# Equitable access to medicines via primary healthcare – a review of the literature

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Commissioned by PHARMAC September 2018

#### **Executive Summary**

#### Introduction

This report examines the literature regarding equitable access to medicines to identify key barriers to access for different subpopulations in New Zealand, and interventions that enable more equitable access. PHARMAC commissioned this review to inform the achievement of their strategic objective 'Bold Goal One', which is to 'eliminate inequities in access to medicines by 2025'.

The scope of the review examines barriers and enablers to accessing medicines with a focus on access via the primary healthcare sector. Medicines funded by PHARMAC are accessed via "designated prescribers such as General Practitioners, Nurse Practitioners, Pharmacist Prescribers, Midwives, Dietitians, Dentists and Specialists".(2 p.7) This fundamental reliance on healthcare providers to facilitate patient access to prescription medicines means consideration of the barriers and enablers of access to healthcare providers is an essential part of examining equitable access to medicines.

'Equity' can be confused with 'equality', however, these words are not synonymous. 'Equality' is about 'sameness', uniformity and about fair distribution assuming everyone is at the same starting level. It does not account for contextual differences between people such as ethnicity, socio-economic status and barriers that some groups face even to get to the 'assumed' starting point.

#### Literature search methodology

A rapid review was conducted to synthesise the current state of knowledge in relation to the barriers and enablers of equitable access to medicines. While we primarily focused on New Zealand literature to examine our unique context we included international literature, particularly to examine innovations and interventions that showed evidence of improving equitable access to medicines. In total 86 sources of academic and grey literature were utilised for this review.

#### Limitations on available literature

The available literature does not provide a comprehensive overview of factors relating to equitable access to medicines as studies focus on certain subpopulations and specific conditions rather than looking across populations. It is likely that some of the barriers and interventions identified in this review would be relevant for a variety of subpopulations. There are substantial gaps in our knowledge about effective interventions.

#### Social determinants of health disparities

Research by the World Health Organisation (WHO) has shown that social disparities due to the unfair distribution of money, power and resources, are the social determinants of health disparities. Health disparities are differences among population groups in the incidence, prevalence and outcomes of health conditions, diseases, and related complications of diseases.

PHARMAC has identified that health disparities experienced by some population groups are the "result of broader systemic social determinants of health [and are] avoidable, unnecessary and unjust". Research in New Zealand has shown the population groups experiencing health disparities compared to the rest of the population are characterised by the following characteristics: ethnicity such as Māori and Pacific peoples and some ethnic minorities; low socio-economic status; refugee status; and those living in geographically remote areas. These are not mutually exclusive groups and there are multiple intersections between these characteristics and other factors that may influence health disparities.

Structural factors that lead to social disparities are perpetuated through political, economic, and social institutions. Imbalances arise when one group is dominating these institutions at the expense of other groups leading to inequities and barriers to accessing services and resources. How this translates into barriers for disadvantaged groups is complex and difficult to address when biases masquerade as 'norms' and racism and discrimination are unconsciously enacted. This highlights the importance of the health system and providers being aware of how their policies and practices, including their own cultural perspectives, impact on others. It also indicates that the causes of inequity are situated within a much broader context than the health system and require action across government sectors and communities.

## Conceptualising enablers and barriers to equitable access to medicines

There is no clear definition of a patient's 'access' to healthcare in the literature with different conceptualisations of what factors should be included. A more comprehensive concept of 'access' would consider factors pertaining to the structural features of the health care system, features of individuals (consisting of predisposing and enabling factors), and process factors (which describe the ways in which access is realised) and pertains to dimensions of availability, accessibility, accommodation, affordability and acceptability.

PHARMAC has developed a model based on the primary drivers of access to medicines related to availability, accessibility, affordability, and acceptability. Each of these drivers include elements that can either enhance access or act as a barrier resulting in inequitable access to funded medicines by different population groups. Availability of medicines is not within the scope of this literature review. Affordability relates to direct and indirect costs; accessibility includes physical and timely access to medicines and healthcare; and acceptability includes patient's / whānau experiences with health providers and how this informs their future engagement with healthcare and medicines.

## Barriers to accessing medicines and primary healthcare in New Zealand

#### Structural barriers

The key findings emerging from the literature for structural barriers included Māori being under-represented in leadership and policy-making in the health sector which limits their participation in decision-making. It was also identified that Pacific peoples are under-represented across the healthcare workforce.

While there are a number of strategic plans developed by New Zealand government agencies and professional bodies related to equitable access to healthcare, there is however a lack of evidence available on the effectiveness of these strategies and how they have translated into practice.

The barriers to access related to affordability, acceptability and accessibility to medicines via primary healthcare identify the pervasiveness and complexity of structural inequities related to the historical, economic, political, and social development of our society and the health system.

#### **Affordability barriers**

Studies show that those with low socio-economic status across the population groups experience similar barriers in terms of direct and indirect costs. Direct costs related to copayment for prescriptions and were found to be a barrier for picking up prescriptions. The cost

of consultation fees was also a barrier to visiting primary healthcare providers and led to patients deferring visits and waiting until conditions became very serious and/or there were multiple reasons to visit the doctor.

Indirect costs emerged as a significant barrier and studies highlighted transport costs in particular. The loss of income due to taking time off work to attend appointments during usual working hours and costs related to care of dependents such as young children or elderly relatives were also factors cited in studies. There are likely to be other indirect costs that have only received limited attention in the literature to date, such as the cost of using mobile phones to make appointments and pick-up voice messages.

#### **Acceptability barriers**

Studies showed that subpopulations experienced forms of institutionalised racism, both conscious and unconscious bias, leading to negative experiences of healthcare services and errors in prescribing medications.

Studies identified a lack of provision of appropriate and adequate health literacy strategies by some healthcare providers which also limited access (and utilisation) of medicines.

The dominant Euro-centric approach was a barrier to some subpopulations whose preference would be for a more holistic approach to health and an understanding of their cultural perspectives and experiences of mental, physical and spiritual health.

Challenges were also identified in terms of continuity of care and language/communication barriers in relation to patients with limited proficiency in English such as refugees and island-born Pacific peoples.

The short consultations times offered by most primary healthcare providers was identified as a constraint for engaging with patients and especially when there were language and cultural differences.

#### **Accessibility barriers**

Accessibility issues were identified in terms of geographical barriers where patients had to travel long distances to get to a healthcare provider. Some studies found patients experienced difficulties in accessing transport.

There were issues identified with the inconvenience of opening hours which clashed with patients working hours which also relate to the indirect costs of taking time off work.

# Interventions to enable equitable access to medicines and primary healthcare

#### **Addressing structural barriers**

To facilitate the institutionalisation of equity approaches we suggest a review of existing policy, strategies, frameworks and alliances to identify gaps and encourage alignment and consistency of approach to equitable access to medicines. We support authors recommendations that plans to address structural barriers be institutionalised beyond the health sector to other sectors such as education, social welfare and housing.

It was recommended that strategic plans to address structural barriers to equitable access to healthcare and medicines be systematically implemented so that they become institutionalized throughout the health sector. Evaluating the implementation and effectiveness of strategies related to equitable access to healthcare and the impact for subpopulations is required.

To enable the more equitable decision-making and representation of the views and voices of marginalised populations initiatives to encourage them into leadership and policy-making positions within the health sector are required. This was highlighted particularly for Māori which is important given their status as Tangata whenua and the obligations under the Treaty of Waitangi.

Developing the Pacific health workforce was also seen as essential for achieving health equity. We suggest that the promotion of diversity generally within the health workforce both vertically and horizontally would promote more equitable practices and approaches.

The Bay of Plenty District Health Board 's (BOPDHB) organisational culture change from being systems-centric to patient and family-centred looks like a promising approach to whole of organisation structural change. This type of complex and comprehensive change takes time and it would be useful to know how the changes are being implemented and progressing towards the proposed outcomes. This would potentially provide valuable learnings for other DHBs and organisations considering adopting this approach.

#### Addressing affordability barriers

Affordability was shown to be a major barrier and yet there is a lack of studies on the effectiveness of interventions to address these barriers. Studies that did demonstrate positive outcomes and promising practices included the following examples.

- Collaborative and flexible initiatives to enable more continuous access to subsidised
  medicines: The Hutt Valley District Health Board, in collaboration with the Ministry of
  Social Development and community pharmacies, achieved positive health outcomes
  and financial savings by removing the direct cost of medicines for patients with multiple
  chronic conditions who would usually have to pay for the first twenty items at the start
  of the pharmaceutical subsidy card annual cycle.
- Flexible healthcare provider services incorporating home and workplace visits and extended clinic opening hours made healthcare more accessible as well as more affordable as they mitigated some of the indirect costs from transport and taking time off work.
- Collaborative initiatives between primary healthcare providers and non-governmental
  organisations (NGOs) looks to be a promising practice to reduce transport barriers for
  patients, for example by the provider arranging the use of Red Cross Community
  Transport for patients to attend their appointments.

#### **Addressing Accessibility Barriers**

Nursing outreach and home healthcare provided by community health workers makes healthcare more accessible especially for those living in remote areas. Mobile services such as screening services were found to be effective for enhancing access and reducing transport costs.

Technological solutions can also address accessibility both in terms of geographical and time barriers:

• The National Telehealth Service (NTS) provides a number of services including phone lines, such as Healthline through which registered nurses provide health triage and advice, as well as web-based services including symptom checkers and self-help information. A review found that in the first year of operation "equity of access results for Māori and Pacific people varied by NTS services. Māori were high users of Healthline but lower users of Quitline. In contrast, Pacific people used both services less".(1 n.p)

- Video-conferencing initiatives can address geographical barriers so that patients who
  live far from cities can have consultations with a specialist, located in the city, from their
  local healthcare centre rather than having to make long journeys to city centres.
- A forthcoming trial of medical drones could improve accessibility and adherence by delivering medicines to patients living in remote areas via drones.

#### Addressing acceptability barriers

Many studies called for complete workforce development approaches and full-scale organisational culture change to deliver on cultural competence, health literacy and patient-centred care. Promising approaches included:

- The patient and family-centred approach developed by the BOPDHB within a whole of organisational cultural change promises a more engaging and equitable approach.
- The key role of community health workers (CHWs) to cultural safety, health literacy and patient/family/whānau-centred care. In New Zealand CHWs and Whānau Ora Kaitiaki play a pivotal role for Māori and Pacific communities. International studies demonstrate how essential the CHW role is to bridging cultural gaps between mainstream healthcare providers and indigenous communities. However, they have a very difficult and stressful role working within a dual and often competing framework, continually being pulled between the expectations of the health system (their employer) and the cultural expectations of their community.
- The 'Roberts Ngaruawahia Pharmacy', whose clients predominantly identify as Māori, represents a promising local initiative to address acceptability barriers. Understanding the link between cultural safety and health literacy, the pharmacy is breaking down access barriers by integrating health literacy and promoting a predominantly oral interaction/intervention approach to their organisational culture.
- Health literacy sessions held in marae have proved successful for Māori patients, not only in terms of learning more about the management of chronic conditions, but also for learning about general health and maintaining healthy lifestyles.

## Addressing knowledge gaps about what works to enable equitable access to medicines

This review highlights knowledge gaps in understanding the complexity of the multiple barriers to medicines via primary healthcare and what works to address these barriers.

To inform future policy and practice we suggest that a research and evaluation strategy be developed that prioritises evaluating existing initiatives to identify good practice and provide more evidence about 'what works' and for whom. We would encourage a coordinated approach across commissioning agencies to fund research and evaluation and to collaboratively identify priority areas. We suggest that any research and evaluation programme should build on existing studies and culturally appropriate research methodologies that have been conducted with Māori, Pacific peoples and ethnic communities.

#### **Enabling patient and whānau-centred approaches**

The literature strongly indicates that a patient and whānau centred approach is required in which patients are enabled to have access to medicines, are well engaged and informed by their provider, and feel comfortable discussing their condition, treatment and any concerns. To support patient-centred approaches it is important to tailor these to the cultural needs of the patients and consider the importance of engaging whānau and family support to enable access to medicines.

The findings from the literature suggest the following strategies should be considered to enable a more patient and whānau-centred approaches.

- Workforce development initiatives to support the cultural competence of healthcare providers at organisational and individual practitioner levels
- Longer consultation times to enable communication and discussion between health professional and patient to enable engagement and building a trusting relationship
- Improving health literacy resources and delivery by health professionals to more clearly communicate information to patients and their whānau
- Technological supports to enable pragmatic and engaging experiences to support equitable access to medicines

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#### Introduction

This report examines the literature regarding equitable access to medicines to identify the primary barriers to access for different subpopulations in New Zealand and the interventions and promising practices that enable more equitable access. PHARMAC commissioned this review to inform the achievement of their strategic objective 'Bold Goal One', which is to 'eliminate inequities in access to medicines by 2025'.

PHARMAC's key role is to make decisions about funding particular medicines to achieve the best health outcomes obtainable from pharmaceutical treatment within the available funding. PHARMAC has four main functions:

- Managing the Pharmaceutical Schedule on behalf of DHBs
   (Consisting of about 1900 Government-subsidised community pharmaceuticals, 2600 medicines used in public hospitals, and 20,000 hospital medical devices (August 2016)
- 2. Promoting the responsible use of medicines
- 3. Managing the Named Patient Pharmaceutical Assessment policy for patients in exceptional circumstances
- 4. Engaging in research as required.

PHARMAC selects which medicines to fund based on a number of factors including need for medicines within the population. The Factors for Consideration (FFC) framework guides this selection process.

PHARMAC states that while it "has been successful at securing and ensuring medicines are available consistently to all eligible<sup>1</sup> New Zealanders, it relies on the rest of the health system to ensure medicines are prescribed, accessed and utilised equitably so that all population groups can achieve the best health outcomes".(2 p.0) Medicines funded by PHARMAC are accessed via "designated prescribers such as General Practitioners, Nurse Practitioners, Pharmacist Prescribers, Midwives, Dietitians, Dentists and Specialists".(2 p.7)

This fundamental reliance on healthcare providers to facilitate patient access to prescription medicines means consideration of the barriers and enablers of access to healthcare providers is an essential part of examining equitable access to medicines (see figure 1). Therefore, we have included literature that focuses both on access to medicines and to healthcare providers on the assumption that barriers and facilitators to access providers would by extension relate to access to prescription medicines. The scope of the commissioned review focuses on patient access in the primary healthcare context.

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<sup>&</sup>lt;sup>1</sup> Eligibility in this context relates to all those who meet the appropriate clinical criteria and for whom the medicines is indicated as appropriate. PHARMAC provide the access on an 'equal' basis and rely on the health system to manage 'equitable' access.

Figure 1: Medicines Access via health system and healthcare providers

PHARMAC funds medicines utilising Factors for Consideration (FFC) framework

Funded medicines are prescribed & dispensed via healthcare providers (PHOs, hospitals, pharmacies)

Population access to medicine (including utilisation) is mediated by factors at structural, organisational, cultural, geographical and community/whānau/ individual levels.

#### 'Equity' is different from 'Equality'

'Equity' is often confused with 'equality', however, these words are not synonymous. 'Equality' is about 'sameness', uniformity and about fair distribution assuming everyone is at the same starting level. It ignores contextual differences between people such as ethnicity, socioeconomic status and disability as well as the barriers that some groups face even to get to the 'assumed' starting point.

In contrast, 'equity' is an ethical construct acknowledging that different approaches may be required for different groups to achieve the same outcomes. Thus, equal approaches become inequitable if differences such as socio-economic status, or severity of health conditions are not taken into account.(3) For example, in terms of populations that are known to have a greater burden of disease "equality of access is inequitable in the face of unequal need". (4 p.12)

The New Zealand Medical Association, following Braveman and Gruskin (2003), define 'health equity' as:

An ethical principle concerning the absence of systematic disparities in health (or in the major social determinants of health) between groups with different levels of underlying social advantage/disadvantage.(5 p.1)

In terms of 'health inequity' Global Health Europe states that it "refers to unfair, avoidable differences arising from poor governance, corruption or cultural exclusion while inequality simply refers to the uneven distribution of health".(6 n.p) Inequity is a complex, multi-factorial, deeply-rooted problem likely to be spread across whole systems rather than being contained within one sector.(4)

Inequity pervades all sectors of the health system and other social systems across New Zealand, consequently PHARMAC acknowledges that eliminating access inequities will require collaboration and commitment with people and organisations across the health system and beyond. It is important to keep in mind what is within PHARMAC's sphere of control and influence and what is not when it comes to addressing barriers to accessing medicines.

PHARMAC currently have two population based strategies to address equity issues, Te Wahioranga the Māori Responsiveness Strategy and Pacific Responsiveness Strategy. (7 n.p.) Equity is also considered within the criteria for selecting medicines to fund (Factors for

Consideration) and its Implementation Programmes that aim to promote the responsible use of funded medicines.(2)

#### Concepts of 'access' in the health literature

There is no clear definition of a patient's 'access' to healthcare in the literature with different conceptualisations of what factors should be included. Levesque et al. review of the literature identified a range of views about the concept of access in terms of attributes, focus and scope. 'Access' has been conceived with a narrow focus on the process of seeking care to initiation of care; an intermediate view takes the concept further beyond first contact with a provider to the ongoing care aspects of health care. A broader perception of 'access' includes aspects such as "trust in and expectations towards the health care system, health literacy, knowledge about services and their usefulness".(8 p.9)

Access has been conceived as a 'functional relationship' between the population and healthcare providers and resources and differentiation is influenced by various enablers and barriers.(8) Authors such as Penchansky have conceptualised 'access' in terms of the 'fit' between characteristics of providers and health services, and characteristics and expectations of clients.(8 p.2)

Predisposing factors include an individual's perception of an illness, as well as population-specific cultural, social, and epidemiological factors. Enabling factors include means available to individuals for using health services. Health system factors include resources, structures, institutions, procedures and regulations through which health services are delivered.(8 p.2)

Foote and colleagues (2016) New Zealand study 'Making Services Reachable' identified elements of the service system that enhanced engagement with so called 'hard to reach' populations. This study used the concept of 'sufficient fit' between the provider and the patient/client using a systems analysis to identify the multiple components that constitute provider and patient worlds that can act as barriers or enablers to service engagement.

