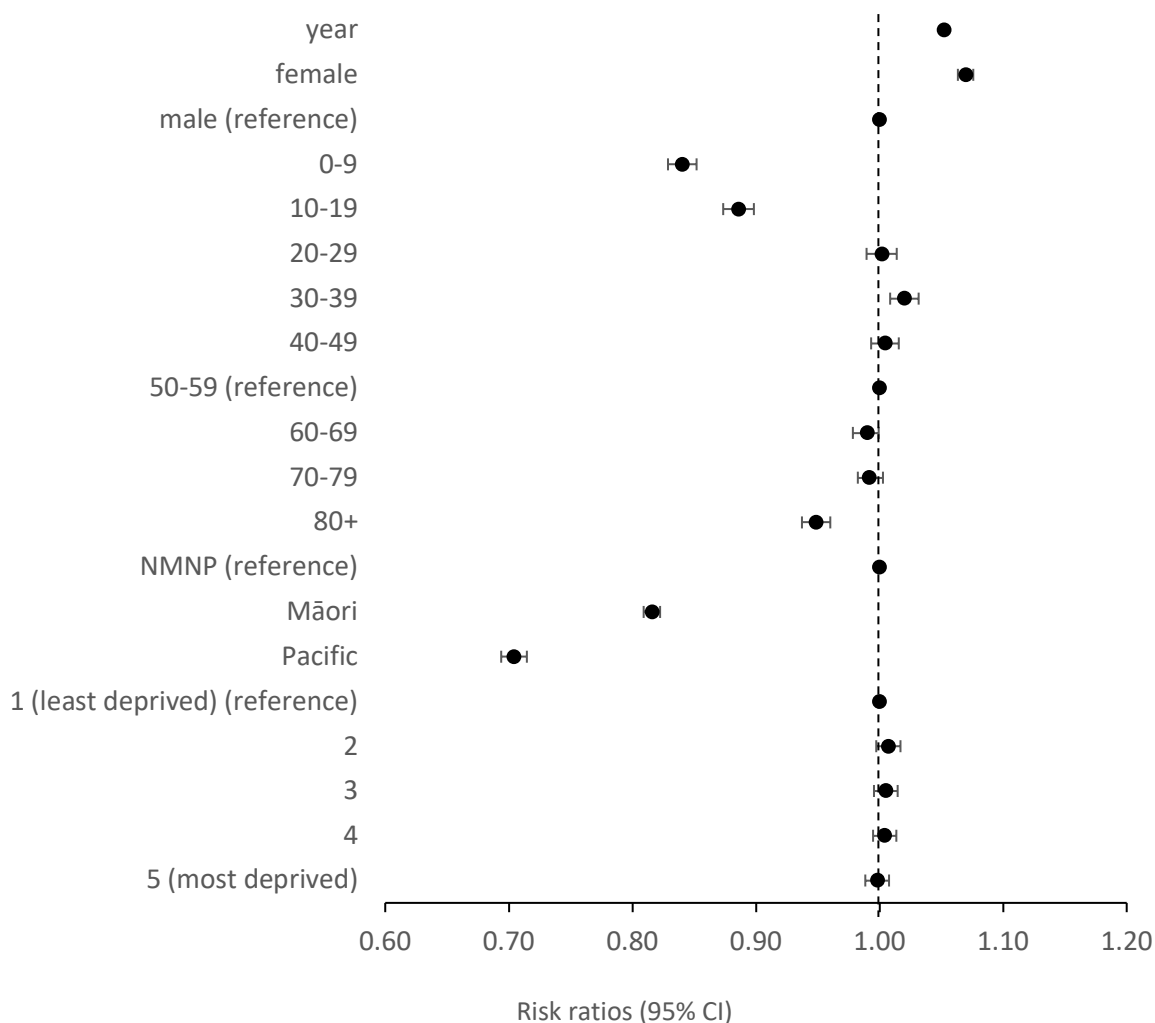


Figure 14 displays a suite of regression results, stratified by sex, age, ethnicity and deprivation for the association (risk ratio) between prioritisation outcome declined and year. In other words, this figure shows whether declined rates are changing over time (from 2018 to 2022) for each sub-population of interest, controlling for other sociodemographic characteristics and referring DHB.

Results show that across all sociodemographic groups, the risk of being declined at prioritisation significantly increased over time. Risk of being declined increased slightly more for males (RR, 1.055; 95% CI, 1.052-1.058) than for females (RR, 1.049; 95% CI, 1.045-1.052). The increased risk of being declined was relatively consistent by age, except

among the 0-9 year age group who experienced the smallest change over time (RR, 1.010; 95% CI, 1.002-1.019). NMNP (RR, 1.057; 95% CI, 1.055-1.060) experienced the largest rate of increased risk of being declined over time compared to Māori (RR, 1.035; 95% CI, 1.029-1.040) and to Pacific (RR, 1.030; 95% CI, 1.020-1.041). In addition, there was a strong gradient in increased risk of being declined over time by deprivation, with those living in the lowest levels of deprivation (RR, 1.070; 95% CI, 1.065-1.076) experiencing the greatest increase compared to those living in the highest levels of deprivation (RR, 1.035; 95% CI, 1.030-1.039).

Figure 14: Risk ratios for the association between prioritisation declined and year, overall, and stratified by sociodemographic sub groups

