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Disparities in experiences of access to care for Australians with mental health conditions

Thesis submitted by

Lisa Corscadden
BSc, MSc

In fulfilment of the requirements for the degree of
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College of Public Health, Medical and Veterinary Sciences

James Cook University, Australia

Advisors Dr. Emily Callander, Dr. Stephanie Topp, Dr. Kerrianne Watt

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Statement of the Contribution of Others

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Co-authors of this publication have given their permission for the publications to be included in this thesis.

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Ch. 9	Thesis	Conclusion	EC ST KW contributed.

Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

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Abstract

Background

A high performing health system is one where care is both accessible and equitable. While healthcare in Australia ranks highly among international systems, not all Australians have the same opportunities to access care. In particular, people with mental health conditions face challenges.

Aim

This thesis highlights evidence of disparities in experiences of access to care for Australians with mental health conditions. It is presented in three sections. The first addresses factors associated with unmet need for mental health care. The second section explores disparities in experiences of access to healthcare more broadly in Australia, with international comparisons. The third section assesses disparities in experiences of emergency and maternity care for Australians with mental health conditions. Findings point to opportunities to improve measurement of equity and patient-centred access in healthcare performance reporting.

Methods

The analyses present disparities in patient-centred access to care for people with mental health conditions through secondary analysis of the Commonwealth Fund International Health Policy Surveys (2013, 2016 and 2017) and of patient experiences surveys of emergency department and maternity care in New South Wales Australia in 2017. The populations covered include the adult, general population for Australia and 10 other countries (2013, 2016), Australian adults aged 65 years and over (2017) for the international surveys. The populations covered for New South Wales in 2017, include emergency department patients of all ages in larger hospitals, and women who gave birth in a public hospital. Patient-centred access and experiences of care are considered through multi-dimensional frameworks highlighting key areas of disparities for people with mental health conditions.

Results

There are multiple ways people with mental health conditions face additional challenges when accessing care. An estimated one in 10 people who experienced emotional distress reported unmet need for services in Australia (12%) between 2013 and 2016. This group also had higher out-of-pocket costs for healthcare, lower income, and were more likely to forego care due to cost.

When exploring experiences of healthcare more broadly, people with mental health conditions were more likely to experience barriers accessing care in Australia as well as 10 other higher-income countries. Australian adults with mental health conditions were more likely to experience barriers accessing care for a large majority of experience measures considered (24 of 33 measures). The average 'gap' or percentage point difference in barriers ranged from five to nine percent across countries. Where Australians, with mental health conditions were more likely to say they experienced disparities by nine percentage points on average across the 33 access-related measures. This was the highest among other international comparators. Compared to people with no mental health conditions, people with mental health conditions were more likely to have foregone care due to cost, and say they had received conflicting advice after adjusting for age, sex, immigrant status and income in all countries.

To go deeper into the theme of affordability, a targeted analysis of Australians aged 65 years and over, showed there were also disparities for older adults with mental health conditions. High out-of-pocket healthcare costs and lack of private insurance were key factors contributing to greater odds of affordability barriers for older Australians with mental health conditions.

In addition, new analysis of maternity and emergency department care also point to disparities for people with long-standing mental health conditions. In New South Wales (NSW), patients with a mental health condition using emergency care for any reason had less positive experiences on most measures in 2017-18 (40 of 53), with an average gap of seven percentage points. There were similar findings for analysis of maternity care experiences in 2017 in NSW. Experiences of maternity care for women with mental health conditions were less positive on most measures (41 of 64) and more positive for one (information on safe sleeping). On average women with a mental health condition had less positive experiences by eight percentage points. In both ED and maternity care sectors, disparities were pronounced for overall ratings of care, physical comfort such as pain management, information provision (clear communication), respect for patients, and emotional support or trust. There were fewer disparities for measures related to the facilities and physical environment. Of particular note, for maternity care measures related to guidelines for care for women with mental illness (e.g. discussions of emotional health, alcohol, weight gain) there were smaller or no differences in experiences.

Conclusions

In addition to unmet need for mental health care, people with mental health conditions are more likely to have less positive experiences and barriers accessing healthcare across a wide range of services in Australia. Notably, analyses presented show that disparities in access to care were more pronounced in Australia than in other countries including the United States. However, disparities are not inevitable. In some countries and within Australia for some measures there were no differences in experiences for people with and without mental health conditions.

There are opportunities to improve collection and measurement of equity and experiences of access to care. People with mental health conditions should be considered as a priority population, with regular reporting including stratifying key measures by presence of a mental health condition and summarising disparities. Further, adding a measure of unmet need for mental health care in Australia to regular surveys along with annually measured unmet need for primary care, dental care services may help to address this key sector and reduce stigma of seeking mental health care. Finally, there is a need to include more patient centred measures in regular performance to adequately measure patient-centredness of care and to ensure there is more emphasis on what matters to patients.

Findings from this thesis pointed to priority areas for action to improve experiences of care and reduce barriers to accessing care for Australians with mental health conditions. However, broader mixed methods analysis could provide additional context. Qualitative analysis of patient comments would bring more depth to the quantitative analysis presented here. Including perspectives of people with lived experience of mental illness and seeking care should be considered to help prioritise the most important areas for improvements in experiences of access for this group. Improving disparities in experiences of access for people with mental health conditions can help to support reduced disparities in health outcomes such life expectancy.

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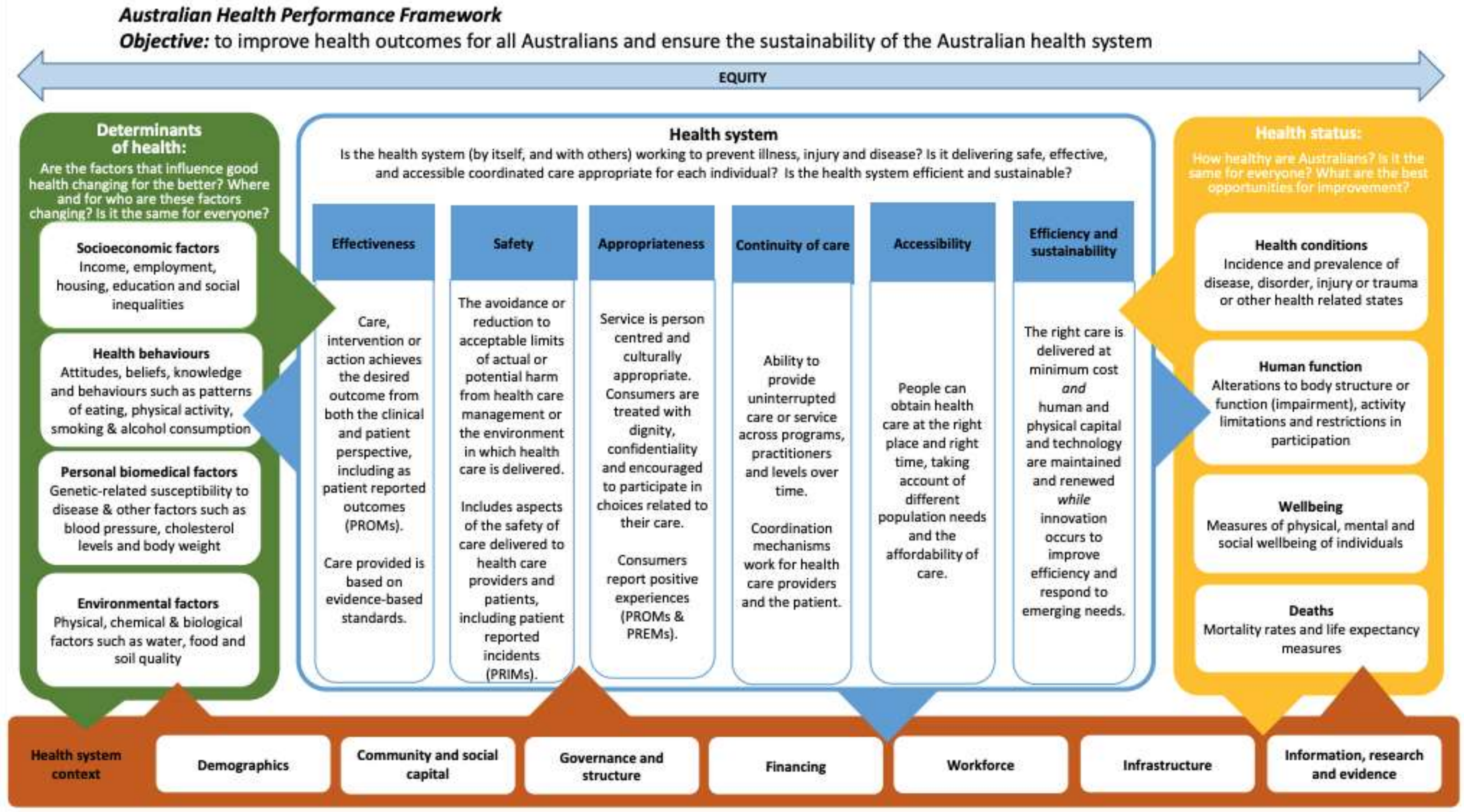
Chapter 1: Introduction

Measuring the performance of healthcare systems in countries, states, and regions shows variation in both health outcomes and the quality of healthcare. Regular monitoring of healthcare performance is the mandate of many government funded organisations to inform quality improvement and accountability of publicly financed services. In Australia, organisations such as the Australian Institute for Health Information, the Australian Commission on Safety and Quality in Health Care, the Bureau of Health Information in New South Wales, and the Victorian Agency for Health Information play a key role in ensuring accountability to the public and informing quality improvement efforts in healthcare. They provide information to decision-makers at all levels, who need to understand why variation occurs in the quality of healthcare and health outcomes. This information informs policies to improve care. Approaches to measure healthcare performance have identified access to care, patient-centredness and equity as key elements of a high-quality health system along with concepts safety, overall appropriateness and good outcomes of care. However, in practice the measurement of equity, access and patient-centredness are limited in Australia, (Australian Institute for Health and Welfare, 2019a), particularly from the perspective of people accessing care.

Key concepts: patient centred care, access and equity of care in performance reporting

Patient centred care means “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001). In the context of healthcare performance measurement in Australia (Figure 1.1) ‘appropriateness’ of care is the dimension that considers if services were delivered in a respectful way, and people are encouraged to participate in their care. Patients themselves are uniquely placed to reflect on the patient-centredness of care and experience surveys provide essential information to measure patient centred care. Healthcare organisations are investing more in measuring, reporting and improving patient experiences of care (Australian Commission on Safety and Quality in Health Care, 2019, NSW Health, 2019). To establish valid measures for comparisons, and to inform quality improvement, more work and evidence is needed to validate experience measures for use in performance measurement and quality improvement, including exploring how different populations respond to surveys (Santana et al., 2019).

Figure 1.1 Australian Health Performance Framework



Australian Health Performance Framework

Objective: to improve health outcomes for all Australians and ensure the sustainability of the Australian health system

EQUITY

Determinants of health:

Are the factors that influence good health changing for the better? Where and for who are these factors changing? Is it the same for everyone?

Socioeconomic factors
Income, employment, housing, education and social inequalities

Health behaviours
Attitudes, beliefs, knowledge and behaviours such as patterns of eating, physical activity, smoking & alcohol consumption

Personal biomedical factors
Genetic-related susceptibility to disease & other factors such as blood pressure, cholesterol levels and body weight

Environmental factors
Physical, chemical & biological factors such as water, food and soil quality

Health system

Is the health system (by itself, and with others) working to prevent illness, injury and disease? Is it delivering safe, effective, and accessible coordinated care appropriate for each individual? Is the health system efficient and sustainable?

Effectiveness
Care, intervention or action achieves the desired outcome from both the clinical and patient perspective, including as patient reported outcomes (PROMs).

Care provided is based on evidence-based standards.

Safety
The avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.

Includes aspects of the safety of care delivered to health care providers and patients, including patient reported incidents (PRIMs).

Appropriateness
Service is person centred and culturally appropriate. Consumers are treated with dignity, confidentiality and encouraged to participate in choices related to their care.

Consumers report positive experiences (PROMs & PREMs).

Continuity of care
Ability to provide uninterrupted care or service across programs, practitioners and levels over time.

Coordination mechanisms work for health care providers and the patient.

Accessibility
People can obtain health care at the right place and right time, taking account of different population needs and the affordability of care.

Efficiency and sustainability
The right care is delivered at minimum cost *and* human and physical capital and technology are maintained and renewed *while* innovation occurs to improve efficiency and respond to emerging needs.

Health status:

How healthy are Australians? Is it the same for everyone? What are the best opportunities for improvement?

Health conditions
Incidence and prevalence of disease, disorder, injury or trauma or other health related states

Human function
Alterations to body structure or function (impairment), activity limitations and restrictions in participation

Wellbeing
Measures of physical, mental and social wellbeing of individuals

Deaths
Mortality rates and life expectancy measures

Sources: The National Health Information and Performance Principal Committee, 2017, Australian Institute for Health and Welfare, 2019b

Access to care is more than reaching services or how long people wait to receive care, it encompasses the continuum from people perceiving a need for care, to receiving services that are deemed to have helped. In the context of performance reporting in Australia, access to care has been defined as people being able to: “obtain healthcare at the right place and right time irrespective of income, physical location and cultural background” (Australian Institute for Health and Welfare, 2016). From a broader perspective, patient-centred access to care has been broadly conceptualised as a process including perceived needs for care, ability to seek care and reach care, that one has the ability to pay for and to engage in care of sufficient quality for people to benefit from care (Penchansky and Thomas, 1981, Levesque et al., 2013, Franks and Fiscella, 2008). Further this conceptualisation of access goes beyond reaching care in a timely manner, and includes the concept of appropriateness of care from a person’s perspective. In this way, access could be seen as extending to cover key dimensions commonly considered in patient experiences of care; including physical comfort, emotional support, respect for their preferences and continuity of care (Jenkinson et al., 2002).

Equity in healthcare encompasses ideas of fairness: equal health, equal access for equal need, and equal use for equal need (Mooney, 2003, Bureau of Health Information, 2014). In Australia, equity has been tied to access in particular where “Government involvement in health services is predicated on the desire to improve the health of all Australians and to ensure equity of access and the sustainability of the Australian health system” (Steering Committee for the Review of Government Service Provision, 2016). Equity is a domain in frameworks for measuring healthcare performance in Australia (Figure 1.1) and internationally (Bureau of Health Information, 2014, Canadian Institute for Health Information, 2015, OECD, 2015, Steering Committee for the Review of Government Service Provision, 2016, Davis et al., 2014). Consideration of equity as part of healthcare performance reporting in Australia is most commonly addressed by reporting other measures of performance disaggregated by remoteness, rurality and Aboriginality (Australian Institute for Health and Welfare, 2019a, Productivity Commission, 2019a). From a measurement perspective, equity can be considered as minimising avoidable differences between groups. Therefore, to create valid indicators of equity, it is necessary to define measures of these differences (Campbell, 2002). There is a gap in defining ‘measurable items’ in reporting equity that describe the extent of differences across population groups, time and place (Wyatt et al., 2016, Poynter et al., 2017).

Priority populations

In the most recent Australian government report on the performance of healthcare services, there were selected population groups as a focus from an equity perspective (Productivity Commission, 2020). These groups included, Aboriginal and Torres Strait Islanders, people living in rural areas, those from a non-English speaking background and people with a disability. These priority populations were selected as they face availability, affordability, acceptability or other challenges accessing care. More broadly, vulnerable groups face both health and socioeconomic challenges, and face barriers due to out-of-pocket costs, travel, communication, and cultural appropriateness that make accessing care difficult (McRae et al., 2012, Reichard et al., 2017). These factors can have interacting and accumulating effects on access to care (Shi and Stevens, 2005, Stevens et al., 2006, Stevens et al., 2010).

Identifying people with mental health conditions as a priority population

People with mental health conditions are increasingly being recognised as a priority population, in need of targeted efforts to improve their access to healthcare. The World Health Organisation has initiated a special initiative to help improve coverage of care for those with mental health conditions (World Health Organization, 2019). In Australia, a large proportion of people with a diagnosed mental health condition do not access services for their condition each year, and perceive they have unmet needs (Meadows and Burgess, 2009). Despite increased funding of mental health services in recent years, there is little evidence that the quality of care received is helping to manage the need (Jorm, 2018). One reason suggested was that people may not be accessing mental health care of sufficient quality or quantity to help.

It is essential to improve monitoring of disparities and considering the experiences of people with mental health conditions more explicitly in performance reporting as part of reducing gaps in health outcomes. People with a mental illness have an average life expectancy of 10 years less than the general population. For those with a serious mental illness such as schizophrenia or substance disorder the gap in life expectancy is over 20 years (The Royal Australian and New Zealand College of Psychiatrists, 2016). Australian research shows that physical health conditions are one of the main causes of early mortality among people with mental illness (Lawrence et al., 2013). Improved access to both mental and physical care could help reduce the gap in life expectancy for people with mental illness (The Royal Australian and New Zealand College of Psychiatrists, 2016, Thornicroft, 2011).

How mental health is defined as part of efforts to examine access to care by different population groups is dependent on the data source used. When considering patient experiences of care through surveys, the primary method to ‘define’ a mental health condition group is via people self-reporting. Survey questions also include examples of mental health conditions for respondents to consider, where often ‘anxiety and depression’ are noted. The survey sources cited did not include substance use or addictions as separate examples or examples for respondents to consider as part of ‘a mental health condition’ (Bureau of Health Information, 2019, OECD, 2019). When administrative data is used, conditions are based on diagnoses codes, where some substance use is sometimes mentioned as a comorbid condition (The Royal Australian and New Zealand College of Psychiatrists, 2016) (Lawrence et al., 2013).

Policy context

Monitoring access to mental health care and disparities in access to overall care for people with mental health conditions were identified as priorities for governments in Australia. Beginning in 2006, the Council of Australian Governments announced a National Action Plan for Mental Health to reform mental health services and outlined key areas for improvement including unmet need for mental health services. More recently in 2017, mental health care has been identified as one of the National Health Priority Areas by state and commonwealth governments in Australia in the Fifth National Mental Health and Suicide Prevention Plan where they laid out a commitment to improve integration and delivery of mental health services (Department of Health, 2016). The policies were targeted at helping to address the burden of disease of mental health conditions on the health of the population, and the known unmet needs for services (Whiteford et al., 2013, Meadows and Burgess, 2009). In addition, in 2018, the Australian government announced an inquiry with submissions and consultation into the importance of mental health in productivity and economic participation (Productivity Commission, 2019b), acknowledging that mental health is an issue of responsibility and importance across sectors beyond health.

Gaps in measures and measurement of access and disparities in care from the perspective of people with mental health conditions

The experiences of care of people with mental health conditions are not well understood or monitored in performance reporting. A review of performance measures for public reporting in Australia recommended that regular reporting for priority populations with mental health conditions should be considered (Hibbert et al., 2013). Current efforts to measure experiences and disparities in access to care for people with mental health conditions are limited in what is collected and how it is used for performance measurement and monitoring.

Existing measures of access to mental health care services commonly assessed in Australia focus on measures of service use and do not capture quality of services, or the experiences of people that did not reach care (Australian Institute of Health and Welfare, 2016). A world-recognised measure of perceived needs and unmet need for mental health care was based on an Australian Mental Health Survey, however the last survey was in 2007 (Meadows and Burgess, 2009). Regular annual surveys of patient experience in Australia capture unmet need for general practitioner, specialist and dental services, but exclude mental health (Australian Bureau of Statistics, 2018). There are patient experience surveys of mental health services in hospitals and in the community in Australia which provide valuable insights on experiences of these services (Australian Institute for Health and Welfare, 2019).

There is a paucity of measures covering access to care more broadly, including people's abilities to perceive a need and seek care, patient experiences of affordability and appropriateness of care. Finally, there is limited research that examines disparities from the perspective of people with mental health conditions, as compared to those with no condition. Recent examples have emerged in grey literature (Bureau of Health Information, 2019, OECD, 2019) that consider measures of access, comparing experiences of people with and without mental health conditions. There are opportunities to go further and improve methods of comparison and synthesis of mental health related disparities in access to care. Summarising the extent of disparities in experiences across different domains of access of care can also help to prioritise areas to act to improve experiences of care for people with mental health conditions.

Thesis aims

Analyses in this thesis will add evidence of the types and extent of disparities in experiences of access to care for people with mental health conditions. A secondary aim is to demonstrate opportunities to improve the measurement of disparities in patient-reported measures in healthcare performance reporting.

The specific research questions I will answer are:

1. What are the factors associated with experiences of unmet need for mental health care?
2. Are Australians with mental health conditions more likely to report experiencing barriers in access to general health care, compared to those with no mental health conditions?

3. How do disparities in experiences of care for people with mental health conditions in Australia compare to those internationally?
4. When considering patient-centred access and experiences more broadly, for which healthcare sectors and types of experiences are disparities most pronounced?

The approach

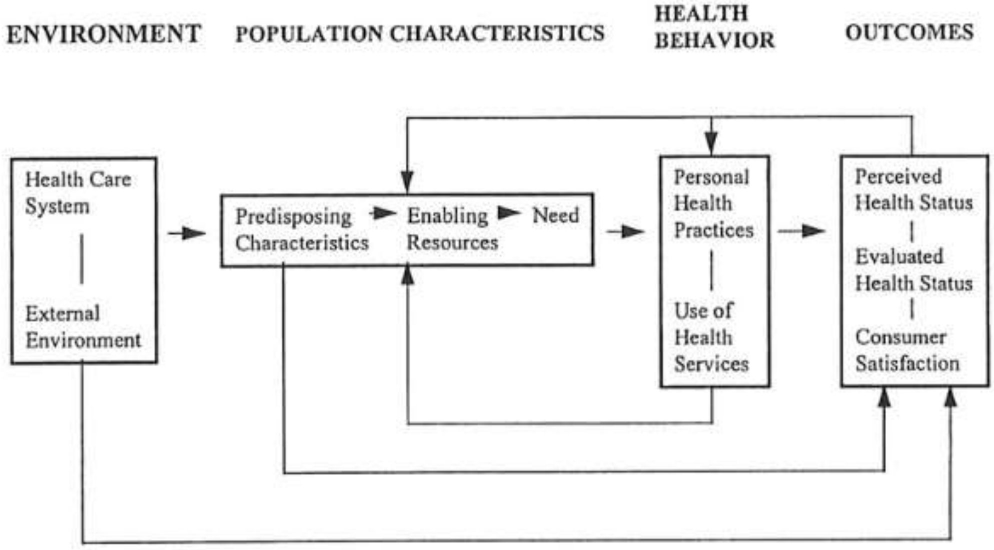
I approached these questions through secondary analysis of multiple survey data sources, across a range of care sectors and encompassing dimensions of access and patient experiences of care, through the perspectives of people who self-reported having a mental health condition (as either long-term or doctor diagnosed) condition.

The analysis and chapters to follow are explored through conceptual frameworks.

To explore factors associated with accessing care, I adopted a vulnerability approach that reflects the cumulative nature of patient factors such as income, gender, and ethnicity. Bringing an understanding of social determinants of health to bear on analysis of access to care is consistent with an exploration of disparities. Unmet needs analyses look at understanding interconnected factors of vulnerability by looking at predisposing, enabling and need factors that can drive patterns of accessing care (Figure 1.2). This framework is used to explore vulnerabilities in accessing mental health care (Shi and Stevens, 2005, Aday and Andersen, 1981, Shi et al., 2008, Andersen, 1995).

Next, I considered access through the lens of care seeking and access pathways. This pathway crosses; perceived needs, approachability, availability and affordability of services as well as perceptions of the acceptability of services all influence access to care (Figure 1.3). This broad framework was helpful to improve the understanding of where people with mental health conditions are most likely to experience barriers. It also has an aggregated perspective, where experiencing barriers at more stages can prevent people from fully accessing care (Levesque et al., 2013).

Figure 1.2 Andersen's behavioural model of health service use



Source: Andersen, 1995

Figure 1.3 Conceptual framework for patient-centred access to healthcare

Source: Levesque et al., 2013

Finally, an organising framework outlining key principals of patient experience was used to categorise types of experiences of care after individuals have reached care. The eight dimensions of patient care, have been traced back to work from the early 90's on understanding and promoting patient centredness of care (Peschel and Peschel, 1994) (Beatrice et al., 1998) The dimensions of experience covers concepts from timeliness and coordination of care, to respect for patient preferences and continuity of care (Jenkinson et al., 2002) (Figure 1.3). These principles are interconnected with the appropriateness dimension of the access framework and picks up where it leaves off to look deeper at people's interactions with care providers while attempting to realise access to care.

Figure 1.4 Organising framework for measures of patient experiences of care

Sources: Peschel and Peschel, 1994, Ehrler et al., 2017.

The starting point for this Thesis was the concept of patient centred access. Levesque et al (Figure 1.3) identify six 'elements' of access, and 5 supply-side (health service) capabilities and 5 demand side (person/patient) capabilities that influence those access elements. This Thesis was particularly focused on the patient experience – and so on the demand side of this framework. Of note, the framework explicitly recognises the influence of social determinants (via population, community, household and individual characteristics, and related vulnerabilities). Such vulnerabilities, may differentially impact access capabilities and contribute to inequities in access at different points as considered through the Andersen behavioural model of health service use (Figure 1.2). Further, the organising framework for measures of patient experience of care (Figure 1.4) was used to look more in-depth at the final capability of the Levesque at al framework, patient's 'ability to engage' in their care. This approach is used to consider whether barriers arose in people's experiences after reaching services that prevent them from fully accessing care.

Thesis structure

This thesis comprises three sections, pre-empted by Chapter 1 (current introductory chapter which provides context and rationale) and Chapter 2 which provides a more in-depth discussion of the concepts of equity and access. Chapter 2 includes a literature review and grey literature scan to establish how healthcare aims of equity and access have been communicated and operationalised in Australia and internationally.

The remaining chapters (six manuscripts interspersed with traditionally written chapters) contribute evidence exploring disparities in experiences of access to care. It is divided into three sections:

I: unmet need for care,

II: patient-centred access, and

III: patient experiences.

Section I of the thesis (Chapter 3– published manuscript) addresses aim one by exploring self-reported unmet need. Chapter 3 presents secondary analysis of survey data of factors associated with unmet need for people with mental health conditions in Australia and Canada. Factors associated with unmet need are considered through the Andersen framework of predisposing, enabling and need factors (Figure 1.2).

Section II (Chapters 4 to 6) addresses aims 2, 3 and 4 of the thesis by exploring disparities for people with a mental health condition in five dimensions of patient-centred access to care (Figure 1.3). In this section, following a brief introduction to a framework for patient-centred access, Chapter 4 (published manuscript) presents priority areas of disparities in access to care from the perspective of Australian adults with self-reported mental health conditions. Chapter 5 (published manuscript) presents a comparison of disparities in experiences in Australia with disparities across 10 other countries that participated in the survey. The section concludes with a further exploration of affordability of care for older Australians with mental health conditions in Chapter 6 (a manuscript currently in consideration for publication following one round of peer review).

Section III (Chapters 7 and 8) addresses aim 4 by examining people's experiences of maternity and emergency department care, to help assess whether they have fully accessed care through how they rate their experiences. Following background on measuring patient experiences of care across a range of dimensions (Figure 1.4), chapter 7 and 8 present analysis of experiences of care in emergency departments and maternity care respectively. These areas were selected as they represent important sectors, where patients may need both mental and physical health support at the same time and integration of care is particularly important

Finally, chapter 9 summarises the main findings, and what this analysis has added, as well as highlighting the opportunities to do more to monitor disparities in experiences of access to care.

The analysis presented in this thesis build on international and Australian survey data sources. More detail of the sampling, representativeness of each of these large-scale representative surveys is provided in the Appendix section to supplement to the high-level information provided in each chapter.

There is deliberately no reference section for the thesis as a whole. References are self-contained within each chapter of this thesis and presented at the end of each publication or at the end of the chapter in chapters that do not contain a publication.

Visual overview of thesis aims, structure and publications

Aims

1. What are the factors associated with perceived unmet need for mental health care?
2. Are Australians with mental health conditions more likely to experience barriers in access to general healthcare, compared to those with no mental health conditions?
3. How do disparities in experiences of care for people with mental health conditions in Australia compare to those internationally?
4. When considering patient-centred access and experiences more broadly, for which types of experiences are disparities most pronounced across different healthcare sectors?

Introduction and rationale (chapter 1)
Literature review: access and equity from patients' perspectives (chapter 2)

Section 1: Unmet need (chapter 3)	Section 2: Patient-centred access (chapters 4, 5, 6)	Section 3: Patient experience (chapters 7, 8)
Aim 1,3	Aim 2, 3, 4	Aim 4
Chapter 3: Corscadden, L., Callander, E.J. and Topp, S.M., 2019. Who experiences unmet need for mental health services and what other barriers to accessing health care do they face? Findings from Australia and Canada. The International journal of health planning and management, 34(2), pp.761-772.	Chapter 4: Corscadden L, Callander EJ, Topp SM. Disparities in access to health care in Australia for people with mental health conditions. Australian Health Review. 2019 Dec 17;43(6):619-27. Chapter 5 Corscadden L, Callander EJ, Topp SM. International comparisons of disparities in access to care for people with mental health conditions. The International journal of health planning and management. 2018 Oct;33(4):967-95. Chapter 6 Corscadden L, Callander EJ, Lewis V, Topp SM. Paying for healthcare among older Australians – how do those with mental health and other chronic conditions fare? (*in revision with: Journal of Aging and Mental Health)*	Chapter 7: Experiences of emergency department care for people with mental health conditions in New South Wales (*accepted by Australasian Emergency Care awaiting publication)* Chapter 8: Corscadden, L., Callander, E.J., Topp, S.M. et al. Experiences of maternity care in New South Wales among women with mental health conditions. BMC Pregnancy Childbirth 2020,20, 286.

Discussion and Conclusion (chapter 9)

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Chapter 2: Concepts and literature review

Providing high quality accessible care to all, without having people suffer serious financial consequences is a key aim of health systems. Governments and health system decision makers put data collection and public reporting of healthcare performance into place to monitor these aims including equity and access to care.

Following an introduction of concepts, this chapter highlights findings from a literature review identifying how access and equity in care have been measured in quantitative analysis in government reports, and academic literature. The focus of the summary is to categorise what types of access measures are commonly used, and identify which population groups are considered as priority groups in equity analysis. Next, I will consider how mental health and patient reported measures of access to care are addressed in this literature base. The starting assumption is that there is a gap in both patient-reported measures, and a gap in considering people with a mental health condition as a priority population group.

These concepts and methods form the foundation for analysis in this thesis, exploring equity and access to care from the perspective of people with mental health conditions. The findings also point to opportunities for improved measurement of equity in performance reporting in Australia.