Sufficient fit is an idea that recognises that there are gaps that separate clients and those offering service (e.g., skill, attitude, knowledge, culture, life experience). Sufficient fit is a way of bridging such gaps well enough to overcome differences and find enough commonality and connection to enable a positive service experience for the client.(9 n.p)

A more comprehensive concept of 'access' would consider factors pertaining to the structural features of the health care system (e.g. availability), features of individuals (consisting of predisposing and enabling factors) and process factors (which describe the ways in which access is realised) and pertains to dimensions of availability, accessibility, accommodation, affordability and acceptability.(8 p.2 ,9)

PHARMAC is developing a similar model based on the primary drivers of access to medicines via healthcare providers as related to availability; accessibility; affordability and acceptability (see table 1). Each of these drivers include elements that can either enhance access or act as a barrier resulting in inequitable access to funded medicines by different population groups.

This model "articulates the four primary drivers and related secondary drivers as those potentially contributing to medicines access. The driver diagram covers multiple dimensions of access to medicines:

- How decisions are made by PHARMAC to invest in a medicine
- How a patient can physically access the medicine

- Whether the patient can afford it
- Whether the patient accepts the medicines as treatment and persists with it.' (2)

Table 1: PHARMAC's Medicines Access Equity Primary Drivers

<b>Primary Driver</b>	Considerations for primary driver
Availability	<ul> <li>PHARMAC's decision making processes for investment in medicines</li> <li>Prescriber awareness of funded medicines available</li> <li>Funding Restrictions &amp; Schedule Rules</li> <li>Unwarranted variation in prescribing</li> </ul>
Accessibility	<ul> <li>Physical &amp; timely access to a prescriber/prescription</li> <li>Physical &amp; timely access to a community pharmacy</li> <li>Physical &amp; timely access to diagnostic and monitoring services (e.g. labs, scans, x-rays)</li> </ul>
Affordability	<ul> <li>Prescriber costs (consult fees, repeat prescription fees, medicine administration fees)</li> <li>Prescription costs (co-payment, blister pack costs, prescription subsidy card)</li> <li>Indirect costs e.g. transport, time off work, childcare</li> </ul>
Acceptability	<ul> <li>Patient's/whānau experience of bias from the health system</li> <li>Beliefs and perceptions of treatment prescribed not adequately explored or sought</li> <li>Medicine suitability is not adequately considered</li> <li>Patient/ whānau is not empowered with knowledge about the medicine(s)</li> </ul>

The mechanisms that act either as barriers or enablers across the above domains are a complex interrelation of structural factors, healthcare provider factors and individual situational factors. Table 2 provides an explanation for each of these levels and includes the concept of 'fit' between individuals and healthcare providers and considerations of the primary drivers outlined above. Structural factors pervade all these levels as they are perpetuated through social, cultural, political and economic institutions.

Table 2: Conceptual framework for understanding interaction between structural, healthcare provider and individual factors that influence access to medicines

nealthcare provider and individual factors that influence access to medicines							
Explanation	Examples						
'Structural' factors occur at the macro collective level and develop over time (historical influences e.g. colonialisation) and are perpetuated through institutions that are developed by societies e.g. political, economic, social systems. Inequities and barriers to accessing services and resources arise when one group is dominating these institutions at the expense of other groups. The dominant groups beliefs and practices becomes the standard, the 'norm', leading to discrimination and structural inequalities. There is an insidious element where these beliefs have become so entrenched and pervasive that discrimination can be unintentional and unconscious but nevertheless just as effective at subordinating	Examples of structural barriers that impact on acceptability is unconscious bias by mainstream providers in favour of a Eurocentric world view in regard to healthcare that may marginalise other cultural views and understandings of health. Underlying barriers to affordability are socioeconomic disparities in the way our economy has been developed resulting in increasing						
	inequities. This can influence social determinants of health						
	'Structural' factors occur at the macro collective level and develop over time (historical influences e.g. colonialisation) and are perpetuated through institutions that are developed by societies e.g. political, economic, social systems. Inequities and barriers to accessing services and resources arise when one group is dominating these institutions at the expense of other groups. The dominant groups beliefs and practices becomes the standard, the 'norm', leading to discrimination and structural inequalities. There is an insidious element where these beliefs have become so entrenched and pervasive that discrimination can be unintentional and unconscious but						

#### as the intersectionality of ethnicity, gender, age (quality of housing and food) and socio-economic status combine to influence and access to medicines via people's experiences and perceptions of healthcare providers. structural barriers. Health Occurring at the level of service provision this Examples of health provider barriers are a lack of cultural Provider relates to how health services structure, competency/safety; organise and provide their services to address prescriber bias, inadequate the needs of local communities. This also communication about health relates to the capability and capacity of literacy; lack of prescriber's healthcare providers to engage, understand appropriate knowledge and and address a person's needs and the needs skills. Service barriers may of their family or whanau. The healthcare also include opening hours; providers are influenced by structural factors cost; limited capacity resulting such as funding, legislation, wider workforce waiting times. seeina availability and training etc different GPs at each visit (continuity of care) etc Enablers and barriers to accessing medicines are influenced by factors such as availability, acceptability, affordability, accessibility. The ability of healthcare providers and the health system to engage with different people requires capabilities, capacity and flexibility to 'fit' with them and provide a service that enables equitable access. (Foote et al 2016) Individual/ Occurring at the individual level and influenced Examples include whether whānau or by their situation and their lived experience. thev have had negative family This relates to a person's identity and the experiences with health situation intersections of ethnicity, gender, services: low sociosexuality etc; their family and whānau/hapu/iwi economic status that has relations; their socio-economic situation; implications cost for where they live and their community and accessing healthcare. geographic location etc medicine. paying for transport and childcare. The availability of health care services in their area

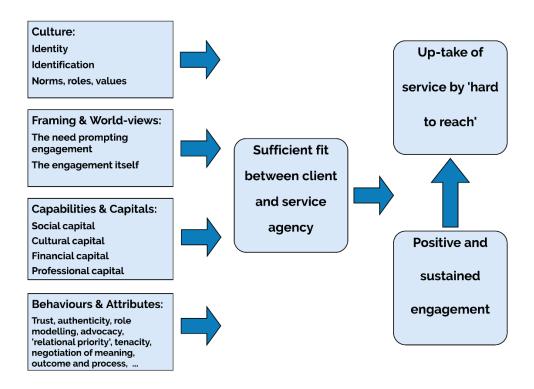
The identification of the interaction between multiple factors across structural, organisational and individual levels aligns with a socio-ecological view. This has implications about how policies and practices should target barriers and enablers. Levesque and colleagues (2013:2) observed that barriers such as cost, waiting time, transportation time can be more easily addressed by policies than broader socio-economic characteristics of the population.

and public transport etc

The Making Services Reachable project depicted elements that influenced engagement and uptake of services which can be applied to interactions between people and primary healthcare providers and by extension equitable access to medicines. Making the service system more responsive to creating the conditions for better uptake and engagement with primary healthcare providers may also lead to a better 'fit' and sustained engagement by patients. For example, patients are enabled to visit a primary healthcare provider earlier rather than waiting until conditions become severe, they have an opportunity to develop a relationship with providers that gives them confidence in advice and medications they receive.

Figure 2 outlines the elements that influence both patients and providers interactions and the concept of 'sufficient fit' leading to uptake of services and engagement (similar to concepts of access and utilisation).

Figure 2: Elements influencing 'sufficient fit' between provider and individual leading to up-take of services developed by Foote et al (2016)



#### Scope of review

This review examines barriers and enablers to accessing medicines, and access to primary healthcare providers who prescribe and dispense medicines. The two areas are closely interrelated and while some of the studies focused on access to primary healthcare providers do not directly examine medicines, they provide valuable insights into barriers and enablers of access.

The literature takes into consideration the primary drivers of access articulated within the conceptual framework (table 1) with the exception of 'availability', which is outside the scope of this literature review.

Regarding adherence to prescribed medicines, please see our companion review 'Adherence to medicines – a review of the literature' (Donovan, Carswell, Pimm 2018).

This report comprises three main sections:

- 1. Section 1 provides an overview of the causes of inequities between populations and the resulting disparities in health.
- 2. Section 2 reviews the literature on what is known about barriers to accessing medicines and primary healthcare in New Zealand to get a sense of what the main barriers are, recognising that people may be experience multiple barriers unique to their situations.
- 3. Section 3 synthesises the current state of knowledge relating to successful interventions in reducing health disparities by focusing on improving equity access between population groups in New Zealand and internationally.

The subpopulation groups examined are:

- Māori
- Pacific Peoples
- Low socio-economic status
- Refugees
- Mental Health Patients
- Those living rurally/remotely
- Older People
- Younger People.

A summary of structural barriers, health provider barriers, and situational access barriers for each subpopulation such as Māori, Pacific Peoples etc. is provided in appendix 2.

#### Limitations

This review is necessarily limited by the available literature. Studies tend to focus on specific populations and issues which can limit examination of the complexity and interrelationship between issues. We have identified some of the areas where there are gaps in knowledge and would benefit from more research.

#### Search methodology and criteria

Search terms were developed in consultation with PHARMAC and academic literature databases were searched (see appendix 1 for list of databases). For the grey literature search, relevant organisational websites were targeted (see appendix 1 for list) as well the use of Google and Google Scholar search engines. Appendix 1 has a list of key search terms utilised.

#### Section 1: Health disparities and social determinants of health

Literature for section 1 focused primarily on New Zealand literature but also included international literature on theoretical and practical understandings of social determinants of health. Much of the literature was found during searches for sections 2 and 3.

#### Section 2: Barriers

The search for section 2 included examining general access barriers and population-based barriers such as indigenous disparities; structural barriers; and the ability of providers to address a person's needs.

Search criteria:

- New Zealand only literature
- Date range 2007 2017 (some earlier seminal studies were included)
- English language only

#### Part 3: Interventions

The search for section 3 focused on policies and programmes that have sought to address these barriers and evidence from, for example, evaluations, reports and case studies that examine effectiveness of initiatives and identify good practices. Due to a lack of research and evaluation in this area we have also included New Zealand examples of strategies, initiatives and practices to facilitate more equitable access to healthcare and medicines that show promise. We have identified areas that require further research to assess effectiveness.

#### Search criteria:

The primary focus was New Zealand literature to identify what works in our context.
 International literature was also searched to scan the evidence for interventions that

- have enabled equitable access to medicines in countries such as Australia, Canada, UK, United States of America, and Scandinavian countries.
- Date range 2012 2017 years (more recent literature was searched to identify contemporary innovations and due to the volumes of national and international literature)
- English language only.

# 1 Health disparities and social determinants of health

#### 1.1 Introduction

In this section we will be examining social determinants of health resulting in health disparities or inequities. It is worth noting the difference between health disparities described in this section and healthcare disparities which will be explored in the barriers section (see box 1). Health disparities between populations show differences in health conditions while healthcare disparities are differences in access and quality of healthcare services received.

#### Health disparities verses Healthcare disparities<sup>2</sup>

**Health** disparities are differences among population groups (that is, ethnicity, gender, income) in the incidence, prevalence and outcomes of **health conditions**, diseases, and related complications of diseases.

**Healthcare** disparities are differences among population groups in the availability, accessibility, and quality of **healthcare services** aimed at prevention, treatment, and management of diseases and their complications, including screening, diagnostic, treatment, management, and rehabilitation services.

#### 1.2 Overview of social determinants of health

Research by the World Health Organisation, among others, has shown that social disparities due to the unfair distribution of money, power and resources, are the main drivers of health inequities i.e. "the unfair and avoidable differences in health status" across the world.(10) The Ministry of Social Development conclude from their Social Report of 2016, that "having a low income and low material wellbeing and living in an area of high deprivation result in relatively poor social wellbeing outcomes across most domains".(11) This also translates into poorer health outcomes as those of low socio-economic status including Māori and Pacific Peoples experience higher levels of chronic illness which is the major cause of "mortality, morbidity and inequitable health outcomes" in New Zealand.(4)

That lower socio-economic status has a major impact on health is almost universally accepted and is viewed as a structural barrier to good health. However, the relationship between social determinants and health is complex. Two different pathways have emerged as potential explanations for the link between income inequality and health inequity. The first is the material deprivation pathway which focuses on individual lack of resources and negative exposures as well as the persistent lack of investment in social and health infrastructures, for example, education, housing, and health services. The second is the psychosocial pathway which maintains that income inequality affects people's health through their "perception of place in the social hierarchy" resulting in experiences of stress and distrust.(5 p.3) People likely experience a combination of these factors.

Braveman and Gottlieb (2014) in their review of evidence of social determinants of health also point to the "strong and pervasive relationships between socioeconomic factors and physical health outcomes" reflective of more complex long-term linkages that may not have health behaviours as a key moderator. For example, the "allostatic load" which is biological "wear-and-tear" resulting from long-term exposure to social and environmental stressors. Studies

<sup>&</sup>lt;sup>2</sup> http://guides.lib.umich.edu/c.php?g=283106&p=1886147

are also showing that epigenetic processes are impacted by social stressors that can affect whether certain genes are suppressed or expressed.

Overall, there appear to be both cumulative effects of socioeconomic and related social stressors across the lifespan, manifesting in chronic disease in later adulthood, and heighted effects of experiences occurring at particularly sensitive periods in life (e.g. before age 5).(12)

#### 1.3 Health disparities in New Zealand

PHARMAC has identified that health disparities experienced by some population groups are the "result of broader systemic social determinants of health [and are] avoidable, unnecessary and unjust".(13 p.1) The 'Bold Goal' to eliminate inequities in access to medicines is designed to contribute towards reducing health disparities. Research in New Zealand has shown the population groups experiencing health disparities compared to the rest of the population are characterised by:

- Ethnicity such as Māori and Pacific peoples and some ethnic minorities
- low socio-economic status (NZ Dep 9-10 deprivation)
- refugee status
- Sub-regionally deprived populations (geographical areas in NZ where residents face significantly greater health disparities than other geographical areas e.g. those living in rural remote areas.)
- PHARMAC acknowledges that these are not homogenous or mutually exclusive groups.(13)

Health disparities are evident when life expectancy figures between different ethnicities are compared. For example, based on mortality rates in New Zealand in 2012–14, life expectancy at birth is 77.1 years for Māori females and 73.0 years for Māori males, compared with 83.9 years for non-Māori females and 80.3 years for non-Māori males (14). Life expectancy figures between rural and urban are very similar for the overall NZ population, but for Māori those living rurally have a slightly lower life expectancy to urban Māori (1.5 years for men and 1.2 years for women).(15)

- Other examples of health disparities include:
- Māori have higher rates of cardiovascular disorders, asthma, diabetes, arthritis, chronic pain, mental health disorders, than non-Māori. (16)
- "Māori, Pacific and socioeconomically deprived children are disproportionately more likely to be admitted to hospital for asthma".(17 n.p)
- Diabetes is more prevalent in areas of high deprivation (deciles nine and ten).(13)
- After adjusting for other risk factors, low socioeconomic status is a strong predictor of poor survival in breast cancer patients.(13)
- Pacific peoples, Māori, and those of low socio-economic status experience higher levels of chronic conditions.(4)
- Pacific peoples and Māori experience a higher burden of mental illness, but poor uptake of mental health services.(18,19)

#### 1.3.1 Sub-populations, diversity, and intersections

A risk of categorising people into sub-populations is the potential perception of homogeneity. This could lead to healthcare providers expecting to be able to provide a generalised service

to all members of that group, whereas in reality there is diversity within, as well as between the groups. For example, Māori have diverse iwi and geographical regions as well as differences between rural and city dwellers. For Pacific Peoples, the category covers a variety of nationalities, ethnicities, languages, religions and cultures. Although there are many similarities among the Pacific peoples, there are also many key differences which may include beliefs about health and expectations of healthcare services.(19) Similarly for refugees who come to New Zealand not only from different countries but from different continents across the world. For this group, their refugee experience is the shared characteristic, but it is likely that there are more differences than similarities within the subpopulation.

The other subpopulations examined in this review are age groups (older people and younger people) which intersect across the whole population. Māori, however, are under-represented in the older people group, given their significant lower life expectancy.(15) Pacific peoples also have lower than average life expectancy at birth although not as low as Māori. In contrast to the majority, the Pacific peoples population is young with the over half of this group being under 25 years old.(20) Similarly, the 2015 census data showed that "1 in 3 Māori are under 15 years of age, while only 1 in 17 are aged 65 years and over. By comparison, 1 in 6 non-Māori are aged under 15 years of age, while 1 in 6 are aged 65 years and over."(21 n.p) Navigating through the transitional development stage between childhood and adulthood presents major challenges. The health needs that arise during this period are linked with higher risk-taking, alcohol and drug misuse, higher rates of accidents, mental and sexual health issues. There are specific concerns about the high levels of depression and other mental health disorders, as well as youth suicide.(22) However, there is no official youth health strategy.(23)

Māori, Pacific peoples and refugees are overrepresented in both the low socio-economic and mental health subpopulations and disparities resulting from these intersections are examined below.