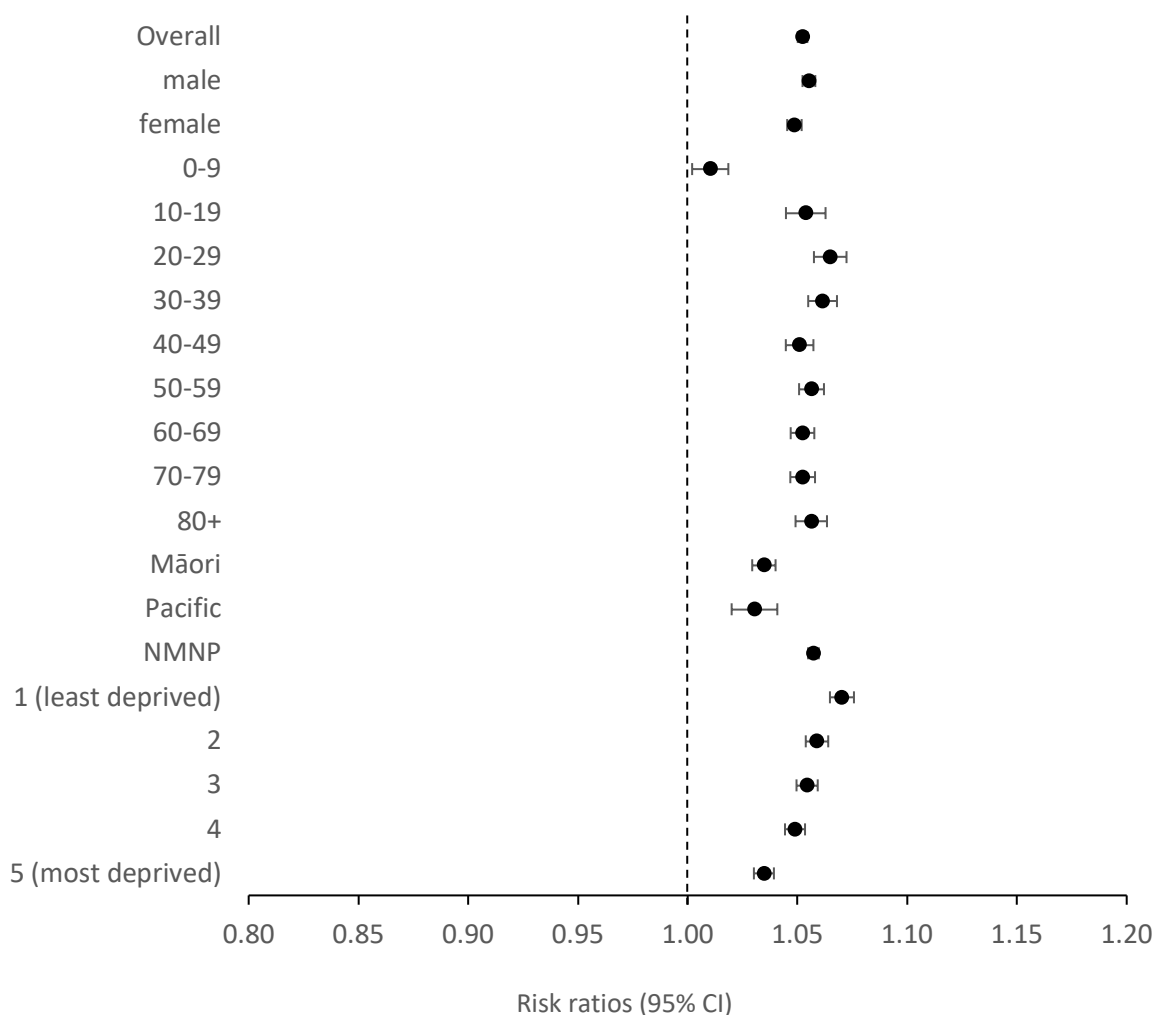


Figure 15 displays a suite of regression results, stratified by health specialty for the association (risk ratio) between prioritisation outcome declined and year. In other words, this figure shows whether declined rates are changing over time (from 2018 to 2022) for each of the 12 highest volume health specialties, controlling for sociodemographic characteristics and referring DHB.

Results show that in 10 out of 12 health specialties the declined rates increased significantly over time. The risk of declined increased the most for neurology (RR, 1.144; 95% CI, 1.130-1.156), gynaecology (RR, 1.117; 95% CI, 1.108-1.125), and cardiology (RR, 1.110; 95% CI, 1.110-1.112). In contrast, the risk for declined decreased significantly for gastroenterology (RR, 0.962; 95% CI, 0.953-0.971) and ophthalmology (RR, 0.973; 95% CI, 0.966-0.981).

Figure 15: Risk ratios for the association between prioritisation declined and year, stratified by health specialty

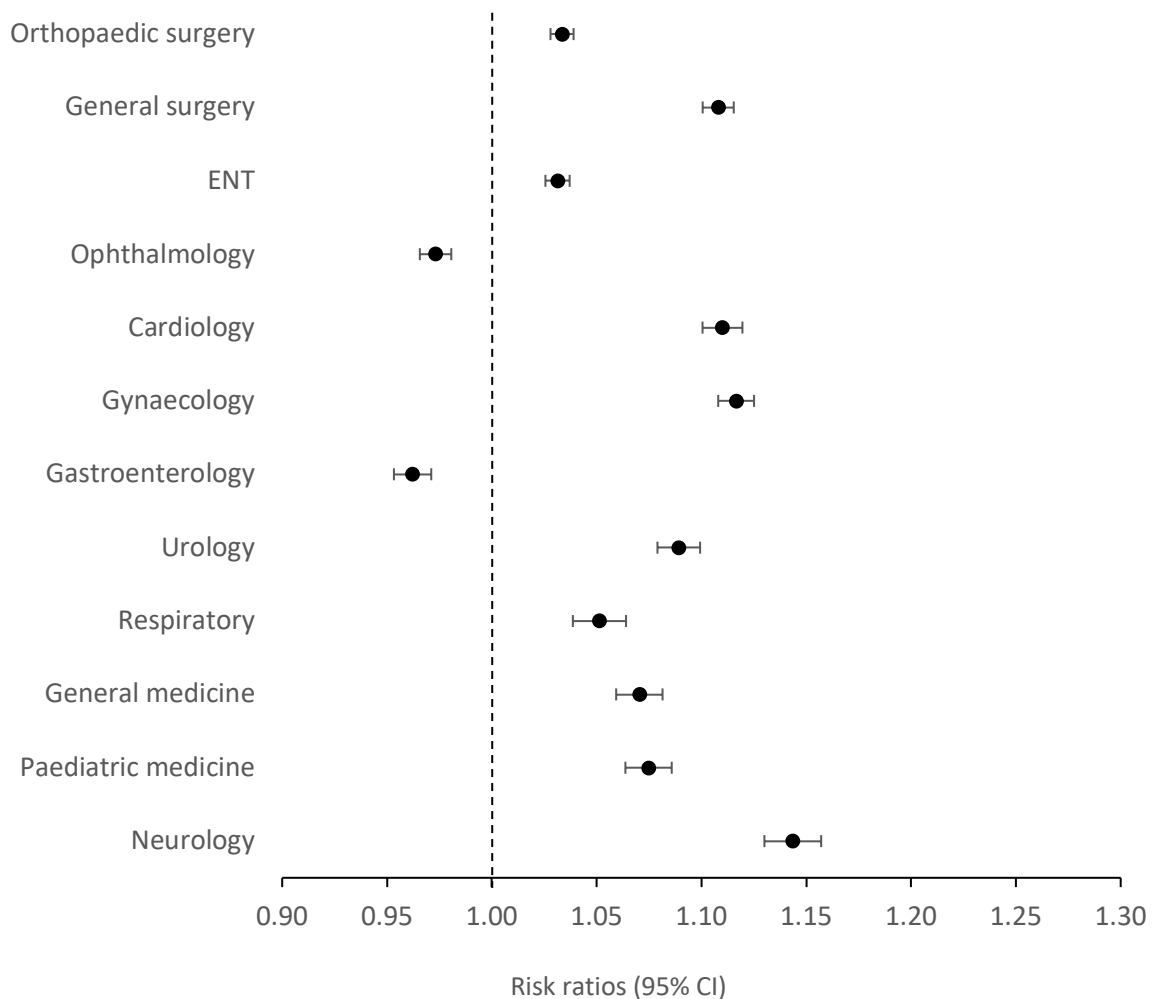
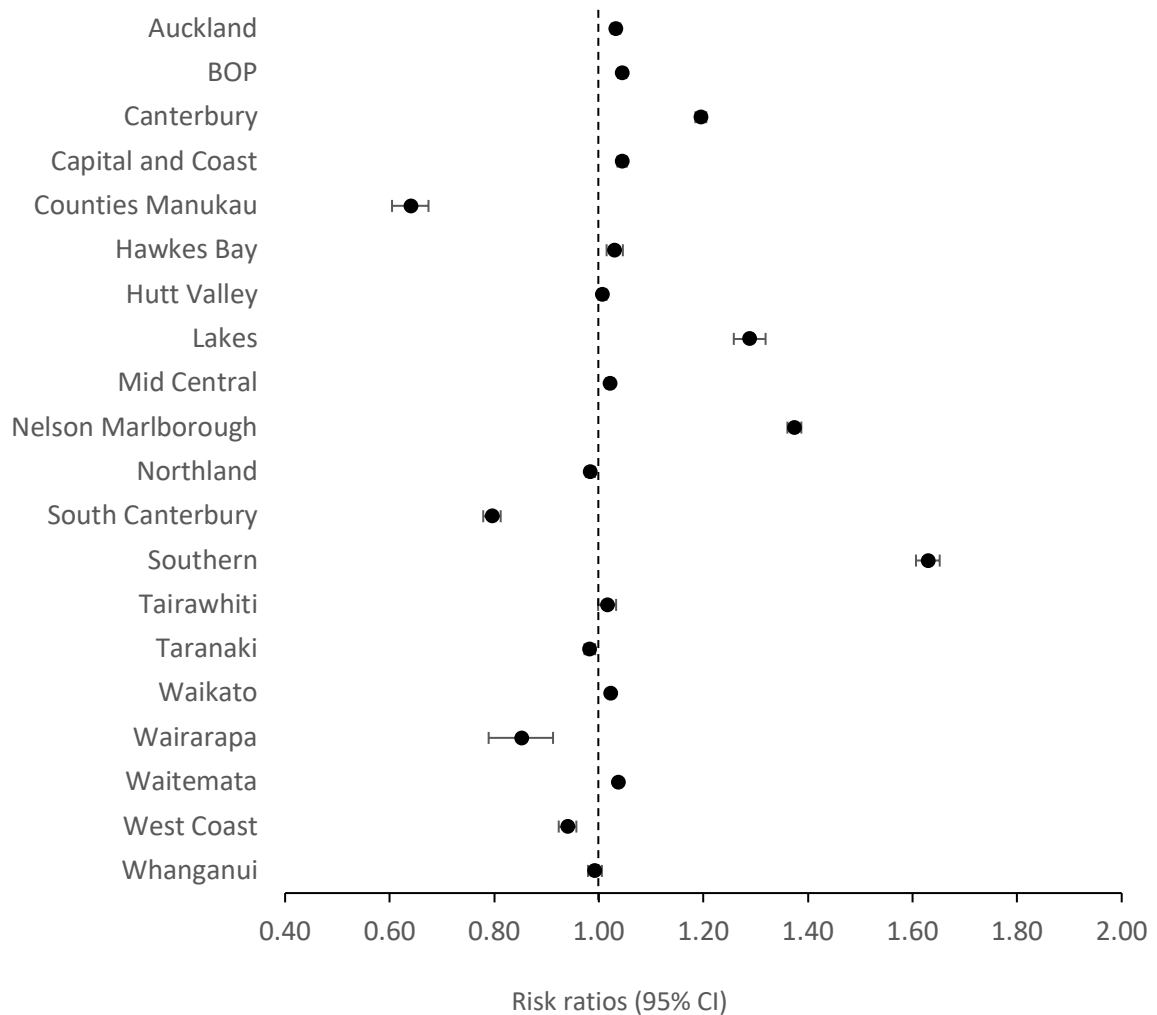