2.1 Background and Concepts

Access to care is an important factor influencing the health of populations. Better access to care, particularly primary care, has been associated with better health (lower mortality)(Starfield et al., 2005). Further, poorer health in rural areas in Australia has been attributed in part to poorer access to care (Australian Institute for Health and Welfare, 2019). Access to care is broadly conceptualized as the ability of people to identify a need for, and obtain, appropriate healthcare services. Access involves the interaction between the supply of services (the location, cost or availability) and the demand of the population, including their needs and expectation (Penchansky and Thomas, 1981, Levesque et al., 2013, Franks and Fiscella, 2008). Access to care thus requires consideration of a range of elements, including: people's ability to identify that services exist, services which are reachable in a timely manner, affordable and culturally and socially acceptable, and that care is appropriate in a technical and interpersonal manner. Reaching care that is of poor quality, therefore, represents sub-optimal access.

Equity and access to care are intertwined. In the context of performance monitoring in Australia, accessibility of services is defined with the aim that “people can obtain health care at the right place and time irrespective of income, physical location and cultural background” (Australian institute for Health and Welfare, 2009). Incorporated into this definition of accessibility, is a sense of fairness that everyone can obtain access to care regardless of external factors, a sense of equity. Common conceptualizations of equity in access to care consider equal care for equal need. Assessing the extent to which people with the same needs get the same access to, and quality of care, is referred to as horizontal equity (Van Doorslaer et al., Van Doorslaer and Masseria, 2004). The extension that people with greater needs should receive more services, is referred to as vertical equity (Whitehead, 1992).

Equity is acknowledged as a concept which cannot be measured directly (Sen, 2001), however, there are various methods to bring an ‘equity lens’ to assess differences in health and healthcare. The term *disparities* is commonly used to describe differences in between population groups in academic (Hussey et al., 2008, Fiscella et al., 2000) and grey literature (Agency for Healthcare Research and Quality, April 2016, Bureau of Health Information, 2016). The term disparities will be used in this thesis, as synonymous with inequalities, and distinct from inequities. Inequities are disparities that are systemic, unwarranted and unfair. To discuss fairness would require assessment of policy contexts and societal preferences (Asada and Kephart, 2007, Keppel et al., 2005, Whitehead, 1992) and is beyond the scope of this research. Similarly, measurement of vertical equity, in terms of how many more services people with greater needs should receive, will not be assessed.

Population groups at risk of poorer health and healthcare disparities are considered vulnerable groups (Grabovschi et al., 2013, Shi and Stevens, 2005a) or priority populations (Agency for Healthcare Research and Quality, 2016a). Measures of access to care are often reported by age, sex, Indigenous status, area-based deprivation and remoteness in Australia to monitor differences in access to healthcare for different population groups (Australian Institute for Health and Welfare, 2016, Australian Institute of Health and Welfare, 2016b, Steering Committee for the Review of Government Service Provision, 2017). Reporting on access to care through an equity lens also includes consideration of population groups beyond income, rurality and ethnicity. Health-related factors including disabilities (Meade et al., 2015), cancer (Maddison et al., 2011) and mental health (Dorning et al., 2015) have also been considered when identifying vulnerable groups in the context of equity measurement. Assessing healthcare access and quality for people with mental health conditions has been a noted knowledge gap in performance measurement (Glied et al., 2015). In particular, a review of performance measures for public reporting in Australia recommended that reporting for vulnerable populations with mental health conditions should be considered (Hibbert et al., 2013).

2.2 Literature review: reporting equity and access

A literature review was conducted to summarise quantitative analyses describing equity and access to care. A grey literature review of healthcare performance reports in Australia, Canada the United States and the United Kingdom were also included. The questions of interest were as follows:

- Which measures have been used to operationalize access to care (in high income countries)?
- How is the concept of equity defined and measured?

Based on the resulting articles, three additional questions were also considered:

- Which population groups and health care needs were considered?
- Are patient reported measures included?
- How was mental health considered, (as a vulnerable group, outcome or need)?

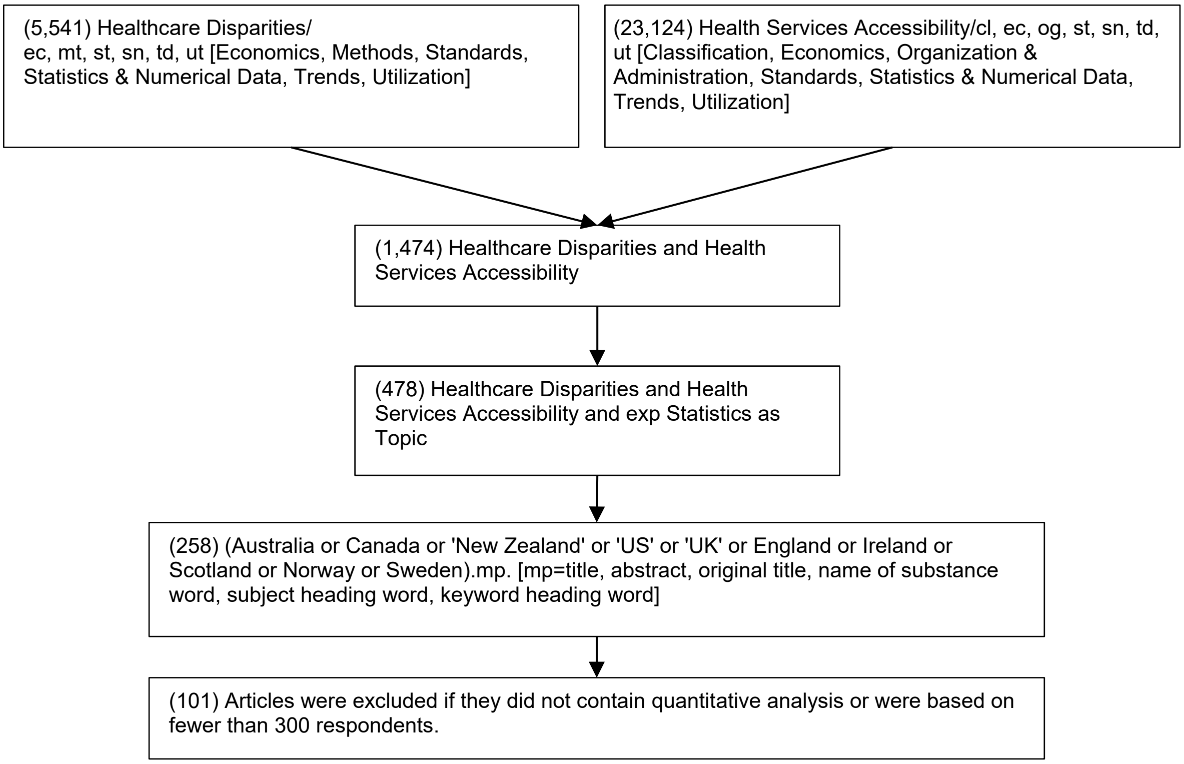
Methods

A grey literature search of performance reporting organisations in Australia, Canada, the United States (US), and the United Kingdom (UK) and international reporting organisations (Organisation for Economic Cooperation and Development and the Commonwealth Fund) was conducted to find regular reporting products that included measures of access to care. These regions and organisations were selected as they reflected health systems with high-level performance monitoring mechanisms. The definitions and operationalisation of access and equity in each product and the population groups considered in regular reporting were summarised.

A search of MEDLINE databases was completed to locate recent articles containing quantitative analysis measuring disparities in access to care. Search terms used focused on “health services accessibility” and “healthcare disparities” as the key MESH TERMS. The term *disparities* became a MESH term in 2008. Measurement of access and equity in access is a rapidly evolving field. The review was, therefore, most interested in recent literature highlighting the most current developments in measurement, and focused on articles published between 2008 and 2019. Articles were included if published in English, and from

Australia, Canada, the UK, or the US ,and the focus was quantitative analysis (Table 2.1). A few cases of examples from other countries were retained if they came up in the search or were noted in papers as a key reference and quantitative methods were strong. Articles were excluded if they did not contain quantitative analysis which included an assessment of disparities or differences by population groups in access to care or if results were based on fewer than 300 respondents. A snowball search also included key references noted in the literature or grey literature. In total, 101 articles were reviewed in more detail for methods, vulnerable groups and access measures used.

Table 2.1 Literature search strategy



How is access to care operationalised?

As part of the National Health Performance Framework in Australia accessing care is defined as people being able to: "*obtain health care at the right place and right time irrespective of income, physical location and cultural background*"(Australian Institute for Health and Welfare, 2016). As part of regular reporting in Australia, access is assessed through a range of indicators or measures.[1] Several indicators reflecting service use are included: bulk billing

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[1] The terms indicators and measures will be used somewhat interchangeably here as they are in the literature. Specifically, what distinguishes an indicator in performance measurement is that there is a clear direction of 'good' or improvement. For example, regions with shorter waiting times for surgery have better performance, however regions with higher use of services are not clearly better or worse than those with lower levels of service use. Therefore, waiting times may be an indicator of performance whereas service use is a contextual measure.

rates, or potentially avoidable ED presentations, prescriptions filled or health checks for priority populations (Australian Institute for Health and Welfare, 2016) (Steering Committee for the Review of Government Service Provision, 2017) (Table 2.2). In Australia as well as internationally, waiting times for elective surgery make up a number of indicators of access to care (OECD, 2015, Steering Committee for the Review of Government Service Provision, 2017). Population-reported indicators of foregone care due to cost and having a regular care provider are also commonly reported.

Access to care was assessed in a broader sense in the literature (Table 2.3). Measures were grouped according to the framework outlined by Levesque et al.(Levesque et al., 2013). The framework suggests five domains of access from a ‘supply’ or provider perspective: approachability, acceptability, availability, affordability and appropriateness, with five corresponding abilities of patients (from the ‘demand’ side) to perceive, seek, reach, pay, and engage. General measures of service utilisation as realised access (Aday and Andersen, 1974, Andersen, 1995) and unmet need (Chen and Hou, 2002, Allin and Masseria, Carr and Wolfe, 1976) and composite measures which could not be specifically categorised were included as separate groupings. Commonly covered aspects of access included approachability (affiliation with a regular provider), availability (long waits for care, after-hours access, transportation issues) and affordability of care (foregone or delayed care due to cost (Table 2.3, rows 1,3,4). In terms of appropriateness, or technical and interpersonal quality of the care, there are a range of possible measures including clear explanations, engagement of patients in decisions, spending enough time (Table 2.3, row 6). Acceptability of care, reflecting cultural and social factors associated with people accepting the service that is available to them, was the least commonly covered domain. Some potential measures regarding (un)acceptability of care include patients feeling worried about what others thought about them seeking care, needing an interpreter to understand the provider, or being refused care (Table 2.3, row 2). Measures of utilisation (use of GP, specialist, dental, mental health, preventive/screening or hospital services) and general unmet need (self-reported unmet need for care or delayed care) were assessed in over half of the papers combined.

Composite measures of access to care, which combined multiple measures, were included in several studies. These measures incorporated several services or survey questions into one overall measure of access. In some cases, measures reflected a positive concept – having a medical home (Singh et al., 2009), or regular preventive care across a range of services (Fulkerson et al., 2013). For example, fourteen questions were used to measure features of medical homes including access, continuity, comprehensiveness, family-centred care, and coordination (Stevens et al., 2009). In other cases, the perspective of barriers to access was adopted, and measures included the average or count of access barriers (Cheung et al., 2012, Rosen-Reynoso et al., 2016, Clouston et al., 2012) or experience of any of a range of barriers (Iezzoni et al., 2011). At a higher level, country rankings across a range of access measures were also used to provide an overall ranking of performance on access to care (Davis et al., 2014).

Measures of access to care were often simplified to reflect dichotomous outcomes, or either having access or not. Common dichotomous measures included; having a regular provider, having problems with after-hours care, or unmet need for care (Table 2.3). However, when measuring the use of services, the number of services used is often considered (Siddiqi et al., 2016, Mullachery et al., 2017, Asada and Kephart, 2007, Abraham et al., 2013). The time until treatment can be measured. For example, access to transplants or to receive results of cancer screening (Hogan et al., 2015, Primeau et al., 2014, Saunders et al., 2015).

There are many examples of patient reported measures of access to care in the peer-reviewed literature, where performance reporting mainly includes administrative measures. For example, patients report their perceived or unmet needs, having a regular care provider, having difficulties with getting access after-hours, and affordability barriers (Table 2.3). In the examples of public reporting of access to care in Australia, most measures focus on waiting for elective surgery or emergency care, or measures of use of screening or bulk-billing services (Steering Committee for the Review of Government Service Provision, 2017) (Australian Institute for Health and Welfare, 2016). There was one example of a patient-reported measure of foregone care due to cost as reported by individuals (Productivity Commission, OECD). Most of the performance reporting examples of access to care from Australia, Canada, the US and England in Table 2.2 are mainly administrative data focused, and do not capture people’s experiences of access to care.

Table 2.2 Illustrative examples of approaches to access and equity measures in Australian and international health care performance reporting

Organisation and reporting aim:	Access to care defined as:	Measures of access include:	Equity defined as:	Population groups:	Equity considered as:
Australia's Health(Australian Institute for Health and Welfare, 2016) Since 2008 as part of this biennial report, a report on the National Health Performance Framework (NHPF) covers health status, determinants of health and health system performance. Accessibility is one of six domains of health system performance.	"*People can obtain health care at the right place and right time irrespective of income, physical location and cultural background*"	Bulk-billing for non-referred (GP) attendances, potentially avoidable GP-type ED presentations, waiting for elective surgery and ED care, cancer screening rates, differential access to hospital procedures, pregnancies with a timely antenatal visit. Mental health: Proportion of those with mental illness with a GP care plan	The question 'Is it the same for everyone?' is asked in terms of health system performance, determinants and health status aspects of the NHPF.	Indigenous Australians, gender for access measures in 2016 (age remoteness, area based deprivation used for other measures)	No regular assessment of the extent of disparities was made, or comparison between regions or over time
Report on Government Services 2017 (Steering Committee for the Review of Government Service Provision, 2017) Outlines performance indicators from the National Healthcare Agreement (NHA) between Australian and state and territory government annually (since 1993) across dimensions of equity, efficiency and effectiveness of government services. Access **is defined** within effectiveness and equity.	Measures how easily the community can obtain a delivered service (output). 'Access to services compared to need by type of service' is an indicator of governments' objective that Australians have a health system that reduces disadvantage, especially for Aboriginal and Torres Strait Islander Australians.	*Equity/access measures:* PBS prescriptions filled at concessional rate, GPs, female GPs and dentists per population, older Indigenous Australians who had a health check, mental health service use by selected groups, new client index (Mental health) *Effectiveness/access measures:* bulk billing rates, deferring visit to GP or medication due to cost, timeliness of urgent GP appointments, ED wait times. Treatment rates/community follow up	"Are services are equally accessible to everyone regardless of personal characteristics such as cultural background or location"	Indigenous Australians, Remoteness, Deprivation of area (SEIFA)	No assessment of the extent of disparities was made, or comparison between regions or over time.
Canadian Institute for Health Information (Canadian Institute for Health Information, 2015, Canadian Institute for Health Information, 2016) Indicator library updated regularly based on performance Measurement Framework. Includes measures of: health system	"Getting needed care at the right time, without financial, organizational or geographical barriers. It also reflects the fit between health services and needs, as well as the comprehensiveness of publicly funded services"	Time spent in ED, regular care provider, hip fracture surgery time, specialist wait times, radiation wait times, joint replacement wait times No mental health access measures. However, repeat hospitalizations for mental illness may be a proxy of poor community access	"*Capacity of the health system to deliver comprehensive, high-quality outputs (services) to individuals and populations in an equitable way, without the imposition of financial or other barriers to receiving care that is person-centred, safe,*	Area-based income measure, gender	**Disparity rate ratio** (of quintile 1 vs quintile 5), **Potential rate reduction** (or the reduction in an indicator if all groups had the same level as that of the highest socioeconomic status areas). Can be compared over time and by region with

Organisation and reporting aim:	Access to care defined as:	Measures of access include:	Equity defined as:	Population groups:	Equity considered as:
inputs, outputs and outcomes, social determinants. Access is contained within the outputs domain.			*appropriate and effective, and efficiently delivered”*		95% Confidence interval. Not consistently reported for all indicators, at the time there were no access examples.
Agency for Healthcare Research and Quality (US) (Agency for Healthcare Research and Quality, 2016a, Agency for Healthcare Research and Quality, April 2016)	*'the timely use of personal health services to achieve the best health outcomes” Includes four components: Coverage (insurance), services (usual care provider, screening, prevention services), timeliness, and workforce of capable, culturally competent providers*	Having a usual source of care, encountering difficulties when seeking care, and receiving care as soon as it is wanted (21 measures total including structural, utilization measures and assessments of ease of access). No mental health specific measures.	"*Some Americans routinely face more barriers to care and receive poorer quality of care when they can get it".*	Ethnicity, Income (low vs high). Each year a focus population is chosen. Disability (as defined by activity limitation) was the focus in 2013.	**Relative difference** between group and reference. Trend: linear regression of access measure improving for priority population if annul improvement of 1% per year and p<0.1.
Quality watch (UK) (QualityWatch, 2013) : An independent research organisations Nuffield Trust and Health Foundation in England, tracking over 300 quality indicators to assess changes in health and social care quality. Includes domains of access, capacity, effectiveness, equity, percent centred care, and safety.	*“Care services should be timely and provided within the appropriate setting with access to necessary skills and expertise”*	Waiting times for ambulance, ED care, elective surgery, GP care, also includes use measures; prescribing of antidepressants, end-of-life care (21 measures) Mental health measures: antidepressant prescribing variation, percentage of people with depression or anxiety receiving and completing psychological therapy.	*Equity: Care should be provided on the basis of need, regardless of personal characteristics such as age, gender or ethnicity; and in such a way as to reduce differences in health and wellbeing status and outcomes across sub-groups.*	age, deprivation decile, include focus reports on groups such as those with mental illness (Dorning et al., 2015)	Some measures stratified by population groups, size of disparities not commonly reported with the exception of Excess mortality for people with mental illness.
Health at a glance: OECD annual publication since 2001**(OECD, 2015)**. Presents comparable data for member countries on health and healthcare. Includes access as part of an overall framework including health status, determinants of health, health quality and equity(Arah et al., 2006).	*"Accessibility is the ease with which health services are reached. Access can be physical, financial, or psychological and requires that health services are a priori available"*	Insurance coverage, waiting times for elective surgery, foregone care due to cost, geographic distribution of doctors/dentists No access related measures for mental health, however there is focused reporting on mental health (Hewlett, Forti) and a measure of excess mortality for people with mental illness (	*"extent to which a system deals fairly with all concerned. Equity deals both with the distribution of the burden of paying for health care and with the distribution of health care and its benefits among a people "*	unmet care needs for dental or medical care are reported by country and income level in access chapter	Size of disparities not compared commonly income related inequalities in health service use has been reported in a focus report (Devaux and de Looper). Measure of excess mortality for people with mental illness.

Organisation and reporting aim:	Access to care defined as:	Measures of access include:	Equity defined as:	Population groups:	Equity considered as:
Mirror, Mirror On The Wall: How the Performance of the U.S. Health Care System Compares Internationally (Davis et al., 2014) Since 2004, Commonwealth Fund has produced this report every three years across domains of access, quality, equity and efficiency of healthcare as well as healthy lives.	"*Patients have good access to health care when they can obtain affordable care and receive attention in a timely manner*"	Cost-related access problems (unmet need due to cost, problems paying bills, high out-of-pocket expenditure) and Timeliness of care (GP visits on same/next day, after-hours access ED, specialist and elective surgery timeliness) reported both by patients and some measures from primary care providers. No mental health measures.	*"providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status." (IOM 2003)*	Self-reported income	The difference in indicator results between high and low income groups are calculated and the size of the difference is ranked across countries. The country with the smallest gaps between income groups (or gap favouringå low income group) is ranked the highest.

Table 2.3 Summary of measures of access considered in the literature by domain

ACCESS DOMAIN	MEASURES
1.Approachability/ ability to perceive	• Have a medical home(Stevens et al., 2009, Singh et al., 2009, Cheak-Zamora and Thullen, 2017) • Have a regular care provider (Fang et al., 2014, Stimpson et al., 2012, Vargas Bustamante et al., 2012, Singal et al., 2013, Skopec and Long, 2015, Valenzuela et al., 2014, Siddiqi et al., 2016, Lau et al., 2012, Liss and Baker, 2014, Reichard et al., 2017, Fulkerson et al., 2013, Horner-Johnson et al., 2014, Iezzoni et al., 2011, Kulkarni et al., 2010, Mullachery et al., 2017, Hughes et al., 2015, Flores and Tomany-Korman, 2008, DeVoe et al., 2009) • Perceived need: did not seek care as symptoms were mild (Lee et al., 2010, Harris et al., 2011, Sorkin et al., 2009) • Did not seek care as didn't know where to go (Davis et al., 2016) • Accepting new patients (Fahmy et al., 2018) • Likelihood of attachment to a regular provider, wait time for attachment (Smithman et al., 2018) • Cancer diagnosis stage (Dasgupta et al., 2017)
2.Acceptability/ Ability to seek	• Worried what people would think (stigma) (Davis et al., 2016) • Interpreter needed (Flores and Lin, 2013) • Patient was refused service by doctor (Reichard et al., 2017)
3.Availability/ Ability to reach	• Barriers getting to office, transport barriers, time to travel to centre with appropriate cardiac care (PCI) (Lau et al., 2012, Currow et al., 2012, Davis et al., 2016, Hsia and Shen, 2016, Reichard et al., 2017) • Difficulties with available time, inconvenient times, couldn't get an appointment (Davis et al., 2016, Lee et al., 2014, Rosen-Reynoso et al., 2016) • Could get immediate care for injury, got reply from clinic by phone (Cheung et al., 2012, Stevens et al., 2009) • Difficulty accessing a health care provider for an infant (Brandon et al., 2016) • Difficult after hours care (Davis and Ballreich, 2014) • Geographic; access (distance) to pharmacies (Wang and Ramroop, 2018) to primary care providers (Gilliland et al., 2019) • Long waits for appointment, waiting lists, time to get on wait lists, time from wait list to procedure/transplant, long wait in ED(Cheung et al., 2012, Davis and Ballreich, 2014, Allin et al., 2010, Saunders et al., 2015, Udayaraj et al., 2010, Vargas Bustamante et al., 2012, Jones et al., 2018)
4.Affordability/ Ability to pay	• Foregone care due to cost (Allin et al., 2010, Davis and Ballreich, 2014, Reichard et al., 2017, Skopec and Long, 2015, Rosen-Reynoso et al., 2016, Creedon and Lê Cook, 2016, Hughes et al., 2015, Kulkarni et al., 2010, Fang et al., 2014, Lee et al., 2014, Henning-Smith et al., 2013, Valenzuela et al., 2014) (Paul et al., 2016) • Insurance or coverage issues, percentage reimbursed (Kandolf Sekulovic et al., 2017) (Liss and Baker, 2014, Lau et al., 2012, Flores and Lin, 2013, Davis et al., 2016) (Ngo et al., 2018, Perri et al., 2018, Perera et al., 2018)
5.Appropriateness/ ability to engage	• Patient is a partner in decision making (Cheak-Zamora and Thullen, 2017) • Receives transition services (Cheak-Zamora and Thullen, 2017), coordinated care(Stevens et al., 2009, Singh et al., 2009) Referral problems (Currow et al., 2012) Referral to Psychological Therapy Services (Pettit et al., 2017) • Explained things clearly (Stevens et al., 2009) • GP spent enough time (Flores and Lin, 2013) • Received information of treatment (Rosen-Reynoso et al., 2016, Harris et al., 2011) • Primary care relationship continuity (Levene et al., 2018) • Provider understands condition, shows respect, encourages you to ask questions, Care provider answers questions (Valenzuela et al., 2014) • Timely diagnosis provided (Primeau et al., 2014 • Access to/use of guideline recommended diabetes care among diabetics (Perera et al., 2018)
Uncategorized/general	
6.Unmet need	• Self-reported unmet need for medical, dental or prescription drugs, any difficulties getting care, delaying care (medical, dental, drugs) (Valenzuela et al., 2014, Stevens et al., 2009, Skopec and Long, 2015, Singhal et al., 2014, Shi and Stevens, 2005b, Reichard et al., 2017, Peiris-John et al., 2016, Mahmoudi and Meade, 2015, Lau et

ACCESS DOMAIN	MEASURES
	al., 2012, Kulkarni et al., 2010, Iezzoni et al., 2011, Horner-Johnson et al., 2014, Henning-Smith et al., 2013, Flores and Lin, 2013, Du and Xu, 2016, DeVoe et al., 2009, Clouston et al., 2012, Allin et al., 2010, Connolly and Wren, 2017, Paul et al., 2016, Giblon and Bauer, 2017)
7.Utilisation/ realised access	• Use of GP, specialist care, dental visits, ED, hospital, medication use, screenings, immunization (Allin et al., 2010, Asada and Kephart, 2007, Baade et al., 2011, Cheung et al., 2012, DeVoe et al., 2009, Dumont et al., 2013, Fiscella and Holt, 2007, Fulkerson et al., 2013, Horner-Johnson et al., 2014, Hughes et al., 2015, Jimenez-Rubio et al., 2008, Kulkarni et al., 2010, Lee et al., 2014, Liss and Baker, 2014, Maharaj et al., 2014, Mullachery et al., 2017, Palencia et al., 2010, Reichard et al., 2017, Salinas et al., 2015, Singal et al., 2013, Stevens et al., 2009, Stimpson et al., 2012, Vargas Bustamante et al., 2012, Cheak-Zamora and Thullen, 2017, Buchmueller et al., 2014, Wagenius et al., 2019, Mosquera et al., 2017) • Eye care use (Lee et al., 2018), Eye examinations (Shickle et al., 2018) • Mental health service use (Alegria et al., 2010, Chen and Vargas-Bustamante, 2011, Cooper et al., 2016, Diaz-Granados et al., 2010, Flores and Lin, 2013, Harris et al., 2011, Lau et al., 2012, Sorkin et al., 2009, Spoont et al., 2009, Anderson et al., 2018, Branstrom, 2017) • Treatment access rates for mental health (Martin et al., 2018) • Variation in: rates of coronary angiography, or general surgery (Ahmed et al., 2019, Chew et al., 2016) • Receiving a transplant, colonoscopy, revascularization (Creedon and Lê Cook, 2016, Hogan et al., 2015, Lumme et al., 2008) • Palliative services at end of life, access and referral (Currow et al., 2012, Macfarlane and Carduff, 2018) • Use of clinical telepharmacy, telehealth (Patterson et al., 2014)
8.Composite multiple access measures	• Medical home composite measure (Singh et al., 2009) • Access to care index (regular provider, routine checkups, multiple barriers related to cost, provider or structure) (Fulkerson et al., 2013) • Count of barriers to timely primary care (unable to: get through on telephone, obtain appointment soon enough, long wait in the physician's office, limited clinic hours, lack of transportation) (Cheung et al., 2012) • Count of barriers before and after reaching primary care (Corscadden et al., 2018) • Count of process barriers: contextual (understand condition), communication (respect, explain listen discuss questions), getting information (answer your questions) (Valenzuela et al., 2014) • Counts of barriers (Iezzoni et al., 2011, Rosen-Reynoso et al., 2016)

How is equity in access to care measured in quantitative analyses?

In Australia, the concept of equity has been incorporated as part of healthcare performance reporting by the Australian Productivity Commission through the following question: “Are services equally accessible to everyone regardless of personal characteristics such as cultural background or location" (Steering Committee for the Review of Government Service Provision, 2017). Despite the intention to measure equity, there is no regular assessment of the extent of disparities by population groups, region or over time in regular reporting of healthcare performance reporting in Australia.

There are three notable examples of summarising disparities in access to care among the international organisations considered in the grey literature search. Since 2003, the National Healthcare Disparities Report has been produced annually in the US (Agency for Healthcare Research and Quality, 2016a). Income and ethnicity-related disparities are summarised across 21 measures of access to care regarding where low income and ethnic minority groups have significantly poorer access. In addition, an assessment of where disparities have improved or worsened over time is provided. This is the only example found that includes summary statements made about the extent of disparities across multiple groups and over time in a comprehensive healthcare performance report. Secondly, in Canada, measures of the size of income-related disparities are calculated which both compare the size of the ‘gap’ between the lowest and highest quintiles, as well as the change in the indicator if all groups had the same result as the best. These measures of disparity can be compared over time and between regions. One limitation is that the method is not applied to all measures of access (Canadian Institute for Health Information, 2017a). Finally, multi-national studies have calculated income-related disparities by country as the percentage-point differences between high and low-income groups in measures of access and overall views. The difference is ranked across Australia and ten other countries, the country with the best equity ranking is the one with the smallest gaps between income groups (Davis et al., 2014, Schneider, 2017).

In the literature, a range of methods were used to assess disparities in access to care. Most commonly, to determine the likelihood of a population group being more or less likely to have access to care, logistic regression methods were used for the dichotomous outcomes. However, there were exceptions. When access measures of interest were based on service use, such as the number of GP visits or medications, Poisson regression (Cooper et al., 2016, Liss and Baker, 2014, Mullachery et al.), negative binomial models (Abraham et al., 2013, Asada and Kephart, 2007, Clouston et al., 2012), and zero truncated binomial models were used (Asada and Kephart, 2007). In terms of analysis regarding waitlists for transplants

(Saunders et al., 2015, Udayaraj et al., 2010), survival analysis or cox-proportional hazards models were used to consider the time until treatment. These methods assess whether a disparity exists, and whether it remains after adjusting for other correlated factors. However, it does not assign a ‘size’ to the disparity.

A basic percentage point difference measure can be used to describe the disparities in access to care between population groups. An international health system comparison report ranked the size of differences in measures of access between low and high income groups across 11 countries to compare disparities in access (Davis et al., 2014). However, there are limitations with basic differences, which have not been adjusted for age or need, and are not easily compared with other groups or over time.

There are also more advanced, economics based methods to assess equity as a full distribution. For example, the concentration index measures how far away from ‘equal’ resources are distributed, and is used often in analysis of equity in access to care by income, where income is an ordinal or continuous variable (Allin, 2008, Macinko and Lima-Costa, 2012, Cheng et al., 2008, Jimenez-Rubio et al., 2008, Lumme et al., 2008). The slope index of inequality is a similar concept that measures a ‘gradient’ or the relationship between income and the level of access in each income group (Cheng et al., 2008, Palencia et al., 2010, Cookson et al., 2016b). These methods focus on characteristics such as income that are ordinal, and there were no examples that used other vulnerable groups.