#### Impact of low socio-economic status across subpopulations

Socio-economic status (SES) is a measure of income, education and occupation. Low socio-economic households experience the most deprivation and healthcare needs and have the least power and fewest resources. In addition to Māori, Pacific peoples and refugees, who are over-represented, there are New Zealanders of European descent/Pākehā and non-refugee migrants of various ethnicities.(13) Those of low socio-economic status will experience more social disparities, in factors such as housing, employment, income, education, the criminal justice system and general deprivation which, as discussed above, are social determinants of health inequities.

#### Māori

Generally, when compared with non-Māori, Māori are consistently found to be more disadvantaged across all socioeconomic indicators. They persistently experience greater rates of illness and face multiple barriers to accessing medicine and healthcare. The causes of the inequitable health outcomes experienced by Māori are not easily discerned, but are likely to be multifactorial, systemic and embedded in the effects of colonisation, as well as failures to uphold the principles of Te Tiriti o Waitangi (24–27).

In relation to the non-Māori population, Māori are "almost as disadvantaged in 2006 as they were in 1981 in the employment and income domains, and more disadvantaged in the education domain".(28 p.1) These inequities cannot be fully understood without taking into account the history and effects of colonisation. Indeed, there is a growing body of evidence demonstrating that the continuity of such inequities are due to the "social and economic marginalization of Māori"(29 p.152), contemporary colonisation and institutional racism.(24,25,29,30)

#### **Pacific peoples**

A study by Southwick and colleagues 'Primary Care for Pacific People' conducted in 2012 used cultural methodologies for diverse Pacific communities. A Pacific Expert Advisory Group oversaw the development and implementation of a narrative methodology and data was collected at 36 'fono'. Eight fono were conducted in English, and the other 28 were in Samoan, Tongan, Cook Islands Māori, Niuean, Tuvaluan, Kiribati or Tokelauan. The results were analysed using ethnic-specific cultural frameworks to ensure maintenance of cultural integrity.<sup>3</sup> A common finding from participants' narratives about their experiences of accessing healthcare was the impact of poverty and a lack of resources.(19) It is recognised that Pacific peoples experience health disparities in New Zealand (13) and yet in comparison to the country's other main ethnic groups, they seem to have "gained least advantage from changes to delivery in primary care in the last decade".(19 p.18)

#### Refugees

The United Nations defines refugees as:

any person who, owing to a well founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear, is unwilling to avail himself/herself of the protection of that country.(31 p.1)

This definition is the shared characteristic of an otherwise hugely diverse group of people. Quota refugees, for example, come from variety of African countries, Afghanistan, Iran, Iraq, Burma, Bhutan and Colombia. Thus, the New Zealand refugee population comprises multiple nationalities, ethnicities, languages and religious beliefs. Each refugee will have had a 'refugee experience', but that experience will vary depending on the situation in their home country – some enduring years of warfare, others suffering repression or being held under siege conditions. Many will have experienced physical violence and undertaken long hazardous journeys in search of safety, ending up living in overcrowded refugee camps. Approximately 40% of refugees have experienced 'severe trauma' such as having witnessed the killing of family members. Having been exposed to such events before their arrival in New Zealand, Refugees have higher rates of post-traumatic stress disorder and severe depression than other migrants. Furthermore, the continued separation from other family members who may remain in refugee camps or have been re-settled in other countries, detrimentally effects NZ refugees psychological and general wellbeing.(31–33)

Refugees living in New Zealand comprise three categories; those who come through the quota system, 'spontaneous refugees' or 'Convention refugees' who arrive at the border seeking asylum, and family members sponsored by refugee families already here. Those arriving through the quota system undergo a comprehensive health screening including dental and mental health as part of their re-settlement programme. This service is available for other refugees but is not part of a formal process. The countries of origin of former refugees generally have poorly equipped health systems and high prevalence of infectious diseases. Once settled in New Zealand refugees have high and complex physical and mental health needs.(31,32,34)

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<sup>&</sup>lt;sup>3</sup> "The research project was guided by the Talatalaga a Aiga methodology and talanoa (talk), which underpinned information gathering. Both methodologies are embedded in on-going relationships or va (sacred space) between communities, families and individuals. The invitation to talanoa and acceptance by participants was part of on-going reciprocal interactions between senior members of the Pacific health sector and communities. As part of this on-going reciprocity, researchers provided food and a small financial contribution to show appreciation, and promised to return and share their research results." [ref.]

Refugees are likely to be beneficiaries and thus would share similar conditions as others of low socio-economic status. They are likely to be unemployed or underemployed, and live in poor, unhealthy and often overcrowded homes.(35) Additionally, language is "a major barrier to achieving good health" (35 p.5) for refugees with some females and older refugees of both genders facing additional barriers due to the lack of educational opportunities in their country of origin they are 'pre-literate' in their first language.(31) Intersections with other groups include people with chronic conditions, mental health, disabilities, elderly, and youths.

#### Impact of mental health across subpopulations

People with mental health conditions can have greater healthcare needs and often need medicines for both physical and mental health. Some may not be able to access subsidies they are entitled to due to their cognitive impairments. People with mental health conditions are more likely to have addiction problems, however, research has found "the rate of abstinence from alcohol was significantly higher among people with mental illnesses".(36 p.8)

There are major intersections between mental health and each of the other subpopulations in this literature review. Māori, Pacific peoples, low socio-economic and refugees, are over-represented in the community of people with mental health conditions. Significantly higher mortality and morbidity rates are experienced by people with mental illnesses and yet they continue to face multiple and complex barriers to accessing both physical and mental healthcare. The causes of the increased mortality and morbidity are multifactorial and include "stigma and discrimination within the health sector" (36 p.12) and side effects of their medication. For example, studies have found links between antipsychotic medications and physical conditions including "obesity, cardiovascular disease, poor oral health and type 2 diabetes".(37 p.7)

The following two sections examine what is known about barriers and enablers to accessing medicines and healthcare. The New Zealand College of Public Health Medicine argue that "inequities are by definition preventable and fixable. Hence, the existence of ongoing and unmitigated inequities in health outcomes is evidence of inaction in [the face of] need at multiple levels of social and health policy and practice".(24 p.2) The importance of understanding and eliminating barriers to accessing healthcare for groups, such as Māori, should not be underestimated, as poorer access to healthcare is linked with lower survival rates.(38)

# 2 Barriers to accessing medicines and primary healthcare in New Zealand

#### 2.1 Introduction

This chapter reviews the evidence on what is known about the different types of barriers to equitable access to medicines experienced by different subpopulations. The types of barriers are; structural, affordability – both direct and indirect, health provider barriers, lack of capability in regard to provision of cultural safety and health literacy. There are, of course, many intersections, however, it is organised in this way in an effort to simplify the overlaps and intersectionality. Structural barriers although pervasive are perhaps the least likely to be perceived as barriers.

#### 2.2 Structural barriers

Structural factors are at the macro collective level. They develop over time and are perpetuated through institutions such as political, economic, and social systems. As they become deeply entrenched, they tend to be accepted as 'the way things are' and therefore are difficult to change. They reflect the beliefs, practices, and norms of the dominant group in society and so serve as structural barriers to minority groups. For example, not having enough Māori and Pacific peoples representation in policy-making and leadership teams in the health system comprise structural barriers. Indeed, insufficient representation across all levels of the healthcare workforce serves as structural barriers for those subpopulations. Policy and funding decisions that do not acknowledge the specific needs of these subpopulations are the manifestation of structural barriers.

In 2011, Sheridan et al conducted a national survey that focused on chronic condition management as a lens to measure healthcare inequities. They found that strategic intentions to reduce inequity were not reinforced by systematic implementation plans and so to reduce this barrier they recommended that equity approaches be "institutionalized throughout the health sector and beyond to other sectors such as education, social welfare and housing".(4 p.12) However, they considered national and regional efforts focused solely on Māori achieving health equity, to have been successful because "equity for Māori is embedded in policy".(4 p.1) In the results section, they reported that health plans had been developed for defined populations: Māori 13, Pacific 7, Refugee & Migrant 1, Asian 0 and concluded that Māori are the "most explicitly prioritized population" because of their Treaty status.(4 p.10) The researchers advocate transferring such "policy mechanisms and implementation methods" to other groups such as Pacific Peoples and those with low income.(4 p.12) While this may be the case, the evidence on continuing (and increasing in some areas) health disparities experienced by Māori overall would indicate that 'success' in terms of health equity is still a long way off.

Having to tailor services to different ethnicities may require more effort and more funding. An unwillingness to do so could potentially create further barriers. As one healthcare provider, who may not fully understand the other life pressures Pacific peoples endure daily, commented about chronic condition care "it is much easier to develop ... programs for the people who actually comply with what you say, we get paid the same amount of money".(4 p.10 italics in original)

#### 2.2.1 Experiences of subpopulations

Examples of the type of structural barriers experienced by specific population groups in New Zealand are provided below. Some of the themes such as lack of representation at leadership and policy levels and across the health workforce generally would apply to other disadvantaged subpopulations.

#### Māori under-representation in leadership and policy making

A critique of the New Zealand Health Strategy in 2016 highlighted a disjuncture between high-level policy aspirations of health equity and everyday practice. The authors ascribed this primarily to a "fragmented approach" to health equity and the absence of Māori being "structurally and consistently engaged in decision-making about health policy and investment decisions".(25 p.75)

A mixed method research study in 2014 examined Ministry of Health policy documents from 1999 -2011 as "master narratives" and compared these with "counter narratives" represented by "first-person accounts from Māori health leaders".(30 p.215) Research findings included: an under-representation of Māori in health leadership roles resulting in the Māori voice not being heard; deficiencies in cultural competency among senior healthcare professionals; and flawed consultation practices. The impact of "Crown filters" in the policy development process also served "to dilute Māori content in policy".(30 p.217)

#### Pacific peoples under-representation in healthcare workforce

Pacific peoples are the fourth largest ethnic group in New Zealand representing 7.4% of the whole population in 2013 and the proportion continues to grow.(20) The need for a workforce in healthcare that reflects the ethnicity of the patient group is generally accepted and yet there is a paucity of Pacific peoples working in the healthcare system. There is an acknowledgment that Pacific representation is essential across the health system – not just in clinical settings, but also in terms of policymakers and researchers, however, there is particular concern about the low numbers of Pacific doctors and nurses. This is a very important factor for Pacific peoples who traditionally perceive health holistically and highly value the relationship between the health professional and the patient. This will be discussed further in the cultural fit barriers section.(4,19,39)

#### Structural barriers in a two-tier refugee community

Although the United Nations Refugee Convention does not distinguish between quota refugees and asylum seekers, in New Zealand the difference between the two groups in terms of support provided is stark. New Zealand has an annual quota of 750 refugees who are eligible for the assisted re-settlement programme which provides a wrap-around service including health screening. These refugees are assigned social workers and community volunteers to help them settle into their new homes including being registered with a local general health care practice. However, approximately 300 people apply for asylum in New Zealand per year with about one third of those applications being successful.(34) For example, in the financial year 2013/14, a total of 122 asylum seekers were granted 'Convention refugee' status in New Zealand.(40) Convention refugees are "not eligible for the services, resources and settlement support available to quota refugees".(34 p.70)

A qualitative study with 18 participants conducted in 2014 found that the asylum seekers received no support and were unable to access services including healthcare. They were not informed of their rights and entitlements and some were detained in prison despite not having

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<sup>&</sup>lt;sup>4</sup> "Crown filters" is a term to describe how Crown officials manage the policy development process and navigate its sign-off. Crown filters are visible throughout the drafting of policy and are most prominent in the final policy steps. Crown filters often serve to dilute Māori content in policy.

committed a crime. Some asylum seekers only learned about their entitlements to healthcare through their participation in the research programme some years after they had arrived in New Zealand. Others talked about being turned away from primary health care providers and hospital emergency departments despite presenting proof of their Convention refugee status. Even when they knew they were entitled to healthcare, they often did not have the confidence to challenge or complain when they were being turned away or over-charged.(34)

For the asylum-seeking refugees in this study their experience in New Zealand was characterised by exploitation, intimidation, and discrimination. This results in low self-esteem, insecurity and at times feeling suicidal.(34) Although the numbers of Asylum-seekers in New Zealand is low, they tend to be from diverse background including professionals, such as, lawyers and doctors in addition to students and sole parents/caregivers. Their experience of living with great uncertainty and fear in New Zealand following their 'refugee experiences' in their country of origin, lie at the root of their later mental health and anxiety disorders. Some reported having lived in cars for prolonged periods of time without access to shower or toilet facilities. Their lack of access to housing and healthcare causes severe detrimental impacts on their general health and well-being.(34)

#### 2.2.2 Key Findings emerging for structural barriers

- Strategic intentions to reduce inequity are not reinforced by systematic implementation plans
- Māori are under-represented in leadership and policy making
- Pacific peoples are under-represented across the healthcare workforce
- Although they have the same international human rights, asylum seekers in New Zealand face more barriers to accessing healthcare than quota refugees.

#### 2.3 Affordability - direct and indirect costs

There are a variety of cost barriers, both direct costs, such as general practitioner (GP) consultation fees, out of hours clinic costs, and prescription charges; and indirect costs to attend appointments, such as travel costs, childcare costs and loss of wages.(41)

Cost barriers are likely to partially account for the cause of health disparities and failing to receive timely healthcare may result in later hospitalisations. These "preventable hospitalisations" (42 p.9) as well as visits to hospital emergency departments for minor problems by those who cannot afford the co-payment GP fee ultimately result in additional avoidable costs to the health care system. Thus, removing the cost barriers to access primary healthcare and prescription medicine may result in savings for the health care system. (42)

Research has demonstrated links between low socio-economic status and a reduction in access to healthcare as well as higher exposure to major health risk factors.(13) Cost barriers were reported as the reason for deferring doctor's visits for nearly three-quarters of people experiencing the greatest deprivation.(42)

Significant differences were found between the most deprived and least deprived neighbourhoods in terms of unmet primary healthcare needs and this difference increased when cost was specified as the reason. The biggest difference between the two groups, however, was when the reason was 'lack of transport' which is an indirect cost, with the most deprived areas being nearly six times more likely to defer a GP visit for this reason. In terms of deferring the collection of a prescription due to cost, adults in the most socioeconomically deprived areas were three times more likely to defer.(16)

Higher levels of chronic illness with earlier onset have been recorded for those with lower socio-economic status which translates to higher healthcare needs and associated costs.

Furthermore, as healthcare expenses, such as the cost of visiting a GP and prescription fees, represent a higher proportion of their income, this group continue to remain in disadvantaged positions despite the provision of 'equal' access to healthcare.(4)

#### 2.3.1 Experiences of subpopulations

The studies reviewed focused on the experiences of different subpopulations and the key findings in relation to cost barriers to accessing medicines and primary healthcare are outlined below.

#### Māori

Many Māori are among the most deprived in New Zealand, and struggle to feed their families, pay the rent and bills etc., so the direct and indirect healthcare costs would have to be weighed against their essential daily expenses.(43) In such scenarios, they may question whether a GP visit was 'value for money' given their other priorities.(41)

Research has found that Māori were more likely than non-Māori to defer getting their prescription (42,44) and to have experienced unmet needs for primary healthcare.(16,45) Furthermore, the differences in prescription collection rates from pharmacies between Māori and non-Māori "persist after adjusting for social deprivation".(43 p.8) These findings imply that the co-payment scheme in New Zealand may represent a cost barrier. Certainly, in terms of unmet GP needs, significant differences were found between Māori and non-Māori due to the direct cost of the consultation fee. However, the ratio was larger when the reason was due to transport (an indirect cost), with Māori being nearly three times more likely to have deferred a GP visit because of unavailability of transport.(16)

Studies have highlighted some of the other indirect costs related to visits to primary healthcare providers. For example, for Māori living in rural areas, geographic barriers to healthcare including long distances and a lack of transport exacerbate the numerous healthcare access barriers for Māori. Healthcare providers opening times limited to business hours can be problematic if patients are unable to arrange medical appointments around their work hours, they might not be able to get time off work or may lose wages if they can (we note those in casual employment arrangements are likely to be particularly susceptible to loss of income). Primary caregivers would have to arrange childcare or other support if they are caring for an elderly relative or other dependent.(41,43,46)

As Māori generally experience a greater burden of disease, they have a greater need for healthcare, so it would be expected that they would have more medicines dispensed than average. A study examining variation in the use of medicines over the period of 2006/2007 found particularly in relation to "high health need such as heart disease, infections, diabetes, mental health and respiratory disease" that Māori had nearly one million fewer prescription medicines dispensed than non-Māori.(47 p.14) In a follow-up study for the period 2012/2013, the researchers found that the "overall disease burden-adjusted inequalities in medicine dispensings between Māori and non-Māori have widened for the cohort of medicines available in 2006/2007 (comparing Māori vs. non-Māori age-standardised rate ratio overall in 2012/2013 against that in 2006/2007)".(27 p.2) The researchers attributed the "overall increase in the apparent gap ... to a further deterioration in access" for Māori while acknowledging that "persistence has improved".(27 p.2) Although cost is probably a major factor in these variances, the researchers acknowledge the causes are "likely to be complex and systematic".(27 p.65)

The 2017 Health Quality and Safety Commission (HQSC) primary care patient survey found significant differences between Māori and European descendent respondents in terms of cost

barriers preventing them from seeing a GP or other health professional and picking up a prescription. The biggest difference found was in relation to prescription medicines with approximately 25 percent of those identifying as Māori stating that cost was a barrier to collecting prescriptions compared with fewer than 7 percent of those identifying as Europeans.(48)

The 2017 New Zealand Health Survey results were similar but slightly lower in terms of finding that Māori were just over twice as likely to have not picked up a prescription due to cost. (16) However, both surveys had a reason 'cost' incorporated into the question with no other option for giving alternative reasons, such as, for example, the associated side effects, or not agreeing with having to medicate, but unable to discuss alternatives with the GP.