Figure 16 displays a suite of regression results, stratified by DHB for the association (risk ratio) between prioritisation outcome declined and year. In other words, this figure shows whether declined rates are changing over time (from 2018 to 2022) for each DHB, controlling for sociodemographic characteristics.

Among the 20 DHBs, over half (11) experienced significant increases in the risk of declined over time. Among these, there was substantial variation across DHBs in this increase. Southern observed the highest increase (RR, 1.623; 95% CI, 1.607-1.652) followed by Nelson Marlborough (RR, 1.374; 95% CI, 1.361-1.387) and Lakes (RR, 1.289; 95% CI,

1.259-1.320). Six DHBs had significant decreases in declined rates over time. These included Counties Manukau (RR, 0.640; 95% CI, 0.606-0.676), South Canterbury (RR, 0.796; 95% CI, 0.779-0.813), and the Wairarapa (RR, 0.853; 95% CI, 0.794-0.917).

Figure 16: Risk ratios for the association between prioritisation declined and year, stratified by DHB



APPENDIX

Table 2: prioritisation outcomes declined – annual rates of declined by sociodemographic characteristics, district health board, and health specialty, 2018 to 2022

	2018	2019	2020	2021	2022
Overall	11.4	12.3	12.9	14.3	14.2
<i>Sex</i>					
Male	11.0	11.7	12.3	13.9	13.5
Female	11.7	12.7	13.5	14.7	14.9
<i>Age (years)</i>					
0-9	10.4	10.3	10.4	11.0	10.9
10-19	10.2	11.0	11.1	12.6	12.8
20-29	11.4	12.1	12.9	14.8	14.5
30-39	11.6	12.6	13.6	14.9	15.0
40-49	11.7	12.5	13.2	14.4	14.6
50-59	11.4	12.6	13.2	14.6	14.5
60-69	11.4	12.7	13.2	14.7	14.4
70-79	11.8	12.7	13.6	14.9	15.0
80+	11.4	12.4	13.3	14.9	14.7
<i>Ethnicity</i>					
Māori	10.5	10.9	11.1	12.4	12.1
Pacific	6.6	7.0	7.6	8.1	7.9
NMNP	12.1	13.1	13.9	15.5	15.5
<i>Deprivation</i>					
1 (least deprived)	11.3	12.5	13.5	15.2	15.3
2	11.5	12.6	13.4	14.9	14.8
3	11.6	12.4	13.3	14.7	14.6
4	11.7	12.7	13.3	14.5	14.5
5 (most deprived)	11.1	11.7	12.0	13.3	12.9
<i>DHB</i>					
Auckland	6.4	7.2	8.1	7.6	7.3
BOP	13.2	15.3	15.1	15.5	16.4
Canterbury	10.6	10.2	18.9	20.1	20.6
Capital and Coast	9.6	10.3	12.2	11.5	11.4
Counties Manukau	0.8	0.2	0.3	0.2	0.2
Hawkes Bay	7.7	7.0	9.0	8.5	8.0
Hutt Valley	19.4	20.3	19.9	20.9	19.8
Lakes	11.9	3.5	5.1	17.5	12.2
Mid Central	25.3	23.6	18.8	25.4	26.8
Nelson Marlborough	2.6	6.4	19.1	20.4	20.8
Northland	11.4	10.8	10.9	11.2	10.3
South Canterbury	9.9	13.1	3.9	5.0	6.1
Southern	7.6	9.5	8.1	27.8	54.4

Tairāwhiti	11.3	14.0	13.7	12.5	13.4
Taranaki	10.8	13.5	11.6	11.1	10.8
Waikato	18.7	19.4	20.1	20.6	20.5
Wairarapa	0.0	4.8	3.9	3.9	2.8
Waitemata	18.5	20.3	19.6	21.4	21.7
West Coast	14.8	16.1	16.2	14.8	11.0
Whanganui	20.6	21.7	18.3	20.9	20.5
<i>Health Specialty</i>					
Orthopaedic surgery	15.2	16.9	17.7	18.3	16.7
General surgery	10.6	10.9	11.9	15.3	14.8
ENT	17.7	18.3	19.3	21.1	19.5
Ophthalmology	12.0	11.8	12.4	10.8	11.5
Cardiology	8.4	9.5	11.4	13.5	14.5
Gynaecology	11.0	14.6	17.1	15.7	18.2
Gastroenterology	13.7	11.0	10.9	11.3	11.7
Urology	11.5	13.8	14.0	15.7	17.9
Respiratory	7.1	8.6	10.0	9.7	9.3
General medicine	11.1	11.9	12.0	15.3	16.7
Paediatric medicine	14.2	14.1	14.8	16.7	17.9
Neurology	10.4	10.5	11.6	17.8	16.2

6. QUALITATIVE STUDY

METHODS

The qualitative component of this study entailed site visits to six New Zealand general practices. The practices were selected purposively, in collaboration with GPNZ, to enable representation of both mainstream and Kaupapa Māori practices, and ensure diversity in terms of geographical location, patient demographics, and practice size and structure (see Box).