Population groups considered

In Australia, healthcare services are meant to be accessible regardless of personal characteristics such as cultural background or location (Australian Institute for Health and Welfare, 2016). Towards assessing this aim, measures of access are often reported by Indigenous status, and the remoteness or Socioeconomic index for areas (SEIFA) as defined by the postal code, as well as age and sex (Australian Bureau of Statistics, 2008, Australian Institute for Health and Welfare, 2016, Australian Institute of Health and Welfare, 2016b, Department of Health and Ageing, 2013, Steering Committee for the Review of Government Service Provision, 2016). In other countries, area-based income measures are also used in the absence of detailed personal information on all health service data (Canadian Institute for Health Information, 2015, Canadian Institute for Health Information, 2016, Agency for Healthcare Research and Quality, 2016a, QualityWatch, 2013). In the US, measures of access to care by ethnicity are also commonly reported (Agency for Healthcare Research and Quality, 2016a), with regular reports on priority populations such as those with disabilities.

Similarly, in the UK, both area-based deprivation (QualityWatch, 2013) and focus groups such as those with a mental health condition are reported (Dorning et al., 2015).

The most commonly considered vulnerable groups in the literature were those identified by ethnicity (including race or immigration status) and income or socio-economic status (SES) (Table 2.4). In addition, other reports went into more depth including characteristics such as sexual orientation (Skopec and Long, 2015) and incarceration (Kulkarni et al., 2010). People living with health conditions and disabilities were also commonly considered (Horner-Johnson et al., 2014, Iezzoni et al., 2011, Reichard et al., 2015, Reichard et al., 2017, Stevens et al., 2009). In addition, the populations of focus in studies exploring issues of equity in access are often not the entire population. For example, there are many studies exploring disparities within vulnerable groups (Table 3), such as immigrants (Stimpson et al., 2012), children with special needs (Lau et al., 2012), people awaiting transplant (Udayaraj et al., 2010, Saunders et al., 2015), or those in need of palliative care (Thomas et al., 2013).

Factors that make people vulnerable to poor access to care do not occur in isolation. Several studies of populations with and without disabilities looked at the increased likelihood of people with multiple disabilities or chronic conditions experiencing problems accessing care in adults (Horner-Johnson et al., 2014, Iezzoni et al., 2011) (Reichard et al., 2015, Reichard et al., 2017) as well as children (Stevens et al., 2009). In other cases, vulnerable groups as identified by ethnicity (Liss and Baker, 2014) or rurality (Davis et al., 2016) were considered along with the presence of low income, lack of private insurance and other factors. These studies emphasize the importance of considering combinations of, and intersections between, vulnerability factors.

Table 2.4: Summary of population groups considered through an equity lens in the published literature

GROUP OR CHARACTERISTIC of focus	COUNT OF STUDIES
RACE OR IMMIGRANT STATUS	20
SOCIOECONOMIC STATUS OR INCOME	18
DISABILITIES	11
GEOGRAPHIC VARIATION/DISTANCE	6
RURALITY	5
PUBLIC/PRIVATE FUNDING/INSURANCE	3
SEXUAL ORIENTATION	3
AGE	1
INCARCERATED	1

Note: People with mental health conditions were not specifically considered as a population group of focus in any of the studies observed.

How is mental health incorporated in current assessments of equity in access to care?

Mental health was most commonly considered in terms of service use for mental health reasons or unmet need within the broader healthcare literature reviewed. In contrast to outcomes in broader studies of access to care summarised in Table 2.5, almost all measures for mental health services were based on use or unmet need, and were dichotomous. There were no mental health service related measures reflecting other domains of access such as availability, acceptability or appropriateness. International reporting offers further examples of measures of access to mental health care for a range of services, including addictions specific services which go beyond use, and focus on completion of treatment (Amaddeo and Tansella, 2013, Fisher et al., 2013, Hermann et al., 2006, Lauriks et al., 2012, Lauriks et al., 2014, Spaeth-Rublee et al., 2010) (Glied et al., 2015).

People with mental health conditions were rarely considered as a vulnerable group in peer reviewed or grey literature. There were some disability related studies that considered mental health conditions. In one study, children with special needs were categorised based on whether they had: physical health conditions, mental health conditions, developmental disabilities, along with each combination of the two, and all three conditions combined (Cheak-Zamora and Thullen, 2017). In studies of adults with disabilities, access for people with cognitive conditions was assessed in reference to those with hearing impairments (Horner-Johnson et al., 2014) as well as in comparison to people with no limitations (Reichard et al., 2015, Reichard et al., 2017). These studies address co-occurring conditions through the consideration of a ‘multiple impairment group’. There was also a study that considered women who had post-partum depression as a vulnerable group for having difficulty accessing a health care provider for their baby (Brandon et al., 2016). As part of the grey literature, there was one study comparing hospital use for people with mental health conditions, serious mental health conditions (schizophrenia, bipolar disorder or psychosis diagnosis) and physical health conditions where mental health condition was based on a diagnosis (Dorning et al., 2015). The mental health cohort may have other physical health conditions, while the physical health cohort did not use any services for mental health reasons.

Self-reported mental health conditions were also considered as a health-related need, which was considered in models of access to care. Specifically, mental health was commonly considered in terms of: distress, (Allin et al., 2010, Rosen-Reynoso et al., 2016) and self-rated mental health (Asada and Kephart, 2007, Du and Xu, 2016, Horner-Johnson et al., 2014, Reichard et al., 2015). In some cases specific diagnosis were considered, including: dementia (Cooper et al., 2016), alcohol and substance use, (Davis et al., 2016) depression (Alegría et al., 2008) and anxiety (Harris et al., 2011).

Table 2.5 Summary of mental health related access measures in literature by type

THEME	EXAMPLE MEASURES
SERVICE USE: MEDICATION SPECIFIC	• received prescription for psychotropic drugs by type of drug and provider (Wastesson et al., 2014) • use of antidepressants (Branstrom, 2017) • use of selective serotonin reuptake inhibitors (Clouston et al., 2012) • pharmacotherapy for alcohol dependence/dispensing rates (Mosquera et al., 2017) • number of substance use disorder medications prescribed (Abraham et al., 2013), • any use of medication for mental health reasons people with anxiety or depression(Chen and Vargas-bustamante, 2011)
SERVICE USE	• access to physician or health professional for MH reasons (Sorkin et al., 2009, Abraham et al., 2013) , • any use of mental health services among children (Lau et al., 2012) and adults (Alegría et al., 2002) (Diaz-Granados et al., 2010), • past-year receipt of mental health treatment (inpatient, outpatient, or pharmacy) among those with serious psychological distress, past-year substance use treatment among those with a diagnosis of a substance use disorder (Creedon and Lê Cook, 2016) • any GP visit for mental health reasons among patients with anxiety or depression (Chen and Vargas-Bustamante, 2011) • any use of psychological services, receipt of counselling, cognitive behavioural therapy, information (Harris et al., 2011) • Early psychosis intervention services(Anderson et al., 2018) • initiation of treatment: receiving at least one prescription, continuation as receiving 60 consecutive days of doses among people with dementia (Cooper et al., 2016), proportion of veterans with PTSD receiving services (any prescription or counselling and recommended levels (4 one month supplies or 8 sessions) • Referral to and use of psychological therapy services (Pettit et al., 2017)
PERCEIVED NEED/ABILITY TO SEEK	• Perceived need (Sorkin et al., 2009, Davis et al., 2016) • Knowledge of treatment options related to substance use (Davis et al., 2016)
UNMET NEED	• identified a need but did not receive care (Creedon and Lê Cook, 2016) • barriers involving cost, insurance (Creedon and Lê Cook, 2016, Davis et al., 2016) • reasons included: distance, logistics, availability, personal choice, stigma, worried what other would think (Davis et al., 2016)

Discussion

This review points to gaps in available measures of access to care from patient perspectives that would need to be improved through collection and reporting efforts to improve performance reporting of equity and access to patient-centred care. There are notable gaps in available indicators to measure access to care, that can be seen when considered through a broader framework proposed by Levesque et al. (Levesque et al., 2013). In fact, there are a limited number of measures in regular reporting that focus on experiences of access to care from the patient's or potential patient's perspective for those seeking care. A large range of measures of experiences that cross the continuum of access, from care seeking to affordability and appropriate care, will be considered in this thesis when exploring disparities in access for people with mental health conditions.

In the grey literature, there were no direct measures of access. Instead, proxy measures of access to mental health care focus on service use, such as the number of services used (Australian Institute of Health and Welfare, 2016b, Australian Institute of Health and Welfare, 2016a, Steering Committee for the Review of Government Service Provision, 2017). International reporting and other mental health specific reviews offer examples of measures of access to mental health care for a range of services, including addictions specific services which go beyond use, and focus on completion of treatment (Amaddeo and Tansella, 2013, Fisher et al., 2013, Hermann et al., 2006, Lauriks et al., 2012, Lauriks et al., 2014, Spaeth-Rublee et al., 2010) (Glied et al., 2015). In this thesis, analysis will reflect on unmet need for emotional distress as one way of exploring factors associated with access to mental health care.

Access to care is defined as a positive construct: "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care" (Levesque et al., 2013). For domains of access (including approachability, availability and appropriateness), measures are commonly positively framed, such as having a regular doctor or medical home, or having doctor who listens, engages the patient and spends enough time. However particularly in disparities analysis, the concept of barriers in access is commonly used, with focus on unmet needs, or affordability issues (Flores and Tomany-Korman, 2008, Haggerty and Levesque, 2015, Henning-Smith et al., 2013, Horner-Johnson et al., 2014, Hughes et al., 2015, Iezzoni et al., 2011, Liss and Baker, 2014, Rosen-Reynoso et al., 2016, Stevens et al., 2006). There is value in balancing a barriers approach with measures of positive experience of access to care, therefore this thesis will examine disparities in both.

Quantifying disparities

Methods used to indicate where disparities exist often stop short of specifying the extent or *size of disparities* that could be directly comparable between places, times, or different dimensions of access. This is a likely limitation preventing measures of equity from being incorporated as part of common performance reporting of healthcare where indicators are compared across place and time. Only 15 of 101 articles quantified the size of disparities and even fewer compared disparities by place or time (Cooper et al., 2016, Lumme et al., 2008, Flores and Lin, 2013, Mullachery et al., Singh et al., 2009, Cookson et al., 2016b). International performance reporting examples also descriptively summarise the number of significant differences, rate ratios and proportional rate reduction measures over time (Agency for Healthcare Research and Quality, 2016b, Canadian Institute for Health Information, 2017b, Cookson et al., 2016a, Schneider, 2017). Analysis presented here will aim to learn from these methods and quantify the size of disparities.

Challenges with measurement related to mental health

There are additional considerations for measuring disparities in access for people with mental health conditions. In large population-based survey data, mental health conditions are often self-reported, while in others measures are based on validated scales such as distress (Creedon and Lê Cook, 2016, Harris et al., 2011, Sorkin et al., 2009, Enticott et al., 2016), or assessed through administrative data and service use assumptions (Meadows et al., 2015). These sources will differ in the cohort of people identified as having mental health conditions regarding the severity of conditions captured, and the extent to which prevalence of general or specific conditions are underestimated. In addition, various combinations of coexisting physical and mental health conditions make comparisons between condition groups challenging. Studies of multiple risk factors and disabilities offer some options for considering single and combinations of conditions, acknowledging the cumulative nature of vulnerability factors (Reichard et al., 2015, Meade et al., 2015, Shi et al., 2008). Despite the challenges, there is a clear need to better assess disparities for people with mental health conditions. The limitations should be noted. However, despite limitations it is worth exploring options to measure disparities in access for a group who is underrepresented in the evidence. In this thesis, the aim will be to look at a range of experiences across both subjective and objective measures to determine if there are consistent response tendency differences, across measures and places or surveys. Consistent differences might point to differences in response tendencies, but where there are disparities in particular types of experiences or in some places and not others, it is more likely differences are amenable to change and improvement.

Conclusion

Reducing disparities in access to care can contribute to the overall aim of reducing disparities in health experienced by vulnerable groups in Australia. Building on the literature, analyses presented provide evidence of disparities in access to care from the perspective of people with mental health conditions. Improving methods to assess and compare disparities is one key step to improve equity measurement for all vulnerable groups. Monitoring disparities in access to care, over time and across different regions with help draw attention to issues of equity in access. This may help to bring equity measures more in parity with other health performance measures, such as waiting times in emergency departments or readmissions. Large disparities in access that are more clearly identified, are more likely to be addressed.

This review has shown that there are some pragmatic approaches to extend current literature to better assess disparities in access to care for people with mental health conditions. First by including more patient reporting measures of experience across a broader range of dimension of access. Next with more impactful methods and messaging that could be used to draw attention to important disparities. These efforts could be carried out alongside more complex methods (modelling and adjusting, or quantifying disparities) to dig deeper and help unpack the complexities of disparities and multiple risk factors when it comes to mental health in particular.

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Section I: Unmet need

This section focuses on people's experiences of unmet need for mental health care. It includes a brief introduction of measures of perceived unmet need to set up the foundation of a framework for considering factors associated with unmet need. Chapter 4 (a published manuscript) includes a secondary analysis of international survey data profiling the factors associated with unmet need for mental health care. The Appendix A and Appendix B at the end of this thesis include additional detail about the respondents, response rates and representativeness of these survey sources. Factors associated with unmet need were considered for Australia and Canada addressing aims 1 and 3.

Section 1: Unmet need (chapter 3)	Section 2: Patient-centred access (chapters 4, 5, 6)	Section 3: Patient experience (chapters 7, 8)
Aim 1, 3	Aims 2, 3, 4	Aim 4

- *What are the factors associated with perceived unmet need for mental health care? (aim 1)*
- *How do disparities in experiences of care for people with mental health conditions in Australia compare to those internationally? (aim 3)*

Measuring unmet need

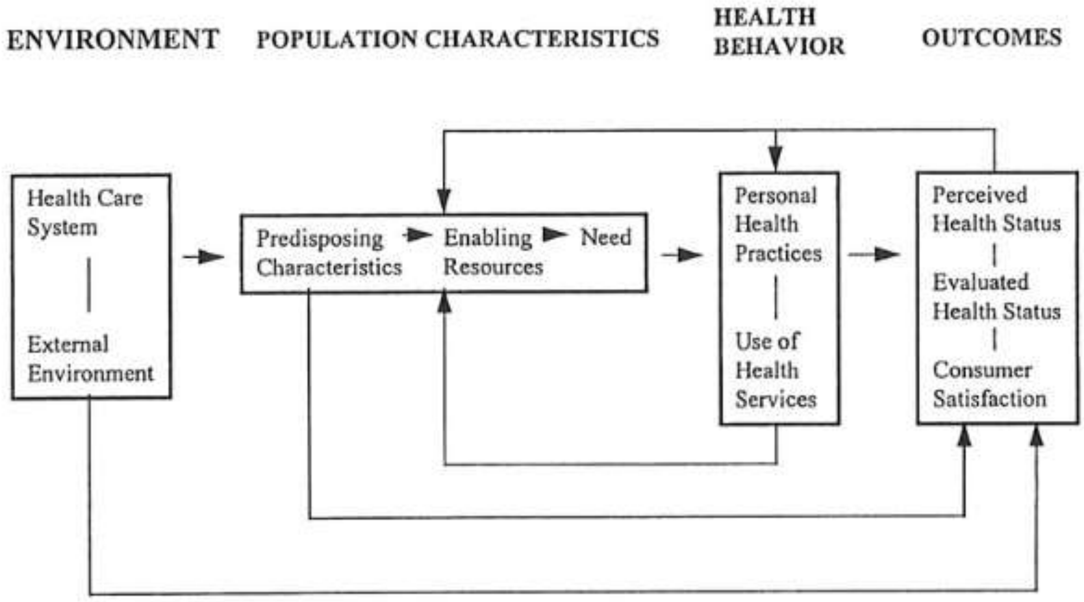
It has been argued that measuring unmet need through surveys is one of the best ways to measure access, or absence of access to care (McGinnis et al., 2015). Unmet need occurs when someone does not receive an available treatment that could have improved their health. From the perspective of (potential) patients, survey questions are commonly used to reflect unmet need, where people are asked if they needed services but did not or could not reach (Allin et al., 2010, Sibley and Glazier, 2009, Sunderland and Findlay, 2013). Further, if care is received but is not appropriate or sufficient, an unmet need still exists (Allin et al., 2010, Carr and Wolfe, 1976). Not everyone with a health condition who perceives they may have a need for care will want to seek care (Sunderland and Findlay, 2013).

In Australia, unmet needs for mental health services vary by population and measure of unmet need. In all cases, there is a large proportion of people that have unmet mental health needs. In one study, over one in four children and adolescents (27%) had a mental or behavioural health need according to their carer, however 30% reported their child's needs were unmet (Lawrence et al., 2015). Similarly, a study of Australian adults in 2007 found that 65% of people with a mental disorder used services, and only a minority had their needs fully met (Australian Bureau of Statistics, 2008). In terms of mental health service use, unmet need has also been discussed as a 'treatment gap' based on administrative records rather than patient perceptions, it reflects the percentage of people with an illness who remain untreated (Kohn et al., 2004). The treatment gap for mental illness is estimated at over 50% worldwide (Patel et al., 2010).

The reasons for unmet need are complex, particularly when it comes to mental health. Many people who do not seek care or had an unmet mental health-related need said the reason for this was that they wanted to solve the problem themselves (Prins et al., 2011). Cost and stigma are also commonly reported causes of unmet needs for mental health (Alang, 2015).

The factors behind unmet need for medical care are commonly considered through the conceptual framework by Andersen and Aday (Andersen and Newman, 1973, Andersen, 1995, Aday and Andersen, 1981), these models assess predisposing factors inherent to the person such as ethnicity, enabling factors such as income, and need factors such as health conditions or perceived needs. The model has been expanded to consider vulnerability, as a cumulative factor impacting access and quality of care (Shi et al., 2008). The association between predisposing, enabling and need and unmet need for mental health services is explored in Chapter 4.

Figure I Andersen's behavioural model of health service use



Source: (Andersen, 1995)

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Chapter 3: Factors associated with unmet need

This chapter consists of the following published article:

Corscadden, L., Callander, E.J. and Topp, S.M., 2019. Who experiences unmet need for mental health services and what other barriers to accessing health care do they face? Findings from Australia and Canada. The International journal of health planning and management, 34(2), pp.761-772.

THE INTERNATIONAL JOURNAL OF
Health Planning AND **Management**

RESEARCH ARTICLE

Who experiences unmet need for mental health services and what other barriers to accessing health care do they face? Findings from Australia and Canada

Lisa Corscadden, Emily J. Callander, Stephanie M. Topp

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Introduction

Mental health conditions affect many people in their lifetime. In a review of the global prevalence of illness, an estimated one in five people met the criteria for a mental health disorder in one year (Steel et al., 2014) (Kessler et al., 2009). However, mental health service use is less prevalent than conditions. Just over one in ten people use mental health services in a given year in countries such as Australia (15%)(Australian Bureau of Statistics, 2016b) and Canada (14%) (Surveillance et al., 2015). As services are used both by people with and without a diagnosed condition, many people with mental health need may not receive treatment. Indeed, it is estimated over half of those with diagnosed conditions do not receive treatment (Patel et al., 2010, Jorm et al., 2017). Yet, studies suggest that simply providing more services may not reduce the burden of mental illness in the population (Jorm et al., 2017). Rather, it is suggested improving the adequacy of services and targeting them to people who may benefit the most may help to reduce the impact of mental health conditions (Jorm et al., 2017). Therefore, is imperative to understand who is not receiving services.

Unmet need for mental health services

There is growing consensus of the need to improve access to care for people with mental health conditions. The United Nations Sustainable Development Goals, to which the governments of both Australia and Canada have committed, have brought a renewed focus on mental health and universal health coverage, with a commitment that 'no one will be left behind' (United Nations, 2015, Votruba et al., 2016). Yet, a person's perception of their own unmet need for mental health services is not regularly monitored. The Perceived Need for Care Questionnaire (PNCQ) was developed in Australia by Meadows et al. specifically for mental health services (Meadows et al., 2000a, Meadows and Burgess, 2009). The question set has been used extensively as part of mental health surveys in Australia, Canada and other countries (Anne et al., 2015, Burgess et al., 2009, Fleury et al., 2016, Meadows et al., 2002, Meadows and Burgess, 2009, Prins et al., 2011, Sunderland and Findlay, 2013). In Australia, about 14% of adults perceived a need for services, with about half of people reporting their needs were met in 2007 (Meadows and Burgess, 2009). An estimated 17% of Canadians reported a need for services and two thirds reported their needs as met (Sunderland and Findlay, 2013). The mental health surveys which include the PCNQ questions are infrequent, with the most recent iterations 2000 and 2007 in Australia and 2002 and 2012 in Canada (Meadows et al., 2000b, Meadows and Burgess, 2009, Nelson and Park, 2006, Sunderland and Findlay, 2013). There is a gap in current data and monitoring. Understanding the contemporary factors associated with unmet need for mental health services, and how they might differ between Australia and Canada will provide further evidence of disparities in access to mental health care and thus identify groups which policies and programs might target to improve access.

There is also a need to improve regular reporting of barriers accessing mental health care. Unmet need for general practice, specialist and dental care are commonly reported annually through general population surveys (Australian Bureau of Statistics, 2016a, OECD, 2017, Osborn et al., 2016). The Commonwealth Fund International Health Policy Survey contains a question related to unmet need for mental health services as well as other questions related to barriers to general medical and dental care. While not as nuanced as the PNCQ for considering mental health, the Commonwealth Fund Survey question provides a potential opportunity to consider unmet need for mental health care more regularly. This also allows comparisons across countries, and in the context of other barriers to accessing care. Results from the 2016 Commonwealth Fund Survey showed 20% of Australian adults and 27% of Canadian adults said they experienced distress and felt they could not cope at some point in the year prior. Of those who experienced distress, 50% of Australians and 61% of Canadians across said they got professional help (Bureau of Health Information, 2017). Thus, results based on single question survey measures align relatively well with more robust mental health survey findings which also identify around one in five with ‘need’ for mental health services and over half of this group with ‘met need’ (Meadows and Burgess, 2009, Sunderland and Findlay, 2013). This suggests there is value in using broader population surveys for monitoring access to mental health care as well. Further, general population surveys also encourage a system-based approach, considering access for mental health care as part of all services.

Aims

Building on the existing analysis of unmet need for mental health services, this analysis examined international survey data to answer the following questions:

- What groups are more likely to have unmet need for mental health services?
- To what extent are people reporting unmet need for mental health care more likely to experience other specific barriers to accessing healthcare?

Methods

Perceived unmet need for mental health services

The data sources for this secondary analysis were the 2013 and 2016 Commonwealth Fund International Health Policy Surveys. The surveys provide representative samples of adults aged 18 years and over in 11 higher income countries including Australia and Canada. More information on the survey data collection and response rates for all countries is available in the survey publications (Osborn et al., 2016, Schoen et al., 2013). Australia and Canada were selected as two countries in the international survey with comparable geographic and population characteristics (similar population size, large geographic area with some sparsely populated regions, local Indigenous populations who have poorer health outcomes, and comparatively high levels of financial protection for health care). A further methodological consideration was that both countries had larger numbers of Commonwealth Fund survey respondents, as well as results reported from independent national mental health surveys for comparison purposes. To increase the number of respondents in the analysis, pooled 2013 and 2016 Commonwealth Fund survey data was used to consider the factors associated with unmet need. Pooling surveys is a common technique when the collection instrument has remained consistent and the population of interest is a smaller subgroup (Bilheimer and Klein, 2010).

The cohort of interest for this study was people experiencing general mental health-related issues based on the question ‘*In the past two years, have you experienced emotional distress such as anxiety or great sadness which you found difficult to cope with by yourself?’.* Those who answered ‘yes’ were asked the follow up question: “*When you experienced emotional* *distress such as anxiety or great sadness which you found difficult to cope with by yourself, were you able to get help from a professional when you needed it?*'. People who said 'yes' were considered to have perceived met need, those who said 'no, did not want to see a professional' were considered as having potentially unmet need, and those who answered 'No, could not get help or could not afford to see a professional' were considered to have unmet need.

Factors associated with unmet need for mental health services

The next step in the analysis was to consider factors associated with unmet need. Characteristics associated with unmet need were considered based on Andersen behavioural model of health services use (Andersen and Newman, 1973) which is commonly used in the analysis of mental health related service needs (Prins et al., 2011, Sunderland and Findlay, 2013, Urbanoski et al., 2008, Fleury et al., 2016). This model identifies predisposing, enabling and health need factors associated with access to care. For our analysis, we looked at the predisposing factors of age, sex, and immigrant status; enabling factors of income, education, social support such as living with other adults; and health needs factors including having a diagnosed mental illness, multiple chronic conditions, fair or poor self-rated health, and activity limitations due to health conditions. Logistic regression models (SAS 9.4) were used to assess how these factors were associated with two separate outcomes, potential unmet need (not wanting professional help), and unmet need (wanting help but not receiving it) within each country. A sensitivity analysis was conducted to test whether the survey year was a significant predictor of unmet need suggested that it was not, confirming the validity of our pooled sample.

Unmet needs for mental health services and associations with other access barriers

Next, we examined the differences in other access barriers to healthcare experienced by people grouped by whether their needs for mental health care were met or unmet. Affordability-related barriers were based on responses of 'yes' to the questions: '*during the past 12 months, was there a time when you i) had a medical problem but did not consult a doctor*, ii) '*skipped a test, treatment or follow up*', or iii) '*skipped medication or doses', 'because of cost'*? As medication is an important part of care for mental conditions, a related barrier to access was considered if respondents answered 'no' when asked if '*in the past 12 months, has a doctor, nurse, or pharmacist reviewed with you all the medications you take*'. Finally, we sought to consider a measure reflecting a potential lack of trust in the system. From previous analysis of potential barriers to accessing care, negative views of the health system were found to be more common people with mental health condition than people without a condition (Corscadden et al., 2018b, Corscadden et al., 2018a). Respondents were asked '*which of the following statements comes closest to expressing your overall view of the healthcare system* *in your country?*' We considered responses suggesting the system '*has so much wrong with it that we need to completely rebuild it*' as a proxy for respondents' potential lack of trust in the system, and a possible perceived barrier as to the approachability of care.

Results

Perceived need and unmet need for mental health services

More than one in five adults in Australia (21%) and in Canada (25%) said they experienced emotional distress 'such as anxiety or great sadness which they found difficult to cope with on their own' (Table 3.1). Of those who experienced distress, just over half received professional help. In Australia, 51% of respondents said they received help, and 59% in Canada. Most of the people who did not get help noted it was because they 'did not want to see a professional', being 37% of those experiencing emotional distress in Australia and 30% in Canada. When considering only the people who said they wanted professional help, 19% felt they could not get professional help in Australia, and 15% in Canada.

Factors associated with unmet need and not wanting professional help

Characteristics of three groups of people with distress, those with: met need, potentially unmet need and unmet need for mental health services are described in Table 3.2. The associations between each of the predisposing, enabling and need factors with reporting unmet need are highlighted in Figure 3.1. The associations between each of the predisposing, enabling and need factors with reporting unmet need are highlighted in Table 3.3. The factors associated with unmet need for mental health services were broadly similar across countries. People with below average income were more likely to say they wanted help but could not get it in both Australia (OR=3.27 p=0.01) and Canada (OR=2.55 p=0.002). Higher out-of-pocket costs on healthcare were also associated with not getting help in both countries (Australia OR=3.01 p=0.01, Canada=1.73 p<0.01). In Australia, lower education was significantly associated with unmet need (OR=2.62 p=0.019). In terms of other health need related factors, people with activity limitations, and fair or poor self-rated health were also more likely to experience unmet need in both countries. However, in Canada having a chronic physical condition was associated with unmet need (OR=1.65 p=0.048), a difference not significant for Australia with the association reversed (OR=0.73).

Table 3.1 Number of respondents and percentage of adults experiencing emotional distress and perceived unmet need for mental health services in Australia and Canada

	AUSTRALIA			CANADA			
	N	%	95% CL	N	%	95% CL	Pr > ChiSq
In the past two years, have you experienced emotional distress such as anxiety or great sadness which you found difficult to cope with by yourself?							
Experienced emotional distress	1320	21	(19, 23)	2284	25	(23,26)	0.005
No	6048	79	(77,81)	7619	75	(74,77	
Not sure/decline (excluded)	40			56			
When you felt this way (i.e. Experienced emotional distress), were you able to get help from a professional when you needed it?							
Yes	689	51	(45,57)	1380	59	(56,63)	0.059
No, did not want to see a professional	486	37	(32,43)	667	30	(27,33)	
No, could not get help or could not afford to	122	12	(7,16)	198	11	(9,13)	
Unmet need among those who experienced distress and wanted professional help							
Got professional help	689	81	(75,88)	1380	85	(82,88)	0.347
Could not get professional help	122	19	(12,25)	198	15	(12,18)	

Notes: Percentages are based on weighted responses from pooled surveys and not the number of respondents. There were 23 respondents in Australia and 39 in Canada who said they had emotional distress but did not respond to the question about receiving help that were excluded.