These survey results reflect previous research by Jatrana and colleagues conducted in 2010 who found that Māori and Pacific people were more likely to defer filling a prescription because of cost than NZ Europeans after controlling for sociodemographic and other confounding variables. The researchers used data from "SoFIE-Health (wave 3), which is an add-on to the Statistics New Zealand-led longitudinal Survey of Family, Income and Employment (SoFIE)".(49 p.454) However, the data from SoFIE does not reveal "which aspects of prescription charges are causing the differences found between ethnic groups".(49 p.459) It could have been the prescription charge which was \$3 per item when the research was carried out and possibly a barrier for low income families with high health needs. If the family are eligible for a Prescription Subsidy Card which covers the costs of prescription items after the first 20 per year, they still would have had to pay \$60 in that initial period which is likely to be unaffordable for them.(49)

The authors discuss another possibility that Māori and Pacific people might be prescribed more partially subsidised or unsubsidised medications<sup>5</sup> and they provide three potential reasons for this "(1) they receive more prescriptions and therefore the chances of receiving partially subsidised or unsubsidised medicines is higher; (2) the medicines they are likely to take are more likely to be only partly subsidised or unsubsidised; or (3) prescribers and pharmacists do not make the decisions required to select a fully subsidised medicine for Māori and Pacific patients at the same rate as they do for other patients.".(49 p.459) However, prescribers would usually offer the fully subsidised alternative available for most partially subsidised medicines and if they did not and the patient was unhappy, the pharmacist could also request that the prescription is changed.(49) Further research on how prescribing practices, co-morbidities leading to taking multiple medicines, and current medicine subsidies intersect to impact on costs for Māori and Pacific patients is required.

Jatrana and colleagues, using the same data from SoFIE found that in terms of comorbidities, Māori and Pacific people were twice as likely to defer buying medicines than NZ Europeans, however, Asians were eight times more likely to defer. The authors discuss a possible cultural influence on "medication-taking in the presence of other illnesses" (p.458), however it was beyond their scope to explore this further.(49)The researchers also found that poor self-assessed health was significantly correlated with deferring prescription medications for Māori, but not for other ethnicities. They do not offer any explanation about why this has occurred, but state that it is consistent with previous research that showed that "those with a greater number of health problems or poorer health were most vulnerable to medication non-use due to cost." (p.459)

Similarly, Norris and colleagues investigating psychotropic medicine use by the elderly in 2011 were struck by the big difference between Māori and non-Māori. Fewer than 20 percent of elderly Māori were taking psychotropic medications compared with over a third of non-Māori

<sup>&</sup>lt;sup>5</sup> This study was conducted in 2010 and there have reportedly been changes to which medicines are subsidised and partially subsidised by PHARMAC.

elderly, despite Māori experiencing much higher rates of mental health problems than non-Māori (as reported in The New Zealand National Mental Health Survey - Te Rau Hinengaro).(18) The authors acknowledge the complexity involved and argue that discourses of medicalisation<sup>6</sup> and inequality are pertinent to comprehending these disparities. They discuss possible cost barriers given that people living in the most deprived areas had lower levels of use (26 percent) compared with those living in medium and higher socio-economic areas (both at 34 percent). Previous research suggested not having access to transport as a potential barrier for rural Māori, however, the results from this study showed that even though dispensing were lower overall for those living rurally, "rural non-Māori had higher rates of dispensing than urban Māori".(18 p.210)

Māori have also been reported as more likely to defer dental care visits due to cost barriers which is liable to impact negatively on the healthcare system, given the "overwhelming evidence that adverse oral health may have a profound impact on general health".(42 p.9)

#### **Pacific Peoples**

Similar to Māori, Pacific peoples experience both direct and indirect cost barriers.(45) Being among the most deprived in the country, they struggle to cover everyday expenses and so healthcare costs have to be balanced with the needs of housing and feeding their families. Many Pacific people have additional responsibilities of supporting extended families still living in the islands and traditional financial obligations. For example, the Samoan fa'alavelave obligations can be a stressful financial burden. Nevertheless, although low socioeconomic status clearly plays a significant role in the inequities experienced by Pacific peoples, research has shown that "health equity is not reducible to socio-economic determinants alone".(19 p.21)

Affordability of healthcare was discussed by Pacific Peoples within a culturally appropriate qualitative research programme setting. Having outstanding debts at the primary healthcare providers was likely to deter people from seeking medical attention. Likewise, some participants spoke about waiting until there was more than one problem before seeking help to make the doctor's visit more cost effective. Indirect cost was also a barrier to receiving recall notices in terms of the cost of retrieving voicemail message or returning calls on mobile phones.(19) The cost of telecommunications is likely to be a factor for others with low SES.

Pacific peoples experience greater rates of illness including chronic conditions and so would be expected to have higher prescription medicine usage, however studies have found this not to be the case.(4,47,50) The 2017 HQSC primary care survey and the 2017 NZ Health Survey both show significant differences between Pacific and non-Pacific peoples in terms of reporting cost as a barrier to picking up prescriptions.(16,48)

The 2017 NZ Health Survey found there was no significant difference between Pacific and non-Pacific adults in terms of unmet need for GP due to cost (non-significant 1.12 ratio after controlling for age and sex), but when the reason was due to lack of transport the difference was statistically significant (significant 2.57 ratio after controlling for age and sex).(16) Transport is a major indirect cost barrier to accessing primary healthcare for Pacific peoples.(4) This was the most common reason given by Pacific Peoples for not attending appointments particularly for elderly Pacific peoples who rely on younger relatives to take them in their cars and if those younger relatives are working, they may not be able to get time off work. However, the cost of parking also deters Pacific peoples from attending appointments and may partially explain the high rate of recorded DNAs (Did Not Attend).(19)

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<sup>&</sup>lt;sup>6</sup> Medicalisation discourses focus on how issues with a 'social' origin become defined as a medical problem e.g. male baldness.(44)

#### Refugees

Refugees have full entitlement to health and disability services, but their use of those services has been found to be limited and inequitable as 'Convention refugees' may not be informed of their entitlements. Having low income and greater health needs, the direct costs of accessing healthcare in terms of GP consultation fees and prescription charges, is an issue for most refugees, both quota and Convention. They also reported that their low income and the high cost of living in New Zealand prevented them from being able to afford to buy healthy food. Hospital waiting times were an issue and cost was mentioned in terms of being unable to afford private health insurance in order to get treatment quicker.(31,34,35)

#### People with mental health conditions

People with mental health conditions generally are of low socio-economic status. They have low incomes due to difficulties of maintaining a job whilst managing their mental health symptoms. Many live in temporary housing and the high levels of discrimination they encounter often results in them having to pay higher accommodation costs. The poorer quality of some temporary housing can also effect their health.(36)

Due to such social disparities, this group, in addition to their mental health requirements, also experience greater physical healthcare needs. Therefore, their healthcare costs are likely to be high and despite subsidies for low-income Community Card holders, the healthcare copayment represents a cost barrier. This barrier to GP services is particularly important in relation to receiving an initial diagnosis and making referrals to specialist services where required, and in seeking medical attention for the physical conditions caused by side effects of the psychotropic medication. Barriers to accessing healthcare for those with mental health issues may depend on which geographical region they live in as "the approach to mental health care is not consistent across the country" (36 p.20). Like other subgroups, indirect costs such as arranging and paying for childcare during their treatment and costs of travel. (36,37)

#### Populations living in Rural/Remote areas

Small remote rural communities are characteristically widely spread over large geographic areas so people usually live further away from healthcare and emergency services and are less likely to have access to phone services either via a landline or via cell phone coverage. Indirect cost barriers to accessing primary healthcare and medicines include transport issues and longer distances to travel to the nearest primary healthcare provider and pharmacy, and telecommunication problems, although cell phone coverage continues to improve. While these barriers are applicable to all rural people they are particularly pertinent to older people, those with disabilities and those of low socio-economic status who may be less mobile or less able to access transport.(15,45)

# Age related affordability barriers Older people

Given, their high healthcare needs, cost is likely to be a major barrier for older people, particularly those of low socio-economic status. Transport is also a barrier for elderly people who may have to rely on younger relatives to give them a lift to the healthcare practice.(19) Unsurprisingly, older people were more likely than those of working age to have deferred GP visits and picking up prescriptions because of cost. However, generally older people reported having more positive healthcare experiences than those of working age.(48)

#### Younger people

Most young people experience many of the barriers related with low socio-economic status due to low personal income including the cost of healthcare and prescription medicines. However, there are other barriers more specific to this group including their frequent relocation.(22) Young people (16-24 year old) also tend to have poorer health literacy.(51)

#### 2.3.2 Key findings emerging for affordability barriers

- Our review of studies across the subpopulations show that those with low socioeconomic status experience similar barriers in terms of direct and indirect costs. Those on benefits and low incomes have very limited choices about how they can spend their money and have to prioritise basic living costs such as food and housing.
- Direct costs related to co-payment for prescriptions were found to be a barrier for
  picking up prescriptions across the subpopulations. The cost of consultation fees was
  also a barrier to visiting primary healthcare providers and led to deferring visits and
  waiting until conditions became very serious and/or there were multiple reasons to visit
  the doctor. Anecdotally some general practices are limiting visits to discuss only one
  condition which would further act as a barrier to those with limited resources.
- Indirect costs emerge as a significant barrier. Studies highlighted transport costs in particular. This would be dependent on peoples' personal situations such as whether they have access to transport, can drive, and what costs are involved (petrol, public transport costs, parking). The two other most identified indirect costs highlighted in studies was loss of income if they were unable to be compensated for taking time off work and costs related to care of dependents such as young children or elderly relatives.
- There are likely to be other indirect costs that may have only received limited attention in the literature to date, such as the cost of using mobile phones to make appointments and pick up voice messages.

# 2.4 Barriers to primary healthcare providers related to accessibility and acceptability

This section examines literature on barriers to accessing primary healthcare providers which can be related to the concepts of accessibility and acceptability. There is overlap between this and the following two sections of Cultural safety/Cultural fit and Health Literacy. As stated accessing a healthcare provider is a prerequisite for accessing both PHARMAC subsidised and unsubsidised prescription medicines.

#### 2.4.1 Experiences of subpopulations

#### Māori

Besides cost, other factors that prevent Māori patients being able to fully access primary healthcare include the inflexibility of healthcare systems, previous bad experiences in terms of long waiting times, a lack of response to complaints, inconsistency in diagnoses and prescribing. During a health literacy programme focussed on gout, it was reported that in "every" follow-up interview, "the topic of time constraints in GP consultations" was raised as an issue by the interviewees.(52 p.26)

Implicit health provider bias was considered as contributing to the significant differences found between Māori and non-Māori in the management of care of group A streptococcal (GAS) pharyngitis during a government initiative to reduce the rate of acute rheumatic fever (ARF).(41,53) Healthcare provider barriers can be due to a lack of cultural understanding which is a major issue for Māori and will be discussed in section 2.5.

#### **Pacific peoples**

The appointment system (having to wait for appointments) and the way mainstream primary health facilities are organised can cause frustration for Pacific peoples. If they cannot get an

appointment on the only day they have available, they are likely to put off going so they would prefer a walk-in system. However, for many who highly value developing relationships of mutual trust, continuity of care, in terms of seeing the same doctor each time, was more important. Staff working at healthcare providers catering for the Pacific community suggest accommodating both systems by having one doctor for those with appointments and another doctor for the walk-in patients. Having extended opening hours as well as having multiple services on site would also be considered beneficial for Pacific peoples who work or for those who relying on working relatives for transport.(19)

Language and the absence of an effective interpreting service can also be strong barriers. Although there is an obligation for primary healthcare providers to provide interpreter services, some healthcare providers reported limited access to interpreter services as a healthcare barrier.(4 p.10) In one qualitative study, non-Pacific staff of healthcare providers serving Pacific communities reported that they had never used the interpreter service, relying instead on the patients' relatives to translate for them. During a research discussion which revealed that interpreter services were seldomly used, one healthcare provider said

Well, I don't [use interpreter services] and there's two reasons. One is that it's very expensive ... (even if it is free to the patient) somebody's still paying for it, and it's expensive. The second reason, is that its time consuming so you know, you're extending the time that you've got to see somebody and that means you see fewer people.(19 p.68)

However, effective communication is important to Pacific people and language was the third most cited healthcare access barrier after cost and lack of transport. Many Pacific people will travel further and overcome other difficulties in order to see a doctor who speaks their language. Pacific peoples often lack confidence when talking to doctors and some find the experience intimidating.(4,19)

#### Refugees

Language is also a major access barrier for refugees as they tend to have limited English skills and therefore find it very difficult to explain their illness. Two studies, Change Makers Forum and Mortensen, conducted in 2011 with refugees and service providers found that access to interpreting services was not consistent. In some cases, interpreters were not provided by the healthcare provider and the healthcare professionals were impatient with the former refugees and did not allow sufficient time to work through communication problems. (35,54)

Typically, medical consultations for refugees cannot be completed within the standard allocated 15-minutes appointment. Thus, from the healthcare provider's perspective, treating former refugees is likely to incur more costs than treating other patients. Sometimes when an interpreter was provided, they were not of the same gender as the patient. Women found it culturally inappropriate to have to explain personal health issues to a male interpreter. The same applies to male healthcare professionals. Women often would rather forego the treatment than have to discuss personal issues with a man. Some prefer to have someone they knew from their community to interpret for them, but others thought that raised confidentiality issues. They also commented that professional interpreters needed to have medical terminology training to be able to fully explain what the doctor is saying to the patient. (32,35,54)

Continuity of care was raised as an issue as having to see different health professionals at appointments rather than the same doctor each time was also noted by refugees as a barrier to obtaining good quality healthcare. They discussed how many of their health issues were

<sup>&</sup>lt;sup>7</sup> This likely to also apply to island born Pacific peoples, however, it was not highlighted as an issue in the literature reviewed.

caused by stress related to their refugee background but reported that healthcare professionals tended to just treat their physical symptoms rather than taking a more holistic approach. They talked about how healthcare professionals didn't seem to understand their background and didn't take the time to address related psychological issues or refer them to psychologists. There was also a concern among former refugees that many of them do not have the knowledge, confidence or language skills to make complaints about poor healthcare treatment.(35)

#### People with mental health conditions

Barriers exist in terms of accessibility to healthcare programmes. For example, administrative requirements related to some programmes may inadvertently exclude those with mental health issues. Furthermore, specifically targeted programmes often serve only those with less complex issues such as anxiety and depression, but do not address the needs of those with more serious mental health problems such as psychosis.(36 p.20)

Social stigma experienced within the wider community can lead to isolation for those with mental health conditions which can worsen the effects of depression. However, research has shown that people with mental health issues also encounter stigma and discrimination from some healthcare providers which deters them from enrolling at the most convenient practice thus possibly incurring additional transport costs. Furthermore, mental health patients report that their physical health issues are often ignored because all the focus is on their mental health symptoms.(36)

#### Younger people

Young people, particularly teenagers are highly sensitive to privacy and confidentiality issues. A survey of Secondary school students revealed that only 37% of those who had accessed healthcare over the last year were given the opportunity to talk to the health professional in private and more than half of them were not given assurances about confidentiality. However, these two factors are crucial for young people feeling comfortable about discussing their health issues. Many reported not being able to access healthcare and the most common reasons were; that they just hoped the problem would go away (51%), that they didn't want to cause a fuss (46%) and not having access to transport (28%).

# 2.4.2 Key findings emerging for barriers to healthcare providers related to accessibility and acceptability

#### **Accessibility**

- Consultation times too short the standard 15 minute consultation time was identified as too short in some studies, particularly for patients who required time to discuss issues and where there was communication issues and for those who required interpreters.
- **Getting to a healthcare provider** transport barriers were not only related to cost but also the ability to access transport and travel distances. Requirements to visit multiple providers can add to these difficulties. Research identified having multiple services in one place makes them more accessible.
- Convenience of opening hours studies identified the importance for those in employment being able to access the healthcare provider out business hours so they did not have to take time off work. This is also important for patients who rely on relatives who work to drive them to the healthcare provider.

#### **Acceptability**

- Experiences of implicit bias has been shown to contribute to the differences between Māori and non-Māori (discussed further in next section).
- Challenges developing continuity of care most patients would prefer to see the same doctor each time in order to develop a relationship with that doctor and to ensure good quality healthcare. This was found to be a challenge where patients wanted to see a doctor that day and their doctor was not available.
- Language/communication barriers as noted time pressures and lack of continuity
  of care put pressure on developing good communication. There were also issues
  noted with providing interpreting services related to time, cost to provider, whether
  interpreter from local community or not which could raise confidentiality concerns.
  Some cultures required having an interpreter of the same gender. It was also
  suggested as beneficial having access to interpreters with relevant medical
  terminology.
- Sensitivity/confidentiality concerns Sensitivity and confidentially were identified as particularly important for young people. People requiring interpreters identified confidentiality concerns with relatives interpreting for them or interpreters from the same community. People experiencing mental health conditions reported lack of sensitivity and discrimination by healthcare professionals which acted as a barrier to accessing healthcare and thus medications.