Box: The six participating practices

Mt Wellington Family Health Centre, Penrose Road, Auckland.

Porirua Union and Community Health Services, Porirua, Wellington.

Mapua Health Centre, Mapua, Nelson.

Three Rivers Medical Centre, Gisborne.

Te Korowai Hauora O Hauraki, Paeroa and Hauraki PHO, Thames.

Te Kaika, Caversham, Dunedin

Site visits, including the recruitment of individual participants, were facilitated through practice owners and managers, and one of the research team (JB) visited each practice for one day to collect data. Data collection comprised of either one-on-one interviews, or focus group discussions (FGD), with health professionals working at the practice, including general practitioners, house officers, nurse practitioners, practice nurses, health improvement practitioners, community pharmacists, as well as professionals involved in the governance and administration of the practice. In total 43 individuals from across the six practices participated in this study.

This research adopted a pragmatic methodological position, allowing for the voices of the participants to lead interpretation.¹⁴ A schedule of questions was developed (see Appendix), though interviews and FGDs were semi-structured, so the precise questions varied depending on how the interview or FGD developed. All interviews and FGDs were conducted face-to-face and, with the permission of participants, audio recorded. Audio recordings of the interviews and FGDs were transcribed verbatim using Otter.ai. Transcripts were checked for accuracy against the audio-recordings by a member of the research team and managed using NVivo software.

The transcripts were analysed using thematic analysis, a fluid method which identifies,

analyses and reports patterns within the data, and can easily be applied in different theoretical frameworks.¹⁵ Analysis involved coding of repeated words and phrases; evaluating relationships between codes; identifying patterns, commonalities and differences; and creating a set of higher-order themes.¹⁵ Emergent themes and subthemes were then analysed by the authors. Thematic analysis is a recursive process, and involved back and forth movement between each of these steps.¹⁶ Data, including anonymised quotes from participants, and discussions of each theme are integrated in the following section to provide a cohesive interpretation for readers.

FINDINGS

We identified six overarching themes from the interviews and FGDs:

1. Different manifestations of unmet secondary care need;
2. Temporality of unmet secondary care need;
3. Specific services for which secondary care needs are commonly unmet;
4. Management of patients with unmet secondary care needs;
5. The impact of unmet secondary care need on primary practice; and
6. Suggestions for improving the incidence, management and impact of unmet secondary care needs.

Within each of these overarching themes, numerous sub-themes were identified and are outlined in the following subsections, illustrated with exemplar quotes.

Different manifestations of unmet secondary care need

We identified six different manifestations of unmet secondary care need from the data. The first, and most commonly identified by participants, was when a referral is made by the primary care provider, but declined by the secondary care provider:

“unmet need is a problem that a patient has that we can’t give an answer for. So we refer to the hospital, but they decline the referral because they don’t have the facilities or capacity to offer that service” (Participant 4).

The second manifestation of unmet secondary care need, a variation on the first, occurs when the primary care provider deems a patient to be in need of secondary care, but does not make a referral because their knowledge and prior experience of that service indicates that the referral will be declined:

“And then there is a group of people who know they have a problem, and we know they have a problem, so they come and see us...but we knowingly not refer them because we know that it is a waste of our time, because they will just get declined” (Participant 10).

It is important to acknowledge that there were divergent views on this practice. Some stating that not spending time on a referral that they know will be declined is a pragmatic response in the context of a high workload and stretched resources, but stressing the need to manage patient expectations in this scenario:

“You talk to specialists, and they'll say, please refer anyway, even if it's going to get declined, because we need to tell the managers that there's this unmet need, but we don't have the time or energy to do that. It's pointless for us to do the work to refer for that reason, like if it takes us 5-10 minutes per referral, that's generally unpaid work for us, for no benefit for the patient. So most of us won't” (Participant 11).

“Because I have a part-time role at the hospital so I kind of know what gets accepted and what doesn't get accepted, I often don't refer. Whereas other doctors might refer and have it declined, I know it's going to be declined, so I tend not to rush there...Some patients, of course, want to be referred regardless, and so if they meet the clinical threshold for referral, and they want to be referred, absolutely, I will do the referral even though I know it will be declined. But often it's just about managing the patient's expectations...” (Participant 14).

Others, however, stated that if in their assessment there was a clinical need, then they would always make the referral. Reasons participants gave for this stance were because they felt it was their responsibility to advocate for their patient; to ensure they had done everything in they could to meet the needs of the patient; and to protect themselves from liability:

“No [I will always make the referral], because the patient needs to know that they're being listened to. Just because you've lost faith in a system doesn't mean you shouldn't do your job. If it's something that the patient doesn't need, like, medically, I don't think you don't need it, you know, I'll tell them I don't need it. And that's, that's the job. That's not a yes, you can have whatever you want, but it's a, you need that so I'm going to make sure you get it” (Focus Group Discussion 2, Participant 1).

The third manifestation of unmet secondary care need identified was when a referral is accepted, but the patient is not seen by secondary care services, and/or the need is not resolved, in a timely manner:

“And the other one is in areas, I can think of specifically something like orthopaedics, where your referral is accepted, but you have like an 18 to 24 month wait, at best. That's pretty unmet, I'd say” (Focus Group Discussion 1, Participant 8).

The fourth, which again is a variation on the third, was where a referral is initially accepted, but the patient is discharged back to primary care if they have not been seen within a certain time frame. Participants who identified this scenario argued that it was a cynical attempt by the secondary care service to make it appear that their wait lists comply with guidelines, and clear the backlog post-covid:

“where they [the patient] get the appointment, they are recommended for surgery, and then the hospital says that they are at capacity and refer them back to us. So that's really important, because they are getting to see a specialist. It's happening in orthopaedics, it's happening all over the place. The surgeons agreeing that they need surgery and meet the criteria, and the hospital sends a letter back to us, which has become very familiar now saying they don't have capacity at the hospital, therefore, they're referring back to the GP. At that point, the only way to get them back in to the system is to re-refer, to go through the process again. So you need to pick up on that. Because I think that's the most damaging and hidden forms of unmet need...it's actually going through the four month, or five month, or six month waitlist and then getting referred back to the GP. It's happening all the time. I've got a real bee in my bonnet over this issue because all they are doing is hiding the waiting list. Anyone who is accepted by the specialist for surgery should just be put on the waiting list, regardless how long it gets. But by doing that they hide it because they take them off. So it's hidden, it's actually dishonest, and I'm hot under the collar about it because they shouldn't be doing that” (Participant 17).

The fifth manifestation of unmet secondary care needs was when a referral is accepted, but the patient did not attend the appointment with the secondary care service:

“We have a lot of people who get referred to secondary services, and get appointments to see a consultant, but they don't show up. So their needs are also unmet, but the system just writes them off as DNA, it's very pejorative” (Participant 22).

And the sixth manifestation of unmet secondary care need is when a referral is accepted, but the cultural needs of the patient are not met by the secondary care service:

“where [secondary care] services are not culturally fit for purpose...I think there's an expectation, certainly it is my expectation that our secondary services, where possible, can respond to the cultural needs of, for the want of a better term, the client base...and I'm not entirely sure that that always happens, obviously, from secondary care workforce perspective, you're not going to have a whole bunch of neurosurgeons trained who come from Tolaga Bay, but certainly cultural safety would be a bottom line really. And if that's not in place, then irrespective of whether a service is available, or timely, is the totality of the person's need being met?” (Participant 1).