Figure 3.1 Access problems by whether or not a person experienced unmet needs or did not want mental health services, Australia and Canada

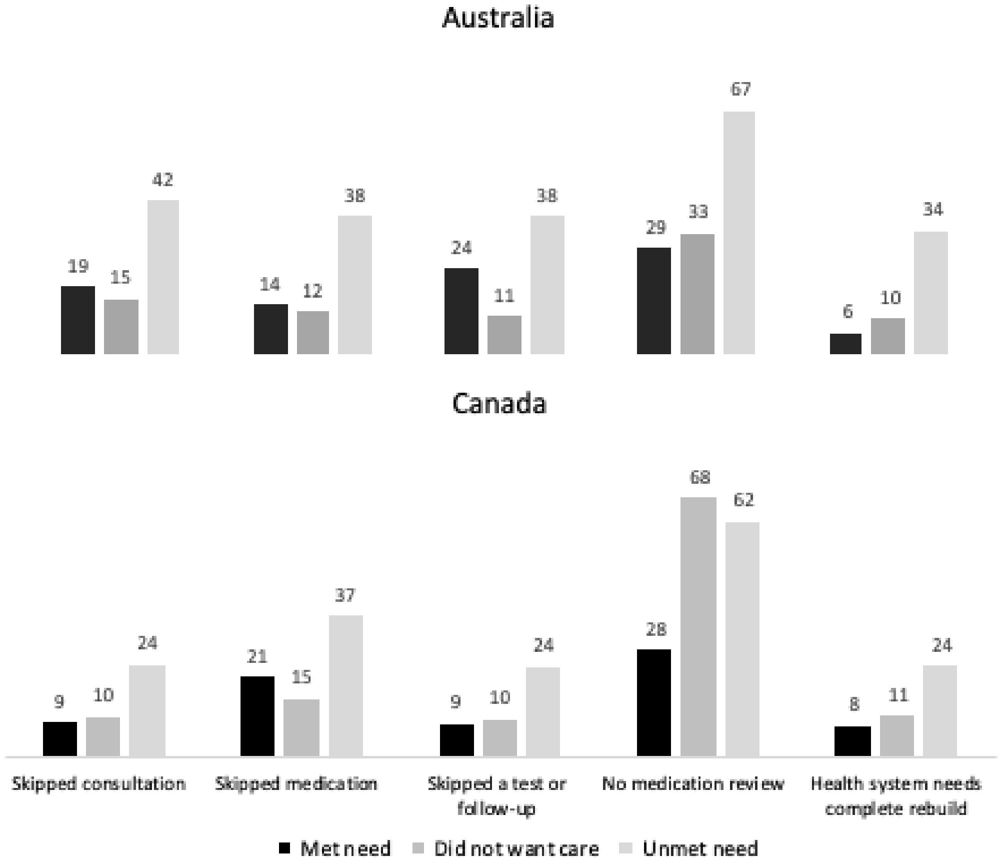

Table 3.2 Population characteristics of groups defined by level of unmet need for mental health services

	AUSTRALIA			CANADA		
% of column with indicated characteristic	Met need	Did not want care	Unmet need	Met need	Did not want care	Unmet need
Predisposing factors						
18 to 34 years	25	34	31	33	35	28
35 to 49 years	31	22	20	30	27	39
50 to 64 years	26	28	40	27	20	22
65 years and over	18	16	9	11	18	10
Male	31	46	49	35	50	44
Born in the country	81	78	71	88	78	82
Enabling factors						
Above-average income	22	19	9	29	22	15
Average income	24	23	19	21	20	18
Below-average income	45	40	59	45	53	59
Missing income	9	18	13	6	5	8
Only adult in household	20	28	29	23	26	29
Above high school	52	45	29	60	47	47
Spent $1000 or more out-of-pocket on healthcare	28	26	54	16	17	25
Need factors						
Have a (diagnosed) mental health condition	63	18	55	67	22	61
Chronic physical health condition	61	46	53	64	56	75
Fair poor self-rated health	18	13	54	28	23	46
Limited in daily activities due to health condition	30	19	48	37	24	59
Health service use						
Number of prescriptions: None	28	50	27	21	50	34
One	19	17	24	23	12	13
Two or more	53	33	49	55	38	52
Used ED in past 2 years	45	27	49	60	47	55
Used hospital	26	24	34	25	17	24
Barriers related to access to healthcare						
No medication review (of those on 2+prescriptions)	29	33	67	28	32	38
Skipped a consultation due to cost	19	15	42	9	10	24
Skipped medication due to cost	14	12	38	21	15	37
Skipped a test treatment or follow up due to cost	24	11	38	9	10	24
Trust in the system						
System works pretty well, only minor changes	40	35	12	36	31	8
Some good things, but fundamental changes are needed	54	55	54	56	58	58
So much wrong with system, need to completely rebuild it	6	10	34	8	11	24

Table 3.3 Odds ratios of experiencing unmet need and potentially unmet need for mental health related services by population factors, Australia and Canada

		Wanted help but could not get it (unmet need)				**Did not want professional help (potentially unmet need)**			
		Australia		Canada		Australia		Canada	
		Odds	Pvalue	Odds	Pvalue	Odds	Pvalue	Odds	Pvalue
Age	18 to 34 years	1.00		1.00		1.00		1.00	
	35 to 49 years	0.53	0.288	1.53	0.145	0.57	0.128	0.80	0.249
	50 to 64 years	1.25	0.729	0.95	0.874	0.76	0.431	0.69	0.054
	65 years and over	0.43	0.191	1.10	0.792	0.77	0.471	1.57	0.018
Sex	Female	0.47	0.102	0.70	0.123	0.62	0.055	0.58	<0.001
	Male	1.00		1.00		1.00		1.00	
Immigrant	Born in country	1.00		1.00		1.00		1.00	
	Not born in country	1.71	0.214	1.69	0.057	1.07	0.810	2.02	<0.001
Income	Above-average income	1.00		1.00		1.00		1.00	
	Average income	2.01	0.389	1.69	0.140	1.02	0.952	1.21	0.377
	Below-average income	3.27	0.010	2.55	0.002	0.84	0.607	1.37	0.071
	Missing	3.48	0.058	2.80	0.064	1.91	0.119	1.04	0.903
Education	Above high school	1.00		1.00		1.00		1.00	
	High school or less	2.62	0.019	1.66	0.029	1.09	0.729	1.52	0.002
Living arrangements	Only adult	1.61	0.406	1.39	0.177	1.42	0.275	1.13	0.405
	Other adults in household	1.00		1.00		1.00		1.00	
Out-of-pocket Costs on care	Less than $1000	1.00		1.00		1.00		1.00	
	$1000 or more (US)	3.01	0.013	1.73	0.047	0.72	0.223	0.92	0.622
Activity limitation	Not limited	1.00		1.00		1.00		1.00	
	Activity limitations	2.15	0.098	2.45	<0.001	0.48	0.005	0.48	<0.001
Mental health	Mental health condition	0.70	0.410	0.76	0.229	0.14	<0.001	0.15	<0.001
	No condition	1.00		1.00		1.00		1.00	
Physical health	No chronic condition	1.00		1.00		1.00		1.00	
	One or more physical condition	0.73	0.493	1.65	0.048	0.58	0.032	0.67	0.007
Self-rated health	Good very good or excellent	1.00		1.00		1.00		1.00	
	Fair or poor	5.20	<0.001	2.15	0.001	0.45	0.004	0.66	0.010

Note: Results are highlighted where p<0.05.

In terms of the factors associated with potentially unmet need, people with more health needs, such as activity limitations, a diagnosed chronic condition, or fair or poor self-rated health, were significantly less likely to say they did not want professional help. However, in Canada, people over 65 years, and those not born in the country were more likely to say they did not want professional help. In both countries, males were more likely to say they did not want professional help however the result was only significant in Canada (females compared to males, OR=0.58, p<0.001).

Unmet need for mental health care and associations with other barriers to accessing care

Next, we compared other barriers to access to health services between the three groups of adults experiencing distress who had: met needs for mental health services, those who did not want professional help, and those with unmet needs for mental health services, adjusting for age and sex (Table 3.4). Compared to people who had their needs for mental health services met, the group who had unmet needs were more likely to say they also had to forego consultations (AUS aOR=3.41 p=0.007, CAN aOR=3.33, p<0.001), and to forego medication due to cost (AUS aOR=3.16 p=0.008, CAN AOR=2.41, p=0.001). In Canada, skipping tests or treatments due to cost was also more likely to be reported by people who had unmet needs for mental health services compared to people who had accessed services for mental health care (aOR=3.36, p<0.001). For people on two or more prescriptions, those who had unmet need were more likely to say they had not had a review of their medication in the past year with a doctor or pharmacist (aOR=6.99 p=0.001).

In addition, people with unmet needs for mental health services had less positive views of the health system in both countries. Of people with unmet needs for mental health services, 31% in Australia and 23% in Canada said they felt the health system needed to be completely rebuilt – more than double the percentage in the group who had partially unmet needs and significantly higher than the 6-8% of people with met needs in the two countries respectively (Figure 3.1). After adjusting for age and sex, the association remained for both Australia (aOR=7.49 p<0.001) and Canada (aOR=3.22 p<0.001).

Table 3.4 Adjusted odds ratios of experiencing access problems by whether or not a person experienced unmet needs or did not want mental health services, Australia and Canada

	AUSTRALIA				CANADA			
	AOR	P value	aOR 95% CI		AOR	Pvalue	aOR 95% CI	
No medication review for people on two or more prescriptions								
Met need	**1.00**				**1.00**			
Did not want help	**1.41**	0.332	0.702	2.839	**1.29**	0.238	0.845	1.967
Unmet need	**6.99**	0.001	2.168	22.56	**1.64**	0.120	0.880	3.053
Skipped consultation due to cost								
Met need	**1.00**				**1.00**			
Did not want help	**0.84**	0.621	0.421	1.675	**1.17**	0.554	0.691	1.992
Unmet need	**3.41**	0.007	1.388	8.357	**3.33**	<.0001	1.912	5.809
Skipped medication due to cost								
Met need	**1.00**				**1.00**			
Did not want help	**0.73**	0.427	0.336	1.588	**0.76**	0.169	0.51	1.125
Unmet need	**3.16**	0.008	1.351	7.402	**2.41**	0.001	1.44	4.045
Skipped test or treatment due to cost								
Met need	**1.00**				**1.00**			
Did not want help	**0.40**	0.006	0.205	0.772	**1.19**	0.502	0.714	1.989
Unmet need	**2.05**	0.104	0.862	4.858	**3.36**	<.0001	1.925	5.867
System needs complete rebuild								
Met need	**1.00**				**1.00**			
Did not want help	**1.78**	0.147	0.816	3.891	**1.50**	0.08	0.952	2.369
Unmet need	**7.49**	<.0001	2.921	19.20	**3.22**	<.0001	1.761	5.891

Notes: Results were adjusted for age and sex. Results were shaded where p<0.05. The number of respondents for the medication review question was 648 for Australia and 859 for Canada as it included only people on multiple medications. For all other models the number of complete records included in each model were ~1300 for Australia and ~1900 for Canada.

Discussion

The analysis presented above examines the factors associated with unmet need for mental health services for people in Australia and Canada who experience emotional distress and felt they could not cope on their own. Analysis goes beyond findings based on only mental health services to show that people experiencing unmet needs for mental health services were also more likely to experience other barriers to access to all healthcare services. In doing so, findings evidence to existing studies demonstrating the layered and multiple challenges experienced by people with unmet mental health care needs (Cairney et al., 2014).

Both health care needs and unmet needs for mental health conditions are likely underestimated (Boardman et al., 2004). However, estimates of unmet need for mental health services presented here, based on a broad population survey compare well with findings from more robust surveys on mental health. In this study, over one in five people in Australia and Canada experienced emotional distress, and of those, just over 10% perceived an unmet need. Therefore, the population prevalence of unmet need for mental health services was approximately 3% in each country (Australia 21%*12%, Canada 25%*11%). These estimates of population level unmet need are in line with, other reports on perceived unmet need for mental health services of 3-5% (Roll et al., 2013, Sunderland and Findlay, 2013).

This current analysis adds to evidence of the factors associated with unmet needs for mental health care. Findings presented here showed unmet need was associated with being male, having low income, having higher out of pocket costs, having other chronic conditions, or poorer self-rated health. Low income has been found to be a risk factor in other studies in Australia (Edlund et al., 2002, Prins et al., 2011). One Canadian study also showed an increasing association between the number of chronic conditions and unmet need for mental health services (Sunderland and Findlay, 2013). The consistency of these findings suggests it may be possible to include some simpler measures of perceived unmet need on non-mental health specific surveys to capture access barriers for mental health services along with other services. In addition, this study demonstrated that people experiencing distress and not seeking care were distinct from the group of people who wanted help but did not receive it. Lower income was associated with unmet need, or not receiving care but was not associated with not wanting professional care when experiencing distress. Further, those who do not seek professional help seem to be healthier than people who sought out help and had either met or unmet needs. Therefore, attempts to improve access to services to people who are not receiving care and those who do not seek professional care must carefully consider the population groups of interest, as they are not the same.

Not seeking care is common for mental health services. In a study comparing reasons for not seeking care in Canada, the Netherlands and the United States the two most common responses were that people wanted to solve the problem on their own, and they thought the problem would get better by itself (Prins et al., 2011, Sareen et al., 2007). Consistent with that finding, we have highlighted that a large percentage of people who experienced emotional distress did not want to seek professional help: 37% in Australia and 30% in Canada. In both countries, people with more complex conditions were less likely to say they did not seek care. In Canada, being over 65 years of age, and an immigrant were more likely to report not seeking professional help than younger people and non-immigrants respectively, a finding not observed for Australia. A noted reason people may not seek care, or fully participate in care is the stigma surrounding the label of mental illness and the perceived judgement it brings from others (Corrigan, 2004). It has also been shown that social support and cohesion in neighbourhood settings may reduce the need to seek care among people without mental disorders (Mosher et al., 2014). We considered how living with other adults as opposed to being the only adult in the household would be related to seeking care but there was no clear association. From the literature, additional reasons people do not want to seek mental health care included a lack of trust in provider, or the feeling that care is too costly (Nelson and Park, 2006, Thompson et al., 2016).

We investigated how trust in the health system may influence mental health care seeking or be influenced by it through responses to the feelings about the health system. We found that people with unmet needs for mental health services were significantly more likely to say they thought the health system needed to be completely rebuilt in Australia (31%) and Canada (23%) – two to three-fold higher than people with met needs and those who did not want professional help. There was no association between not wanting professional care and expressed (dis)trust in the system. However, caution is warranted. The interplay of trust and access to care is dynamic and causation notably difficult to establish. For example, with cross-sectional data, it is impossible to say whether a report of 'unmet need' was what contributed to negative views of the system; or conversely whether (pre-existing) negative views of the system meant that respondents anticipated their inability to access care or poor-quality care, and so did not want to seek it in the first place. Also, trust is not fixed and not tied to a whole system but parts of care, and care providers. For example, in a study of general medical care, people with unmet needs for services were more likely report a mistrust and lack of confidence in physicians compared to those whose service needs were met (Mollborn et al., 2005). Yet, seemingly innocuous events or interactions within the health system, can shape judgements and trust about the system at large; e.g. it could be that experiences in other parts of the health system influence willingness to access mental health care. Nonetheless, our findings highlight the likely need for further mixed methods research to help clarify the nature of this interplay between trust, care seeking and unmet need.

Limitations

Many studies on unmet need for mental health care include a diagnostic question set for assessing mental illness, and perceived unmet need for mental health services. This analysis is based on the cohort from a general population survey with a single question to identify emotional distress and a single question to identify unmet need. While the validated scales have an important role in deeper understanding of unmet needs, the simpler alternative measures align reasonably well and thus may offer helpful alternatives for more regular monitoring of unmet need. In addition, the collection of survey respondents was not designed to provide representative estimates for subgroups, such as those with a mental health condition. The results are likely to reflect an underestimate of people with mental illnesses that may be residing in supportive housing and not easily sampled in surveys. Despite these limitations, the basic estimates of prevalence of need and unmet need appeared reasonable when aligned with the more robust estimates, which strengthens findings regarding the factors associated with unmet need in our view.

Conclusion

People who experienced emotional distress and wanted but did not receive professional help also experienced many other challenges in both Australia and Canada. In addition to unmet needs for mental health care these people more likely to have below-average income, have other chronic conditions, and experience unmet needs for services such as consultations, medication and medication reviews compared to people who had their needs met. Understanding the factors associated with unmet need for mental health services may help programs to target population groups or services areas to improve access to services overall. Considering other unmet needs of people with problems accessing mental health care allows a more system-based approach at building in mental health as part of all services. Further it recognizes that unmet need for ‘general services’ may be regarding mental health, thus contributing evidence to the acknowledged underestimate of needs and unmet needs for mental health services. Finally, the comparability of results from a general population survey with more robust mental health survey findings highlight the opportunity and value of including simplified survey questions about mental health care as part of unmet needs for other services. Including unmet needs for mental health as part of collecting and reporting measures of unmet needs for other services such as dental care, may help to improve parity of attention and funding on mental health services.

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Section I focused on people’s experiences of unmet need for mental health care, thereby addressing aim 1 of the thesis.

The next section, Section II (2 published manuscripts and 1 under consideration for publication) focused on patient-centred access and addresses aims 2, 3, and 4.

Section II: Patient-centred access

This section presents analysis examining disparities in experiences of access to care for people with and without mental health conditions. The focus is on people's experiences of accessing healthcare, regardless of the reason they sought care. To start, I provide the context for measuring patient-centred access to care through a framework considering a range of dimensions across a patient's journey in accessing care. This section (chapters 4 to 6) focuses on patient-centred access and comprises 2 published manuscripts, with one chapter in traditional thesis format (manuscript in review). Analysis are based on international survey data, Appendix B and Appendix C at the end of this thesis includes additional detail about the respondents, response rates and representativeness of these survey sources. Collectively, this section addresses aims 2, 3 and 4 of this thesis.

Section 1: Unmet need (chapter 3)	Section 2: Patient-centred access (chapters 4, 5, 6)	Section 3: Patient experience (chapters 7, 8)
Aim 1, 3	Aims 2, 3, 4	Aim 4

- *Are Australians with mental health conditions more likely to experience barriers in access to general healthcare, compared to those with no mental health conditions? (aim 2)*
- *How do disparities in experiences of care for people with mental health conditions in Australia compare to those internationally? (aim 3)*
- *When considering patient-centred access and experiences more broadly, for which types of experiences are disparities most pronounced across different healthcare sectors? (aim 4)*

Chapter 4 presents a secondary analysis of people's experiences of accessing healthcare in Australia, with a comparison of barriers to accessing care between people with and without self-reported mental health conditions. Next, in Chapter 5, results presented for Australia are compared with the patterns of disparities internationally, to determine if the size of barriers to access or disparities faced by people with mental health conditions are similar. Finally, Chapter 6 presents a more detailed analysis of disparities in affordability related barriers to accessing care for older Australians, as affordability was a particular area of pronounced disparities for Australians with mental health conditions.

Measuring patient-centred access

To access care, people must first recognise their needs, consider possible options for providers to approach for care, and find a time, a place and cost that is manageable for them, and they have to engage and interact with the care provider to actually access care that can help them. A broad conceptualisation of access to care reflects these person-centred considerations from a demand perspective, with provider characteristics from a supply perspective (Penchansky and Thomas, 1981, Levesque et al., 2013, Franks and Fiscella, 2008).

In Chapter 2, the literature review presented considered access to care from the perspective of Figure I, and the framework for patient-centred access to care proposed by Levesque et al. with a focus on the patient perspective from the demand side. This framework identified five key domains of access. From a patient perspective, these domains include:

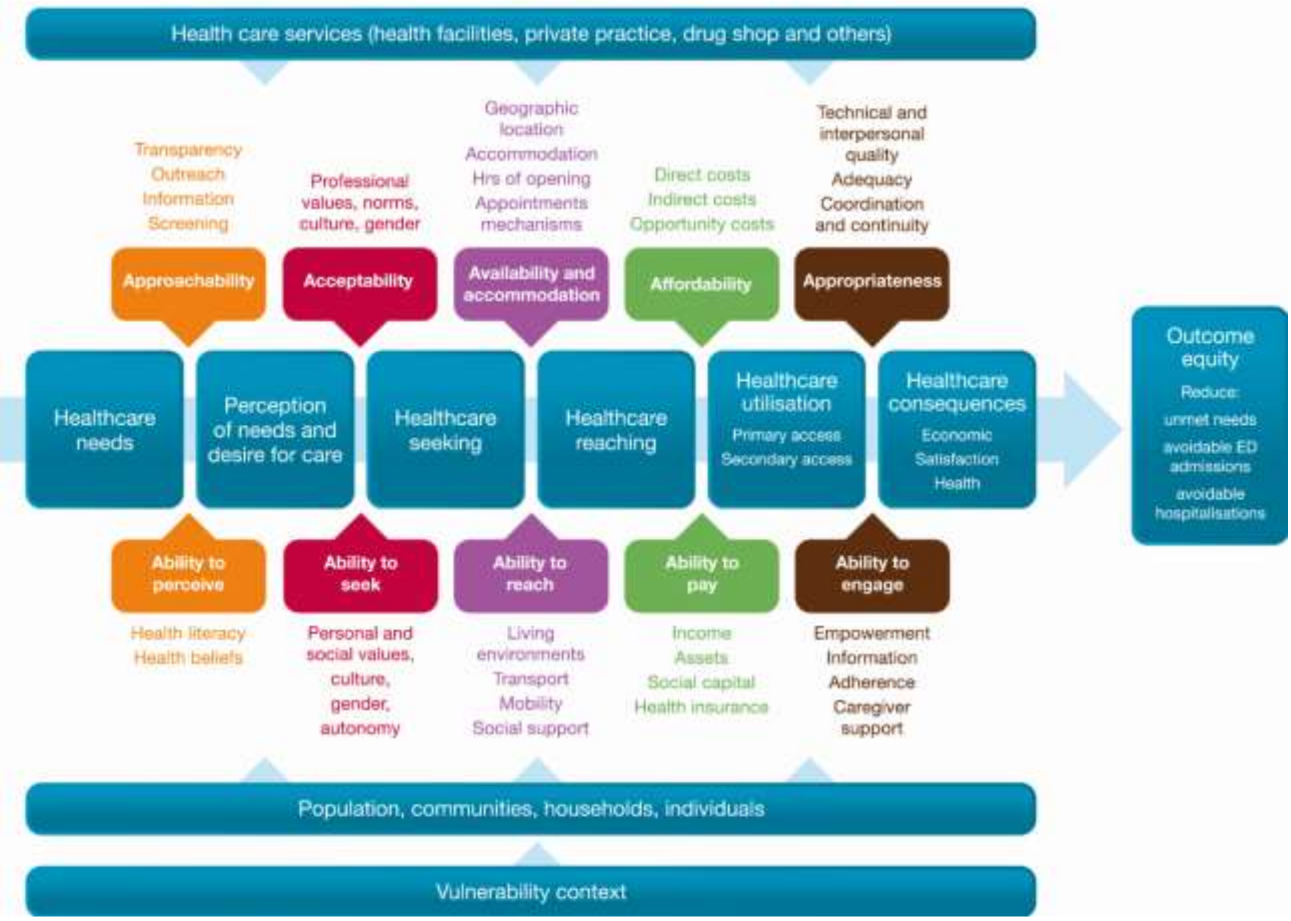
- Approachability, or the ability to perceive the existence of services that can improve health,
- Acceptability, or the ability to seek out socially and culturally acceptable services,
- Availability, or the ability to reach care both physically and in a timely manner,
- Affordability, or the ability to pay for any cost associated with services or reaching services
- Appropriateness, or the ability to engage in care.

The focus of this section is the demand side, or people’s abilities to access care (Figure 1.3, repeated as Figure II below).

Grey and peer reviewed papers with quantitative assessments of access and equity in care were reviewed, with measures mapped to the five main domains of access to care from the framework. The review highlighted gaps in measures of care at the earlier stages of care: in approachability of care, and acceptability of care.

In the chapters to follow in this section, measures related to patient perspectives of access to care are mapped to the access framework. Then disparities in access to care are summarised across these dimensions for people with mental health conditions to highlight where they are most likely to face barriers accessing care.

Figure II Levesque et al. conceptual framework for patient-centred access to health care



Source: (Levesque et al., 2013)

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Chapter 4: Disparities in access to care in Australia

This chapter consists of the following published article:

Corscadden L, Callander EJ, Topp SM. Disparities in access to health care in Australia for people with mental health conditions. Australian Health Review. 2019 Dec 17;43(6):619-27.

RESEARCH ARTICLE

Disparities in access to health care in Australia for people with mental health conditions

L. Corscadden [A B D], E. J. Callander [A] and S. M. Topp [C]

+ Author Affiliations

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Introduction

Ensuring access to healthcare for everyone in need is a goal of the health system in Australia. In 2017, The National Mental Health Commission released a concensus statement with a vision to improve the lives of people living with mental illnesses, by improving equity in access to quality health care (National Mental Health Commission, 2016). As part of the National Health Performance Framework accessing care is described as people being able to: "o*btain health care at the right place and right time irrespective of income, physical location and cultural background*" (Australian Institute for Health and Welfare, 2016). Access can be considered as the 'fit' between the patient's needs and expectations and the service delivered (Penchansky and Thomas, 1981). Access to care has been broadly conceptualised across five dimensions: approachability (awareness of the existence of services, how to reach them and the impact they have on one's health), acceptability (social or cultural factors that affect the use of services), availability (ability to reach the service both physically and in a timely manner), affordability (ability to pay for services) and appropriateness (the ability to engage in care that is of a reasonable quality) (Penchansky and Thomas, 1981, Levesque et al., 2013, Franks and Fiscella, 2008). Barriers in access to care can occur at any or all of these stages.

Disparities in access to care have been shown to exist across a range of population groups. Within the literature regarding equity in access to care both globally and in Australia (Australian Institute for Health and Welfare, 2016, Steering Committee for the Review of Government

Service Provision, 2016), there is a focus on income when identifying groups ‘vulnerable’ to barriers to access to care. Australians from low socioeconomic status areas are more likely to face barriers in terms of foregone dental care, delayed prescription medication due to cost compared to those from the highest socio-economic status areas (Australian Bureau of Statistics, 2016). Barriers in access to care have also been shown to disproportionately affect Indigenous Australians and those living in rural areas (Australian Institute for Health and Welfare, 2016, Steering Committee for the Review of Government Service Provision, 2016). There is also some evidence that compared to people with no conditions, people with chronic conditions are more likely to have barriers reaching care after-hours and to wait several days to get an appointment when sick (Schoen et al., 2010). However, research exploring access to overall care for people with mental health conditions is a notable gap given that people with mental health conditions have been shown to have higher out-of-pocket healthcare costs and to be more likely to forego care due to cost than people with no chronic conditions (Callander et al., 2016). Indeed, a review of performance measures for public reporting on healthcare in Australia recommended that populations with mental health conditions be considered (Hibbert et al., 2013).

Studies have shown that disparities in healthcare provision faced by people with mental illnesses contribute to poor physical health outcomes (Kisely et al., 2007, Lawrence and Kisely, 2010). For example, people with a mental health condition have an average life expectancy of over 10 years less than the general population. For those with a serious mental illness such as schizophrenia or substance disorder the gap in life expectancy is over 20 years (The Royal Australian and New Zealand College of Psychiatrists, 2016). Australian research shows that physical health conditions are one of the main causes of early mortality among people with mental illness (Lawrence et al., 2013). Improved access to care could help reduce the gap in life expectancy for people with mental illness (The Royal Australian and New Zealand College of Psychiatrists, 2016, Thornicroft, 2011). Identifying disparities in access to all care is thus an essential first step in strengthening equity and improving health outcomes for people with mental health conditions.

This study will examine disparities in barriers to accessing healthcare for people with mental health conditions using a broad conceptualisation of access to care. We seek to address the following questions:

- Are Australians with mental health conditions more likely to experience barriers to access to care across a range of access measures?
- Do disparities remain after considering factors such as income, education, age and rurality?

- Which access measures reflect the largest disparities between Australians with and without mental health conditions?

Methods

The 2016 Commonwealth Fund International Health Policy Survey of adults aged 18 years and over, was conducted in Australia and 10 other countries. The focus of the analysis in this paper were the 5,248 respondents from Australia, responding by landline and mobile phone with a response rate of 25.4%. Results of the analysis were calculated using sample weights provided so that the estimates are representative of the age, sex, regional and education profile of Australia.

The Commonwealth Fund International Health Policy survey contains more than 60 health and health care related questions. Thirty-nine survey questions that were considered a measure of access or a reasonable proxy were retained as they mapped to one of the five dimensions of access based on the conceptual model proposed by Levesque et al (Levesque et al., 2013). The objective was to examine differences in access by mental health status using the framework as a guide. We excluded questions related to processes where no clear direction of good could be established (e.g. do you email your doctor), and those about safety or efficiency of a service (e.g. given the wrong medication or dose, unnecessary tests ordered). Responses were selected to frame each question as an access barrier. Where responses were not dichotomous, responses of ‘sometimes’, ‘rarely’ and ‘never’ were categorised as no, while ‘always and often’ grouped as ‘yes’.

Survey responses, as access barriers, were mapped to each dimension of access to care as follows:

1. Approachability: no affiliation with a regular provider and aspects of a lack of trust are captured in questions that reflect whether respondents do not have a regular doctor, if they were not treated with respect, or felt medical care was poor, or the health system needed to be completely rebuilt.
2. Acceptability: reflections of challenges in autonomy or ability to seek care for people with chronic conditions were captured in responses where people felt they had no professional support for their condition, or they could not manage their health problem at home.
3. Availability: barriers of long waits: to get a primary or specialist care appointment, time waited in emergency or to get to elective surgery were captured under this dimension, as well as perceived availability of after-hours care.
4. Affordability: problems paying medical bills or foregoing different types of care due to cost were included.

5. Appropriateness: problems with coordination of care, aspects of communication with care providers where records were not available, as well as a lack of engagement of patients in their own care with an absence of written plans, lack of involvement in decisions were captured in this dimension.

Complete questions are available the Appendix.

For the purpose of this analysis, people with mental health conditions were identified as respondents who reported they had been diagnosed with a mental illness, or answered yes when asked if in the past two years they experienced anxiety or great sadness which they found difficult to cope with themselves. Participants who did not respond to both questions (n=13) were excluded from the analysis. The resulting prevalence of people with a mental health condition (Table 4.1, 23%) aligns well with national prevalence estimates which was the primary reason for considering not only those who had a mental illness but include people who experienced emotional distress. In 2007, 20% of Australian adults had a mental illness based on the Mental Health and Well-Being Survey (Australian Bureau of Statistics, 2008). In 2014-15, 18% had a mental health condition (Australian Institute for Health and Welfare, 2016) and 12% psychological distress based on the National Health Survey (Australian Bureau of Statistics, 2015).

Descriptive analysis was conducted to estimate the prevalence of each access barrier for people with and without a mental health condition. The percentage of respondents reporting each barrier was calculated by group as well as the percentage point difference between groups. Logistic regression models were run using SAS/STAT software Proc Surveylogistic, Version 9.3 (Copyright © 2005 SAS Institute Inc.) to assess the likelihood of experiencing barriers in access to care for people with mental health conditions, unadjusted and adjusting for age, sex, income, immigrant status, rurality and highest level of education.