#### 2.5 Cultural safety/ Cultural fit barriers

Holistic health perspectives have always been central to many indigenous peoples' traditional beliefs and practices. In Aotearoa/New Zealand Māori Nurses first coined the term 'cultural safety' (kawa whakaruruhau) to emphasise that medical practitioners' have cultural responsibilities when working with Māori. However, today the term 'culture' is used in a wider sense to include "age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability".(55 p.5) Cultural safety involves health professionals reflecting on their own cultural identity to identify potential impacts on their practice. "Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual".(55 p. 7 italics in original) In a research interview about cultural safety, a Māori PHO manager asserted, "Cultural competence is about awareness ... not just about Māori and Pacific Islanders, it is about everyone."(4 p.10 italics in original)

Cultural competence impacts patients' outcomes and is important in removing barriers to healthcare. Internationally, cultural literacy is perceived as "a component of health literacy". (56 p.12) This is because "culture (including the culture of the health system) affects attitudes, perceptions and behaviours at both the patient and provider end, or for those receiving and delivering health services". (56 p.12)

We have reviewed research with Māori, Pacific peoples and refugees. We suggest further research and examination of how cultural safety to accessing healthcare and medicines relates to other subpopulations. For example, LGBTQI, low socio-economic status, and young people.

#### 2.5.1 Experiences of subpopulations

#### Māori

Māori holistic health philosophy incorporates four dimensions Taha tinana (physical health), Taha wairua (spiritual health), Taha whānau (family health) and Taha hinengaro (mental health). Māori believe that these four aspects, often depicted as cornerstones of a house as in the Te Whare Tapa Wha Model, need to be kept in balance in order to maintain good health.

There is a disjuncture between healthcare providers who prioritise physical health and do not acknowledge a spiritual dimension and their Māori patients who believe taha wairua to be essential for their wellbeing often serves as a barrier for Māori.(57)

Examples of unsafe cultural practice were uncovered in research that took a "Kaupapa Māori, 'by Māori, for Māori" (41 p.9), approach. This was a multi-stage research project which began with a series of ten hui with Māori healthcare consumers. In the hui setting, Māori felt more comfortable critiquing aspects of the health service, for example discussing their perceptions of some health providers having racist attitudes. They talked about feeling that they were being "talked down to" (41 p.9) or generally being treated disrespectfully by condescending healthcare professionals. In order to be culturally sensitive, healthcare practitioners need to be aware of the power imbalance between them and the health service users. Māori health service users have reported being too "shy" (41 p.9) to ask questions and are generally reticent to challenge any person in authority such as healthcare professionals. For Māori with disabilities (ngā hunga hauā), these barriers had a greater impact. (41,55) Research has also shown that Māori men may be more reluctant than Māori women to visit healthcare professionals resulting in female whānau presenting with proxy symptoms to obtain the required medicine raising further issues about accessibility and barriers. (29)

Unsafe cultural practice or unconscious bias could potentially be an explanation for the disparities found between Māori and non-Māori in terms of poor coordination between healthcare services and inconsistent flow of patient information, an area which requires further investigation. Significant differences between those identifying as Māori and those identifying as European were found in relation to the coordination of services including; being given the wrong medication or the wrong dose by a health professional outside of hospital, test results not being available at the time of appointments, and failures in the flow of information about the patients' treatment between health professionals.(48) Experiences of such errors and poor coordination is likely to lead to Māori mistrusting the healthcare system and serve as future access barriers.

Norris and colleagues discuss Māori being less likely to identify mood problems or other mental health issues as 'illness' that needs medication and thus are less likely to report such symptoms to their GP. They suggest the reason for Māori not discussing such matters also could be that they are not given enough time or made to feel comfortable. The authors cite a study by Crengle et al. 2005 which reported on the National Primary Medical Care Survey demonstrating that consultation times for Māori were generally shorter and GPs reported feeling less rapport with their Māori patients but did not provide any further information about this finding. Norris and colleagues also postulate that non-Māori doctors may feel uncomfortable discussing mental health problems with their Māori patients because the doctors perceive Māori as having different world-view perspectives tending to attribute their symptoms to causes beyond the doctors' comprehension such as "breaches of cultural practices".(18 p.214)

Māori experience higher levels of chronic illness which is the leading cause of morbidity and mortality in New Zealand. Sheridan and colleagues (2011) explored the equity of health services by focusing on variations of provision of care in chronic care management systems across New Zealand. They found that diversity and cultural safety training delivery was inconsistent and often not tracked within DHBs, and PHOs. In addition to conducting a survey, they also interviewed expert informants who were selected "on the basis of national prominence in long term condition management, ethnicity, occupation, employer and geography".(4 p.5) The researchers report that "several expert informants commented that many programs were Euro-centric and poorly adapted for Māori and Pacific peoples, risking failure".(4 p.10)

#### **Pacific peoples**

Pacific peoples traditionally take a holistic approach to health and wellbeing which includes a spiritual dimension. For example, the Fonofale Model is an interpretation of the Samoan health perspective which, similar to Māori, uses a house to illustrate the interconnectedness. Here, 'family' form the foundation, 'culture' the roof with physical and spiritual dimensions, among others, forming the pillars connecting the two.(39) One respondent summed up their holistic balanced philosophy of health "if you have a happy soul and mind then you find wellness" (19 p.37). Cultural practices and spirituality are important factors for Pacific peoples in terms of managing the stress associated with living with limited resources which is often exacerbated by the need to meet extended family obligations.(19)

Studies have found cultural insensitivities and racist attitudes that include; using an unfriendly tone of voice, being rude, being impatient, and making assumptions without giving the person an opportunity to talk. These would be classified as unsafe cultural practices and serves to deter Pacific peoples from seeking healthcare if there is not a Pacific healthcare professional available.(19)

As mentioned previously healthcare programmes tend to be "Euro-centric" rather than being culturally adapted to meet the needs of Pacific patients.(4 p.10) For Pacific peoples reciprocity and obligations are central to developing interpersonal relationships. Rather than the Euro-centric transactional perspective of paying for services provided, Pacific peoples regard the quality of their healthcare in terms of whether "the va" was being respected.(19 p.50) "Va is the space between, the between-ness, not empty space, not space that separates but space that relates, that holds separate entities and things together ... giving meaning to things".(58 n.p) It is clear that Pacific people would like "culturally competent health care services".(37 p.22 italics in original) However, being able to deliver this will not be easy as the Pacific population comprises of multiple ethnicities.(19)

#### Refugees

Cultural differences in health assessment and treatment can be a barrier for refugees. For example, a qualitative study by the Change Makers Forum (2011) with 24 former refugees from eleven different communities found that patients experienced a general lack of cultural awareness among health professionals and suggested it would be beneficial if doctors had information about the situation in the patient's country of origin and the culture. They also described how healthcare professionals and staff could be unwelcoming, discriminatory, rude, judgemental, impatient, demonstrating inaccurate preconceived stereotypical ideas and generally culturally insensitive leaving the refugees feeling alienated.(35) These descriptions of their experience of the healthcare service constitutes "unsafe cultural practice".(55 p.7)

#### 2.5.2 Key findings emerging for cultural safety barriers

- Lack of holistic approach studies found differences in health treatment approaches could be a barrier as the dominant approach is Euro-centric. Particularly where patients' preference was for a more holistic approach and understanding of their background, cultural perspectives and experiences of mental, physical and spiritual health.
- Unsafe cultural practice or unconscious bias could potentially be an explanation for the disparities found between Māori and non-Māori in terms of being given the wrong medication or the wrong dose by a health professional outside of hospital; poor coordination between healthcare services resulting in inconsistent flow of patient information about the patients' treatment between health professionals.
- Experiences of racism (conscious and unconscious bias) led to patients from subpopulations not wanting to access and engage with healthcare service providers. For example, a study suggested that experiences of healthcare provider medication

- errors and poor coordination is likely to lead to Māori mistrusting the healthcare system and serve as future access barriers.
- Workforce lack of cultural competency studies identify a number of ways this is manifested including unconscious bias, lack of cultural awareness, fear of breaching cultural practices leading to lack of engaging on some issues.

# 2.6 Barriers to the provision and uptake of health literacy strategies

In 2004, the US Institute of Medicine portrayed health literacy as a dynamic state that "emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services". (cited in 56 p.4). Focusing more on the individual patients, the New Zealand Ministry of Health (MoH) defined health literacy in 2015 as "the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions" (59 n.p). Although the MoH acknowledges the crucial role of healthcare providers in supporting consumers in understanding and accessing health services, the emphasis of both definitions is on patients' skills meeting health providers expectations to be better able to navigate the health system without acknowledging the complexity of the system which was not designed to be user-friendly.(56,59) Health Literacy NZ's newer (2015) definition clearly places the responsibility for health literacy in the domain of health practitioners and assert that "health practitioners are responsible for making sure that appropriate information is provided to consumers in a way that makes sense to consumers". Furthermore, they emphasise that health provider and practitioners "need to identify and remove any barriers to a person taking action on the new health information they have obtained".(51 n.p) Thus, health literacy is a complex construct evolving over time and across different health contexts.(56)

Previously, when health literacy was focused on patients, a number of assessment tools emerged, particularly in the US. However, these tools have been severely criticised by health literacy experts in terms of validity and comprehensiveness. Given that all patients, "even highly skilled individuals may find the systems too complicated to understand, especially when these individuals are made more vulnerable by poor health" (Institute of Medicine cited in 56 p.6), the approach preferred by the experts is to "apply the principle of universal precautions to health literacy (which is familiar to health professionals and organisations in the context of preventing blood-borne diseases)".(Baker et al (2011); Paasche-Orlow and Wolf (2007); DeWalt et al (2010); Reid and White (2012) cited in 56 p.6) "Taking a universal precautions approach to health literacy involves finding out what patients already know, sharing clear information with patients and helping patients build their understanding of how their body works, their health issues and associated treatment".(56 p.6)

#### 2.6.1 Experiences of subpopulations

#### Māori

More than half of all adult New Zealanders have poor health literacy skills, that is, their level of understanding is below the minimum deemed necessary to cope with everyday demands. Although health literacy is important for people of all ages and socioeconomic status, Māori generally have poorer health literacy particularly Māori youth (16 - 24 years old) and Māori over 50 years old. It is very important to address these literacy needs as health literacy is clearly linked with health status.(51)

To illustrate how issues with health literacy can impact on access to healthcare and medicines two examples are provided of conditions in which Māori are over-represented; rheumatic fever and gout.

Rheumatic fever has been described as a disease affecting Māori and Pacific peoples "almost exclusively" and is exacerbated by poor housing conditions and overcrowding related to low socio-economic status and the high cost of housing.(60 p.22) Health literacy is important to ensure that people understand, not only the links between sore throats and rheumatic fever and the importance of seeking healthcare early, but also the reasons why it is important to complete the full course of antibiotics and not stop as soon as the patient feels better.(51)

Gout is another condition more common in Māori and Pacific peoples. Studies have shown that people with gout and their whānau often have strong, but inaccurate beliefs, about the condition. They have often gained their knowledge about gout, not from healthcare practitioners, but from people in their community or the internet and frequently mistake prevention advice for management strategies. Due to these misunderstandings, gout is often joked about within the Māori community with the consequent stigma serving as an additional barrier preventing gout sufferers from seeking medical attention.(52,61) In addition to looking at barriers for patients, the researchers also focused on health provider barriers in terms of health literacy and found that health practitioners lacked up to date knowledge about gout and generally lacked understanding about health literacy strategies.(61)

#### **Pacific Peoples**

The information above relating to rheumatic fever and gout also apply to Pacific peoples. (60,61) Research undertaken using culturally appropriate methods and language, found that participants clearly understood the connection between poverty, poor housing and poor health. Despite this knowledge, even when the link had been confirmed by a doctor, finding solutions proved difficult due to lack of resources. The participants were also found to be very knowledgeable about the health benefits of a balanced diet, exercise, good hygiene, sufficient rest and sleep. The researchers concluded that it was lack of resources restricting availability of options and not a lack of knowledge on the part of Pacific patients that resulted in unhealthy lifestyles. However, from the healthcare provider perspective, the same study found low levels of health literacy in terms of Pacific patients being unable to successfully navigate the health system, poor adherence, unable to understand medical jargon, as well as language and communication problems. Unfortunately, although the authors acknowledge this disconnect between health providers and patients, they do not provide further analysis. (19)

Anecdotally, we have heard that many Pacific people, especially those born in the islands, are used to going to the hospital or a nurses' station as their first port of call and possibly prefer this practice as it is familiar. Although we did not find specific evidence of this in the literature we reviewed, Southwick and her colleagues who undertook research into 'Primary Care for Pacific People' stated in their quantitative methods section "Although our aim was to describe Pacific peoples' use of primary care, we considered that use of *emergency departments*, hospital admissions and *outpatient service* can be complementary to, and sometimes an alternative to, primary care".(19 p.86 italics added)

#### Refugees

The Change Makers Forum study found a general lack of awareness about the health services available in New Zealand among former refugees and they attributed that partly to their language difficulties, but also felt that healthcare providers could be more proactive about disseminating health information. They wanted advice about how to maintain good health in terms of eating healthily and keeping warm as the participants were not used to living in such a cold climate. Women reported that they and their children's health had actually deteriorated since their arrival in New Zealand due to increased rates of respiratory conditions.(35)

#### Older people

A longitudinal study of advanced ageing, called Life and Living in Advanced Age: a Cohort Study in New Zealand used a population-based sample of Māori (aged 80 to 90 years) and non-Māori (aged 85 years), living in the Bay of Plenty. The researchers found that 92% were on regular prescribed medicines.(62) Similarly, Norris and colleagues found that over a third of people over 65-years-old were dispensed a psychotropic medication in one year and, as discussed Māori in this age group were significantly less likely to be dispensed psychotropic drugs<sup>8</sup>. The researchers highlighted the complexity and intersections between ethnicity, age, low SES, and institutionalised biases. This was further impacted by discourses of inequity and medicalisation that related to 'over-medicalising' for some subpopulations who could be seen to 'afford it'. There are implications that drivers are pharmaceutical companies wanting to increase their markets by so-called 'disease mongering' - creating new medical conditions for non-pathological problems and normal aging processes. However, such capitalist entrepreneurial practices may be assisted by social-cultural factors. Studies showing highlevels of medication use tend to have an over-representation of women and older people. (18)

Continuity of care was important for older people and research has shown that those who rated their doctor's care as 'very good' or 'excellent' were more likely to understand what their medication was for than those rating their doctor's care as 'good' or 'poor'. Thus, it is likely that for older people not having a good relationship with their GP could be a barrier to health literacy.(62)

## 2.6.2 Key findings emerging for barriers to the provision and uptake of health literacy strategies

- Some healthcare providers were found to lack up-to-date knowledge about specific conditions such as gout.
- Some healthcare providers were not taking responsibility to ensure patients have the
  required knowledge about their condition and medications. Barriers included
  communication issues due to language and use of medical jargon. There was a
  possible lack of exploring patient's beliefs and perceptions of the treatment prescribed
  (e.g. perceptions of gout)
- Low income rather than lack of knowledge can restrict patients' options to maintain a
  healthy lifestyle such as access to housing and warm homes, and access to healthy
  foods.
- Continuity of care and having a good relationship with the doctor is linked with good health literacy.

#### 2.7 Conclusion

This chapter examined the literature on barriers to accessing medicines via primary healthcare providers. The social and economic factors that negatively impact on health outcomes leading to health disparities can be seen to also impede access to medicines and healthcare. Structural factors that lead to inequities are perpetuated through institutions that are developed by societies through political, economic, and social systems. Power imbalances arise when one group is dominating these institutions at the expense of other groups leading to inequities and barriers to accessing services and resources. How this translates into barriers for

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<sup>&</sup>lt;sup>8</sup> Fewer than 20 percent of elderly Māori were taking psychotropic medications compared with over a third of non-Māori elderly, despite Māori experiencing much higher rates of mental health problems than non-Māori (as reported in The New Zealand National Mental Health Survey - Te Rau Hinengaro)

disadvantaged groups is complex and can be all the more difficult to address when biases masquerade as 'norms' and racism and discrimination are unconsciously enacted. This highlights the importance of the health system and providers being aware of how their policies and practices, including their own cultural perspectives, impact on others.

The subpopulations are not mutually exclusive and there are major intersections between them, for example ethnicity, low socio-economic status, mental health, rural/remote, older and younger people. Thus, many of the barriers to accessing medicines and healthcare are experienced across the board, especially those relating to 'affordability' of both direct and indirect cost. However, there are also key differences between and within the groups and while on the surface it may seem as if the barriers are related to low socio-economic status, research has shown that they are often not reducible to those factors alone.

The 'acceptability' by patients and their family and whānau of health service provision and treatment was identified as a significant barrier to access particularly when they had negative experiences of services and difficulties with communicating their needs. Studies showed that subpopulations experienced forms of institutionalised racism, both conscious and unconscious bias, leading to negative experiences of healthcare services and errors in prescribing medications. Lack of provision of appropriate and adequate health literacy strategies by providers also limited access (and utilisation) of medicines.

The concept of 'sufficient fit' between patients from disadvantaged subpopulations and healthcare providers challenges the health system and healthcare providers to make their services more accessible. Interventions that enable more equitable access and quality service are examined in the next section.

# 3 Interventions to enable more equitable access to medicines via primary healthcare providers

#### 3.1 Introduction

This chapter examines New Zealand and international literature to identify evidence of interventions to address the barriers highlighted in chapter two. We found that there were few evaluations of initiatives and that much of the literature provides strategies and guidelines or describes proposed or current initiatives. There are considerable gaps in knowledge about what is effective and also for whom given the variety of subpopulations, intersectionality of those populations and the different contexts they live in. Key themes do emerge about good practices to address access barriers, and there are interventions that look promising and we recommend should be further examined to verify if they do improve equitable access to medicines.