Temporality of unmet need

The theme relating to the temporality of unmet secondary care need is two-fold. First, participants referred to the frequency with which they face the myriad manifestations of unmet secondary care need described above. Most stated that they would spend some time on the management of a patient with unmet secondary care need daily or at least once every two

days; some indicated once every week; and the longest period of time given was once every two weeks:

“You’ll be seeing someone daily who is waiting for something” (Focus Group Discussion 1, Participant 5).

“Yeah, so I’m only doing a morning session today, so after this meeting finishes, I’m only seeing six patients, and I already know that one of those has got a declined referral” (Focus Group Discussion 1, Participant 8).

“...everyday, everyday, we could open up my inbox today. And I can show you how many declines I've got” (Participant 9).

Secondly, participants referred to patterns in the incidence of unmet secondary care need over time. Most generally felt it had increased over time, with the remainder either saying it had remained the same, or that they were unsure. No participants said they felt the incidence of unmet secondary care need had decreased over time:

“It’s always been there, so it’s not a new problem, but waitlists and wait times have certainly got worse. And there seems to be a lot more departments that have got a blanket ‘don’t refer because we are not going to do anything about it” (Participant 16).

Specific conditions where needs are commonly unmet

Specific conditions or services for which needs are commonly unmet varied at different sites, but mental health and dermatology were frequently discussed by participants across all six sites. The extent to which participants found these services difficult to access is evident in the following quotes:

“I don't really refer anyone to mental health services, unless they are severely incapacitated, or they actually try and kill me during the consult. That would be the criteria, it is virtually impossible to get them seen unless they are homicidal or suicidal - and when I say that, I don't mean, thinking about it, I mean, actually have their hands around someone's throat - because it's just a waste of time, they just don't have ability to see anyone. And if I did, I would be referring them via the emergency department. Because they don't see anyone in a non-acute capacity, seemingly, there's no capacity for that kind of stuff.”

“You just can’t get into dermatology here, either publicly or privately. And there are blanket ones like mental health, or pain clinic, where it’s only the pointiest of cases that are accepted” (Focus Group Discussion 1, Participant 5).

Other services commonly mentioned by participants included gastroenterology, cardiology, radiology, oncology, orthopaedic, and paediatrics.

Management of patients with unmet need in primary care

While the management of patients with unmet secondary care needs is nuanced, and dependent on the patient and the condition being treated, participants described a plethora of strategies utilised to manage patients with unmet secondary care needs. Participants, for example, described using tools such as ‘HealthPathways’ which helps clarify the clinical pathway and likelihood of referrals being accepted, and ‘Manage my Health’, which aids communication with patients. Most participants also discussed the importance of managing patient expectations in relation to referrals into secondary care, and drawing on their own knowledge and experience of secondary care services to do so:

“It's largely to do with managing their [the patient's] expectations. We know what referrals get accepted, and what ones get declined, so we just try and manage the expectations of the patient as best we can. There are the ‘worried well’ who feel more entitled to health care, and want all the investigations, and so we have to try to discourage them from wanting unnecessary referrals. And then there are patients with poor health literacy, who aren't even aware that they should see a doctor, so it's the opposite, we almost have to talk them into a referral. But most patients we are able to rationalise with, manage their expectations, and they trust our judgement” (Participant 12).

Participants commonly discussed the importance of teamwork within the practice, both formally and informally, to help manage patients with unmet needs that they are not as familiar with:

“We had a peer review meeting this morning, and we are probably not supposed to discuss things like that, but we did discuss a few cases of unmet need, and how best to manage them. It is a useful forum to be able to draw on the experience of colleagues” (Participant 19).

“Luckily here we have people like [name of colleague], who has been doing this for ever, and ask advice when you are feeling completely out of your depth with the needs of the patients that you are dealing with” (Participant 3).

“I'm pretty often being like, what's this dermatology thing for everyone else? You know?” (Focus Group Discussion 1, Participant 8).

Further, a number of participants also stated that while their role required them to remain generalists, more and more General Practitioners are becoming more specialised in areas of interest or where there is unmet need within their population. This then magnifies the teamwork model outlined above, whereby General Practitioners with specialised areas of

interest are utilised by colleagues within the practice to help manage patients with unmet secondary care needs would be referred to:

“I think one of the things about general practices more and more, you have kind of your own specialties within space. Because we have to, but also because it’s enjoyable, I like doing my niche areas...So in the areas that I don't do and you know, I’ve become more comfortable saying this is an area, I don't do well, you’d actually, you'd be better off seeing [names of colleagues] for that (Participant 11).

Another strategy implemented to help manage patients with unmet needs was to integrate allied health providers within the practice. The emergence of the Health Improvement Practitioner (HIPs) workforce is an example of this, with a number participants referring patients with unmet mental health needs into onsite HIPs services:

“We have the HIP here, which is actually great, because for a lot of people that’s actually all they need. It doesn’t have to be high tech, just someone to talk to and deal with the immediate stress” (Participant 13).

Other examples identified by participants included onsite health coaches, health navigators, physiotherapists and community pharmacists. While integrated care models are not new, at least one participant described employing an allied health practitioner as a response to unmet secondary care need:

“We have a health coach and community health worker and a cross cultural worker. They are our extended arm because a lot of us practice inside the clinic, but they actually help with transitioning inside and outside of clinic. We've got a health coach that just bends over backwards for some of our patients and see patients coming and self-discharging or discharging at a hospital because they feel like their needs haven't been met” (Participant 22).

“And we’ve got allied health roles, the physio was the latest one. We thought that might support some of the orthopaedic issues. It might help them on the waitlist. It doesn’t take the wait list away, but it gives us the ability to retain people's mobility for a bit longer while the waiting, and hopefully means a better outcome post-surgery” (Focus Group Discussion 2, Participant 2).

Some participants also gave examples of bringing secondary care services to the practice to help meet the needs of patients not otherwise being met:

“We’re lucky to have a diabetes endocrinologist who comes down periodically and has discussions with us, and runs a clinic. And a gynaecologist comes out and talks us through patients that we can manage in the community, rather than having to refer them all in, because it is sometimes more culturally appropriate to be seen in this kind of clinic” (Participant 19).

Another approach was sending queries, as opposed to referrals, to secondary care providers. For example, some participants described sending photographs of skin lesions to a dermatologist asking for advice, or asking mental health services for advice about medications, rather than formally referring patients into those services:

“So there's a lot of times where, say, 10 years ago, I would have just straight referred Someone, please see this person. And now I am sending through a request for advice with a photograph. And sometimes it's good quite often. In fact, that's all you need. It's a way of asking a question without having to phone up a consultant and disrupt their day. You know, you send an email, this person has X Y, Z, what's the next step? Do I need to worry? Can I tell them go home?” (Participant 13).

Another workaround was recommending private treatment, either through medical insurance or self-funded, though the ability to do this varied significantly between practices:

“We have quite a high rate of insurance, I get quite a few people who come through. And it took a bit of learning because I was working [name of place] before I came here. And that was quite a quite a different vibe. Yeah. And so what's really interesting is when I came here, it took me a little bit to realize that actually, you could say to somebody, oh, if you want to get that done, it's like 300 bucks, and they are like sweet. Just send it off. I'll get that scan done. Yeah, right. So when you have patients who are like, just, you know, and then I'd say all you know, if you're going to go and see the surgeon for that, you know, you know, if you're going to get your hip done, they're probably looking at maybe 15k, maybe 20k. And they'll be like, oh yeah, can you pop through the referral” (Participant 7).

“Nobody here has insurance, so you can't funnel any patients privately” (Focus Group Discussion 1, Participant 10).