Table 4.1 Population characteristics by presence of a mental health condition, Australia, 2016

	Mental health condition		**No mental health condition**		**Total**	
	%	**n**	**%**	**n**	**%**	**n**
Age						
18 to 34 years	28	171	36	1185	34	1357
35 to 49 years	27	282	26	1226	26	1516
50 to 64 years	28	348	20	946	22	1298
65 years and over	16	215	17	800	17	1015
Sex						
Female	59	609	47	2094	50	2709
Male	41	422	53	2110	50	2539
Income						
Below average	47	447	31	1260	35	1711
Average	23	197	28	1043	27	1241
Above average	20	256	27	1238	25	1495
Not sure/Decline to answer	11	131	14	663	13	801
Highest level of education						
More than year 12	42	604	56	2811	53	3420
Year 12 or less	58	406	44	1276	47	1687
Aboriginal or Torres Strait Islander						
Non-Aboriginal	95	993	98	4154	97	5160
Aboriginal or Torres Strait Islander	5	38	2	50	3	88
Rurality						
Metropolitan	65	538	70	2451	69	2996
Non-metropolitan	35	493	30	1753	31	2252
Born in Australia						
Non-immigrant	79	819	78	3309	78	4137
Immigrant	21	201	22	841	22	1044
Self-rated health						
Good very good, excellent	80	784	93	3879	90	4675
Fair or poor	20	245	7	322	10	568
Number of chronic conditions						
None	23	209	66	2660	56	2872
One	27	270	18	818	20	1088
2 or more	49	537	14	643	22	1181
Mental health diagnosis						
Has been diagnosed	57	545			14	545
None	43	486			86	4585
Emotional distress						
Experienced emotional distress	24	874			20	874
No experience of distress	76	153			80	4309
Mental condition or distress						
Yes	100	1031			23	1031
No			100	4204	77	4204

Results

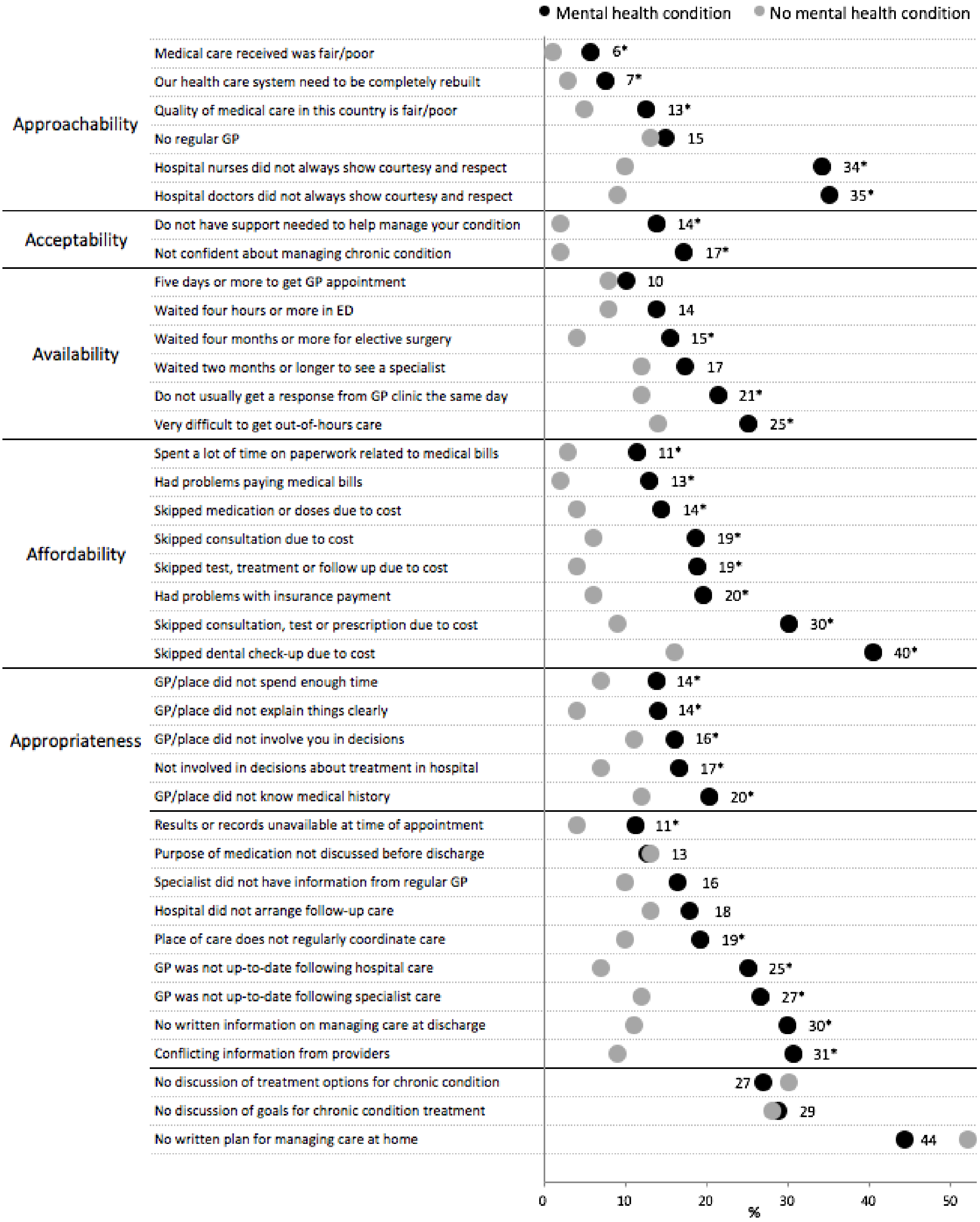
Almost one quarter of Australian adults said they had been diagnosed with a mental illness, or experienced emotional distress and felt they could not cope in the two years prior (23%, Tale 4.1). Those with a mental health condition were more likely to be female, Aboriginal or Torres Strait Islander, and have lower education and income than adults with no mental health conditions.

Compared to people with no mental health condition, adults with a mental health condition were more likely to experience barriers to access to care on 29 of 39 access-related measures grouped into five dimensions of access (Figure 4.1).

The size of disparities is described as unadjusted and adjusted odds ratios for each of the 39 access-related barriers in (Table 4.2). In four measures, differences were no longer significant after adjusting for these factors including: approachability measures related to trust, availability measures, and appropriateness measures related to engagement. For the remaining 25 measures, disparities experienced by people with mental health conditions remained statistically significant after adjusting for age, sex, education, income, rurality and immigrant status.

The largest disparities, measured as differences and ratios are shown in (Table 4.3). People with a mental health condition were more likely than those with other chronic conditions to report that they were not confident about managing their condition (OR=9.2 (C.I.=4.0-21.0)) and that they did not have the professional support needed to manage their condition (OR=7.5 (CI=2.7-21.1)). Adults with a mental health condition were over 20 percentage points more likely to experience a lack of courtesy and respect in hospital, to forego dental or other care due to cost, and to receive conflicting information from care providers – the largest absolute differences.

Figure 4.1 Percentage of adults reporting access barriers by presence of mental health condition



Notes: Descriptive results based on unadjusted percentage within countries by population group. Results sorted within access dimension grouping or sub grouping in ascending order by the size of the barrier for the mental health condition group. *Unadjusted odds ratios >1, p<0.05.

Table 4.2 Disparities in access to care for people with mental health conditions, as differencs, odds ratios and adjusted odds ratios versus those with no mental health conditions in Australia

	Mental health group (%)	Percentage point difference (%)	OR	CI	p-value (OR)	AOR	CI	p-value (AOR)
1- Approachability								
No regular GP	**15**	**2**	1.18	(0.68,2.07)	0.552	1.21	(0.67,2.20)	0.5268
Medical care received was fair/poor	**6**	**5**	5.02	(2.09,12.07)	<0.001	3.79	(1.75,8.21)	0.0007
Health care system needs to be completely rebuilt	**7**	**4**	2.41	(1.17,4.93)	0.017	1.60	(0.83,3.11)	0.1617
Quality of medical care in this country is fair/poor	**13**	**8**	2.70	(1.59,4.58)	<0.001	1.79	(1.05,3.06)	0.0339
Doctors did not always show courtesy and respect^	**35**	**26**	5.11	(2.47,10.55)	<0.001	4.82	(2.20,10.59)	<0.001
Nurses did not always show courtesy and respect^	**34**	**24**	4.60	(2.13,9.95)	<0.001	4.64	(2.11,10.21)	0.0001
2-Acceptability								
No professional support to manage condition^	**14**	**12**	7.54	(2.69,21.1)	<0.001	5.70	(2.27,14.31)	0.0002
Not confident about managing health problem^	**17**	**15**	9.17	(4.0,21.03)	<0.001	7.94	(3.3,19.09)	<0.001
3-Availability								
Five days or more to get GP appointment	**10**	**2**	1.34	(0.81,2.22)	0.259	1.17	(0.69,1.99)	0.5539
GP clinic does not regulalrly respond the same day	**21**	**9**	2.01	(1.29,3.12)	0.002	2.12	(1.32,3.39)	0.0018
Very difficult to get out-of-hours care	**25**	**11**	2.12	(1.38,3.26)	0.001	1.63	(1.02,2.61)	0.0426
Waited 4 months or more for elective surgery^	**15**	**11**	4.41	(1.37,14.16)	0.013	2.22	(0.77,6.44)	0.1403
Waited four hours or more in ED^	**14**	**6**	1.98	(0.69,5.70)	0.207	1.81	(0.72,4.56)	0.2067
Waited two months or longer to see a specialist^	**17**	**5**	1.53	(0.85,2.76)	0.160	1.21	(0.71,2.06)	0.4808
4-Affordability								
Had problems paying medical bills	**13**	**11**	6.37	(3.85,10.54)	<0.001	4.57	(2.58,8.09)	<0.001
Had problems with insurance payment	**20**	**14**	3.60	(2.26,5.75)	<0.001	3.36	(2.08,5.44)	<0.001
Spent a lot of time on paperwork for medical bills	**11**	**8**	4.41	(2.61,7.44)	<0.001	3.23	(1.91,5.44)	<0.001
Skipped consultation due to cost	**19**	**13**	3.66	(2.14,6.28)	<0.001	2.90	(1.72,4.89)	<0.001
Skipped consultation, test or prescription	**30**	**21**	4.39	(2.88,6.69)	<0.001	3.52	(2.31,5.38)	<0.001
Skipped dental check-up due to cost	**40**	**24**	3.59	(2.52,5.12)	<0.001	3.24	(2.22,4.73)	<0.001
Skipped medication or doses due to cost	**14**	**10**	3.95	(2.11,7.43)	<0.001	2.99	(1.60,5.58)	0.0006
Skipped test, treatment or follow up due to cost	**19**	**15**	5.19	(3.21,8.38)	<0.001	3.86	(2.32,6.43)	<0.001
5-Appropriateness (coordination, engagement)								
Place of care does not regularly coordinate care^	**19**	**9**	2.06	(1.25,3.4)	0.005	1.83	(1.13,2.97)	0.0146
Receied conflicting information	**31**	**22**	4.40	(2.80,6.90)	<0.001	3.56	(2.27,5.56)	<0.001
GP was not up-to-date following hospital care^	**25**	**18**	7.37	(3.35,16.21)	<0.001	7.54	(2.65,21.42)	0.0002
Specialist did not have info. from regular GP^	**16**	**6**	1.80	(0.89,3.65)	0.102	1.62	(0.85,3.06)	0.1414
GP was not up-to-date following specialist care^	**27**	**15**	2.76	(1.49,5.12)	0.001	2.24	(1.25,4.00)	0.0067
Hospital did not arrange follow-up care^	**18**	**5**	1.44	(0.43,4.78)	0.554	1.42	(0.51,4.01)	0.505
Results unavailable at time of appointment	**11**	**7**	3.46	(1.87,6.41)	<0.001	2.86	(1.61,5.1)	0.0004
No written info. on managing care at discharge^	**30**	**19**	3.64	(1.64,8.08)	0.001	3.34	(1.51,7.4)	0.003
Not involved in decisions about hospital treatment^	**17**	**10**	2.79	(1.10,7.08)	0.031	2.55	(0.99,6.56)	0.0528
Purpose of medication not discussed at discharge^	**13**	**0**	1.00	(0.25,4.04)	0.995	0.94	(0.33,2.70)	0.9101
GP/place does not explain things clearly	**14**	**10**	3.61	(2.04,6.40)	<0.001	3.20	(1.79,5.72)	<0.001
GP/place does not involve you in decisions	**16**	**5**	1.55	(1.01,2.39)	0.047	1.60	(1.0,2.55)	0.0514
GP/place does not know medical history	**20**	**8**	1.83	(1.19,2.82)	0.006	1.94	(1.28,2.94)	0.0017
GP/place does not spend enough time	**14**	**7**	2.19	(1.37,3.49)	0.001	2.33	(1.42,3.82)	0.0008
No goal discussion for chronic condition treatment^	**29**	**1**	1.03	(0.67,1.57)	0.911	1.14	(0.76,1.72)	0.53
No discussion of treatment options for condition^	**27**	**-3**	0.85	(0.55,1.30)	0.446	0.93	(0.62,1.40)	0.7223
No written plan for managing care at home^	**44**	**-8**	0.74	(0.49,1.11)	0.146	0.82	(0.55,1.24)	0.3514
Average	**20**	**9.92**						

Notes: Shading indicates where odds or adjusted odds are significant at $p<0.05$. Adjusted model includes: age, sex, immigrant status, income, education, self-rated health and rurality.

^denotes question asked of a subgroup population who used the indicated service (e.g hospital care) or had a chronic condition. See technical appendix for number of respondents for each access barrier, all results based on N>30.

Table 4.3 Questions reflecting the largest disparities as adjusted odds ratios or percentage-point differences

	Mental health condtion (%)	Difference vs no condition (%)	AOR	CI	p-value (AOR)	*Largest five AOR*	*Largest five differences*
Not confident about managing health problem^	17	15	7.94	(3.3,19.09)	<0.001	1	
GP was not up-to-date following hospital care^	25	18	7.54	(2.65,21.42)	0.0002	1	
Do not have professional support to manage condition^	14	12	5.70	(2.27,14.31)	0.0002	1	
Doctors did not always show courtesy and respect^	35	26	4.82	(2.2,10.59)	<0.001	1	1
Nurses did not always show courtesy and respect^	34	24	4.64	(2.11,10.21)	0.0001	1	1
Skipped dental check-up due to cost	40	24	3.24	(2.22,4.73)	<0.001		1
Conflicting information from health professionals	31	22	3.56	(2.27,5.56)	<0.001		1
Skipped consultation, test or prescription due to cost	30	21	3.52	(2.31,5.38)	<0.001		1

^denotes question asked of a subgroup population who used hospital care or had a chronic condition.

Discussion

This paper presents an initial analysis of the disparities in access to overall care for Australians with and without mental health conditions. This is the first analysis we are aware of to demonstrate that Australians with mental health conditions are significantly more likely to experience barriers in access to care compared to people with no reported mental health condition. These disparities were large, with the mental health condition group 10 percentage points more likely to report barriers on average, and varied, with disparities spanning affordability, integration and coordination of care measures. Moreover, the disparities persisted after adjusting for social and demographic characteristics, including rurality and income.

In Australia as well as internationally there are evidence based interventions seeking to improve the physical health of people with mental health conditions. Internationally, a Multilevel Intervention Framework To Reduce Excess Mortality outlines interventions for people with mental illness across individual, health system and community levels, to improve engagement around lifestyle factors, early detection of physical health conditions, address stigma and social support (Liu et al., 2017). Domestically, the Mental Health Commission of New South Wales has published the Physical health and mental wellbeing: Evidence Guide. The guide outlines a comprehensive approach across multiple leves as well, including awareness of physical health effects of medications (e.g antipsychotics and obesity), training for staff, and population approaches to reducing stigma (Mental Health Commission of NSW, 2016). For clinicians, Australian research has suggested an assessment and monitoring package to the physical care of people with mental health conditions (Stanley and Laugharne, 2011). While there is growing attention on integrating services to improve access and addressing physical health conditions of people with mental illness, there is little evidence of monitoring the progress achieved by these efforts.

The analysis presented here provides a baseline measure of disparities in access to overall care, and demonstrates substantial disparities in access between those with and without a mental health condition, which can be used by health services with the aim of service improvement. Similar studies have shown people with multiple chronic conditions were more likely to forego care due to cost, have long waits to see the GP or specialist, and have problems with medical bills compared to people with no conditions in Australia, based on findings from the 2010 Commonwealth fund International Health Policy Survey (Schoen et al., 2010). This current study builds on findings demonstrating that people with mental health conditions faced multiple barriers in access to primary care across several countries (Corscadden et al., 2018). We look more broadly at measures of access to care and expanded the definition of mental health conditions to include those experiencing emotional distress but who do not have a diagnosed condition.

Survey data reviewed for this study demonstrates that in 2016, more than one in five Australian adults (23%) had been previously diagnosed with a mental illness, or that they experienced distress and had difficulties coping in the previous two years. Improved evidence and monitoring of the access to and quality of care for people with mental health conditionns is a policy and research priority (Hibbert et al., 2013, Department of Health, 2016). In 2016, the National Mental Health Commission released a concensus statement with a vision to improve the lives of people living with mental illnesses, by improving equity in access to quality health care (National Mental Health Commission, 2016). As noted previously, The Equally Well concensus Statement: Improving the physical health and wellbeing of people living with mental illness in Australia, highlights a goal of monitoring progress through performance indicators that focus on people’s experiences of physical health care services among other measures (National Mental Health Commission, 2016). Disparities in access to care for Australians with mental health conditions identified here may reflect barriers to either physical or mental health related services or both. However, using population surveys to reflect on access contributes evidence toward the goal of monitoring by highlighting particular vulnerabilities of people with mental health conditions in accessing and navigating the health system.

There are limitations to this study that should be acknowledged. The survey does not capture institutionalised populations and therefore likely underrepresents those with severe mental illness. Barriers regarding access to care may reflect either physical or mental health services or both and cannot be attributed to a specific healthcare sector. The conceptual framework of access was used as a guide and is not covered comprehensively by the survey questions, measures of peoples ability to perceive needs and seek care are not considered for example. Further analysis is limited as there are several survey questions are asked only of people who had elective surgery, used specialist or hospital services, or needed after-hours care, or had care for a chronic condition. For these measures based on smaller numbers of respondents, the sizes of disparities were large which highlights possible methodological challenges to be overcome. Measurement of disparities through ratios and percentage point differences does not reflect the population impact of the disparity. The survey questions were dichotomised to focus on barriers in survey questions. There is room for future work to validate disparity measures to ensure they meet rigorous indicator criteria be useful in health system performance reporting.

Conclusions

The findings presented here highlight the vulnerabilities of people with mental health conditions in navigating the health system and throws up a red flag in relation to a key dimension of the Australian National Health Performance Framework – equity and access to care. Results of this analysis speak to disjointed care processes along the continuum of primary through to hospital care which disproportionately affect access to overall care for people with mental health conditions. These findings can be used to inform service delivery improvement, by highlighting areas where health care services are currently performing poorly for people with mental health conditions.

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Appendix Chapter 4 survey question wording

Mental health related questions
Have you ever been told by a doctor you have depression, anxiety or other mental health problems? (Yes, no)
In the past two years, have you experienced emotional distress such as anxiety or great sadness which you found difficult to cope? (Yes, no)

1- Approachability
How would you rate the overall quality of medical care in your country? (Fair or poor)
Is there one doctor you usually go to for your medical care? (No)
Overall, how do you rate the medical care that you have received in the past 12 months from your regular GP's practice? (Fair or poor)
Which of the following statements comes closest to expressing your overall view of the healthcare system in your country? (Our health care system has so much wrong it needs to be completely rebuilt)
During this hospital stay, how often did doctors treat you with courtesy and respect? (Sometimes, rarely or never)
During this hospital stay, how often did nurses treat you with courtesy and respect? (Not always)

2-Acceptability
How confident are you that you can control and manage your health problems? (Not very or not at all confident)
In general, do you feel that you have had as much support from health professionals as you need to help you manage your health problems? (No)

3-Availability
After you were advised to see or decided to see a specialist, how long did you have to wait for an appointment? (2 months or longer)
After you were advised you needed surgery, how many days, weeks or months did you have to wait for the non-emergency or elective surgery? (4 months or more)
How easy or difficult is it to get medical care in the evenings, on weekends, or holidays without going to the hospital emergency department Is it ?(Very difficult)
Last time you were sick or needed medical attention, how quickly could you get an appointment to see a doctor or a nurse? (Over five days)
The last time you went to the hospital emergency department, how long did you wait before being treated? (4 or more hours)
When you contact your regular doctor's office with a medical question during regular practice hours, how often do you get an answer that same day? (Sometimes, rarely or never))

4-Affordability
During the past 12 months, was there a time when you did not fill a prescription for medicine, or you skipped doses of your medicine because of the cost? (Yes)
During the past 12 months, was there a time when you had a medical problem but did not visit a doctor because of the cost? (Yes)
During the past 12 months, was there a time when you skipped a medical test, treatment, or follow-up that was recommended by a doctor because of the cost? (Yes)
During the past 12 months, was there a time when you skipped dental care or dental check-ups because of the cost? (Yes)
During the past 12 months, was there a time when you skipped: a consultation, a test or follow up, or medication or doses, due to cost? (Yes)
In the past 12 months, were there times when you had serious problems paying or were unable to pay your medical bills? (Yes)

In the past 12 months, were there times when you spent a lot of time on paperwork or disputes related to medical bills? (Yes)
In the past 12 months, were there times when your insurance denied payment for your medical care or did not pay as much as you expected? (Yes)

5-Appropriateness
During the past year, when you received care, has any healthcare professional you see for your condition discussed with you your main goals or priorities in caring for this condition? (No)
During the past year, when you received care, has any healthcare professional you see for your condition, discussed with you your treatment options, including possible side effects? (No)
During the past year, when you received care, has any healthcare professional you see for your condition, given you a written plan to help you manage your own care? (No)
After you left the hospital, did the doctors or staff at the place where you usually get medical care seem informed and up-to-date about the care you received in the hospital? (No)
How often does your regular doctor or someone in your doctor's practice/GP's practice help coordinate or arrange the care you receive from other doctors and places? (Sometimes, rarely or never)
In the past two years, have you experienced the following: after you saw the specialist, your regular GP did not seem informed and up-to-date about the care you got? (Yes)
In the past two years, have you experienced the following: the specialist did not have basic medical information or test results from your regular doctor about the reason for your visit? (Yes)
Thinking about the past 2 years, when receiving care for a medical problem, was there ever a time when test results or medical records were not available at the time of your scheduled medical care appointment? (Yes)
Thinking about the past 2 years, when receiving care for a medical problem, was there ever a time when you received conflicting information from different doctors or healthcare professionals? (Yes)
When you left the hospital, did the hospital make arrangements or make sure you had follow-up care with a doctor or other healthcare professional? (No)
Thinking about the last time you were in the hospital, were you involved as much as you wanted in decisions about your care and treatment? (No)
When you left the hospital, did someone discuss with you the purpose of taking each of your medications? (No)
When you left the hospital, did you receive written information on what to do when you returned home and what symptoms to watch for? (No)
When you need care or treatment, how often does your regular GP or medical staff you see involve you as much as you want to be in decisions about your care and treatment? (Rarely or never)
When you need care or treatment, how often does your regular doctor or medical/your GP or medical/the doctor or medical staff you see explain things in a way that is easy to understand Sometimes, rarely or never)
When you need care or treatment, how often does your regular GP or medical staff you see know important information about your medical history? (Sometimes, rarely or never)
When you need care or treatment, how often does your regular GP or medical staff you see spend enough time with you? (Sometimes, rarely or never)

Chapter 5: International comparisons of disparities in access

This chapter consists of the following published article:

Corscadden L, Callander EJ, Topp SM. International comparisons of disparities in access to care for people with mental health conditions. The International journal of health planning and management. 2018 Oct;33(4):967-95.

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RESEARCH ARTICLE

International comparisons of disparities in access to care for people with mental health conditions

Lisa Corscadden, Emily J. Callander, Stephanie M. Topp

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Introduction

The international aspiration to ensure universal health coverage (which is understood to encompass access, equity and quality components) comes with a commitment that “no one will be left behind”. In order to monitor this aim, however it is necessary to disaggregate measures of access by population groups (World Health Organization, 2016, Chapman, 2016). Population characteristics commonly used as disaggregation groups for measures of health system performance include: income, educational level, sex, age, rurality, ethnicity, migrant status, and disability status (World Health Organization, 2016, Agency for Healthcare Research and Quality, 2017). However, a noted gap in relation to disaggregation groups is the population with mental health conditions (Hibbert et al., 2013, Pincus et al., 2016, Matthew L. Goldman et al.).

People with a serious mental illness are known to have much shorter life expectancy than the general population (Chang et al., 2011, OECD, 2017, Gatov et al., 2017, The Royal Australian and New Zealand College of Psychiatrists, 2016), with physical health reasons as the main reason for early mortality (Lawrence et al., 2013). Yet, as is recognized in equity-oriented access to care goals including the SDGs, improved access to overall care for people with mental illness is also likely to help reduce the gap in life expectancy (The Royal Australian and New Zealand College of Psychiatrists, 2016, Thornicroft, 2011). Building evidence through international comparisons to better identify the domains of service access in which different countries are better serving people with mental health conditions can contribute to this evidence base moving all countries towards equal access for people with a mental health condition.

Equity and access to care have been key aspects of international health system performance monitoring for some time, with growing interest recently in incorporating indicators that enable the evaluation of the cross-cutting theme of mental health (Hewlett and Moran, 2014, Braithwaite et al., 2017, Lauriks et al., 2012). Health system performance reporting in many countries utilizes frameworks that monitor access to, and equity in health service delivery (OECD, 2015, Agency for Healthcare Research and Quality, 2017, Steering Committee for the Review of Government Service Provision, 2017, OECD., 2017, World Health Organization, 2016, Canadian Institute for Health Information, 2016, Canadian Institute for Health Information, 2015). Internationally too, the United Nations Sustainable Development Goals have brought a renewed focus on equity and access to care, including the importance of mental health. The SDGs include, for example, the high-level goal "to promote physical and mental health and well-being, and to extend life expectancy for all" (United Nations, 2015, Votruba et al., 2016) and list universal health coverage as one of the key targets for ensuring this goal is achieved.

There is evidence indicating people with mental health conditions have challenges with accessing care compared to those without conditions. A literature review assessing quality of care for people with and without mental illness and found evidence that there were disparities disadvantaging those who have a mental illness (Mitchell et al., 2009). People with mental health conditions were less likely to receive medically necessary procedures for circulatory disease in Canada (Kisely et al., 2007, Dorning et al., 2015). In Australia, people with mental health conditions have higher out-of-pocket healthcare costs and to be more likely to forego care due to cost than people with no chronic conditions (Callander et al., 2016). Adults with mental health conditions were more likely to experience multiple barriers to accessing primary care than those without a condition – a finding observed for Australia, Canada, New Zealand, Switzerland, Sweden and the United States (Corscadden et al., 2018). Evidence based on hospital and emergency patient experiences in the United Kingdom and Australia have shown patients with mental health conditions have poorer experiences of care (Bureau of Health Information, 2016, Care Quality Commission, 2017). However, this literature is fragmented and does not address access to care more broadly. In particular, there are no contemporary studies comparing results across countries, to determine in which health systems people with mental health conditions are more or less likely to experience barriers and disparities in access to overall care. Combining the aims of improved access, equity and improved health outcomes for people with mental health conditions – suggests a need for empirical evidence that directly compares access to healthcare for people with, and without mental health conditions across countries.

Methods for assessing equity and access to care in healthcare performance reporting provide a foundation for comparing access to overall care for people with mental health conditions. Regular reporting on healthcare performance comparing countries on a wide range of measures such access to care, also commonly include an ‘equity’ dimension with results disaggregated by income or ethnicity characteristics (OECD, 2015, Agency for Healthcare Research and Quality, 2017, Steering Committee for the Review of Government Service Provision, 2017, OECD., 2017). For instance, *Mirror, Mirror 2017: International Comparison Reflects Flaws and Opportunities for Better U.S. Health Care* ranked access and equity of care across 11 countries (Schneider, 2017). Countries such as Germany and Australia ranked in the top half of countries in access, but they were among the bottom half in terms of equity as they had among the largest differences in access to care between below-, and above-average income groups. In regular reporting of disparities in the United States, there are examples of states who perform well in overall access to care but have substantial race-based disparities (Agency for Healthcare Research and Quality, 2017). Literature comparing equity in access to care across countries for people with low-income groups make two sets of comparisons; within countries comparing low and high income groups, and between countries, comparing the results for the low-income group (Schoen et al., 2000, Schoen et al., 2002, Davis and Ballreich, 2014). These existing methods and studies show that comparing disparities in access to care by income include both understanding the prevalence of the barriers for the low-income group across countries, as well as the gap or disparity between people of low and high incomes within the country.

In this analysis, we compare barriers in access to healthcare for people with mental health conditions, and examine the patterns of disparities between people with and without mental health conditions across 11 countries.

We leverage the Commonwealth Fund International Health Policy Survey and build on methods that look at income-related disparities to address the following questions:

- Are people with mental health conditions more likely to experience access barriers in some countries?

- Which countries have the most prominent patterns of disparities in access to care for people with mental conditions compared to those with no mental health conditions within the country?
- Are countries with the most pronounced barriers for people with mental health conditions the same countries with the greatest disparities?

Methods

The 2016 Commonwealth Fund International Health Policy Survey of adults aged 18 years and over was conducted in Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom and the United States. Response rates varied from 11% in Norway to 47% in Switzerland (Osborn et al., 2016). Analysis of this survey was calculated using sample weights provided so that the estimates are representative of the age, sex, regional and education profiles of each country.

The Commonwealth Fund International Health Policy survey included more than 60 health and health care related questions. Questions that were considered a measure of access, or a reasonable proxy, were retained and mapped to one of the five dimensions of access based on the conceptual model proposed by Levesque et al. (Levesque et al., 2013). The five dimensions include: approachability (awareness of the existence of services, how to reach them and the impact they have on one's health), acceptability (social or cultural factors that affect the use of services), availability (ability to reach the service both physically and in a timely manner), affordability (ability to pay for services) and appropriateness (the ability to engage in care that is of a reasonable quality) (Penchansky and Thomas, 1981, Levesque et al., 2013, Franks and Fiscella, 2008). For questions with more than two response options, responses of were dichotomized to focus on barriers in access to care.

For the purpose of this analysis, people with mental health conditions were identified as respondents who said 'yes' when asked if they had ever been diagnosed with a mental illness, or answered 'yes' when asked if in the past two years they experienced anxiety or great sadness which they found difficult to cope with themselves. Participants who did not respond to both questions were excluded from the analysis (approximately 1% of records). While the resulting percentage of adults with a mental health-related condition (MHC) is not based on a validated instrument the average percentage of 24% (Table 5.1) and range is in line with international studies of 12-month and lifetime prevalence. A pooled study of found 18% of respondents met the criteria for a mental health disorder in year prior, and 29% in their lifetime (Steel et al., 2014). Comparable results were also noted from a World Mental

Health Survey using a common measurement instrument (Composite International Diagnostic Interview tool) (Kessler et al., 2009).

Descriptive analysis was conducted to estimate the prevalence of each access barrier for people with and without a mental health condition. The percentage of people with a MHC reporting each barrier was calculated as well as the percentage point difference between experiences of people with and without MHCs. Normalized scores were calculated for both 1) levels of barriers for people with MHCs in the country versus the country average 2) the size of the 'gaps' (i.e. differences in access barriers between people with and without MHCs). This method is based on comparisons of health system performance across countries and income groups (Schneider EC, 2017). The scores were averaged across all 33 measures for each country.

To test for significant associations between self-reported mental health conditions and access barriers, logistic regression models were run within each country using SAS/STAT Version 9.4, Proc Surveylogistic (Copyright © SAS Institute Inc.). Model results were adjusted for age, sex, income, and immigrant status. These characteristics were found to be significantly associated with measures related to access to care in analysis of other years of the survey (Hargreaves et al., 2015, Schoen et al., 2010, Davis et al., 2014, Schoen et al., 2013).