#### 3.2 Addressing structural barriers

3.2.1 Examples of strategic frameworks and interventions to effect structural change

### HQSC framework for building quality and safety capability in the New Zealand health system

Addressing inequity within the New Zealand health system, the HQSC (2016) published 'a framework for building quality and safety capability in the New Zealand health system' of which a stated common purpose is "ensuring there is improved health and equity for all populations in New Zealand".(63 p.4) The framework comprises six capability sections:

- Enabling consumers/patients and their families/whānau as members of the health team
- Capabilities of everybody participating in the health and disability workforce
- Capabilities of operational, clinical and team leaders
- Capabilities of quality and safety experts
- Capabilities of senior and organisational leaders
- · Capabilities of governance/boards.

Within each of the six capability sections, there are lists of knowledge and actions for each of seven domains that characterise the specified capability. The seven domains are:

- Partnerships with consumers/patients & their families/whānau
- Quality & safety culture
- Leadership for improvement & change
- Systems thinking
- Teamwork & communication
- Improvement & innovation
- Quality improvement & patient safety knowledge & skills.

For example, in the governance/boards capability under 'action' the domain of improvement and innovation, includes:

- use evidence and industry benchmarks to evaluate organisational performance and inform decision making
- use multiple information sources and a broad range of indicators to assess system performance and reliability.

This comprehensive framework acknowledges a requirement for:

- "effective governance and leadership, both clinical and managerial, across all levels within the health and disability sector to improve quality and safety
- an appropriate infrastructure being in place to support, enhance and sustain capability in quality and safety across the sector."(63 p.8)

While the framework aims to address health and equity across populations in New Zealand it does not specifically identify how to address some of the major structural barriers identified in the literature such as the under-representation of Māori in health leadership and policy making, institutionalised racism, and the underrepresentation of Pacific peoples in the health system workforce.

In 2011, Sheridan et al found that strategic intentions to reduce inequity were not reinforced by systematic implementation plans and so to reduce this barrier they recommended that equity approaches be "institutionalized throughout the health sector and beyond to other sectors such as education, social welfare and housing".(4 p.12)

It was recommended that strategic plans to address structural barriers to equitable access to healthcare and medicines be systematically implemented so that they become institutionalized throughout the health sector. Evaluating the implementation and effectiveness of strategies related to equitable access to healthcare and the impact for subpopulations is required.

To facilitate the institutionalisation of equity approaches we suggest a review of existing policy, strategies, frameworks and alliances to identify gaps and encourage alignment and consistency of approach to equitable access to medicines. We support authors recommendations that plans to address structural barriers be institutionalised beyond the health sector to other sectors such as education, social welfare and housing.

### Interventions to achieve Better Sooner More Convenient Care (BSMC) health policy for Pacific Peoples

Southwick and colleagues make the following recommendations to achieve the 'Better Sooner More Convenient Care' (BSMC) health policy (introduced in 2011) for Pacific peoples:

- Develop Pacific health workforce as a key resource for health equity and to improve the health of Pacific peoples.
- Develop translation policy and approaches to support effective communication between Pacific peoples and health care providers
- Require public funded primary-care organisations to provide appropriately anonymous data for quality improvement and accountability to monitor equity of health services.
- Improve consistency in the application of capitation funding at PHO and practice level.
- Improve availability of public and/or private transport
- Improve appointment system approaches
- Enable targeted intervention and local solutions by the clustering of Pacific peoples requiring chronic care management.
- Provide cultural competence and family-based approach training for health professionals.(19 pp.13-17)

### Changing from systems-centric to patient and family-centred approach in Bay of Plenty

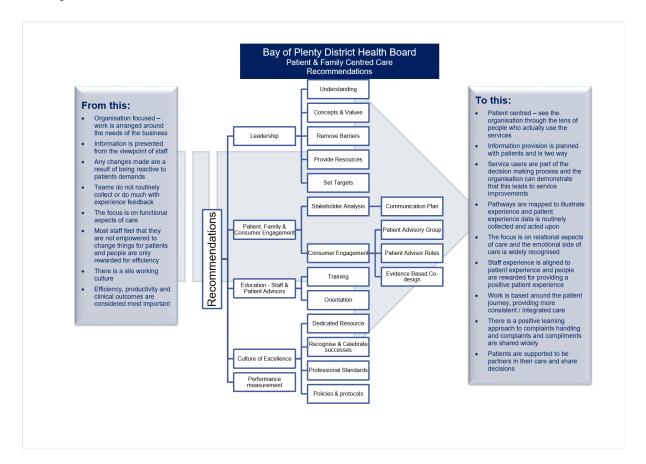
A promising approach announced by Bay of Plenty District Health Board (BOPDHB) was to move from being systems-centric (in which services are organised around the system and the workforce) to an organisational culture "grounded in the values, behaviours, and approaches of patient and family centred care (PFCC)"(67 p.3). The project was initially funded by HQSC as part of their Quality & Safety Challenge 2012 and was researched by Averil Boon, Quality Coordinator at BOPDHB.

Boon (2012) acknowledges that this will be a 'journey' of "continual evolution" rather than "a one-time event".(67 p.3) In order for it to be more than merely aspirational, she asserts that it is essential that PFCC is "incorporated in every activity from health promotion and disease prevention to end of life care. It must also run through all, human resources policies, quality improvement initiatives, patient safety initiatives, policies and programs designed to improve access to care and care coordination".(67 p.6)

Boon (2012) emphasises that in order to achieve a high-quality patient and family centred organisational culture, healthcare "must be delivered by systems that are carefully and consciously designed to provide care that is safe, effective, patient and family centred, timely, efficient and equitable".(68 p.13) It is essential that the needs of the patients and their families are at the centre of system design.

The BOPDHB have chosen "the acronym CARE (compassion, attitude, responsiveness and excellence) as its core values".(68 p.22) A diagram for the proposed culture change is provided in figure 3. This diagram, which was incorporated into the BOPDHB Strategic Plan 2012-2017(69), illustrates the fundamental role of the leadership team. The leaders need to be fully committed to the new culture and part of their role is to identify and remove any barriers that may preclude success.(67)

Figure 3: Bay of Plenty DHB culture change from systems-centric to patient and family centred



#### 3.2.2 Strengthening responsiveness to Māori in health research

Reid and colleagues (2017) maintain that greater engagement with responsiveness to Māori should be considered part of health researchers' commitment to achieving equitable health outcomes. They propose an equity-based approach to responsiveness to Māori which emphasises "four key areas that require careful consideration, namely: (1) relevance to Māori; (2) Māori as participants; (3) promoting the Māori voice, and; (4) human tissue".(64 p.96) They assert that existing Treaty of Waitangi frameworks could be used to develop health researchers thinking in relation to responsiveness to Māori. The frameworks "position the Treaty of Waitangi at the forefront of health research in New Zealand with the Waitangi Tribunal emphasising the Crown's role in upholding and protecting Māori rights and the delegation of these responsibilities to health researchers funded from government agencies".(65 p.97) Te Karu also reiterates the call for the "focus to be on health outcomes rather than outputs as a lens for Indigenous health-care delivery".(66 p.14)

#### 3.2.3 Key findings emerging for addressing structural barriers

Structural barriers to equitable access to medicines via healthcare are often broadly entrenched in the wider socio-economy and therefore complex to address. We have only identified key issues that emerged from the literature we reviewed and there are likely to be many more areas where structural change can be implemented to improve equitable access. The literature reviewed suggests the following actions and interventions would contribute towards addressing structural barriers.

- Plans to address structural equity barriers should be institutionalized throughout the health sector and beyond to other sectors such as education, social welfare and housing.
- Promote Māori health leadership, policy and health research
- Suggestions for development of organisational structure and capacity to work with Pacific Peoples, these would likely relate to good practice with other subpopulations
- The availability of public and/or private transport to healthcare providers should be improved
- Develop Pacific health workforce as a key resource for health equity and to improve the health of Pacific Peoples.
- BOPDHBs' organisational culture change from a systems-centric structure to being
  patient and family-centred could potentially be adopted by other DHBs if found to be
  making a positive difference. No publicly available evaluations were found as the
  published information related to the launch and the start of this initiative.

We suggest a policy review of current strategies across the health sector would be useful to determine if, and how, these strategies are aligned in relation to equitable access to healthcare and medicines to inform future alignment and strengthen implementation plans.

#### 3.3 Interventions to address affordability barriers

Although affordability has been shown to be a major barrier for many of the sub-populations, there are few studies on the effectiveness of interventions to address affordability issues. We have identified a few studies where positive results were found and also provided examples of promising practices that require evaluation to provide evidence of their impact on equitable access to medicines.

#### 3.3.1 Direct costs

Hutt Valley District Health Board (DHB), in collaboration the Ministry of Social Development (MSD) and community pharmacies, achieved positive health outcomes and financial savings by removing the direct cost of medicines for patients with multiple chronic conditions who would usually have to pay for the first twenty items at the start of the pharmaceutical subsidy card annual cycle. The researchers found that for a small initial investment of \$100 per patient (or simply a movement of benefit in some cases), substantial positive results could be attained. They also found that the participating patients' health was stabilised through their improved adherence to their medication once the direct cost barrier had been removed from obtaining the medicines. Additionally, the DHB saved \$1,200 per patient due to a 12% reduction in the average number of hospital bed days per person.(70)

#### 3.3.2 Indirect costs

Health screening services and interventions to enhance access by reducing direct costs and indirect costs in terms of transport/logistics (e.g. by having mobile screening units) were found to be effective.(46)

Barker and colleagues found that indirect costs such as loss of wages through having to take time off work to attend medical appointments were saved by the flexible service offered by district nurses. The district nurses travel to the patients' homes or workplaces to administer monthly antibiotic injections for secondary prophylaxis for rheumatic fever among Māori youth. (71) Likewise, clinics that extend their opening hours to cater for patients who work during weekdays make healthcare more affordable.(19)

Southwick and colleagues highlighted the availability of public and/or private transport as a key factor in enabling Pacific peoples' access to primary healthcare and reported "strategies that work for transport:

- A community health worker picks up people and brings them to the practice, arranged via a receptionist and then community health worker.
- St John's shuttle takes older patients or mothers with children to hospital. The service costs a gold coin donation and must be booked the day before.
- Patients with a "gold card" (age 65 and over) can use the public bus system free in the Auckland region. This requires mobility and confidence." (19 p.58).

Although we did not find any specific studies, we have heard anecdotally of primary healthcare services that arrange for the Red Cross Community Transport service to pick patients up for their medical appointments and take them home afterwards.

#### 3.3.3 Key findings emerging for addressing affordability barriers

Affordability was shown to be a major barrier and yet there is a lack of studies on the effectiveness of interventions to address these barriers. Studies that did demonstrate positive outcomes and promising practices included the following examples.

- Collaborative and flexible initiatives to enable more continuous access to subsidised
  medicines: The Hutt Valley District Health Board, in collaboration the Ministry of Social
  Development and community pharmacies, achieved positive health outcomes and
  financial savings by removing the direct cost of medicines for patients with multiple
  chronic conditions who would usually have to pay for the first twenty items at the start
  of the pharmaceutical subsidy card annual cycle.
- Flexible healthcare provider services incorporating home and workplace visits and extended clinic opening hours made healthcare more accessible as well as more affordable as they mitigated some of the indirect costs from transport and taking time off work.
- Collaborative initiatives between primary healthcare providers and non-governmental organisations (NGOs) looks to be a promising practice to reduce transport barriers for patients, for example by the provider arranging the use of Red Cross Community Transport for patients to attend their appointments.

#### 3.4 Interventions to address accessibility barriers

The following section identifies interventions that enable accessibility by reducing barriers related to travelling to location of providers and opening hours.

#### 3.4.1 Outreach

The flexible service provided by district nurses, as reported by Barker and colleagues and discussed above, is a good example of a successful programme to overcome accessibility barriers. By travelling to the patients' homes or workplaces to administer monthly antibiotic injections, the district nurses made this vital healthcare service more accessible to patients whose work hours prevented them from attending clinics.(71) Likewise, Southwick and colleagues found that some clinics catered for families where both parents are working and cannot attend during weekdays by having extended opening hours.(19)

Nursing outreach "can overcome geographic barriers to accessing health services, such as lack of transportation and geographic isolation" by providing healthcare in patients' homes. (72 p.9) Outreach nurses can develop positive relationships with patients through multiple visits in an environment where patients feel comfortable – their homes. CBG research Ltd published a toolkit for implementing nursing outreach aimed at primary health organisations as outreach nursing can overcome multiple access barriers that would not be addressed by lowering the cost of GP visits. See table 3 for more information.

Table 3: Access barriers addressed by lowering fees vs. outreach (72 p.9)

Barrier	Low cost/free GP visits	Nursing outreach Clinic
Setting frightening	No	Yes
Fees / unpaid bills	Yes	Possible
Unwilling to ask for help	No	Yes
Concern other agency may be contacted	No	Possible
Language difficulties	No	Possible
Worried about NZ residency status	No	Possible
No access to transport	No	Yes
Clinic not open at convenient time	No	Yes

The outreach nursing service could potentially be improved by nurses adopting the prescribing role. A UK study found that, in relation to respiratory care, nurse prescribing "improved and extended points of access to treatment, and supported management of complex patients, particularly vulnerable groups".(73 p.1)

Community health workers have been defined as "member[s] of a particular community who work ... as a bridge between the healthcare system and community members".(Look et al. (2008) cited in 74 p.19) Their work will also be covered under cultural competence as they often work with indigenous or ethnic minority communities bridging 'cultural gaps' and performing various roles including "educator, translator, coordinator, navigator, and peer mentor".(74 p.19) Research has shown that, community health work in relation to diabetes improves patients' "knowledge and self-care, diet, physical activity, and self-monitoring of glucose"(Norris et al. (2006) cited in 74 p.19). However, studies measuring the effectiveness of community health worker interventions in terms of glycaemic control improvement have produced mixed results.(74)

A random-control trial of a community-based model of care for Māori and Pacific patients with type 2 diabetes and chronic kidney disease (CKD) showed positive health outcomes for the home care (intervention) group. The intervention group were visited by every month by "a Māori or Pacific health-care assistant (HCA), and were offered transport assistance to the local pharmacy or laboratory" (74 p.19) thus also addressing affordability as well as accessibility issues. Although there was "no significant difference between the intervention and control groups for changes in DBP, HbA1c, serum creatinine, or total cholesterol" (74 p.20) "compared to the control group, at 12 months the intervention home care group had a significantly greater reduction in SBP and 24-h urine protein".(74 pp.19-20). Thus, optimal healthcare for Māori and Pacific patients with diabetes and CKD can be achieved by providing "culturally appropriate face to face clinical care, allowing patients to have a more frequent follow-up in the community, frequent prompting to take their medications and reduced costs to the patient because of home visits" (Hotu et al. (2010) cited in 74 p.20)

Positive findings from a study by Ingram and colleagues (2007) found significant decreases in HbA1c levels<sup>9</sup> among people with diabetes living in a farmworker community on the US-Mexico border after a year of receiving support from "community-based promotoras (from Spanish term for lay community educator)".(74 p.19) Results showed that 70 out of the 100

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<sup>&</sup>lt;sup>9</sup> The measurement of glycated haemoglobin (HbA1c) provides an overall picture of what average blood sugar levels have been over a period of weeks/months. (www.diabetes.co.uk)

participants, many of who had poor glycaemic control at the start, lowered their HbA1c levels significantly. Within the high-risk group the improvements were even greater. In addition, cholesterol levels were significantly improved.(cited in 74 p.19)

An additional intervention that addresses geographical barriers for those living in remote areas is the placement of defibrillation equipment in ambulances and the installation of fibrinolytic equipment in remote communities with local people trained to use it".(Kerr et al. (2010) 75 p.35) This has been shown to save lives as well as improving survival and rehabilitation rates for Māori with Ischemic Heart Disease (IHD).(75)

Pharmacist prescribers integrated into various health services were highlighted by the New Zealand Ministry of Health<sup>10</sup> in a series of short case studies. These roles have potential to improve access as they include outreach services and work with primary and secondary healthcare and kaupapa Māori services. Their specialist knowledge of medications also suggests they are well placed to assess and review current medications which is particularly important for patients with chronic conditions taking multiple medications. We suggest research on the effect of these roles on access to medicines for different subpopulations.

#### 3.4.2 Technological solutions

Telecommunications and new technologies can also be used to overcome accessibility barriers, especially for people living in remote areas.