Similarly, some participants described examples of referring patients out of area, sometimes using the address of a family member living in that area to circumvent residency requirements:

“Because each DHB has a different criteria, so some things you would get in one DHB, you wouldn't be able to get in another. Sometimes they [a patient] might have family in a different DHB, so we might use that address on a referral so that they would be eligible for a service that might not be available in our DHB” (Participant 15).

Impact of unmet secondary care need

We identified three subthemes relating to the impact of secondary care need. First, the impact on the patient. Second, the impact on the clinician. And third, the impact on the practice.

In terms of the impact of unmet secondary care need on the patient, as noted above, it is nuanced, and dependent on the patient and the condition being managed. In general, however, participants indicated that patients with unmet secondary care needs require significantly more consultations than the general population:

“My favourite stat, I remember is if somebody's on a waiting list for an operation, or waiting to see a specialist, they come to the doctor on average six times as much as a person who's not. Yeah, so if you're a GP, and you've got lots of people on waiting lists, or lots of people who have had referrals declined, you're busy seeing them to try and temporize things to give them more pain relief to try and do stuff. I inject lots of knees with steroid injections whilst waiting for operations, and things like that, where you're just doing a procedure, because something else hasn't been done on that up the chain... and then they do worse after their operations, because they've had to wait longer, and they're more deconditioned and all those things. So it [unmet need] just pushes workload, it just makes more workload for other people” (Participant 7).

This can have financial implications for the patient, both in terms of the cost of additional GP visits, as well as the costs associated with it such as transport and time off work:

“We charge \$36, which is a bit hard if you have to come again and again. It's way beyond most” (Participant 16).

Many participants, though by no means all, gave examples of waiving fees for patients requiring multiple consultations due to unmet secondary care needs. Where possible, participants described accessing government and/or PHO funding streams to cover the cost of waived fees, but in some cases acknowledged that the cost was absorbed by the practice. Consequently some participants stated that they would not waive fees unless they could cover the cost through the aforementioned funding streams, out of a sense of responsibility to the practice owner(s). Participants at VLCAs said they would not waive fees as appointment fees were already low, but acknowledged that patients with outstanding accounts would not be refused treatment – thereby implicitly waiving fees:

“ It has to be an owner who makes that decision to waive fees, the practice has to absorb those costs so it is not my decision to make. But now I find there are lots of funding streams with money in the pot, so where I can I will access those if a patient is coming to see me four or five times” (Participant 16).

“They just get a bill. We don't turn people away if they have a bill, but we will just try to work with them in terms of setting up WINZ if they are on a benefit, or automatic payments to pay the bill. But they either pay or they don't, and we don't turn them away if they don't pay” (Focus Group Discussion 1, Participant 2).

Beyond the financial implications for patients, participants described concerns around living with long-term pain, drug toxicity, and drug dependency as a consequence of unmet secondary care needs:

“Long-term pain is a major problem, but you just have to manage it. I’ve got a guy who has been rejected, that's gone through reject, he's come back into my care. So we've sorted out all this pain medication now that that takes a lot to do. You have to get back two or three times yet to review the medication to try and avoid the opiates if you can, but you've got to get a regime that sort of starts to work and see if you can sort of settle things down, you know, With tricyclics at night plus your, with you up into Tramadol to avoid going to morphine and stuff. But um, yeah, that takes a lot of effort and a lot of work. It's not, it's not easy stuff” (Participant 17)

Another consequence of unmet secondary care need on patients is the incidence of co-morbidities, and the potential for the emergence or exacerbation of mental health issues:

“you know, you've got people waiting years for shoulder and they can't work. And they're in pain, and they've got to be on strong opioids or whatever it is to get them through the day. So they've got no quality of life, they come in to see us every three months, it's costing them money, they're on a benefit, mental health, huge impact. The amount of antidepressants counsellors and stuff like that is huge. All these knock-on effects, not actually being able to fix the problem” (Participant 6).

“Depression and mental health issues are significantly magnified by unmet need. I’ve had patients in tears in front of me, just, you know, it helps us you know, the these things we've just got patients that can't sleep, they think they're going to get through the system, the specialist says yeah. And then the system says no. And they often just collapse. So you can deal with all that on top of which worsens pain worse, a whole lot of functional ability and stuff” (Participant 17).

Finally, some participants gave examples of patients dying as a result of unmet secondary care needs:

“I just managed one into the grave. Couldn’t get her in [to cardiology], and she just got worse and worse, then she got liver failure and three days later she died. You can only manage them so much, maybe they get better, maybe they don’t, maybe they die. That's not dramatic, that's the issue. If you go through any GP, they'll be able to tell you they've had at least 10 versions of that every year” (Focus Group Discussion 2, Participant 1).

In terms of the impact of unmet secondary care needs on clinicians, most participants discussed the increased workload associated with writing referrals, following-up referrals with secondary care services, following-up with patients, follow-up appointments to manage the patient, and re-referring patients who have been declined:

“It does mean a lot of wasted time. You know, the referral takes me a good five minutes to type out. And I've only got 15 minutes to see the patient...and I have to tell the patient that I'm going to write, write the referral, get the response back, tell the patient they have said no, and then come up with another plan. So yeah, a lot of wasted time” (Participant 8).

“I don't think primary care ever unnecessarily refers, you know, it's either that we don't have the skill set, or we haven't made the progress, we're concerned about something. So we're referring in for a reason, you know, whether that's to emergency department or an outpatient clinic, and when they can't see them for a reason or answer a question or see the patient, then that's an issue, isn't it? And them bouncing them back to us, the issue hasn't gone anyway... I refer them back in, you know, and say, okay, well, look, we're still at the same square, or we've now significantly progressed down and we're worse, or you do referrals into private, you know, so you're constantly doing more paperwork. And through the different ways people can access us now. So through manage my health portals, which I find really valuable, but, you know, they can now contact us nearly 24/7. You know, so that can have an impact” (Participant 3).

As a result, a number of participants described opportunity cost as a consequence of their increased workload. This manifested in a number of different ways, but included fulltime employment not being viable for most GPs; “days off” being needed to “catch-up” on tasks such as those outlined above; and not having time for whānau/friends and outside interests:

“I found it, not so bad when before I had children, but now I've got kids, your time is very precious. And so you know, all of a sudden, it's very noticeable, the impact. And you think, well, I don't want to sit at home in the office calling people for several hours when the kids are right there. And I should be spending time with him, and you miss putting them down to bed and so on” (Participant 8).

“Yeah, [unmet need has increased my workload] hugely, to the point where it becomes unmanageable. And again, like having to drop time clinically, because I have to do so much more paperwork. On top of that, you know, three kids at home and two practices, you know, there's no more hours there. And so, you know, I've got Tuesday off, I've got Tuesday to sit in front of a screen all bloody day to catch up on the screeds and screeds and screeds of paperwork that come out of that hospital, makes it difficult” (Participant 2).

A number of participants also identified financial costs for clinicians associated with unmet need:

“I've got a number of friends leaving general practice. And that's sort of unmet need and how much workload is put on them? And how much of it is unpaid? Yeah, it's massive, like we're not paid enough. All of the stuff that's put on us, practices aren't

paid enough. And individual GPs aren't paid enough. Like, I feel like we more and more taking on the role of what the specialists would be doing, but we are paid half of what they get paid. And a lot of the work we're asked to do and expected to do is unpaid" (Participant 11).