Results

We present findings of analysis of 33 measures for 11 countries. First, comparing the prevalence of experiences of access barriers for people a mental health condition across countries. Then comparing experiences between people with and without MHCs within countries.

The prevalence of barriers experienced by people with mental health conditions varied by type of barrier and by country (Table 5.1) Of overall health services where most adults aged 18 and over responded, the most prevalent barriers on average included: issues with after-hours care (29%), skipping care due to cost (26%) and receiving conflicting information from providers (26%). For questions regarding acute hospital and chronic disease care, over a quarter of people with a MHC who used hospital services said they did not have follow-up care arranged (26%) and over one third said doctors or nurses did not always treat them with respect (33%, 38% respectively). Regarding chronic disease care (that could be for a mental health or other condition), an average of 37% of people with a MHC said they had not discussed goals for caring for their chronic condition(s) and 38% said they had no discussion of treatment options, and 61% who said they had no written plan for managing care at home.

Across countries, people with MHCs in Canada, France, Norway, Sweden and the United States had a higher prevalence of barriers than the average. These five countries ranked 7 to 11 respectively, based on average normalized scores across 33 measures (Table 5.2) In contrast, the Netherlands, New Zealand and the United Kingdom ranked 1 to 3, where people with MHCs reported consistently lower than average prevalence of barriers for most measures.

We examined the differences in access barriers between people with and without MHCs in each country as reported in Table 5.3. The difference in the prevalence of barriers between people with and without MHCs is referred to as the 'gap' in barriers to accessing care. Across all measures combined, people with mental health conditions had higher prevalence of barriers, with a gap of seven percentage points between people with and without MHCs. Among the largest gaps, were those regarding foregone tests or treatments due to cost, and conflicting advice – barriers were an average of 15 percentage points higher for people with mental health conditions. People with a MHC were less likely to experience barriers than people without a condition for three measures: not having a regular GP, not discussing goals or treatment for chronic conditions. The large majority of gaps in barriers to access for each country and question combination were greater than zero (305 of 363) – in other words, people with MHCs were consistently more likely to experience barriers.

Table 5.1 Percentage of adults reporting mental health-related condition and population characteristics by presence of a mental health condition, by country

						Characteristics of mental health condition(MHC) and no MHC groups									
	Mental Health Diagnosis (A)	Emotional Distress(B)	Mental health condition (A or B)	Total respondents (n)		18 to 34	35 to 49	50 to 64	65 +	Female	Immigrant	Above-average income	Average income	Below-average income	missing income
Australia	14	20	23	545	MHC	24	27	32	17	65	18	19	22	51	8
				4585	No MHC	36	26	20	17	48	22	26	28	32	14
Canada	20	27	33	821	MHC	30	29	29	12	67	10	21	21	54	4
				3713	No MHC	24	27	28	21	48	20	37	23	32	7
France	4	12	14	40	MHC	11	24	26	38	61	18	36	17	44	2
				1050	No MHC	26	25	25	24	52	21	15	29	40	17
Germany	9	7	12	85	MHC	10	21	40	28	58	8	16	27	50	7
				912	No MHC	26	25	25	24	51	17	17	41	34	9
Netherlands	8	19	22	94	MHC	20	17	37	26	62	5	34	19	42	5
				1129	No MHC	27	26	25	22	50	7	44	24	20	12
New Zealand	13	21	25	119	MHC	28	17	33	22	66	12	28	20	49	3
				874	No MHC	29	29	24	18	52	20	32	34	27	7
Norway	16	20	26	155	MHC	41	23	18	18	58	10	32	9	55	4
				930	No MHC	27	27	25	21	48	7	43	17	37	4
Sweden	20	24	30	1066	MHC	34	30	22	14	63	14	31	14	49	7
				6023	No MHC	26	23	23	28	48	14	43	18	32	7
Switzerland	13	21	26	194	MHC	19	32	30	19	66	29	16	21	57	6
				1294	No MHC	25	26	25	23	49	30	28	19	44	10
United Kingdom	11	17	21	110	MHC	25	26	30	19	61	4	29	22	33	16
				877	No MHC	30	26	22	22	50	11	28	29	22	21
United States	23	26	34	456	MHC	31	21	34	14	61	9	28	15	52	5
				1532	No MHC	30	26	23	21	49	17	40	21	34	6

Table 5.2 Barriers: percentage of adults with a mental health condition experiencing barriers to access across access measures, summary of normalized scores and rankings by country

	AUS	CAN	FRA	GER	NED	NZ	NOR	SWE	SWI	UK	US	Average
Approachability												
1. No regular GP	15	13	1	0	1	9	5	53	7	21	21	13
2. Medical care received was fair/poor	6	9	20	5	7	3	11	16	5	5	10	9
3. Health care system needs complete rebuild	7	10	11	3	14	9	8	12	4	9	28	10
4. Fair/poor quality of medical care in country	13	18	23	4	18	13	17	22	6	9	29	16
5. Hospital doctors did not show courtesy/respect	35	38	26	61	36	15	33	29	37	24	28	33
6. Hospital nurses did not show courtesy/respect	34	45	56	53	30	36	37	26	42	21	36	38
Acceptability												
7. Lack of professional support to manage condition	14	23	14	0	5	8	29	22	8	19	23	15
8. Not confident about managing health problem	17	16	47	29	22	3	17	25	13	12	14	20
Availability												
9. Five days or more to get GP appointment	10	32	19	14	6	6	29	34	9	21	25	19
10. Did not get response from clinic the same day	21	36	6	14	17	23	29	28	17	34	34	24
11. Very difficult to get out-of-hours care	25	39	21	43	9	20	21	45	28	29	37	29
12. Waited two months or longer to see a specialist	17	34	7	3	9	30	31	23	10	24	9	18
Affordability												
13. Had problems paying medical bills	13	12	53	19	14	13	21	13	20	4	32	20
14. Had problems with insurance payment	20	21	53	23	14	3	3	4	21	2	36	18
15. Time on paperwork related to medical bills	11	9	56	18	12	7	8	5	17	1	22	15
16. Skipped consult, test or medication due to cost	30	28	31	15	13	36	23	16	34	9	47	26
17. Skipped medication or doses due to cost	14	19	10	5	8	15	7	11	12	4	29	12
Appropriateness												
18. No discussion of goals for condition treatment	29	43	27	26	31	36	46	56	34	40	35	37
19. No discussion of treatment options for condition	27	39	26	35	34	31	62	48	34	42	40	38
20. No written plan for managing care at home	44	68	41	55	63	44	84	77	74	63	54	61
21. Conflicting information	31	27	29	17	14	24	29	34	32	18	27	26
22. Place of care does not coordinate care	19	14	19	38	11	13	13	19	10	11	16	16
23. GP was not up-to-date following specialist care	27	28	36	21	25	13	45	39	18	16	32	27
24. Specialist not up-to date from regular GP	16	16	35	21	19	9	26	25	26	17	24	21
25. Results unavailable at time of appointment	11	13	34	15	9	14	13	16	15	10	16	15
26. Hospital did not arrange follow-up care	18	30	33	18	27	21	39	31	20	32	18	26
27. No written information on hospital discharge	30	26	25	21	29	19	47	51	36	26	8	29
28. Not involved in decisions about hospital care	17	25	20	6	14	15	14	20	9	15	22	16
29. Medication not discussed at discharge	13	23	34	10	29	21	31	14	15	17	12	20
30. GP/place does not explain things clearly	14	15	39	29	4	18	22	23	9	14	13	18
31. GP/place does not involve you in decisions	16	20	63	21	8	17	28	25	18	16	17	23
32. GP/place does not know medical history	20	21	39	12	5	18	28	38	17	16	21	21
33. GP/place does not spend enough time	14	29	17	18	9	17	31	36	16	20	22	21
Average prevalence of barriers across 33 measures	20	25	29	20	17	18	27	28	20	19	25	22
Average normalized score	0.3	-0.3	-0.7	0.3	0.6	0.5	-0.4	-0.6	0.3	0.4	-0.3	
Ranking of score	5	7	11	4	1	2	9	10	6	3	8	

SOURCE Author's analysis of Commonwealth Fund International Health Policy Survey 2016. NOTES Shading indicates country result is higher than country average. Normalized score is the country difference from the average divided by the standard deviation as an average across all 33 measures. Rankings are based on unrounded results to avoid ties. Full data available in the Technical Appendices A2 and A3.

Table 5.3 Percentage-point difference in barriers for people with and without a mental health condition, summary of normalised scores and rankings by country

Approachability	AUS	CAN	FRA	GER	NED	NZ	NOR	SWE	SWI	UK	US	Averag
1. No regular GP	2	-4	0	-2	0	-3	0	-6	-11	3	-3	-2
2. Medical care received was fair/poor	5	4	13	2	2	1	5	6	1	1	6	4
3. Health care system needs complete rebuild	4	2	8	0	7	5	4	5	1	3	7	4
4. Fair/poor quality of medical care in country	8	3	15	0	7	5	6	7	3	2	8	6
5. Hospital doctors did not show courtesy/respect	26	24	-6	14	23	-7	12	9	14	1	4	10
6. Hospital nurses did not show courtesy/respect	24	20	10	8	17	17	19	10	16	3	13	14
Acceptability												
7. Lack of professional support to manage condition	12	16	2	0	-1	4	21	13	2	12	15	9
8. Not confident about managing health problem	15	8	26	15	15	0	13	14	8	8	11	12
Availability												
9. Five days or more to get GP appointment	2	2	1	-15	0	3	2	10	-1	4	5	2
10. Did not get response from GP clinic the same day	9	5	-9	1	5	9	9	6	6	16	10	7
11. Very difficult to get out-of-hours care	11	2	4	9	4	8	5	5	9	5	14	7
12. Waited two months or longer to see a specialist	5	5	4	0	3	14	1	5	1	4	4	4
Affordability												
13. Had problems paying medical bills	11	8	35	17	9	11	18	10	12	3	19	13
14. Had problems with insurance payment	14	9	33	17	8	1	1	1	11	1	12	10
15. Time on paperwork related to bills	8	5	32	15	5	6	4	2	7	1	9	9
16. Skipped consult, test or medication due to cost	21	17	16	9	6	24	18	10	11	3	21	15
17. Skipped medication or doses due to cost	10	13	7	2	4	12	5	7	1	2	17	7
Appropriateness												
18. No discussion of goals for condition treatment	1	1	-7	-5	-11	-6	-5	-10	0	0	0	-3
19. No discussion of treatment options for condition	-3	0	-14	-1	-9	-9	5	-13	-5	0	5	-4
20. No written plan for managing care at home	-8	-6	-7	2	3	-9	5	1	4	10	2	0
21. Conflicting information	22	14	24	10	7	12	11	18	18	7	14	15
22. Place of care does not coordinate care	9	3	1	10	2	5	3	8	-1	0	0	4
23. GP was not up-to-date following specialist care	15	9	18	7	7	-1	17	9	1	6	12	9
24. Specialist not up-to date from regular GP	6	4	15	10	3	2	16	7	10	5	10	8
25. Results unavailable at time of appointment	7	7	24	10	5	10	7	8	10	4	6	9
26. Hospital did not arrange follow-up care	5	12	-4	0	8	4	9	7	9	18	3	6
27. No written information on hospital discharge	19	4	-6	12	4	3	7	12	0	15	3	7
28. Not involved in decisions about hospital care	10	16	-7	3	10	-1	2	8	4	10	15	6
29. Purpose of medication not discussed at discharge	0	14	0	1	16	6	9	0	6	6	7	6
30. GP/place does not explain things clearly	10	6	14	15	0	10	8	9	0	6	4	7
31. GP/place does not involve you in decisions	5	7	16	9	2	7	9	7	7	6	4	8
32. GP/place does not know medical history	8	10	17	2	1	7	13	13	1	5	7	7
33. GP/place does not spend enough time	7	13	1	4	4	7	13	14	5	6	5	7
Average gap (difference MHC and no MHC group)	9.1	7.7	8.4	5.5	5	4.8	8.2	6.4	4.8	5.3	8.2	
Average normalized score across 33 measures	-0.4	-0.1	-0.4	0.3	0.3	0.2	-0.3	-0.01	0.4	0.2	-0.3	
Ranking of score	11	7	10	3	2	4	9	6	1	5	8	

SOURCE Commonwealth Fund International Health Policy Survey 2016. Notes: Shading highlights where the difference in prevalence of barriers between MHC and non-MHC groups is >0. Full data available in the Technical Appendices A2 and A3.

The average gap in barriers between people with and without MHCs across 33 barriers ranged from 4.8 percentage points in New Zealand and Switzerland to 9.1 percentage points in Australia. The countries with higher than average gaps were Sweden, Canada, US, Norway, France and Australia, ranking 6 to 11 respectively.

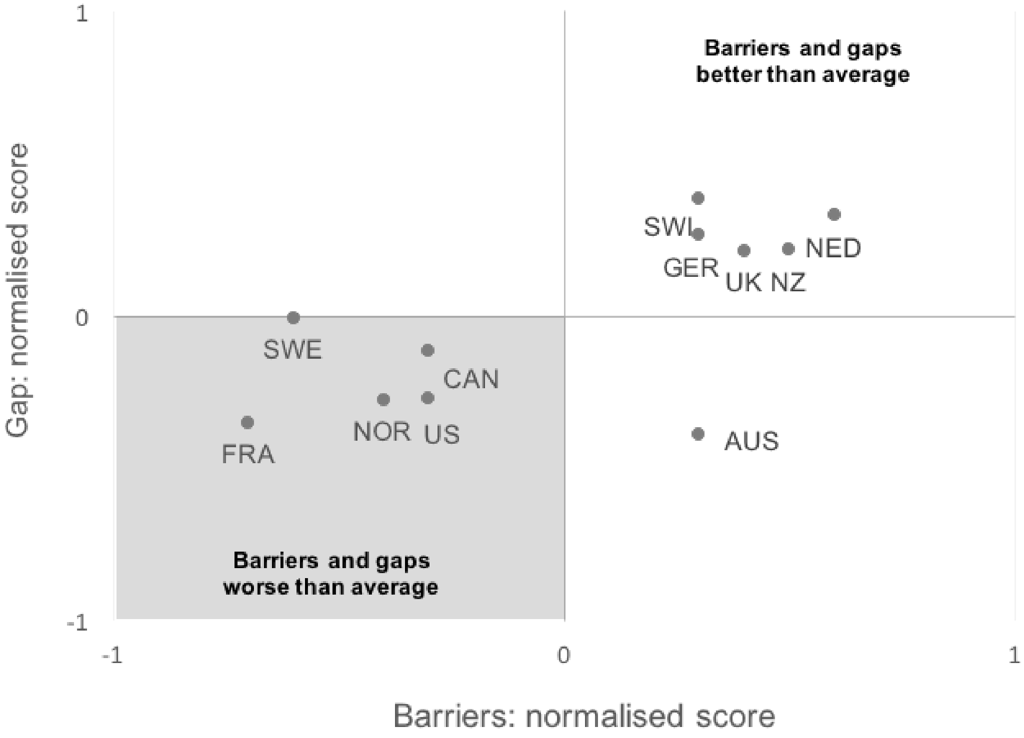
For each country, the average normalized scores across 33 questions for: the percentage of people with a MHC experiencing barriers and gaps between people with and without a MHC are summarized in Figure 5.1. Two main groups of countries emerged:

- Countries with larger barriers and gaps than the country average. Five countries (France, Sweden, Norway, United States, Canada) had both a larger percentage of people with mental health condition experiencing barriers, and larger gaps between people with and without MHCs.
- Countries with smaller barriers and gaps. Five countries (Switzerland, Germany, United Kingdom, New Zealand, Netherlands) had a smaller percentage of people with mental health condition experiencing barriers and smaller gaps between people with and without MHCs than the country average of barriers and gaps respectively.

There was one country that did not fit this pattern. The prevalence of barriers in Australia was lower than average for people with a mental health condition. Yet, the gaps between those with and without MHCs in Australia were among the largest across all countries surveyed.

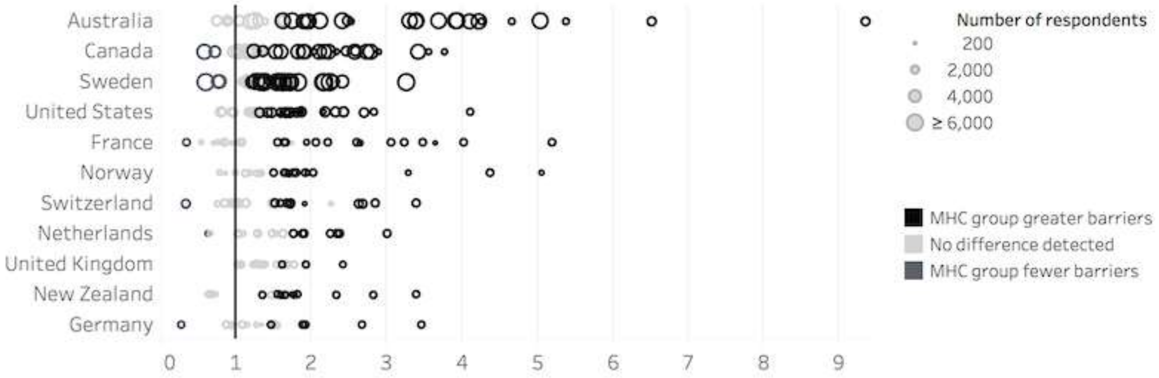
Logistic regression models were used to describe the association between MHCs and the experience of barriers within each country, both before and after adjusting for age, sex, income, and immigrant status (Table 5.5, Figure 5.2). For all countries, having a MHC was associated with higher odds of experiencing barriers of access to care, on several measures with at least one case where the adjusted odds were greater than two. However, effect sizes varied. Australia had larger adjusted odds than most countries. Australians with a MHC were more likely to experience barriers in access to care in 25 of 33 barriers compared to those with no MHC (AOR>1.5 for all 25 measures). By contrast, the United Kingdom had the fewest significant and large associations (based on adjusted and unadjusted odds ratios) between MHC and barriers in access to care.

Figure 5.1 Average normalized score for prevalence of barriers for mental health condition (MHC) group and gaps between MHC and no MHC groups by country



Source: Commonwealth Fund International Health Policy Survey 2016. Note: Score for prevalence of barriers and size of gaps are average normalized scores across 33 survey measures from Tables 2 and 3. Lower scores reflect values less favourable than average (higher prevalence of barriers and larger disparities for people with MHCs).

Figure 5.2 Adjusted odds ratios of experiencing access barriers among people with versus without MHC by country



Source: Commonwealth Fund International Health Policy Survey 2016. Note: For each country only each dot represents one of 33 access barrier measures with sufficient data (numerator > 60 for adjusted odds.

Table 5.4 Odds ratios of mental health condition group experiencing access barriers compared to no MHC group, by access barrier and country

Approachability	AUS	CAN	FRA	GER	NED	NZ	NOR	SWE	SWI	UK	US
1. No regular GP	1.2	0.7	1.5	0.2	0.9	0.7	0.9	0.8	0.3	1.2	0.9
2. Medical care received was fair/poor	5.0	1.8	3.1	1.9	1.5	1.8	2.0	1.7	1.3	1.2	2.6
3. Health care system needs complete rebuild	2.4	1.2	3.5	1.1	2.2	2.1	2.1	1.8	1.1	1.5	1.4
4. Fair/poor quality of medical care in country	2.7	1.2	3.3	0.9	1.9	1.8	1.7	1.5	1.8	1.3	1.6
5. Hospital doctors did not show courtesy/respect	5.1	3.8	0.8	1.7	3.9	0.6	1.8	1.6	1.9	1.1	1.3
6. Hospital nurses did not show courtesy/respect	4.6	2.4	1.5	1.4	2.9	2.3	2.7	1.8	2.0	1.3	1.9
Acceptability											
7. Lack of professional support to manage condition	7.5	3.8	1.2	0.0	0.8	1.9	4.9	2.9	1.3	3.2	3.3
8. Not confident about managing health problem	9.2	2.4	3.3	2.5	3.6	1.1	4.6	2.7	2.7	3.2	5.4
Availability											
9. Five days or more to get GP appointment	1.3	1.1	1.1	0.4	1.1	1.9	1.1	1.6	0.9	1.4	1.3
10. Did not get response from GP clinic the same day	2.0	1.3	0.3	1.1	1.5	1.8	1.7	1.4	1.7	2.4	1.6
11. Very difficult to get out-of-hours care	2.1	1.1	1.3	1.5	1.7	2.0	1.4	1.2	1.7	1.3	2.0
12. Waited two months or longer to see a specialist	1.5	1.3	2.1	0.9	1.4	2.2	1.0	1.4	1.1	1.3	2.1
Affordability											
13. Had problems paying medical bills	6.4	3.7	5.0	10.5	3.5	8.0	8.1	5.0	2.9	7.2	3.0
14. Had problems with insurance payment	3.6	1.9	4.6	5.0	2.5	1.6	1.6	1.3	2.5	2.2	1.8
15. A lot of time on paperwork for medical bills	4.4	2.6	4.1	6.2	1.8	5.5	2.0	2.0	1.9	3.9	1.9
16. Skipped consult, test or medication due to cost	4.4	3.2	2.5	2.9	2.0	4.0	5.9	3.2	1.7	1.5	2.5
17. Skipped medication or doses due to cost	4.0	3.6	3.7	1.7	2.4	6.2	3.3	3.2	1.1	2.0	2.9
Appropriateness											
18. No discussion of goals for condition treatment	1.0	1.0	0.7	0.8	0.6	0.8	0.8	0.7	1.0	1.0	1.0
19. No discussion of treatment options for condition	0.9	1.0	0.5	1.0	0.7	0.7	1.2	0.6	0.8	1.0	1.2
20. No written plan for managing care at home	0.7	0.8	0.7	1.1	1.1	0.7	1.4	1.0	1.2	1.5	1.1
21. Conflicting information	4.4	2.5	7.0	2.7	2.2	2.3	1.9	2.7	2.8	1.8	2.6
22. Place of care does not coordinate care	2.1	1.3	1.0	1.5	1.2	1.7	1.3	2.0	0.9	1.0	1.0
23. GP was not up-to-date following specialist care	2.8	1.7	2.6	1.7	1.5	0.9	2.1	1.5	1.1	1.7	1.8
24. Specialist not up-to date from regular GP	1.8	1.3	2.2	2.2	1.3	1.4	3.2	1.5	1.8	1.4	1.9
25. Results unavailable at time of appointment	3.5	2.2	4.6	3.2	2.3	3.4	2.4	2.2	3.6	1.8	1.8
26. Hospital did not arrange follow-up care	1.4	2.0	0.9	1.0	1.6	1.3	1.5	1.4	2.0	3.0	1.2
27. No written information on hospital discharge	3.6	1.2	0.7	2.5	1.2	1.2	1.3	1.7	1.0	2.9	1.7
28. Not involved in decisions about hospital care	2.8	3.6	0.7	2.4	3.7	0.9	1.2	1.8	2.0	3.4	3.6
29. Purpose of medication not discussed at discharge	1.0	3.1	1.0	1.1	2.8	1.5	1.6	1.1	1.7	1.7	2.6
30. GP/place does not explain things clearly	1.8	2.0	2.2	1.2	1.2	1.8	2.1	1.9	1.0	1.5	1.7
31. GP/place does not involve you in decisions	3.6	1.9	1.9	2.6	1.0	2.5	1.7	1.9	1.1	1.8	1.6
32. GP/place does not know medical history	1.6	1.6	2.0	2.0	1.3	1.9	1.6	1.5	1.9	1.8	1.4
33. GP/place does not spend enough time	2.2	2.1	1.1	1.5	1.7	1.8	2.1	2.0	1.5	1.6	1.4
Mental health condition group worse experience	24	21	16	10	14	13	17	25	12	8	21
Mental health condition group better experience	0	2	1	2	1	0	0	3	1	0	0
Total measures with sufficient respondents	33	33	33	33	33	33	33	33	33	33	33
Number of OR > 1.5	26	20	18	17	19	22	22	21	18	17	22

SOURCE Author’s analysis of Commonwealth Fund International Health Policy Survey 2016. NOTES Shading indicates odds ratios for which pvalue <0.05. Darker shading highlights ratios above 1, lighter shading is significant ratios less than 1.

Table 5.5 Adjusted odds ratios of mental health condition group experiencing access barriers compared to no MHC group, by access barrier and country

Approachability	*AUS*	*CAN*	*FRA*	*GER*	*NED*	*NZ*	*NOR*	*SWE*	*SWI*	*UK*	*US*
1. No regular GP	1.3	0.6				0.7		0.6	0.3	1.3	0.8
2. Medical care received was fair/poor	4.1	1.6	2.2		1.5		1.7	1.4			2.7
3. Health care system needs complete rebuild	1.8	1.2			1.9			1.8		1.3	1.3
4. Fair/poor quality of medical care in country	2.1	1.2	2.6		1.8	1.6	1.8	1.4		1.1	1.5
5. Hospital doctors did not show courtesy/respect	5.4	3.8	0.8	1.5				1.6	2.3		1.4
6. Hospital nurses did not show courtesy/respect	4.7	2.3	1.7	1.4				1.6	1.9		2.2
Acceptability											
7. Lack of professional support for condition	6.5	2.5					5.1	2.3			2.8
8. Not confident about managing health problem	9.4	2.6	3.7					2.4			4.1
Availability											
9. Five days or more to get GP appointment	1.2	1.0	0.9	0.3	1.0		1.1	1.5	1.0	1.4	1.2
10. Did not get response from GP clinic the same day	1.9	1.2	0.4	0.9	1.8	1.6	1.7	1.3	1.7	2.4	1.6
11. Very difficult to get out-of-hours care	1.9	1.0	1.1	1.5		1.8	1.3	1.2	1.6	1.2	1.8
12. Waited two months or longer to see a specialist	1.3	1.3				1.8	1.0	1.2	1.0	1.3	1.9
Affordability											
13. Had problems paying medical bills	5.0	3.4	4.0		3.0			3.3	2.7		2.4
14. Had problems with insurance payment	3.3	2.2	3.2	3.5	2.4			1.2	2.6		1.7
15. A lot of time on paperwork for medical bills	3.9	2.8	3.1		1.9			1.6	1.7		1.9
16. Skipped consult, test or medication due to cost	3.9	2.6	2.1	2.7	1.9	3.4	4.4	2.3	1.5	1.7	2.2
17. Skipped medication or doses due to cost	3.4	2.7						2.2	0.9		2.3
Appropriateness											
18. No discussion of goals for condition treatment	1.1	1.0	0.8	1.0	0.6	0.7	0.8	0.8	0.9	1.1	0.8
19. No discussion of treatment options for condition	0.9	1.2	0.6	1.2	0.7	0.6	1.2	0.8	0.8	1.1	1.2
20. No written plan for managing care at home	0.8	0.7	0.8	1.5	1.1	0.7	1.3	1.2	1.0	1.4	1.0
21. Conflicting information	4.2	2.2	5.2	1.9	2.4	1.8	1.5	2.2	2.9	1.6	2.4
22. Place of care does not coordinate care	1.9	1.1	0.9	1.5	1.0	1.7	1.3	1.7	1.0	1.0	1.0
23. GP was not up-to-date following specialist care	2.5	1.4	2.6	1.3	1.6		2.0	1.5	1.0		1.6
24. Specialist not up-to date from regular GP	1.6	1.2	1.9		1.3		3.3	1.4	1.7		1.9
25. Results unavailable at time of appointment	3.4	2.1	3.5		2.3	2.8	2.0	1.7	3.4	1.7	1.7
26. Hospital did not arrange follow-up care	1.4	2.0	1.0				0.9	1.2			
27. No written information on hospital discharge	4.3	1.4	0.7				1.3	1.7	1.0		
28. Not involved in decisions about hospital care	2.5	3.6						1.5			
29. Purpose of medication not discussed at discharge	0.9	2.9	0.9					1.1			
30. GP/place does not explain things clearly	2.0	1.9	1.6	0.9		1.5	1.8	1.6	1.0	1.5	1.7
31. GP/place does not involve you in decisions	3.7	1.8	1.6	1.9		2.3	1.8	1.6	1.1	1.9	1.4
32. GP/place does not know medical history	1.6	1.5	1.7	1.5	1.3	1.6	1.7	1.3	1.7	1.9	1.2
33. GP/place does not spend enough time	2.4	1.9	1.1	1.1	1.6	1.3	1.9	1.7	1.5	1.8	1.3
Mental health condition group worse experience	24	21	14	5	8	10	13	25	11	4	20
Mental health condition group better experience	0	2	1	1	1	0	0	3	1	0	0
Total measures with sufficient respondents	33	33	27	17	19	16	22	33	25	18	29
Number of AOR > 1.5	25	19	15	6	11	10	13	17	12	8	17

SOURCE Author’s analysis of Commonwealth Fund International Health Policy Survey 2016. **NOTES** Shading indicates adjusted odds ratios for which pvalue <0.05. Darker shading highlights ratios above 1, lighter shading is significant ratios less than 1. For countries with fewer than 60 respondents reporting barriers for a given measure, adjusted odds are suppressed. Adjusted odds ratios are a based include variables for age, sex, income, and immigrant status. Confidence intervals and number of respondents in each model are provided in Technical Appendix A3.

Discussion

We compared both the prevalence of barriers and the disparities in barriers between people with and without a mental health condition across 11 countries using a representative sample with each country and the same survey questions. People with MHCs experienced access barriers across a range of measures. In particular, more than one quarter of adults in each country said they had foregone care due to cost (26%) or had conflicting advice from health professionals (26%) on average. Compared to people with no mental health conditions, people with mental health conditions were more likely to have foregone care due to cost, and say they had received conflicting advice after adjusting for age, sex, immigrant status and income in all countries. In the United Kingdom, the Netherlands, New Zealand, Australia and Germany, the prevalence of barriers among people with MHCs was lower than the country average.

A key finding is the consistency of gaps in barriers in access to care, where barriers were more prevalent among people with a MHC for most measures and countries. A strength of this secondary analysis is that it provides a broad assessment of barriers in access to care for people with mental health conditions. For 84% of country-measure combinations considered (305 of 363 measures highlighted in Table 3) people with a MHC had a higher reported experience of barriers than those without a MHC. There were only three barriers out of 33 where the gap was positive, or people with MHCs had a lower prevalence of barriers across most countries: not having a regular GP, and for people with a chronic condition, reporting no discussion of treatment options or goals for their chronic conditions. Importantly, results from adjusted models confirmed the descriptive results based on gaps, with the disparities in access to care for people with MHCs not being attributable to differences in income, age, sex or immigrant status.