#### **Telehealth**

The National Telehealth Service (NTS), launched in November 2015, by the Ministry of Health in partnership with Homecare Medical brings together a number of Ministry-funded health advice phone lines and other communication channels. Integrated with local, regional and national health services, the telehealth service aims to address accessibility barriers through technology to "deliver right care at the right time by the right person in the right place"(1 n.p). The service includes "advice, support, assessment of symptoms, triage, treatment, and preventative (educational) aspects" (1 n.p) via a variety of communication channels:

- "Personal interaction phone advice, support and counselling, with the ability to refer to other health advice and face-to-face services.
- Online interaction text, email, web chat, and social media including blogs and online forums.
- Personalised automated advice online assessments and guides, apps and symptom checkers, website self-help and health information".(1 n.p)

Their services, which are available all day every day and are free of charge to users, include:

- Healthline registered nurses provide health triage and advice
- Quitline quit advisors provide support for people wanting to quit smoking
- Alcohol Drug Helpline advice, information or support from counsellors about drinking or other drug use
- Depression Helpline (including Depression.org.nz, The Lowdown, The Journal, and 1737 need to talk?) a range of services including counselling by mental health trained counsellors. (The same counsellors service the alcohol & drug helpline and gambling helpline)
- Gambling Helpline support from counsellors for those worried about their or someone else's gambling

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 $<sup>^{10}</sup> https://www.health.govt.nz/our-work/health-workforce/new-roles-and-initiatives/established-initiatives/pharmacist-prescriber/pharmacist-prescriber-case-studies$ 

- Poisons advice advice and initial triage for the public
- Immunisation advice providing immunisation advice to the public
- Ambulance secondary triage clinical assessment by registered nurses for low acuity
   111 calls to St John and Wellington Free Ambulance (1)

A post-implementation review conducted in 2017 that "assessed the transition to NTS and implementation for the first 12 months of operation up to October 2016" (76 p.3) revealed that the NTS delivered services to 417,000 people in New Zealand "from all age groups, ethnicities and areas". (76 p.4) However, the calls to Quitline were lower than expected and the outcomes were "significantly lower than with the previous provider". (76 p.19) Initially the calls were answered by the mental health counsellors but the review found that some staff were not happy answering quit calls so a solution of a dedicated quit advisory team to answer calls was implemented. The reviewers acknowledged that developing an equity-led service requires time. However, they found that in the first year "equity of access results for Māori and Pacific people varied by NTS services. Māori were high users of Healthline but lower users of Quitline. In contrast, Pacific people used both services less". (76 p.4)

The New Zealand Telehealth Forum promotes the use information and communication technologies such as secure video conferencing in the provision of health care. This can make specialist care more accessible. For example, children in Central Otago with type one diabetes, "the second most common chronic condition in children after asthma" (77 n.p.), are required to see a diabetes specialist every three months which involves days off school and work for parents/caregivers for an eight-hour round trip. This is not only time consuming but also costly. However, for children under Dr Wheeler's care these visits have now been replaced by a half hour video conference in the clinic at Dunstan Hospital in Clyde. (77)

#### **Medical Drones**

Dr Lance O'Sullivan was involved in the early stages of development of the innovative use of drones to deliver medicines to people living remotely. (78) "The medical and crisis-support drone trials will lead to a high-quality, high-value service that will make a real difference to people's lives. [Medical Drones Aotearoa are] focused on supporting communities that may otherwise be overlooked when it comes to deploying leading-edge technologies for services."(79) A trial to use drones for delivering to Mitimiti, north of Hokianga Harbour where the nearest pharmacy is a three hour drive, is planned pending Civil Aviation Authority approval.(79)

#### 3.4.3 Key findings emerging for addressing accessibility barriers

- Flexible health provider services incorporating home and workplace visits and extended clinic opening hours makes healthcare more accessible for patients who work.
- Nursing outreach and home healthcare provided by community health workers overcomes geographical barriers.
- Nurse and pharmacist prescribing for certain conditions could address accessibility barriers.
- Mobile services such as screening services were found to be effective for enhancing access and reducing transport costs.

Telecommunications and new technological solutions can also address accessibility both in terms of geographical and time barriers:

• The National Telehealth Service (NTS) provides a number of services including phone lines, such as Healthline through which registered nurses provide health triage and advice, as well as web-based services including symptom checkers and self-help

information. A review found that in the first year of operation "equity of access results for Māori and Pacific people varied by NTS services. Māori were high users of Healthline but lower users of Quitline. In contrast, Pacific people used both services less".

- Video-conferencing initiatives can address geographical barriers so that patients who
  live far from cities can have consultations with a specialist from their local healthcare
  centre rather than having to make long journeys to city centres.
- A forthcoming trial of medical drones could improve accessibility and adherence by delivering medicines to patients living in remote areas by drones.

# 3.5 Interventions to address acceptability barriers and enhance cultural safety practices of healthcare providers

'Acceptability' relates to the perceptions and experiences of patients and their family or whānau of the health system. A range of approaches were identified in the literature that healthcare providers can utilise positively to engage patients including health literacy, cultural safety, communication and patient-centred care.

Cultural safety and competency relates to the ability of healthcare providers to engage with patients via good communication, language, time to consult, continuity of care and relationship building.

#### 3.5.1 Health literacy strategies

As stated the current definition of health literacy clearly places the responsibility in the hands of healthcare providers, for ensuring patients understand their medicine and feel comfortable navigating through the health system. Healthcare providers "need to identify and remove any barriers to a person taking action on the new health information they have obtained".(51 n.p) Thus, health literacy interventions are likely to be initiated by healthcare providers or aimed at them in terms of increasing their knowledge and competency of delivering best 'patient-centred' health literacy practice

In a 2011 New Zealand Guidelines Group (NZGG) report to the Health Quality & Safety Commission (HQSC) scanned health literacy resources and found a lack of "health sector 'systemic' address" in terms of attention to health literacy. (80 p.22) The NZGG made a number of recommendations, including demonstrating to community pharmacies that "health literacy improvement in medications safety is broader than simply providing written information and very brief verbal information". (80 p.23) However, they found one example of an organisational-wide effort to address health literacy by a community pharmacy 'Roberts Ngaruawahia Pharmacy' and suggest that their methods might be developed as part of community pharmacy initiative on health literacy improvement. This pharmacy's initiative will be reviewed in the following section. Other recommendations by NZGG included upskilling the health workforce in "the application of learning theory to health service delivery" as a high priority and noting the "importance of Community Health Workers in lifting health literacy, especially among Māori and Pacific people".(80 p.23)

#### Workforce development approach to health literacy

Various international reports have emerged since the NZGG report was published endorsing a workforce development approach to developing health literacy "within a systemic or organisational frame".(56 p.7) An example is the Institute of Medicine's 10 attributes of a health literate organisation:

- 1. "has leadership that makes health literacy integral to its mission, structure, and operations
- 2. integrates health literacy into planning, evaluation measures, patient safety, and quality improvement

- 3. prepares the workforce to be health literate and monitors progress
- 4. includes populations served in the design, implementation, and evaluation of health information and services
- 5. meets the needs of populations with a range of health literacy skills while avoiding stigmatisation
- 6. uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
- 7. provides easy access to health information and services and navigation assistance
- 8. designs and distributes print, audiovisual, and social media content that is easy to understand and act on
- 9. addresses health literacy in high-risk situations, including care transitions and communications about medicines
- 10. communicates clearly what health plans (in a NZ context: public funding) cover and what individuals will have to pay for services." (Brach et al cited in 56 p.7-8)

In New Zealand, the MOH acknowledges the fundamental role of health literacy. "It is an organisational value that should be considered core business, incorporated into all levels of service planning delivery and even the way health centres and hospitals are laid out". (MoH cited in 56 p.8) A literature review undertaken by Workbase highlights "evidence-based health literacy education and training tools" (56 p.13) for health professionals including:

- Finding out what patients already know asking patients what they already know about the topic of discussion and linking new information to their existing knowledge gives meaning to the new information. This is part of universal precautions approach as it assumes all adult patients have some prior knowledge or experience to build on.
- Checking understanding or teach-back using open questions such as 'what questions do you have' signalling that it is normal to have questions, rather than the closed 'do you have any questions. The teach-back technique is when the health provider asks the patient to restate what was taught. If any important information is not recalled, it should be reinforced. Learning can be reinforced by acknowledging the patient has developed new knowledge.
- Medicine reviews this patient-centred practice sometimes known as brown bag reviews encourages the patient to bring all medicines and supplements they are currently taking to their healthcare appointment so that understandings of medicine instructions, side effects and interactions can be discussed.
- **Providing information in logical steps** patients are more likely to absorb information if it is presented in a logical sequence such as, problem, action, rationale. However, information should also be supplemented with the necessary and appropriate support.
- **Helping patients anticipate the next steps** to enable patients to better navigate the system. This is based on adult learning principles of intrinsic motivation to learn when the learning is relevant to the person's everyday life.
- **Using written materials effectively** to reinforce verbal information by highlighting the relevant information.
- Action plans step-by-step plans devised collaboratively by healthcare provider and
  patient to achieve the patient's health goal. The goals should be 'short, specific and
  realistic' with timely re-evaluation to demonstrate genuine interest and motivate the
  patient.(56 pp13-16)

Particularly important to Māori, Pacific peoples and the refugee population, is to encourage whānau (extended family) involvement in health conversations and to "re-design health education resources, letters and form so they are clear to the audience". (Reid & White cited in 56 p.17) As mentioned above, written materials should be used effectively and discussed with patients and whānau "rather than handing it out to be read later". (Reid & White cited in 56 p.17) An example of good practice was found in a study on the management of childhood asthma in terms of colourful brochure-style personalised action plans which were provided following unhurried personal discussions. Although Māori and Pacific peoples generally prefer the spoken word, the caregivers found the brochures beneficial for managing the children's asthma and detecting symptoms of worsening asthma. These plans were also easy to share with other caregivers such as the staff at day-care facilities.(81)

#### Using culturally appropriate settings (e.g. hui held in marae)

A health literacy project organised by The Māori Pharmacists Association (funded by MoH) in 2014 focused on educating Māori patients and their whānau about gout, its causes, and the associated health risks, as well providing advice on how to manage the condition. This project used a hui setting in maraes to make the participants feel more comfortable discussing and asking questions to increase their understanding of the gout. On evaluating the outcomes, the pharmacists found that not only were people more conscious of gout being a serious long-term condition, more knowledgeable about how it is best managed, more confident to talk to health professionals due to understanding medical terminology, but the hui attendees also reported that they had learned more about their general health and how to maintain a healthy lifestyle through exercise and diet. The project was deemed successful and a further contract was granted.(52)

#### Rheumatic fever prevention and management project (Bay of Plenty)

An example of a promising health literacy practice (that had not been formally evaluated at time of report publication in 2010) is the Toi Te Ora Public Health Service (Bay of Plenty) 'Rheumatic fever prevention and management project'. It had six expected outcomes:

- 1. A well-informed public on rheumatic fever and preventative measures through an extensive awareness campaign using a variety of media including radio adverts, press releases, school information sharing sessions, and pamphlets in Te Reo.
- 2. A health sector with up-to-date knowledge of rheumatic fever and in particular the appropriate use of the NZ Guidelines for Rheumatic Fever. These initiatives included: the development of a specific website for healthcare professionals, direct mail (letter) to all GPs in region, presentations to 89 Western Bay PHO GPs.
- 3. A well planned, implemented and evaluated rheumatic fever prevention and management programme across the BOP. Most of these evaluations were still at planning stage in 2010 but included three school based sore throat swabbing project, a pilot in Opotiki followed by projects in Kawerau and Murupara.
- 4. Complete and timely notification of all new and recurrent cases of rheumatic fever to the Medical Officer of Health through the development of notification protocol and standard operating procedures and presentations to GPs to emphasise and discuss previous audit which identified a 50% under-notification.
- Systems in place for the effective prevention of recurrent rheumatic fever cases and the management of notified cases through the development of a regional register.(82 pp.10-11)

Barker and colleagues assert that "a national register would ensure that when patients left one area they could receive injections without a break as has been supported in prior literature".(71 p.8)

Although regional registers are very helpful for keeping track of patients within the region, Barker and colleagues found that youth on the 'prophylaxis for rheumatic fever regime' to be

highly mobile, moving residence several times. As they need to have monthly antibiotic injections, moving residence especially out of the DHB region serves as a barrier to adherence.

### 3.5.2 Example of a community pharmacy integrating health literacy and cultural safety into their practice for their predominantly Māori clientele.

'Roberts Ngaruawahia Pharmacy' was highlighted by NZGG as an example of an organisational-wide effort to address health literacy by a community pharmacy. Pharmacists, Mary and Steve Roberts have developed a 'Checklist for Assessing Health Literacy' as part of their very comprehensive approach. (80 see appendix 1 pp.25-30) They have integrated health literacy into their practice by changing their organisational culture to a "predominantly oral interaction/intervention approach".(80 p.25) They explain that health literacy is about:

adapting practice to give patients knowledge and skills that allow them to self-manage, feel more at ease and able to make informed decisions within the healthcare environment, and particularly in (but not limited to) relationship to medicines.(80 p.25)

Understanding the link between cultural safety and health literacy, and because the majority of their customers identify as Māori, Mary and Steve Roberts are breaking down access barriers by making their pharmacy more culturally welcoming and comfortable by designing their refit to reflect nature and their community. For example, some of the colours chosen were deep red to represent the earth, blue for the river Waikato and a green koru to represent the renewal of health. All the signage uses Te Reo specific to their region with English translations. In addition, Mary Roberts is taking a course to improve her Te Reo skills and is encouraging other staff members to do the same. The Roberts' perceive health literacy as:

enhancing and improving patient skills, making them feel at ease and able to navigate the health system. It is about removing the 'white coat' both metaphorically and literally in order to recognise and support the patient to manage and/or improve their health.(80 p.30)

The Roberts' have implemented this approach voluntarily as there was no support (or requirement) for health literacy to be addressed by community pharmacies. Although there is no hard 'evidence' about the success of this approach, NZGG recommend to HQSC that the Roberts' approach should be evaluated and publicised as it was the only example of its type to be identified through their scan.(80)

#### 3.5.3 Patient centred approaches

Research has shown that patient-centred care "improves disease outcomes and quality of life, and that it is critical to addressing racial, ethnic, and socioeconomic disparities in health care and health outcomes".(83 p.1) However, although the phrase 'patient-centred care' is frequently used in mission statements and by healthcare professionals, it is still "poorly understood" by many organisations.(83 p.1) The Institute of Medicine (IOM) define patient-centred care as "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".(IOM cited in 83 p.2)

#### Patient and family-centred approach – Bay of Plenty DHB

As discussed earlier, the Bay of Plenty DHB have embarked on an organisational culture change journey to move from being systems-centric to being patient and family centred<sup>11</sup>.

<sup>&</sup>lt;sup>11</sup> Although a number of documents were produced around the launch of this programme we could find no publicly available follow-up evaluations. However, Boon asserts that patients views and experiences should be

Following a review of literature on patient and family centred care at the beginning of the programme Boon (2012) identified four fundamental principles:

- "Dignity and Respect. Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- Information Sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- Collaboration. Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care." (68 pp.2-3)

Boon emphasises the long-term nature of the programme to transform the organisational culture portraying it as a journey that "requires continual exploration of new ways to collaborate with patients and families".(68 p.8) She acknowledges that there are "well intentioned, competent, dedicated [health professionals] who assume they provide patient and family centred care as a matter of course but that assumption often lies at the heart of the problem".(68 p.8) Boon asserts that part of the definition of patient and family centred care must include "its concurrent focus on staff".(68 p.12) She explains that in relation to healthcare staff, their "ability and inclination to effectively care for patients is unquestionably compromised if they do not feel cared for themselves".(68 p.13) Boon does not address the issue of consultation times which have been identified as important for communication and developing relationships.

#### Patient and Whānau Centred Care - Northland DHB

Northland DHB appear to have adopted the BOPDHB patient and family-centred care model in 2017 and have adapted it for their population which experiences "health and socioeconomic inequities ... and increasing prevalence of chronic disease".(84 n.p)

"Their specific objectives are:

- To bring about a cultural change across the Northland health system, to one that is
  focussed on patient and whānau centred care by all personnel from governance and
  leadership through to all staff and influencing all levels of the system: at the individual
  patient level, at a service and organisation level.
- To fully engage all Northland DHB staff in patient and whānau centred care through values-led recruitment and accountability mechanisms.
- To establish respectful partnerships with patients and whānau at all levels of Northland DHB services: as part of the care team in the planning and delivery of a customised care plan; in service planning, design and evaluation; in organisational decision making.
- To inform Northland DHB patients and whānau using language and communication strategies that are patient and whānau centred.
- To create a Northland DHB physical and policy environment that supports patient and whānau centred care and healing." (84 n.p)

systematically and rigorously sought so that services can be accurately measured for improvements to be made.(67 p.21).

## 3.5.4 Workforce development initiatives to enhance the cultural competence of healthcare providers

In New Zealand legislation "demands regulatory authorities of health professions to set standards for clinical and cultural competence alongside ethical conduct".(66 p.12)

The two patient-centred organisational culture change programmes discussed above are likely to encompass improving cultural competence of healthcare providers, given that the fundamental principle of 'dignity and respect' requires that "patient and family [whānau] knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care".(68 p.2) The 'Roberts Ngaruawahia Pharmacy' case, is a good example of a workforce development initiative to enhance cultural safety.

To improve cultural competence with Māori patients the Medical Council of New Zealand recommend developing the following attitudes, awareness and skills:

- "A willingness to develop a rapport with Māori patients. The most effective way to understand the communities you serve is by establishing relationships with local Māori, including Māori health professionals in your area.
- A preparedness to ask patients about their preferences and a willingness to follow their lead.
- An awareness that Māori tradition strongly prefers face-to-face communication and an understanding that Māori place a greater emphasis on the spoken word.
- An awareness that body language can be different between Māori and non-Māori. For example, direct eye contact can be seen as a sign of disrespect in Māori culture.
- The ability to ask patients about their ethnic background. Asking the question not only demonstrates respect for the patient's culture and heritage, but also affords an opportunity to discuss the patient's cultural preferences.
- The ability to involve whanau during consultations.
- The ability to make sure that patients adequately understand their condition and treatment plan, and not simply rely on printed instructions." (Medical Council of New Zealand cited in 56 p.12)

Cultural competency aligned with patient-centred care facilitates communication and helps to develop rapport that demonstrates a genuine interest in the patient. Practices to achieve this are endorsed by the North American Coalition to Reduce Racial and Ethnic Disparities in Cardiovascular Disease Outcomes (CREDO) including:

- "Understanding the patient as a unique person
- Exploration of and respect for patient beliefs, values, meaning of illness, preferences, and needs
- Awareness of one's own biases and assumptions
- Provision of information and education tailored to patient level of understanding" (Yancy et al. (2011) cited in 46 pp.16-17)

#### **Community Health Workers**

Many studies note the essential role played by community health workers' (CHWs) as intermediaries between patients (particularly Māori and Pacific peoples) and GPs in terms of improving health literacy, enhancing cultural safety, providing practical help as well as motivating and supporting those managing chronic conditions. (46,74,80) CHWs help to "bridge the cultural 'gaps' between non-Māori health practitioners and Māori patients and communities".(46 p.16) However, their role requires them to work "within a dual and often competing framework, one which attempts to reconcile indigenous community expectations

and the government's expectations as outlined in formal contracts for service".(85 p.3) Continually having to manage competing demands can be stressful especially when their training opportunities are "short-term and ad hoc, specific to a particular health provider's needs and offering only limited options for career advancement".(85 p.1) Boulton and colleagues argue that "one of the greatest tensions Māori CHWs manage is operating in a manner that delivers on 'whānau ora' concepts yet at the same time delivering healthcare services in accordance with a contract that focuses on western concepts of disease".(85 p.6) Although Boulton and colleagues' paper was published in 2009, we have heard anecdotally that the tension caused by the dual role of CHWs can still be an issue.