A number of participants described feeling unsafe managing conditions outside their scope of practice as a consequence of unmet secondary care need, in terms of both patient safety and personal liability, and one used the term 'moral injury' to describe the necessity of practicing in a way that does not align with their personal and professional values:

"Because I'm reasonably new and just starting out in this GP career I'm still a registrar, I just over refer. So even though I think they're going to say no, I just send it, because I kind of think at the end of the day, if I get pulled up by the HDC, for, you know, say the patient ends up having a bad outcome, at least I'll be able to say, I knew they needed seeing I did refer it, it wasn't my fault that except they said no, and they didn't see them" (Participant 8).

"With mental health I have felt unsafe. We had no psychiatrist for the CAMS Team, the Child and Adolescent Mental Health Team. So you've got these mentally unwell youths who are still growing, you know, under the age of 17. And they [mental health services] had been sending emails, not even like a letter, like emails saying, 'this patient is, you know, actively seeing hallucinations, currently very aggressive and irritated, whatever, please prescribe X, Y, and Z.' And I'm like, Ah, no, these are highly potent psychoactive medications and growing kid that I've never had to prescribe, outside of, like, 18 plus year old. And they're like, well, there's no psychiatrists... well I ain't your back-up. I'm not stepping out and losing my whole career. Because a clinical but not prescribing person who said, Do you want to try some quetiapine with this child. No, that's not okay. So, yeah, the pressure is there. And like a junior DP, who was like, Oh, she's written like, you get an email saying, you know, it's got the dose that they want that stuff. And it seems like an easy thing to do to just prescribe that, push okay, print to the chemist, without realizing the risk, that you take on all the risk for that prescribing. How much have you looked into it, you know, trusting another clinician, but then again, you know, you're under the bus, if anything happened to that kid if he has a severe reaction, or they haven't quite weighed them right. So, yeah, the pressure is a lot stronger to treat outside of your comfort zone" (Participant 2).

"So moral injury is like, so there's a lot of talk of burnout, right. And so it used to be the talk of resiliency, which most doctors will hate when you use that term, and they might not know why they hate it. But the term 'we need to improve resiliency in our doctors' is, it's almost a form of victim blaming. But actually, most doctors are incredibly, incredibly resilient. And that's kind of half the problem, because we will just keep going. And most doctors will have overworked because the patients needed it. And that benefits, the DHBs and things because it's unpaid, you know, they don't

have to hire more staff, can staff just suck it up and do it. So resiliency is not a problem. And then there's also talk about burnout. But the idea of moral injury, which I don't know the exact definition of but it's basically when you are not able to work in a way that aligns with your values because of systemic issues... And this kind of unmet need really plays into that. And in hospital, doctors get the same thing. They can't provide the care that they know patients need, because they're told, you know, you can't. So I recognize that all the stuff is really, really difficult for secondary staff as well. But it creates a this moral injury and I think that's why a lot of my friends or colleagues would be leaving because they know what could be possible, or what should be happening, but they have no way of doing it. And so you end up holding much more than we should be holding for patients...and we are seeing a lot more suffering than should be needed because of that unmet need. Yeah. And so as that as a massive contributor to burnout, and staff retention” (Participant 11).

Another concern raised by participants was that managing patients with unmet secondary care needs meant that nursing and administration staff were also working outside their scope:

“Before I used to be able to check used to be able to check 'Manage My Health', which is how you order your prescriptions and things, every day, and now it's kind of like, every second maybe third day, because you're just trying to keep up with the most abnormal results. So the nurses end up taking flak because I'm behind my prescriptions or maybe behind on contacting patients, especially about normal results. There are days that if you don't hear from me, it's probably okay, but medico-legally that don't work anymore. So, yeah, talk about normal results that is the last of my priority, because I've got people with very abnormal stuff. I'm just trying to keep up with contacting them whereas those fall behind and then again, patients contact reception you know, hammering the walls or the nurses , you know, I haven't heard anything. And then the nurses are trying to work out what that blood test means, and that's above their scope, but the pressure just trickles down” (Participant 3).

A number of participants also described burnout and a loss of job satisfaction as a result of an increase in unmet secondary care need:

“I work part time, and I really used to enjoy it...I used to love coming to work. And I really felt like I could do things and I could make a difference, it is much harder now to manage your patients and make a difference. Because you do the referrals, and then you expect that they're going to be seen, but they're often as I say, getting bounced back, or there's just marked delays, you know, and they're just and then they have to come back to us. And we just sort of prop them up... So you know, if we are unable to help people, it really impacts on job satisfaction” (Participant 3).

Participants also discussed the impact of unmet secondary care need on their practice, and the discipline of general practice more generally. As noted above, many participants stated that

they waive fees for patients who require follow-up appointments to manage unmet needs, which can have financial implications for the practice:

We did a study, and one of our patients with unmet needs, the number of contacts they had with the practice in one year was something like 50 contacts. And it was like 90 scripts separate scripts for like, I can't remember how many, 30 or 40 different medications...And you know, I can't remember exactly how much they paid, but it was something like \$100 dollars, you know, for all that work. That's a huge amount of work, by a number of different people, for not much money" (Participant 19).

More broadly, some participants stated that this contributed to them not viewing practice ownership as a viable career pathway any more:

"I feel like GP ownership used to be something that people strive towards and aspire towards. And being a new GP, we always thought that would do the same. But we were offered to buy into the practice, and we looked at the money, and it's not there at all. This is no longer something. I don't see why anyone would want to buy into a GP practice at the moment, with the way things are right now. And all that means is that all the GP practices are being sold to corporate companies like Greencross, like the big companies who just own the practice, but aren't the actual GPs, and they aren't there, and they don't actually know what it's like. And suddenly, it becomes just a money making process, which is really sad for the state of New Zealand healthcare. I think having a privately run practice, you know, owned by the GP that is there is excellent, because they care about the community, they're actually there to help, but at the moment it just doesn't stack up as a viable option to me" (Participant 8).

Finally, some participants referred to a combination of the impacts described above as contributing to General Practice being seen as a less attractive discipline than other specialties, leading to difficulties in attracting and retaining staff:

"people are reaching the natural endpoint of these chronic conditions where secondary care is required, you know, you're at the point where your hips are bugged, you need a hip replacement, so there's that time lag of responsiveness that then leaves us carrying the can. And so there's moral hazard there, right. And I think a lot of GPs around the country a feeling that that because ultimately the buck stops back here. So we are the guys at the people come to see , and hobble in and go, you know, what's happening, and, and that, I think, again, fuels that feeling of hopelessness and probably is fuelling except from general practice. It's one of the many things causing our workforce crisis" (Participant 1).

Suggestions for better management of patients with unmet need

The majority of participants described the problem of unmet secondary care needs as systemic, relating to a lack of resources and workforce, and therefore difficult to change:

“So there's a lot of people that aren't getting the services that they need. It's no fault of the secondary services that we've got, or the people in them. It's just the reality of the stresses and strain that's on the system. Because it goes for GPs as well, we can't get enough stuff to fill the holes. There's so many holes. So things will get missed” (Focus Group Discussion 2, Participant 1).

Participants did, however, make some suggestions relating to how improvements could be made. A number of participants, for example, stated that there needed to be greater transparency from secondary care services, particularly in relation to thresholds for acceptance and accurate wait times, in real time rather than learning of changes through a declined or delayed referral. They argued that this would help them to better manage patients, and their own workloads:

“Thresholds just change, with no warning. The first we know if it is when we get a declined referral and we think, hang on, that meets all the criteria, that was accepted last time” (Focus Group Discussion 1, Participant 10).