When looking at international patterns of the prevalence and disparities of access barriers for people with MHCs, two main groups of countries emerged. Countries with both more prevalent experiences of barriers among people with a MHC and larger gaps between people with and without MHCs (France, Sweden, Norway, United States, Canada). Second, countries with both smaller barriers and smaller gaps than average (Switzerland, Germany, United Kingdom, New Zealand, Netherlands). International comparisons of access and equity across countries showed Germany and Australia ranked in the top half of countries in terms of access, but were among the bottom half in terms of equity in access for people who have lower than average income (Schneider, 2017). Doing well overall but not for some vulnerable groups such as those with lower income is a finding that seems to be exacerbated for Australia when considering the population who self-report having a mental health condition where access seems even worse. The finding that mental health is particularly associated with access barriers in Australia has been demonstrated elsewhere (Corscadden et al., 2018).

Analysis of patient experiences in hospital care have provided similar findings at a national or state level of disparities for people with a MHC in experiences of hospital care. A study of adult inpatient experiences in the United Kingdom, showed that patients with mental health condition had poorer experiences of hospital care for; information sharing, respect and dignity, coordination of care, confidence and trust and emotional support after adjusting for age, sex, ethnicity, diagnosis and other factors (Care Quality Commission, 2017). In the state of New South Wales in Australia, analysis of admitted, non-psychiatric, hospital patients also showed patients with a self-reported mental health condition had less positive experiences on 40 of 48 measures, where gaps appeared larger for measures of trust, respectful treatment, provision of information, and coordination and continuity of care (Bureau of Health Information, 2016).

Collecting and reporting on patient experience in access to care has become an important part of measuring the performance of health systems internationally, however these efforts often stop short of monitoring population groups who may be left behind. The Organisation for Economic Cooperation and Development has led efforts to standardise international measures to report patient's experiences of access to care. These measures include validated measures from the Commonwealth International Health Policy Survey used in analysis presented here (foregone care due to cost, doctor sepnding enough time with aptients, explaining things clearly and involving patients in decisoins) (Klazinga and Fujisawa, 2017, OECD., 2017). Despite movement in improving international monitoring of experience, comparing countries in terms of 'equity' in access to care is lacking. There is no agreement on how to measure the size or extent of disparities and compare them between regions, with a key concern being the way conclusions differ depending on the data sources and methods used(Martens et al., 2010, Ontario Agency for Health Protection and Promotion (Public Health Ontario), 2013),(Asada and Kephart, 2007, Goddard and Smith, 2001). Notwithstanding such concerns, in many cases there are consistent patterns that may be identified, for example in this analysis, Australia had the largest gaps, both in terms of the average difference between experiences of barriers of people with and without a mental health condition, and as measured by the largest effect sizes of adjusted odds across the 33 measures considered. Yet, these disparities need to be understood in the context that the prevalence of having access problems was lower for people with a mental health condition Australia than the country average. Therefore, it is not straightforward to identify a country with the largest disparities that considers both prevalence and gaps. There is promising work in population health, reporting that combines outcome and disparities measures into one index (Kindig et al., 2018) which may have useful extensions to health system performance monitoring efforts.

Not all countries or measures showed significant disparities for people with MHCs compared to those with no condiitions, therefore considering what is working in these cases may offer insights on how large barriers and gaps might improved. For example, in Canada and Sweden there were several large disparities across a range of access measures, yet for other measures the gaps were reversed. Compared to people with no MHC, people with a MHC condition in these countries were more likely to have a regular GP, and were less likely than report barriers related to chronic disease care. These examples may reflect efforts to integrate care for people with MHCs in primary and chronic disease care. For New Zealand, an income-related analysis of the same survey data showed the country had larger than average income-related gaps (Schneider, 2017). However, in analysis presented here the country performed well for people with a MHC. These findings support the intuitive assumption that different health policies and health systems may do well for some population groups (in this case, those with a mental health condition) and not as well for others (the low-income population). Our findings thus provide evidence to help direct future case-based health systems and policy analysis to generate more robust hypotheses about the policy, organisational and system level factors that may be supporting (better or worse) access to care for people with MHCs in certain countries.

The focus of this quantiative assessment is to present considerations for regular reporting or healthcare performance. Analyses presented may generate discussion and hypothesis. The international survey data is limited in the ability to answer 'why' these disparities may exist. In particular for Australia, further qualitative and mixed methods analysis would be helpful to unpack why people with MHCs are more likely to face barriers to accessing care.

There are several limitations of this analysis to be acknolwedged. First, there are noted challenges with the survey data which is not representative of the population with mental health conditions, and does not capture institutionalized populations. In particular, for Germany and the United Kingdom the mental health group may be an underestimation of those with a condition based on prevalence studies (Steel et al., 2014). There are limitations with the choice and methodology to create the access barrier measures. The survey questions may refer to either physical or mental health services, the focus here was to assess experiences of barriers to any care. We chose to focus on barriers, which is a common approach when measuring disparities. However, dichotomizing categorical variables may introduce measurement issues. Using scoring methods similar to patient experience reporting methods in United Kingdom (Care Quality Commission, 2017) may be an alternative to dichotomous barriers, however may be more challenging to interpret. The survey did not cover all dimensions of the conceptual framework of access to care used as a guide, thus conclusions about what types of access measures have the most prevalent barriers or disparities are limited. There are statistical limitations in comparing countries. In this analysis, Australia, Sweden and Canada had the largest numbers of respondents (double that of other countries) with more power to detect associations in these countries. For many countries, there was insufficient data to do a comprehensive analysis considering the impact of social and demographic factors. More methodological work is needed to identify best-practice methods for monitoring disparities in access to care that are sensitive to different data challenges and can be clearly communicated to the health care systems.

Conclusion

People with mental health conditions experience considerable barriers in negotiating the health care system compared to people without conditions across all the countries in the analysis. The disparities experienced by people with mental health conditions were not attributable to socio-economic or demographic characteristics. Identifying and addressing barriers in access to care for this group is essential to improve outcomes of people with mental health conditions. Currently, there is momentum and policy attention toward addressing equity in access to care and improving outcomes for people with mental health conditions through the Sustainable Development Goals that may offer a broad platform to bring attention to these findings and ensuring ‘no one is left behind’.

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Chapter 6: Disparities in affordability for older Australians

This chapter consists of a manuscript which has undergone one round of peer review and revisions with the Journal of Aging and Mental Health.

Paying for healthcare among older Australians – how do those with mental health and other chronic conditions fare?

Corscadden L, Callander EJ, Lewis V, Topp SM

Background

Affordability of healthcare can be a challenge for older adults with chronic conditions. As people age they are likely to have more, and increasingly complex, chronic conditions. Older Australians with multiple health conditions have been shown to have higher out-of-pocket spending on health care (Islam et al., 2014). But people who have particular health conditions may also be more likely to experience affordability barriers. For example, people with mental health conditions have relatively high out-of-pocket costs and experience greater affordability barriers than those with many other conditions (Callander et al., 2016, Islam et al., 2014) (McRae et al., 2013). Out-of-pocket spending on medication has also been shown to increase with the number of conditions, with the elderly and low-income groups most vulnerable (Sum et al., 2018, Hwang et al., 2001). The cost of medication has been identified as a burden for older patients, with up to 32% of older patients taking less medication than prescribed to avoid cost (Briesacher et al., 2007). Despite being part of a 'universal health system', there are some groups with high needs in Australia who are foregoing care, including those with chronic conditions and disability (Jan et al., 2012, Duckett and Breadon, 2014).

In Australia, there is a system of universal health care (UHC) where taxpayer-funded programs cover the majority of health costs. The two UHC mechanisms, Medicare and the pharmaceutical benefit scheme (PBS), partially fund the cost of medical care and pharmaceutical costs, respectively. However, as the cost of some (privately provided) health services are not regulated, the charges consumers face can exceed the benefits, so there are often co-payments made by the patient. Co-payment is often used by government as a mechanism to prevent over or unnecessary use. However, these 'gap fees' have also been shown to affect people's use of necessary care when it is actually required (Islam et al., 2014, Essue et al., 2013, Yusuf, 2013, Callander, Corscadden & Levesque, 2016).

The reliance on co-payments to regulate over-use of services is complicated by the interaction between socioeconomic status and health. People with lower incomes have poorer health and are more likely to have chronic health conditions than those with higher income (Australian Institute for Health and Welfare, 2016). Yet, those with higher incomes, who have fewer health conditions, are less likely to be affected by co-payments as a dis-incentive to accessing care.

In health systems where gap or co-payments exist, people who choose not to forego care, may still suffer economic burdens from using care. One study suggests that safety net thresholds are failing to protect about one-third of Australians from financial difficulties associated with their healthcare, who have a high need to access healthcare often (Searles et al., 2013). In recognition of the relationship between income and health, Medicare has higher rebates for those with low-income healthcare cards and a Medicare “safety net” designed to give higher rebates to those who incur large out-of-pocket expenses (Australian Government Department of Human Services, 2019a, Australian Government Department of Human Services, 2019b). However, the effectiveness of this safety net, as seen in the interaction between income, level of expenditure on health, and people’s experiences of affordability barriers to care, has not been fully explored.

Affordability of care can be considered as the capacity of people to spend both resources and time to access healthcare services (Levesque et al., 2013). Critically, this capacity extends to the ability to generate resources to pay for health care services, and to pay for services without resulting in catastrophic expenditure (World Health Organization Regional Office for the Western Pacific, 2017). Catastrophic expenditure limits the available resources required for other necessities of life and can may include medical bills comprising a large percentage of household income (De Looper and Lafortune, 2009) (Islam et al., 2014, Carpenter et al., 2015).

Individuals themselves are uniquely positioned to assess how affordable their own healthcare is and what they experience as barriers. Their experiences of the affordability of their own care are a key aspect to understanding care seeking behaviour. Measures of people’s experiences of affordability barriers from literature include reporting foregoing care due to cost, as well having problems paying medical bills (Haggerty and Levesque, 2015, Schoen et al., 2013) (De Looper and Lafortune, 2009). While out-of-pocket spending on healthcare is not necessarily a measure of affordability, it is an important and frequently overlooked part of the picture. People who have higher out-of-pocket healthcare expenditure, lower income, and those without insurance are more likely to experience affordability issues such as skipping care or problems paying bills (May and Cunningham, 2004, Callander et al., 2016). An international study showed connections between different systems of insurance coverage with access, cost burdens, and health conditions (Schoen et al., 2010). Further, for Australians with mental health conditions, challenges with insurance coverage and costs have been demonstrated to be an issue (Meadows et al., 2015), and they are more likely than most to say they had to forego care due to (Callander, Corscadden & Levesque, 2016).

The aim of this study is to explore the complex links between income, private insurance and out-of-pocket costs with experiences of barriers in affordability of care for older adults with chronic conditions. The question of interest is whether having a mental health condition is associated with experiencing affordability problems for older adults after considering other factors such as: income, insurance and out-of-pocket costs and other physical health conditions.

While health policies help to protect people from high out-of-pocket spending and aim to protect them from financial hardship due to health problems, more information is needed to understand how to support those with mental health conditions, as they continue to report high out-of-pocket costs. Effective policy is built on nuanced understanding of causal pathways. Affordability barriers can manifest in different ways, and at different times for different types of people. While many of the major factors influencing affordability could be said to be common across population groups, the way in which they combine and manifest for those with mental health conditions may well be different. Understanding those differences improves our ability to refine policy mechanisms to ensure no one is getting (unintentionally) left behind.

Methods

We completed a secondary analysis of the 2017 Commonwealth Fund International Policy survey of adults aged 65 years and over. The telephone survey was conducted in 11 countries including the country of focus in this analysis, Australia. There were 2,500 respondents, and the survey had a 25% response rate (Osborn et al., 2017).

We considered two *affordability barriers* that reflect experiences before and after accessing care, by looking at the people who answered yes to any of the following questions 1) During the past 12 months, was there a time when you i) did not fill/collect a prescription for medicine, or you skipped doses ii) skipped a recommended test, treatment or consultation, iii) had a medical problem but did not consult with/visit a doctor, due to cost (skip care due to cost) and

2) In the past 12 months, did you have problems paying or were unable to pay any medical bills? (problems paying medical bills).

People with a *mental health-related condition* were considered those who said yes when asked “Have you ever been told by a doctor that you have depression, anxiety or other mental health problems?”. People with *physical health condition* were those who said they had been told by a doctor they had either one or two or more of the following: hypertension, heart disease including heart attack, diabetes, chronic lung disease, cancer, arthritis or stroke. Respondents were categorised into four separate groups those with i) no conditions ii) one physical condition iii) two or more physical conditions or iv) a mental health condition with or without physical health conditions (*mental health plus group*). There were 38 respondents with mental health conditions alone, their affordability barriers were closer to the two plus condition groups than the physical health only group and therefore they were left with the mental health plus group to be included in the analysis (See Appendix A for more information on the condition groups).

Income was based on responses to the Commonwealth Fund Survey question regarding annual household income from all sources before taxes, including any pensions, benefits, or superannuation. Healthcare costs were determined by asking people, in the previous year, how much have they or their family spent out-of-pocket for medical treatments or services that were not covered by insurance. There were 123 records or 5% of respondents were excluded as they did not respond with either a specific amount or category. Insurance status was determined by responses to a question asking if in addition to government funded health services, the respondent was currently covered by any private health insurance that they or an employer or association pays for. For more information on the survey and variables is provided elsewhere (Bureau of Health Information, 2018) (Osborn et al., 2017).

First, we described the social, demographic and health-related characteristics for the four condition groups. Next, we highlighted the associations between the condition groups, age, sex and socio-economic variables with the two affordability outcomes with frequencies through stepwise logistic regression (Proc Surveylogistic (SAS v 9.4)). Stepwise regression was used to see the impact on the adjusted odds ratios (AOR) of the condition groups of adjusting for the socio-demographic and cost variables. The use of stepwise regression to understand associations between patient characteristics, cost or insurance and access to care is an approach in related literature (Callander et al., 2019, Chwastiak et al., 2012).

Results

In 2017, most Australians aged 65 years and over reported having one of eight common chronic conditions including diabetes, heart disease, high blood pressure, stroke, cancer, arthritis, respiratory conditions, and mental health conditions. About three in 10 reported one physical condition (28%), nearly four in 10 had two or more physical conditions (39%) and about one in 10 reported a mental health condition with or without other physical conditions (9%) (Table 6.1).

Characteristics differed across the four condition groups. Those in the mental health plus group were more likely to be female (64% compared to 54% overall) in the lowest income group (31% vs 16% overall), to have no private insurance (64% vs 58% overall) and to report out-of-pocket expenditure of $1000 or more (45% compared to 23% overall). The majority of the group with a mental health condition also had a physical health condition (90%) with an average of 2.9 conditions. People with two or more physical health condition group had 2.6 conditions on average. The estimated out-of-pocket costs increased by condition group from $411 among people with no conditions, $825 for those with one physical health condition, $1,276 for those with two or more physical health conditions, and $1,676 for people with a mental health condition and other conditions Table 8.1). Across the chronic condition groups, the mental health plus group was also most likely to say they had experienced problems affording electricity and other bills, rent and food (27%, 34% and 13% respectively).

Healthcare affordability barriers

Among Australian adults aged 65 and over, 14% said they skipped care due to cost in the past year and 13% said they had problems paying medical bills (Table 6.2). Factors associated with affordability barriers included: low-income (21% skipped care, 25% had problems paying bills), no insurance (18%, 18%), high out-of-pocket costs (21%, 28%), use of a higher number of prescription medications (19%, 20%), two or more physical health conditions (19%, 18%) and mental health and other conditions (27%, 25%). Aboriginal and Torres Strait Islanders were almost four times as likely to say they had foregone care due to cost (50% compared to 12%) and nearly twice as likely to say they had problems paying medical bills (25% compared to 13%) compared to non-Aboriginal and Torres Strait Islander people. However, the power to detect differences is low due to the small number of respondents. Across the condition groups, those in the mental health plus group were most likely to report experiencing both types of affordability barrier (Figure 6.1).

Next, results from stepwise logistic regression models are presented in Table 6.3 for skipping care due to cost. For the mental health plus group, the unadjusted odds of skipping care due to cost were 7.81 times as high as the group with no conditions. After adjusting for age, sex and income, the odds of experiencing barriers for the mental health plus group dropped to 7.10 (CI 3.21-15.72); after adjusting for out-of-pocket expenditure, the odds reduced further to 5.28 (CI 2.18-12.81); and after considering insurance status, the odds were 4.77 (CI 1.95 - 11.67).

Factors associated with experiencing problems paying medical bills are presented in Table 6.4. For the mental health plus group, the unadjusted odds of skipping care due to cost were 15.34 times as high as those with no conditions. After adjusting for out-of-pocket expenditure, age and sex, the odds reduced to 8.84 (CI 3.67-21.3), and after considering insurance status, the odds dropped further to 7.22 (CI 4.29-22.29).

Table 6.1 Characteristics of Australians aged 65+ years, by condition group, 2017

		Cohort Total	No condition (n=772)	One physical (n=637)	Two + physical (n=818)	Mental health plus (n=262)	P value
			24%	28%	38%	9%	
Aboriginal	Aboriginal	3	2	2	5	3	0.062
	Non-Aboriginal	97	98	98	95	97	
Age	65 to 74	55	78	55	41	52	<.001
	75 or older	45	22	45	59	48	
Sex	Female	54	48	58	52	64	0.08
	Male	46	52	42	48	36	
Rurality	Inner regional	19	19	17	20	22	0.269
	Metropolitan	66	67	67	68	53	
	Outer regional/remote	15	14	16	13	24	
Immigrant status	Born in Australia	79	81	75	80	77	0.525
	Not born in Australia	21	19	25	20	23	
Income	Less than $20,000	16	8	17	16	31	0.012
	$20,000 to <$25,000	23	26	23	22	22	
	$25,000 to < $40,000	29	29	28	30	25	
	$40,000 to < $60,000	19	20	17	20	12	
	$60,000 or more	14	17	14	12	10	
Insurance	No private insurance	58	55	53	63	64	0.085
	Private insurance	42	45	47	37	36	
Self-reported out-of-pocket costs	$1000 or more AUD	23	9	18	30	45	<.0001
	$500 to $1000	19	14	23	20	16	
	Less than $500	58	78	59	50	39	
	AUD$ average	$ 986	$411	$825	$1,276	$1,676	
Mental health	No condition	91	0	0	0	0	
	Has condition	9	0	0	0	100	
Physical condition(s)	No conditions	25	100	0	0	10	
	One or more condition	75	0	100	100	90	
	Average number	1.5	0	1	2.6	2.9	
Prescription drugs	None	15	47	9	3	3	<.0001
	One	14	17	23	6	8	
	2 to 3	36	28	47	36	29	
	4 or more	34	5	21	55	59	
	Missing	1	4	1	0	1	
Worried about having money…							
…for meals	Sometimes, usually, always	5	2	4	6	13	0.0001
	Rarely	9	6	11	10	11	
	Never	85	92	85	84	76	
..for rent mortgage	Sometimes, usually, always	12	5	11	12	34	<.0001
	Rarely	16	16	17	17	9	
	Never	72	79	72	72	57	
…for bills: electricity, phone	Sometimes, usually, always	17	8	16	20	27	0.0156
	Rarely	14	11	19	12	15	
	Never	69	80	65	68	57	

Note: Percentages are based on weighted responses. Values may not add up to 100% due to rounding and exclusion of missing values.

Table 6.2 Percentage of adults aged 65+ years that experienced affordability barriers by socio-demographic and health characteristics, 2017

		Skipped care due to cost		Problems paying medical bills	
		%	P-value Chisq	%	P-value Chisq
All		14		13	
Sex	Female	15		13	
	Male	12	0.2922	14	0.683
Age	65 to 74	13		14	
	75 or older	15	0.5497	12	0.290
Aboriginal	Non-Aboriginal	12		13	
	Aboriginal (n=47)	50	<.0001	25	0.146
Immigrant status	Born in Australia	13		12	
	Not born in Australia	15	0.5611	17	0.124
Rurality	Metropolitan	14		12	
	Inner regional	12		17	
	Outer regional/remote	12	0.9695	14	0.260
Income	Less than $20,000	21		25	
	$20,000 to < $25,000	10		12	
	$25,000 to < $40,000	16		10	
	$40,000 to < $60,000	13		11	
	$60,000 or more	6	0.01	9	<.0001
Private insurance	No private insurance	18		19	
	Private insurance	8	<.0001	5	<.0001
Out-of-pocket costs	$1000 or more	21		28	
	$500 to $1000	15		17	
	Less than $500	10	0.0066	7	<.0001
Condition group	No conditions	5		2	
	One physical	8		11	
	Two + physical	19		18	
	Mental health plus	27	<.0001	25	<.0001

Figure 6.1 Percentage of adults aged 65+ experiencing economic stressors, by chronic disease group, 2017

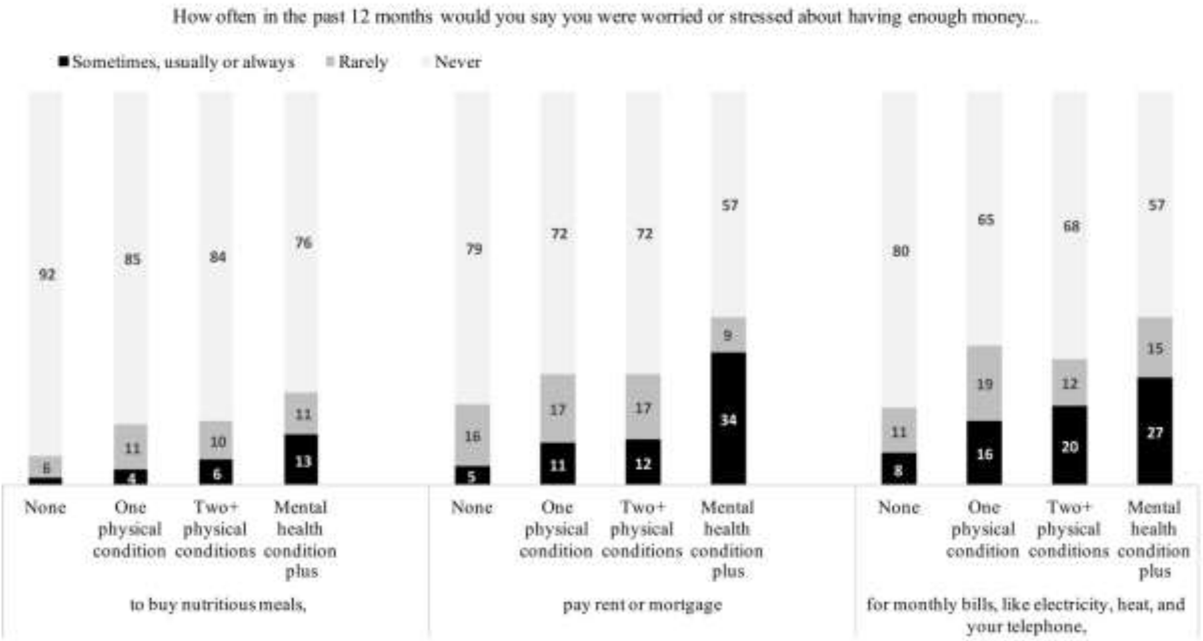
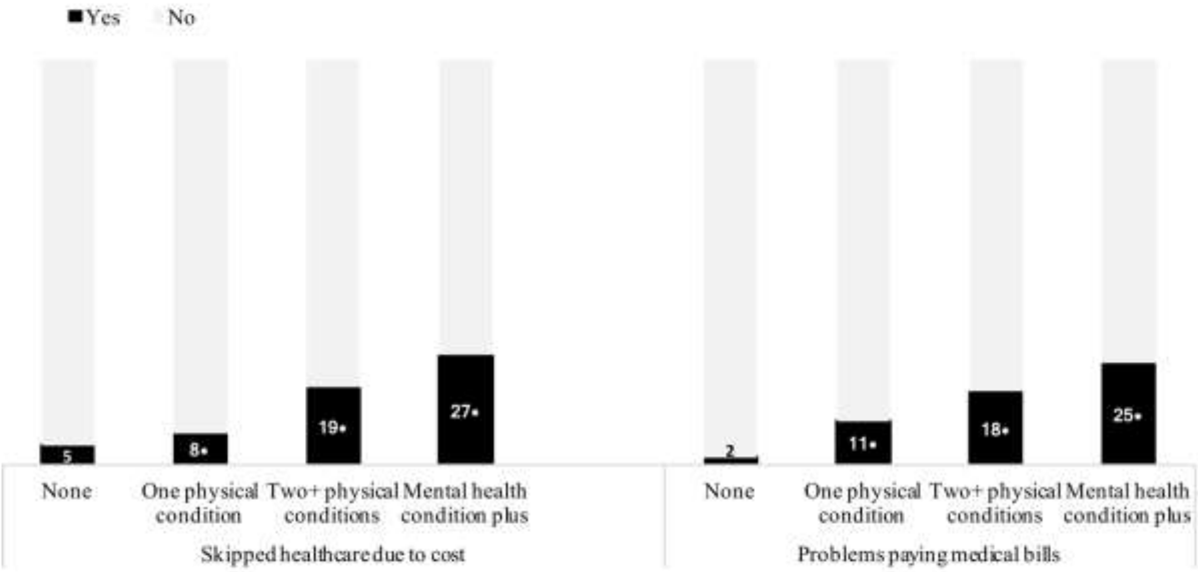


Figure 6.2 Percentage of adults aged 65+ experiencing healthcare affordability problems, by chronic disease group, 2017



*Indicates result significantly differs from the ‘No condition’ group (OR>1 p<0.01)

Table 6.3 Adjusted odds of skipping medication, tests or consultations due to cost, Australians aged 65+ years, 2017

	OR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
No conditions	**1**		**1**		**1**		**1**		**1**	
One physical condition	1.86	(0.84, 4.1)	1.89	(0.84, 4.24)	1.79	(0.78, 4.07)	1.77	(0.72, 4.34)	1.81	(0.73, 4.49)
Two + physical conditions	5.02	(2.42, 10.4)	5.29	(2.52, 11.1)	4.97	(2.36, 10.48)	4.59	(2.01, 10.48)	4.29	(1.85, 9.95)
Mental health condition +	7.81	(3.63, 16.81)	7.88	(3.6, 17.27)	7.1	(3.21, 15.72)	5.28	(2.18, 12.81)	4.77	(1.95, 11.67)
Male			0.79	(0.47, 1.31)	0.84	(0.49, 1.43)	0.83	(0.48, 1.43)	0.78	(0.46, 1.34)
Female			**1**		**1**		**1**		**1**	
65 to 74			1.18	(0.71, 1.96)	1.19	(0.7, 2.02)	1.22	(0.7, 2.13)	1.26	(0.74, 2.16)
75 or older			**1**		**1**		**1**		**1**	
Less than $20,000					3.14	(1.57, 6.29)	3.65	(1.77, 7.53)	3.37	(1.65, 6.88)
$20,000 to <$25,000					1.51	(0.76, 2.97)	1.76	(0.87, 3.56)	1.45	(0.71, 2.95)
$25,000 to <$40,000					2.72	(1.34, 5.51)	3.09	(1.52, 6.31)	2.76	(1.37, 5.57)
$40,000 to < $60,000					2.15	(0.96, 4.83)	2.35	(1.03, 5.37)	2.36	(1.05, 5.3)
$60,000					**1**		**1**		**1**	
Out-of-pocket $1000+							1.73	(1.02, 2.93)	1.93	(1.14, 3.27)
less than $1000							**1**		**1**	
No private insurance									2.87	(1.72, 4.79)
Private insurance									**1**	
C statistic		0.695		0.704		0.711		0.732		0.732

Notes: Results are shaded where category group where $p<0.01$. AOR (adjusted odds ratio) OR (unadjusted odds ratio)

Table 6.4 Adjusted odds of experiencing problems paying medical bills, Australians aged 65+ years, 2017

	OR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
No conditions	**1**		**1**		**1**		**1**		**1**	
One physical condition	5.91	(2.66, 13.14)	6.9	(3.08, 15.45)	6.43	(2.91, 14.23)	6.11	(2.56, 14.61)	6.51	(2.76, 15.34)
Two+ physical conditions	10.15	(4.92, 20.93)	12.82	(6.13, 26.84)	12.22	(5.9, 25.3)	10.39	(4.62, 23.36)	9.78	(4.29, 22.29)
Mental health condition plus	15.34	(6.86, 34.31)	18.59	(8.32, 41.54)	15.63	(7.1, 34.42)	8.84	(3.67, 21.3)	7.72	(3.2, 18.6)
Male			1.17	(0.76, 1.8)	1.34	(0.87, 2.07)	1.46	(0.92, 2.33)	1.31	(0.82, 2.12)
Female			**1**		**1**		**1**		**1**	
65 to 74			1.82	(1.18, 2.81)	1.98	(1.26, 3.11)	2.11	(1.3, 3.41)	2.3	(1.4, 3.76)
75 or older			**1**		**1**		**1**		**1**	
Less than $20,000					3.16	(1.63, 6.15)	5.24	(2.45, 11.2)	4.43	(2.18, 9)
$20,000 to <$25,000					1.47	(0.81, 2.69)	2.42	(1.26, 4.66)	1.66	(0.84, 3.3)
$25,000 to <$40,000					1.14	(0.62, 2.07)	1.64	(0.88, 3.04)	1.27	(0.68, 2.37)
$40,000 to < $60,000					1.11	(0.54, 2.3)	1.34	(0.63, 2.84)	1.35	(0.62, 2.94)
$60,000					**1**		**1**		**1**	
Out-of-pocket 1000+							3.77	(2.37, 6.01)	4.92	(3, 8.07)
less than $1000							**1**		**1**	
No private insurance									5.87	(3.29, 10.47)
Private insurance									**1**	
C statistic		0.721		0.728		0.737		0.810		0.830

Note: Results are shaded where category group at p<0.01. AOR (adjusted odds ratio) OR (unadjusted odds ratio)

.

Discussion

Results of this analysis show that older Australians with more chronic conditions are more likely to experience affordability barriers to accessing care, particularly when they have a mental health condition. The mental health condition group is faced with a constellation of issues: almost half (45%) said they spent $1,000 or more out-of-pocket on healthcare, almost two thirds (64%) did not have private insurance, and nearly a third report having low-income (31%) and a quarter have skipped care due to cost (27%) or problems paying bills (25%). This group was also most likely to say they had problems paying for electricity and other bills, rent and food (27%, 34% and 13% respectively) and had the highest average number of conditions (2.9).

This study explores new ways to unpack some complex connections between conditions, out-of-pocket costs, socio-economic status and affordability barriers for older adults. Findings build on previous results that have demonstrated increasing health care costs with age and number of chronic conditions (Duckett and Breadon, 2014, Carpenter et al., 2015, McRae et al., 2012). Recent studies have suggested out-of-pocket costs are higher for people with more conditions because they need to use several services of many different types (Duckett and Breadon, 2014). The major contributors to out-of-pocket costs in one study of older Australians were medications, medical consultations and tests (Carpenter et al., 2015, Islam et al., 2014). Many older adults have said they had to forego medication and suffered financial difficulties related to medication costs (Searles et al., 2013).