We are aware of Whānau Ora initiatives aligned with primary healthcare organisations (PHOs) to work with whānau to empower their goals and aspirations. How these approaches may be contributing towards equitable access to medicines and medicines adherence from a whānau perspective requires further research. We understand that PHARMAC work with Whānau Ora organisations and are planning future evaluations in this area.

In Hawaii, a culturally tailored diabetes curriculum was developed using a Community Based Participatory Research framework to increase Hawai'ian and Pacific community health workers knowledge of diabetes. Twenty community health agencies collaborated in the design of the curriculum to provide the community health workers with "the knowledge and tools necessary to assist in the delivery of diabetes self-care and management information to Native Hawaiian and other Pacific Island community members" (Look et al. (2008) cited in 74 p.19)

Similarly, Hsu and colleagues (2012) found diabetes education in Hawaii that combined "classroom teaching with activities to reconnect participants with the land"(74 p.18) to be "effective at decreasing participants" (pre- and post-measures) HbA1c and SBP. The success of the programmes was attributed to the provision of education that validated participants' cultural identity, essentially allowing them to be themselves." (74 p.18)

#### 3.5.5 Language initiatives to enable better communication

The government recognises that New Zealand is becoming more ethnically diverse. The 2013 census showed that over 25% of the population was born overseas and the majority of those arriving over the last ten years were from Asia, the Pacific Islands, the Middle East and Africa. However, the main emphasis of the immigration department remains on the newcomers learning English as part of their resettlement.(86)

The Ministry of Business, Innovation and Employment (MBIE) reviewed the use of interpreters across all government agencies in 2016 and compared New Zealand services with those of Australia, Canada and the United Kingdom. The project found that the interpreter services provided in the health sector varied across the country and the reviewers "identified gaps in the current approach to the use and coordination of interpreters that create barriers for former migrants and refugees who want to access services and support".(86 p.8)

The MBIE review recommended the Ministry of Health (MOH) "consider, in conjunction with DHBs, a consistent approach to the funding of interpreters in the primary care sector throughout the country".(86 p.10)

The project made a number of recommendations <sup>12</sup> to "enable former migrants and refugees with limited English to connect effectively with mainstream government services, and government-contracted services".(86 p.8)

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<sup>&</sup>lt;sup>12</sup> Those addressing whole of government changes will be addressed under policy implications in the next section.

One recommendation which may be useful for healthcare providers is the proposal for a Language Portal "as a one-stop-shop for language assistance information, including the contact details of approved providers to government of interpreting and translating services and email links to those providers for interpreter bookings and other communications." (86 pp.9-10)

Other recommendations to support service users directly include providing comprehensive information about the the availability of interpreter services, particularly Language Line to refugees and migrants through a range of media such as websites in their first language. Additionally, they suggest improving the availability of wallet cards "to support non-English speakers to request interpreters and to state the language required".(86 p.9)

Two suggestions relating to systems support were; that flags should be created in client records to highlight the potential need for interpreters; and that government agencies use "telephone interpreters to convey messages and set appointments, along with alternative communication channels such as emails and text messages in clients' first languages ... rather than sending letters in English to clients who are not proficient in English". (86 p.10)

#### 3.5.6 Key findings emerging for addressing acceptability barriers

- There are a number of promising practices and recommendations addressing acceptability barriers, but most of the projects are yet to be evaluated.
- 'Roberts Ngaruawahia Pharmacy' represents a promising local initiative. An evaluation
  of changes in outcomes, in terms of accessing and adhering to medicine, over time
  (before and after their changes) or in comparison with another mainstream community
  pharmacy would be useful.
- Workforce development approaches/organisational culture change approaches were recommended in terms of health literacy, patient-centred care and cultural competence.
- Health literacy sessions held in marae have proved successful for Māori patients, not only in terms of learning more about the management of chronic conditions, but also for learning about general health and maintaining healthy lifestyles.
- Conditions, such as, rheumatic fever require a national register to ensure that highly mobile patients are not lost.
- Community health workers are important in terms of bridging the cultural gap between mainstream healthcare providers and Māori and Pacific patients. However, the difficulty of their 'dual' role needs to be recognised
- Recommendations to address language barriers included:
  - o Interpreters to be used for all communication to patients who are not proficient in English to convey information and set up appointments etc.
  - Websites with health information in migrants and refugees' first languages should be available.
  - Wallet cards to produce to indicate that the patient requires interpreter services should be more widely available.
  - A more consistent approach to the MOH funding of interpreters across DHBs is required.

#### 3.6 Conclusion

This chapter examined interventions that address barriers to accessing medicines via primary healthcare. Due to a lack of studies reporting on the effectiveness of interventions, we have also included some promising initiatives that particularly relate to the New Zealand context.

#### 3.6.1 Policy and practice implications

To facilitate the institutionalisation of equity approaches we suggest a review of existing policy, strategies, frameworks and alliances to identify gaps and encourage alignment and consistency of approach to equitable access to medicines. We support authors recommendations that plans to address structural barriers be institutionalised beyond the health sector to other sectors such as education, social welfare and housing.

It was recommended that strategic plans to address structural barriers to equitable access to healthcare and medicines be systematically implemented so that they become institutionalized throughout the health sector. Evaluating the implementation and effectiveness of strategies related to equitable access to healthcare and the impact for subpopulations is required. To enable the more equitable decision-making and representation of the views and voices of marginalised populations initiatives to encourage them into leadership and policy-making positions within the health sector are required. This was highlighted particularly for Māori which is important given their status as Tangata whenua and the obligations under the Treaty of Waitangi. There were also calls for more Māori health research to increase the relevance to Māori as well as promoting the Māori voice. Additionally, there was a recommendation that health outcomes should be the focus for assessing Māori healthcare delivery rather than focussing on outputs.

Developing the Pacific health workforce was also seen as essential for achieving health equity. We suggest that the promotion of diversity generally within the health workforce both vertically and horizontally would promote more equitable practices and approaches.

New Zealand regulatory authorities are legally required to set standards for 'clinical and cultural competence' however authors noted a lack of consistency across the country. Many studies reviewed called for complete workforce development approaches and full-scale organisational culture change to deliver on cultural competence, health literacy and patient-centred care. Workforce development is a whole of organisation approach and a good example is the BOPDHB organisational culture change programme launched in 2012 to move from being systems-centric to being patient and family centred. This approach was adopted by Northland DHB in 2017.

The key role of community health workers to cultural safety, health literacy and patient/family/whānau-centred care. In New Zealand CHWs and Whānau Ora Kaitiaki play a pivotal role for Māori and Pacific communities. International studies demonstrate how essential the CHW role is to bridging cultural gaps between mainstream healthcare providers and indigenous communities. However, they have a very difficult and stressful role working within a dual and often competing framework, continually being pulled between the expectations of the health system (their employer) and the cultural expectations of their community.

The MBIE review of language services provided a number of recommendations relevant to the health sector to enable better communication and the use of interpreting services. They recommended that language service guidelines setting out best practice for the planning, funding, and delivery of language assistance for people with limited English proficiency need to be developed across all government sectors. The Ministry of Health in particular, in conjunction with DHBs, need a consistent approach across New Zealand in terms of funding interpreters in the primary healthcare sector. Training needs to be provided to healthcare staff in terms of understanding cultural differences, working effectively and respectfully with people from different cultural backgrounds and working effectively with interpreters. Rather than sending out letters in English, interpreters should be used for all communication to patients

who are not proficient in English to convey information and set up appointments etc. Healthcare information websites could also be set up in a range of languages to enable migrants and refugees to access information in their first language.

More collaboration across DHBs would be helpful to increase accessibility. For example, rather than registers for rheumatic fever being held by various DHBs, it has been shown that a national register would be more effective to ensure the patients who move residence from one DHB region to another are not overlooked so they can easily continue with their treatment. We note that in 2017 the National Heart Foundation has begun the first phase of setting up a rheumatic heart disease register funded by charity in order to learn more about prevalence and help to improve care.<sup>13</sup>

#### 3.6.2 Evidence and promising practices

The Hutt Valley District Health Board, in collaboration with the Ministry of Social Development and community pharmacies, achieved positive health outcomes and financial savings by removing the direct cost of medicines for patients with multiple chronic conditions who would usually have to pay for the first twenty items at the start of the pharmaceutical subsidy card annual cycle. This example showed what could be done with a collaborative and flexible approach to overcome access barriers.

The researchers made a number of recommendations to the MSD which if followed would simplify processes and enable a wider roll-out of this practice across other DHBs.

Flexible healthcare provider services in terms of home visits and extended clinic hours helped with affordability and accessibility for working patients as they could plan their healthcare around their working hours and not lose wages by having to take time off for medical appointments. The cost of transport was cited by studies as a major barrier to accessing healthcare and medicines could be addressed by healthcare providers arranging transport for patients through services such as that provided by the Red Cross. Nursing outreach and community health workers deliver healthcare to the community and patients' homes thus making it much easier to access than having to overcome other barriers in order to travel to healthcare practices. A UK study suggests that prescribing nurses could potentially improve accessibility further.

The 'Roberts Ngaruawahia Pharmacy', whose clients predominantly identify as Māori, represents a promising local initiative. Understanding the link between cultural safety and health literacy, they aim to break down access barriers by integrating health literacy and promoting a predominantly oral interaction/intervention approach to their organisational culture. This and any similar initiatives would be well worth evaluating to assess effectiveness and share findings with other pharmacies.

Health literacy sessions held in marae have proved successful for Māori patients, not only in terms of learning more about the management of chronic conditions, but also for learning about general health and maintaining healthy lifestyles.

New technology can also address accessibility both in terms of geographical and time barriers. A forthcoming trial of medical drones could improve accessibility and adherence by delivering medicines to patients living in remote areas by drones. The National Telehealth Service (NTS) provides a number of services including phone lines, such as Healthline through which registered nurses provide health triage and advice and web-based services including symptom checkers and self-help information. Geographical barriers are being addressed

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<sup>&</sup>lt;sup>13</sup> https://www.heartfoundation.org.nz/about-us/news/media-releases/rheumatic-heart-disease-registry

through video-conferencing so that patients who live far from cities can have consultations with a specialist from their local healthcare centre rather than having to make long journeys to city centres.

#### 3.6.3 Enabling patient and whānau-centred approaches

The literature strongly indicates that a patient and whānau centred approach is required in which patients are enabled to have access to medicines, are well engaged and informed by their provider, and feel comfortable discussing their condition, treatment and any concerns. To support patient-centred approaches it is important to tailor these to the cultural needs of the patients and consider the importance of engaging whānau and family support to enable access to medicines.

The findings from the literature suggest the following strategies should be considered to enable a more patient and whānau-centred approaches.

- Workforce development initiatives to support the cultural competence of healthcare providers at organisational and individual practitioner levels
- Longer consultation times to enable communication and discussion between health professional and patient to enable engagement and building a trusting relationship
- Improving health literacy resources and delivery by health professionals to more clearly communicate information to patients and their whānau
- Technological supports to enable pragmatic and engaging experiences to support equitable access to medicines

### 3.6.4 Addressing knowledge gaps about what works to enable equitable access to medicines

This review highlights substantial knowledge gaps in understanding the complexity of the multiple barriers to equitable access to medicines and the lack of studies that identify effective interventions. To inform future policy and practice we suggest that a research and evaluation strategy be developed that prioritises evaluating existing initiatives, such as those outlined above, to identify good practice and provide more evidence about 'what works' and for whom. We would encourage a coordinated approach across commissioning agencies to fund research and evaluation and to collaboratively identify priority areas.

We suggest that any research and evaluation programme should build on existing studies and culturally appropriate research methodologies that have been conducted with Māori, Pacific peoples and ethnic communities.

In the barriers chapter we saw that affordability was a major barrier for many subpopulations and yet there is a scarcity of studies on interventions to address affordability issues. Apart from the Hutt Valley DHB study we did not find any studies reporting successful interventions to address these barriers. We consider the area of interventions to address affordability as important for further research.

Although there are some promising practices and recommendations addressing acceptability barriers, most of the projects are yet to be evaluated and so this is an area for further research. We are also aware that there is considerable attention on cultural safety within the health sector, however it was difficult to find studies that examined how this translated into changes in practice and contributed towards more equitable access to medicines.

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### **Appendix 1: Literature search strategy**

#### Academic literature search strategy

The EBSCO online research database was used to identify academic literature including systematic reviews and individual studies. The EBSCO Academic Database and Medical Database was used which include databases such as:

- MEDLINE
- CINAHL
- Academic OneFile
- Austrom
- Cochrane Library
- ProQuest
- PubMed
- ScienceDirect

#### Grey literature search strategy

The search the barriers section included examining relevant organizational websites with an emphasis on identifying: general access barriers and population-based barriers such as indigenous disparities; structural barriers; and the ability of providers to address a person's needs.

The search for the interventions section focused on policies and programmes that have sought to address these barriers and evidence from, for example, evaluations, reports and case studies that examine effectiveness of initiatives and identify good practices.

Organisational websites searched included:

- Health Quality and Safety Commission Equity Explorer (<a href="https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/equity-explorer/">https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/equity-explorer/</a>)
- Ministry of Health Māori Health (https://www.health.govt.nz/our-work/populations/Māori-health)
- Refugee Health (http://www.refugeehealth.govt.nz/)
- Mental Health Foundation (<a href="http://www.mindnet.org.nz">http://www.mindnet.org.nz</a>)
- Community Health (https://www.healthcarenz.co.nz/support-we-provide/hcnz-community-health/)
- Atlas of Healthcare Variation The Atlas of Healthcare Variation displays easy-to-use maps, graphs, tables and commentaries that highlight variations by geographic area in the provision and use of specific health services and health outcomes. (<a href="https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/">https://www.hqsc.govt.nz/our-programmes/health-quality-evaluation/projects/atlas-of-healthcare-variation/</a>)
- National Health Service (NHS), UK (https://www.nhs.uk)
- Institute for Healthcare Improvement (IHI) (http://www.ihi.org)
- National Institute for Health and Care Excellence (NICE), UK (https://www.nice.org.uk)

A Google and Google Scholar search was conducted to identify any other potentially relevant material not identified through the targeted searches.

#### Search criteria and key terms

Search criteria was based on the specifications provided by PHARMAC and a brief review of the literature to guide our scope in terms of date and range and geographical location of literature.

Boolean logic was used to add and exclude key terms to narrow the scope.

#### Part 1: Barriers to accessing medicines and healthcare in New Zealand

#### Search criteria:

- New Zealand only literature
- Date range 2007 2017 year focus on last 10 years, studies identified as important published prior to 2007 may be included.
- English language only

### Examples of search terms to develop search combinations to identify barriers to accessing medicines and health care in New Zealand

Primary search terms in relation to barriers	By population groups
access attitude/knowledge/cultural competency/cultural safety of health personnel barriers cultural safety engagement health care health services health inequalities health behaviour health care utilisation health disparity health inequalities healthcare quality medicine perceptions of healthcare primary health reforms structural and service barriers survival disparities	Māori whānau/hapū/iwi Pacific people/Pasifika (different Pacific ethnicities) indigenous immigrants refugees racial discrimination language barriers low-income socio-economic variables/disparities beneficiaries mental health stigma ethnicity ethnic differences geographical barriers/transport rural/remote

### Part 2: What is known about reducing disparities in access to medicines and healthcare (Interventions)

Search criteria:

- New Zealand and international literature (Australia, Canada, UK, Scandinavian countries, US (we understand the health system in the US is different, we have found some US authors report on studies carried out in New Zealand and there may be other studies of interest.)
- Much of the New Zealand literature was identified in the Part 1 search, however additional search terms were used to yield more results.
- Date range 2012 2017 years focus on last 5 years, studies identified as important published prior to 2012 were considered.
- English language only

# Examples of search terms to develop search combinations to identify what is known about reducing disparities in access to medicines and healthcare in New Zealand and internationally

Primary search terms in relation to reducing	By population groups
disparities in access to healthcare and	
medicines	

Healthcare/access/improving/increasing

attitude/knowledge/cultural

competency/cultural safety of health

personnel

engagement/practice/improving/sustained

enhancing healthcare access/

equitable access/medicines/healthcare

health care utilisation

healthcare quality

medicines/access/utilisation

positive perceptions of healthcare

primary health care

primary health reforms Māori-led initiatives

Whānau ora initiatives

reducing survival disparities

Māori

whānau/hapū/iwi

Pacific people/Pasifika (different Pacific

ethnicities)

indigenous immigrants

refugees

language barriers

low-income

socio-economic variables/disparities

beneficiaries

mental health

ethnicity

ethnic differences

geographical barriers

rural/remote