“But planning and prioritization should go together. And we have no visibility of it, we don't know what the secondary services are planning. Because that's the other issue, we haven't talked about how secondary services change what they do, unilaterally all the time. And I think other GPs will tell you about them, you know, once upon a time you had x and you could refer for y and then x thing, it doesn't happen anymore, it's gone. And they don't communicate that very well” (Focus Group Discussion 3, Participant 1)

Some participants stated that they, or other clinicians in their practice, have the knowledge and skills to offer treatment beyond what is currently funded and, as noted above, they are already doing in some instances. While this might imply that they have capacity to provide more care and therefore respond to increasing UMN, what they meant was that they have the requisite skills and experience to provide appropriate care but this is not formally recognised or compensated for. They suggested that funding streams that better reflect this would help reduce the amount of unmet secondary care need as it would be dealt with in primary care, and therefore reduce some of the pressure on secondary care services.

Another suggestion for mitigating the impact of unmet secondary care need was to reduce the need for secondary care in the future. This could be facilitated through a greater focus on engaging a larger proportion of the community in primary care, in health promotion, and developing a more holistic approach to patient and whanau care. This is in keeping with ongoing efforts to bolster primary care and the various initiatives aimed at better integrating services and increasing the scope of services available in the primary care sector.

Finally, some participants suggested having greater scope to refer out of area would help reduce the postcode lottery with respect to accessing secondary care, and therefore reduce the

level of unmet secondary care need. While acknowledging that this was one of the stated aims of the 2022 health reforms, they noted that there had been no evidence of this in practice as yet.

7. DISCUSSION

This research has provided new insights into UMN in New Zealand with particular focus on general practices, patient management and patient referrals for secondary care. As noted, the topic is under researched, nationally and globally.⁴⁷⁹ There is limited understanding of the incidence and patterns of UMN, including patient pathways and experiences, as well as how UMN is managed across the health system and population. Indeed, there has never been any explicit government support in New Zealand for measuring or improving understanding of UMN, nor for how those suffering from UMN should be best managed. This means that there is a lack of clarity around UMN incidence and impact and no specified processes for patient management in place for health professionals to follow. This research has, therefore, provided some more in-depth understanding into the topic, and some baseline information. The research contributes to related work on the challenges the New Zealand health system faces with service access and care barriers, workforce capacity and funding.¹⁷

The research has identified that, through the period from 2018-2022 covered by the quantitative study, the volume of referrals by GPs to public hospital specialists has remained relatively stable. However, there has been a decline in access to referred specialist services. To recap, results of the quantitative analyses show that the risk of being declined at prioritisation – following initial GP referral – significantly increased over time. There was a 5.2% increased risk of being declined per year. Females experienced significantly increased risk of being declined compared to males. In contrast, those in the younger age groups (0-9 years, 10-19 years) and in the oldest age group (80 years and over) had significantly lower risk of being declined. Māori and Pacific peoples also had significantly lower risk of being declined. These findings were all statistically significant. There were also important variations by former DHB region with some regions clearly in a more challenging situation than others. The findings have implications for equity and national consistency but also for the impact on managing the growing number of declined referrals in the general practice and primary care sector.

Based on insights from six general practices, the research revealed that UMN is having a significant detrimental effect not only on patients; it is also affecting the health professionals in the primary care sector involved in providing care for these patients, and impacting on the general practices they work for. The research identified that GPs, in particular, are being put at significant risk and under additional pressure managing patients with UMN. This is because GPs are increasingly working with patients who have needs that are not being met by the secondary sector. These patients have no alternative and are directed by the secondary sector when it is unable to deliver on patient needs to seek support from the primary care sector. There is no additional payment to the primary care sector for this work, no extra support from the secondary sector, no formal factoring into the workload of the primary sector, and it requires GPs to manage patients who have a genuine and clinically-determined need for specialist care. In some cases, GPs are not referring patients to secondary services as they know that there is time involved doing so and the referral ultimately will be rejected; in

other cases, GPs are being required to work beyond their usual scope of practice and expectations.

The research raises very important questions. These revolve around whether it is appropriate, in terms of health system design, to require secondary care management in primary settings without a formal arrangement in place or policy recognising that managing UMN is part of a GP workload and service expectations. These questions have a series of implications, including:

- The need to better understand system impact of the increased workload in primary care and general practice in dealing with UMN. This affects not only patients and providers, but also reduces access to primary care for acutely unwell and other patients who have care needs but are not candidates for planned care in secondary care. In turn, this increases pressure on urgent care and emergency departments and is frustrating and distressing for any patient unable to access timely care.
- A conversation is needed around how to gain official acknowledgement of UMN in the New Zealand health system. Some basic data are collected and reported in the New Zealand Health Survey, but there is a need for more explicit acknowledgement and response. There is a clear impact of UMN on the health system and primary care sector in particular. Acknowledgement would bring with it the potential to develop appropriate responses in order to better manage UMN and its impact on those providing care.
- There is a need for discussion around how the secondary sector might better support the primary care sector in managing UMN. There have been ongoing discussions in the context of health alliances, localities and other integrated care models relating to moving more resources into the primary care sector, alongside plans for how patients will be managed using common processes and protocols. It would be timely for these plans to be actively and systematically pursued with a focus on managing UMN. There is also a broad range of local and international research and experience that could be drawn upon to inform discussions.¹⁸⁻²⁰
- It may be useful to progress discussions and practical work on methods for managing UMN. This might involve investing in training for managing UMN and in building UMN teams. This of course would require an explicit acceptance of UMN within the New Zealand health system, along with a commitment to measuring UMN. This would then provide clarity for the resourcing and other elements required for managing UMN, including initiatives designed to relieve the suffering that patients with UMN endure. Of course, this could have wide-ranging impacts on other parts of the economy, such as allied services involved in supporting those unable to work or needing ongoing social assistance while they await health system intervention.
- There is an obvious need to investigate development of an appropriate GP and primary care funding model for UMN. As independent businesses, partially funded from the government health allocation, managing increased levels of UMN is contributing to questions of financial viability in a sector that is already under

significant financial strain; it is also contributing to primary care workloads and this needs to be recognised. There may be a need for special adjustments to capitation funding or for an earmarked fund for supporting UMN service provision to be available for GPs and their practices. Such a fund could also be focused on building innovation in UMN management.

- It is crucial that the declines in acceptance of GP referrals identified in this research be acknowledged and acted upon, along with the variations by region, service and other patient characteristics. There are implications which should be addressed with some urgency, particularly for patient suffering, patient management and GP workload.

Limitations

This research has some limitations which should be acknowledged. The findings from the six case study site visits may not necessarily represent the experience in every single general practice in New Zealand. This is routinely the case with such methods where the findings may be generalisable within each of the study sites but not necessarily beyond. A broader study involving a wide range of practices may produce additional insight. That said, this research found a number of commonalities across each of the study sites in terms of their experiences and responses to UMN. Based on the quantitative data, there is good reason to believe that the experiences beyond the six study sites would be similar. In terms of the quantitative study, this relies on data contained within the NPF. The NPF is a relatively new dataset and to some extent may suffer from inconsistent reporting over time and cross-sectionally.

8. CONCLUSION

There is a history of UMN in New Zealand that has not been adequately documented or evaluated. This study aimed to build an understanding of UMN and its impact on the general practice and primary care sector. Deploying quantitative and qualitative methods, it provides a new understanding of this impact. The study revealed a range of challenges that warrant a response. Some possible responses have been highlighted. It will be important for GPNZ to work with policy makers on a series of activities in order to relieve the pressures general practices are encountering in managing patients with UMN. Of course, it will be particularly important for policy makers to partner with the general practice sector in this.

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