In the current study, the estimated average annual out-of-pocket costs increased by condition group, $411 for those with no conditions, $825 for the one physical condition group, $1,276 among the two or more physical conditions group, to $1,676 among the mental health condition plus group. These self-reported estimates are similar to findings from a survey of Australian adults aged 50+ years (McRae et al., 2012), where the reported average costs were $624 per year for people with no conditions, $1,040 for those with one condition, and $1,444 for those with two conditions, and $1,836 with three conditions. The McRae et al. study estimates were converted from quarterly estimates that also included some transport and home care costs so are somewhat higher. Intuitively, both studies demonstrate that a higher number of conditions is associated with higher out-of-pocket costs. However, the current study additionally demonstrates that people with mental health conditions face high costs, which may be related to both their mental health and co-occurring physical conditions.

In this study, we have shown that older Australians with mental health and other conditions have higher reported out-of-pocket costs than those with only physical health or no conditions, and they are more likely to skip care due to cost. Findings on foregoing care due to costs are consistent with previous findings from the Commonwealth Fund Survey of all adults (Callander et al., 2016). Further, an Australian survey of people aged 16 and over also showed those with mental health conditions were more than three times as likely as those without, to say they experienced barriers accessing healthcare (Jorm, 2018). The main barrier was cost, followed by wait times and availability of appointments. The results of the stepwise regression in the current study also show that adjusting for out-of-pocket costs resulted in a large reduction in the odds of skipping care due to cost, particularly for people with mental health conditions.

Results from this current study have also highlighted that older adults with mental health and other conditions face additional financial hardships because of health care such as problems paying medical bills. In this study, one in four Australians aged 65+ with a mental health condition reported they had problems or were unable to pay medical bills in the year prior. One Australian study looked more in depth at financial stresses due to healthcare. They showed that among older adults who said they could not afford care, about four in 10 borrowed money (42%) or used savings and assets or borrowed money (38%) to pay for health costs (Carpenter et al., 2015). The current study is consistent with the finding that for Australians with multiple conditions the financial protection offered through safety nets may be inadequate. One recommendation suggests broader safety nets, covering more kinds of services, would help to address gaps in affordability and help the most vulnerable groups (Duckett and Breadon, 2014). Further, it has also been suggested an expansion of early intervention services is needed, so more Australians with less severe conditions have access to needed services without referral or cost barriers (Beyond Blue, 2019).

More can be done to monitor affordability of health care, particularly for those most in need. Our research provides evidence in support of calls for routine reporting of affordability barriers for vulnerable groups (Jan et al., 2012) and monitoring of co-payments for medications (Searles et al., 2013). Analysis presented here, helps to quantify the affordability barriers for people with chronic conditions. Further, findings show that affordability experiences need to be considered alongside income, insurance and current out-of-pocket costs to be understood. Linked data studies, that bring administrative information on services, the volume and recommended treatments along with experiences would improve understanding of affordability experiences as well.

Limitations

The prevalence of the sample reporting a chronic condition was lower than in other national survey results (Australian Institute for Health and Welfare, 2016). This is likely to reflect the fact that in the Commonwealth Fund Survey respondents were asked about nine specific conditions. It is likely that some people in the no condition group would have some other health conditions that were not listed. Further, in this study, respondents who said they were ‘no longer treating’ a condition were not included as having a current chronic condition.

While the response rate of 25% for Australia may be considered relatively low, the survey weighting methodology can help mitigate the impacts of lower response rates (Groves and Peytcheva, 2008). Follow-up studies of non-responders have shown they may give similar answers to patient experience surveys as those who respond (Thomson et al., 2018).

The precision is limited for the self-reported out-of-pocket costs in this study, therefore cost estimates by condition group are provided for descriptive purposes only. Further questions about costs considered in this analysis ask about costs for all healthcare, so it is impossible to tell if people with mental health conditions are using services specific to their mental health condition. The survey question regarding skipping care refers to “recommended services”; however, patient reported cost estimates may include patient-preferred non-recommended services.

The general experience of ‘problems paying medical bills’ is not a validated indicator of affordability problems, but rather, a prevalence of an experience that may be interpreted differently by different people. However, the question relating to skipping recommended care due to cost has been asked in several surveys and validated (Klazinga and Fujisawa, 2017).

Conclusions

High out-of-pocket costs and a lack of private insurance increase the likelyhood that older people with chronic conditions foregoe care or face economic consequences, particularly for people with mental health conditions. More effort needs to be made to track the financial impact of healthcare and the affectiveness of safety nets, particularly for vulnerable groups such as older people with mental health conditions.

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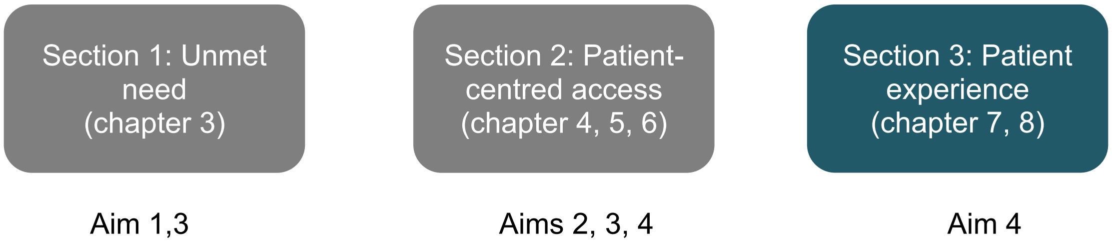
Section I focused on people’s experiences of unmet need for mental health care, thereby addressing aim 1 of the thesis.

Section II focused on patient-centred access and addresses aims 2, 3, and begins to consider aim 4.

In the next section, Section III, (chapters 7 and 8, comprising 1 published manuscript and 1 accepted for publication) focused on the disparities in experiences of patients with mental health conditions in maternity and emergency care addressing aim 4.

Section III: Experiences of care

The focus of Section III is the disparities in experiences of patients with mental health conditions. This is investigated using secondary analysis of patient experience survey data from the Bureau of Health Information in New South Wales (NSW) in two specific settings – maternity and emergency care. Appendix D and Appendix E the end of this thesis include additional detail about the respondents, response rates and representativeness of these survey sources. This section consists of two chapters (one published manuscript and one accepted for publication), which collectively address aim 4 of the thesis.



- *When considering patient-centred access and experiences more broadly, for which types of experiences are disparities most pronounced across different healthcare sectors? (aim 4)*

Exploring patient experiences goes in depth into what happens after patients have reached care, including how they are greeted, their communication with providers, the information provided to them and how they are involved in decisions about their care. This is an extension of the assessment of patient-centred access to care considered in Section II. Where the conceptualisation of patient-centred access began from people's ability to seek care and ends with their engagement in care, the proposed patient experience dimensions go deeper and wider into all that happens to patients as they go through care to help determine whether they accessed high quality, patient-centred care. In this section, analysis of disparities in experiences of care for people with mental health conditions in maternity and emergency department care in New South Wales (NSW) are presented. First, I provide a brief background on measuring patient experiences of care.

Patient-centred care and patient experiences in healthcare performance

Patient-centred care is a key component of high quality healthcare (Arah et al., 2006, Institute of Medicine, 2001). Patient-centred care means “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Corrigan, 2005). The World Health Organisation goes further and suggests that providing integrated ‘people’-centred care is key to the aim of universal health care (de Silva, 2014), where universal health care can be considered the product of equitable coverage, high quality care, and financial protection. Without people-centred care to ensure services are of sufficient quality we could have good coverage and good financial protection of services that are not responsive to the people they are meant to be supporting. This broad conceptualisation of people-centredness encompasses much more than a single clinical encounter, it includes connected services in the community and the dynamic role played by people, carers, and communities. Arguably then, healthcare performance evaluation should be designed considering the patient perspective (Nuti et al., 2017).

Patient experience surveys have been adopted and used widely as one method to measure patient-centredness of care. Patient experience has been defined as “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions, across the continuum of care” (Wolf, 2014). Patient experience measures are increasingly used in quality improvement and healthcare performance reporting (Klazinga and Fujisawa, 2017, Bureau of Health Information, 2019a, Care Quality Commission, 2017). Survey methods have evolved for designing questions, sampling patients and weighting responses toward ensuring the estimates are robust and representative of the patients receiving care (de Silva, 2014). While surveys are a primary method used to collect feedback for performance reporting, there are many other methods for investigating patient experiences such as interviews, focus groups and observing interactions.

In both qualitative and quantitative work, patient experiences can be categorised into various types or dimensions. Some foundational work by the Institute of Medicine and the Picker Institute described types of experiences including: respect for patient preferences, family, physical comfort, emotional support, coordination and timeliness, and continuity of care, with later research adding dimensions related to facilities, or overall impressions (Figure III) (Gerteis, 1993) (Peschel and Peschel, 1994, National, 2012, Jenkinson et al., 2002). The survey questions in this work have contributed substantially to the efforts in regularly reporting patient experiences with similar questions used today in standardised surveys at state and international levels (Care Quality Commission, 2017, Bureau of Health Information, 2019b, Murray, 2012). The analysis presented in this section categorises experiences building on the dimensions outlined in Figure III.

Aims of this section

This section focuses on disparities in experiences in maternity and emergency care for people with mental health conditions. I present findings based on secondary analysis of patient experience survey data from the Bureau of Health Information in New South Wales (NSW).

First, Chapter 7 presents findings of the differences in experiences of care in NSW emergency departments, for people with and without a self-reported mental health condition. In Chapter 8, experiences of maternity care are examined in a similar manner. Both chapters summarise disparities in experiences across dimensions building on those in Figure III.

Figure III. Eight dimensions of Picker's patient-centred care

Sources: Peschel and Peschel, 1994, Ehrler et al., 2017.

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Chapter 7: Experiences of emergency department care in New South Wales

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Disparities in experiences of emergency department care for people with a mental health condition

Lisa Corscadden[a,*], Emily J. Callander[b], Stephanie M. Topp[c], Diane E. Watson[d]

[a] Australian Institute of Tropical Health and Medicine, James Cook University, Queensland, 4812. Bureau of Health Information, Level 11, 67 Albert Avenue, Chatswood, NSW 2067, Australia
[b] School of Medicine, Griffith University, 170 Kessels Rd, Nathan QLD 4111, Australia
[c] College of Public Health, Medical & Veterinary Sciences, James Cook University, Queensland 4812, Australia
[d] Bureau of Health Information, Level 11, 67 Albert Avenue, Chatswood, NSW 2067, Australia

Disparities in experiences of emergency department care for people with a mental health condition

Introduction

The capacity to deliver both equitable and patient centred care are recognised to be important facets of high-performing health systems (Arah et al., 2006, Corrigan, 2005). But in many settings, performance monitoring is still evolving to capture patient experience – a key measure of patient-centredness – and analyse how certain populations – such as those with mental health conditions – might experience services differently. Patient centred care implies responsiveness, respect and engagement with the person receiving care, therefore equitable care suggests all patients, irrespective of their condition, experience care that is respectful to them and responsive to their needs, and they are engaged in their care.

Emergency Departments (ED) are settings of high volume, urgent care, making this an important setting for monitoring the degree to which healthcare is responsive to emergent needs. In the Australian state of New South Wales (NSW), for example, there were 2.8 million ED presentations in 2017–18 (Bureau of Health Information, 2019a). Over the past several years, not only volumes of presentations, but number of repeat visits have been increasing (Lago et al., 2019). Mental health and substance use are some of the main non-injury related reasons for multiple attendances in EDs (Lago et al., 2019). Although relatively few ED presentations (3%) were directly related to acute mental health conditions, mental health related presentations to ED have risen by 70% over the past 15 years in Australia,[13] with volumes of presentations increasing particularly for those aged 15-24 years (Bureau of Health Information, 2019a). Much larger numbers (between 20-30%) of those who present at ED are managing a mental health condition, even where this is not the reason for presentation (Australian Bureau of Statistics, 2008, Fulbrook and Lawrence, 2015).

Experiences in EDs can pose particular challenges for patients who have mental health conditions (Sonis et al., 2018, Nairn et al., 2004). People presenting with an acute mental health condition wait longer to be treated, and their mental health may deteriorate the longer patients wait in ED (Craze, 2014). Regardless of their reasons for presentation, people with mental health conditions may face challenges when waiting in EDs that can be crowded, overstimulating and present challenges for people's privacy (Morphet et al., 2012, Pines et al., 2008, Clarke et al., 2007).

The aim of this study is to explore how people with mental health conditions view their experiences of care, irrespective of the reason for presenting to an ED. Understanding experiences of people with mental health conditions is a noted evidence gap (Craze, 2014). Results can inform priorities to improve experiences of care in ED for people with mental health conditions.

The specific questions the analysis will address are:

- Do people with a self-reported long standing mental health condition have more or less positive experiences of ED care than those with no condition?
- Are there more pronounced disparities in experiences in ED for some dimensions of experience?

Methods

Study design and selection of participants

This analysis is part of research approved by the Human Research Ethics Committee of James Cook University (H7997). It reflects a secondary analysis of the experiences of 15,995 adults and children. The patient or their carer completed a survey in one of 82 emergency departments (EDs) in NSW between July 2017 and June 2018 (weighted response rate 24%). Two to three months following presentation to ED, people were invited to complete a survey either by mail or online, based on a stratified sample of hospitals and patients by age and admission status. The time lag is due in part to incomplete details on hospital records and also to exclude sensitive records from the sample frame. Patients were excluded from the sample if they were subsequently admitted with reasons for admission including intentional self-harm, treated for abuse or similar reasons, or if the patient had deceased following admission to hospital. There is additional information on the sampling and weighting methods provided in the survey technical supplement (Bureau of Health Information, 2019d). Results were weighted using the sample weights provided to represent the age and admission status profile of at each ED, representing over 1.8 million patients.

Measures

Patients were asked ‘which if any of the following long-standing conditions do you have?’. In the analysis, patients were grouped by whether they reported having a ‘mental health condition (e.g. depression)’. Throughout this analysis, we referred to these groups as the *mental health condition* and *no condition* groups.

The ED questionnaire includes experiences covering reception, treatment and discharge. Questions are consistent with those used in hospital experiences and in other countries, thus have undergone testing across a range of audiences (Care Quality Commission, 2017, Ipsos Social Research Institute, 2013). All relevant patient experience questions in the survey were used, with the exception of those based on a small subgroup of patients with small numbers of respondents (e.g. experiences with toys for children, information about tests or x-rays, translation services). This resulted in 53 questions. It is a common practice to use a large set of survey measures in other disparity focused analyses of patient experience surveys (Saunders et al., 2015, Cheyne et al., 2019). Considering individual measures rather than composite scores can be more understandable for quality improvement initiatives, to have a specific actionable focus. Combining questions into composite measures to cover a broad construct, can impact the usability of results in quality improvement efforts.

Selected survey questions were highlighted in more detail as they are the most commonly used measures of experiences or included as part of key performance indicators for health districts (Bureau of Health Information, 2019b, Bureau of Health Information, 2019a). These questions include measures of overall ratings of care and professionals, trust, and organisation of care among others.

To summarise results by mental health condition group across dimensions of experience, we mapped the 53 survey questions onto dimensions of patient experiences of care based on the literature (Jenkinson et al., 2002, Male et al., 2017). The dimensions used in this analysis were:

1. Overall impressions of care and professionals (e.g. overall ratings, kindness and courtesy of doctors),
2. Emotional support and trust (e.g. discussion of fears, confidence and trust),
3. Respect for patient preferences (e.g. treated with respect and involved in decisions),
4. Information and education (e.g. provided information with clear explanations)
5. Involvement of family (e.g. family given information and opportunity to talk to professionals)
6. Physical comfort (e.g. pain management, assistance)
7. Coordination of care and timeliness (e.g. appointments on time, waiting times, no conflicting information)
8. Continuity and engagement in self-management (e.g. involvement at discharge, involvement with medication decisions, know who to contact)
9. Facilities/safety (e.g. were treatment areas clean, parking, feelings of safety while waiting).

Analysis

Each of the 53 survey questions was dichotomised to create a measure based on the most positive response option with missing values excluded. Using the 'top box' or most positive response is a common approach in patient experience reporting (Bureau of Health Information, 2019d, Agency for Healthcare Research and Quality, 2018, Care Quality Commission, 2017). This approach assumes that the most positive response is associated with meaningfully better experiences and outcomes. The factors associated with positive experiences were described using bivariate analysis.

Comparison of the most positive category may not be sensitive to the fact that some groups may have reporting tendencies that avoid extreme responses. In some analyses, scored responses that take into account all survey responses not the most positive responses are used to compare groups (Care Quality Commission, 2017). We conducted a sensitivity analysis on the key survey questions to confirm that based on either a scored response or the most positive category, differences between mental health condition groups would be substantial, while difference based on scored responses are slightly less pronounced.

Next, disparities in experiences of care between patients with and without a mental health condition, were assessed using multi-variable logistic regression analysis separately for 53 measures of experiences of care (SAS PROC SURVEYLOGISTIC) (Appendix Table 7.4). The adjusted odds of reporting positive experiences were reported for the mental health condition group compared to those with no condition, adjusting for age, sex, the language spoken at home and education. These patient characteristics were identified in methods to compare hospital level experiences by the organisation managing the patient survey(Bureau of Health Information, 2019c). Further, some studies used mixed models to analyse hospital based survey data to account for the survey design where patients are clustered within hospitals (Sizmur et al., 2015). There remain differing practices for the analysis method to both incorporate patient-level weights and hospital strata size information in multi-level models.

Finally, to provide a descriptive measure of the size of disparities that could be summarised across dimensions, percentage point difference in reporting the most positive response option was calculated between people with and without a mental health condition. A negative percentage-point difference indicated that people with a mental health condition had less positive experiences.

Results

Characteristics of study subjects

One in 10 patients, who presented to ED for any reason, self-reported having a longstanding mental health condition (Table 7.1). A majority of patients who have a mental health condition were in the 18 to 54-year age groups (64% compared to 39% with no condition). Patients with a mental health condition are also more likely to be female (62% compared to 52%) and English speaking (89% compared to 82%). Further, almost half of people with a mental health condition (48%) said it was not their first visit to the ED, compared to 30% of those with no condition. In fact, 10% of patients with a mental health condition said they attended an ED four or more times compared to 3% of those with no condition. There were less pronounced differences between patients with and without a mental health condition by triage, peer group, rurality, and regarding medication.

Table 7.1 Patient characteristics in sample frame, and in the cohort by mental health condition group, NSW, 2017–18

		Patients in initial sample frame (administrative data, n=2.3 million)	**Mental health condition** (n=1,596, average age 43.4, 10% of patients)		**No condition** (n=13,846, average age 40.5, 90% of patients)	
		%	weighted %	N	weighted %	N
Age (p<0.001)*	0-17	25	7	102	27	3350
	18-34	22	29	407	15	1942
	35-54	20	35	550	24	3075
	55-74	19	20	376	19	3016
	75+	14	9	161	14	2463
Sex (p=0.001)*	Female	49	62	966	52	7187
	Male	51	38	630	48	6659
Language spoken at home (p<0.001)*	Non-English	n/a	11	126	18	2040
	English	n/a	89	1457	82	11705
Quintile of disadvantage (p=0.0001)*	Quintile 1: Most	n/a	17	291	17	2520
	Quintile 2	n/a	22	385	18	2932
	Quintile 3	n/a	27	394	25	3225
	Quintile 4	n/a	21	304	20	2491
	Quintile 5: Least	n/a	14	220	20	2655
Rurality (p=0.0019)*	Major cities	70	67	895	71	8497
	Inner regional	26	26	523	23	4026
	Outer regional/remote	5	7	178	6	1311
Triage category (p=0.008)	1 Most urgent	1	1	8	0	74
	2	13	14	245	12	1963
	3	35	37	625	33	4813
	4	41	39	580	44	5617
	5 Least urgent	10	9	137	11	1371
Admitted (p<0.001)*	Admitted	28	29	694	24	5013
	Non-admitted	72	71	902	76	8833
Prescribed medication (p=0.90)	No medication	n/a	70	596	69	5930
	New medication	n/a	30	270	31	2707
Self-reported Time spent in ED (p<0.001)*	1-30 minutes	n/a	3	55	5	672
	31-59 minutes	n/a	8	122	9	1262
	1 up to 2 hours	n/a	15	234	18	2439
	2 up to 4 hours	n/a	26	388	29	3801
	4 hours or more	n/a	40	605	34	4538
In the past year, how many times have you visited and ED for your own care? (p<0.001)*	1 (this visit)	n/a	52	802	70	9204
	2-3 visits	n/a	38	601	27	3864
	4-6 visits	n/a	6	102	2	390
	6-10 visits	n/a	2	33	1	102
	More than 10 visits	n/a	2	32	0	48

Notes: *The distribution of characteristics for people with a mental health condition are significantly different than without a mental health condition (p.ChiSq<0.001). Results were weighted to represent the hospitalised population; therefore, weighted percentages do not necessarily match unweighted counts. Missing responses were excluded.

The factors associated with experiences of care are described in Table 7.2. A majority of all patients rated their care positively, with 60% reporting very good overall ratings of care, 66% rating health professionals as very good, for example. People with mental health conditions reported less positive experiences than those with no condition for all five measures: of overall ratings of care, and professionals, how professionals worked together, trust in professionals, and recommendation of services to friends and family. Just over half (52%) of patients with mental health conditions reported 'very good' overall ratings of care, compared to 60% of those with no condition for example.

Results range substantially by patient characteristics. For all five measures, patients with mental health conditions, those aged 18 to 34, and those who spoke a language other than English at home gave the lowest experience ratings. In contrast, people in oldest age groups, lower education levels, and more urgent triage categories, those who went to smaller emergency departments and those in rural areas reported more positive experiences.

Differences in experiences between patients with and without a mental health are shown in Figure 7.1 for a subset of 17 key experience measures. The percentage point difference between is highlighted where the difference was significant after adjusting for age, sex, language spoken and education. People with mental health conditions reported significantly less positive experiences for 16 out of 17 measures. For example, 76% of people with a mental health condition said they were 'always' treated with respect and dignity compared to 86% of those with no condition. The most pronounced difference was regarding information to manage care at home where 60% of people with a mental health condition said they were 'definitely' given enough information to manage their care at home if they needed it, compared to 73% of those with no condition.

Table 7.2 Percentage of emergency department patients reporting the most positive response option by question and patient characteristics, NSW, 2017–18

		Very good ratings of care	Very good rating of health professionals	Always had confidence and trust	Professionals worked well together	Recommend to family and friends
All patients		**59**	**66**	**71**	**56**	**70**
Sex	Male	62	69	74	59	73
	Female	57	64	69	53	68
Age	0-17	57	66	73	54	68
	18-34	49	57	66	48	60
	35-54	56	63	69	53	67
	55-74	69	73	72	64	78
	75+	68	75	77	63	81
Education	Not yet started school	55	63	71	53	68
	Less than Year 12	64	71	73	60	75
	Still at primary or secondary	60	68	74	55	70
	Completed Year 12	58	65	72	54	69
	Technical certificate/diploma	61	68	69	58	70
	Post graduate/higher degree	58	64	68	54	71
	University degree	53	62	67	52	67
Language	Non-English	46	57	71	47	62
	English	62	69	71	58	72
Mental health	No condition	60	67	72	56	71
	Longstanding condition	52	58	64	49	62
Socio-economic status	Quintile 1: Most disadvantaged	56	63	69	54	67
	Quintile 2	60	67	71	55	70
	Quintile 3	58	64	71	55	69
	Quintile 4	59	67	73	56	71
	Quintile 5: Least disadvantaged	63	71	72	59	75
Triage	Triage 2- urgent	68	74	72	65	79
	3	59	66	70	56	72
	4	57	65	72	54	68
	Triage 5 - least urgent	56	64	70	52	66
Rurality	Major cities	57	65	71	54	72
	Inner regional	64	69	72	59	70
	Outer regional, remote,	64	69	75	58	72

Notes: Descriptive results where shading represents the lowest (red) to highest (green) results. Results all based on 100 or more respondents. Triage 1, the most urgent category excluded because of small numbers of respondents.

Table 7.3 Average percentage reporting experiences, average number of respondents by condition group, and summary of differences, by experience dimension, NSW, 2017–18

Dimension	Mental health condition		No condition group		Summary of differences	
	Average (%)	Average number of respondents	Average (%)	Average number of respondents	Average percentage- point difference	Count of significant differences of number of measures
Facilities/safety	63	777	65	7,634	-3	3 of 6
Coordination and timeliness	67	663	73	6,377	-5	6 of 8
Respect for patient preferences	75	979	82	9,562	-7	5 of 6
Emotional support/trust	69	972	76	9,111	-7	5 of 5
Information and education	59	815	66	8,329	-7	3 of 4
Overall impression of care/professionals	65	1,020	72	9,902	-8	7of 7
Physical comfort	62	605	70	5,812	-8	3 of 4
Transition/continuity	61	349	69	3,903	-8	8 of 11
Involvement of family/friends	65	685	76	7,189	-11	2 of 2
Total	64		72		-7	40 of 53 measures

Note: People without a mental health condition are the reference group, such that negative percentage point difference values represent less positive experiences for people with a mental health condition. Differences are counted where care experiences are significantly less positive for people with mental health conditions after adjusting for age, sex, language and education or the Adjusted Odds Ratio (AOR) <1 with pvalue<0.01. See Appendix A for results for all 53 questions. The average number of respondents are provided to demonstrate that not all patients answer all questions. For example, discharge related questions in the transition dimension are only asked of patients who leave ED without being admitted to hospital.

Figure 7.1 Percentage reporting the most positive response for key survey questions by condition group, NSW, 2017–18

Notes: People without a mental health condition are the reference group, such that negative percentage point difference values represent less positive experiences for those with a mental health condition. Percentage point differences are shaded where care experiences are less positive for people with mental health conditions after adjusting for age, sex, language and education (AOR<1, p<0.01).

To assess disparities in experiences across dimensions of experiences, Table 7.3 summarises differences between people with and without mental health conditions across all 53 measures and dimension. The table includes a summary for patients by condition group including: the average percentage of the most positive response for each dimension, the average percentage point differences between these two groups, and the count of disparities, or measures where the mental health condition group was significantly less positive. There were no measures where people with mental health conditions had significantly more positive experiences (see Appendix Table 7.4 for all results).

People with mental health conditions had less positive experiences of care in ED across 40 of 53 measures and on all nine dimensions of patient experience. There were disparities on all measures in certain dimensions– overall impressions of care and professionals, physical comfort, and continuity of care. For these types of experiences, people with a mental health condition reported results that were eight percentage points lower or more on average. There was also a large gap of 11 percentage points on average for measures regarding patients' views of involvement of their friends and family.

In contrast, for measures about the facilities, in relation to cleanliness and parking, or feelings of physical safety, there was an average difference of three percentage points, with three of six measures having significant disparities for people with mental health conditions.

There were also areas where there with low levels of positive experiences, where everyone was generally less positive about experiences of care. In particular, for questions regarding information and education, and engagement at discharge, around six in 10 patients with mental health conditions had positive experiences. This is lower than the average positive response percentage for other experience dimensions.

Discussion

Experiences of ED care were positive for a majority of patients, with 60% or more reporting the most 'very good' overall ratings of care. However, compared to those with no mental health condition, people with mental health conditions reported less positive experiences with ED care for overall ratings (52% very good) and for 40 of 53 measures across nine experience dimensions after adjusting for age, sex, language spoken at home and education.

Findings presented here build on results for a subset of questions in the same survey published by the Bureau of Health Information, which concluded that patients in NSW with mental health conditions including lower levels of respect, communication and engagement with families and carers (Bureau of Health Information, 2019a). Findings from an ED experience survey in England showed that experiences were lower than average for people with mental health conditions on four of eight measures of experiences including: involvement and decision-making, confidence and trust in staff, respect and dignity and emotional support (Care Quality Commission, 2017). In the same report, areas where there were no substantial differences included privacy, attention from staff, information and overall experience. Consistent with the English results, this analysis showed that questions about facilities such as cleanliness and parking, or coordination and timeliness include measures with no disparities for patients with mental health conditions.

From a measurement perspective, there are also insights from this analysis. The types of measures where we found no differences were often those with yes/no responses to more objective aspects of care such as whether patients were told how long they would have to wait, or told who to contact if they needed more information when they got home. Further experiences of measures of cleanliness of the facilities, with multiple response options, also showed no significant differences. These measures with no differences may act as a ‘baseline’ to show that patients with a mental health condition are not simply less positive in their response tendencies for all questions. Thus, the questions and dimensions of experiences where there are pronounced differences become more meaningful. By summarising differences across a wide range of experiences, this analysis helps point to priority areas to work on to improve experiences for people with mental health conditions. Priority areas include both experiences with large disparities (overall ratings and impressions of professionals, physical comfort) and experiences where responses were notably low overall (information at discharge).

Understanding the experiences of patients with mental health conditions is important for helping to improve the quality of care and potentially reduce the number of people returning to ED. Evidence for hospital patients has shown those who feel more engaged when leaving hospital are less likely to return to care (Kemp, 2017). Studies have suggested that specific interventions should be developed for groups of patients who frequently return to ED that include people with mental health and substance use disorders (Lago et al., 2019). In this study, patients with mental health conditions said they were more likely to visit ED multiple times in a year, consistent with studies of administrative data (Lago et al., 2019, Niedzwiecki et al., 2018).

The findings of disparities in experiences presented here offer insights for quality improvement initiatives. There are emerging initiatives in the state seeking to improve patient experiences in ED, (NSW Health, 2018) and for providing alternatives to ED care for people with mental health conditions (Irving et al., 2018). A report by the Productivity Commission of Australia called for alternatives to EDs for people with mental health problems such as after-hours services and mobile crisis services which may include providing separate spaces in or near EDs for patients with mental health conditions (Productivity Commission, 2019). ‘Safe Haven’ cafes are one example of efforts to provide alternatives for managing alcohol related emergencies (Irving et al., 2018). These sorts of services for people experiencing a mental health crisis, may help provide alternatives to ED care for some patients (Productivity Commission, 2019). In New South Wales, there are also several evidence-based initiatives being trialled to improve the physical environments, tailoring information to patients and sending it to their mobile device, and professional development for ED staff (NSW Health, 2018).

Limitations

For people with lived-experience of mental health issues, qualitative studies provide examples of more specific patient concerns; such as feeling like their condition is not serious enough, or an 'overshadowing' of their physical symptoms due to their mental health needs (Jones et al., 2008, Clarke et al., 2007). It is important therefore, that the cohort in this study includes people with long standing mental health conditions, even when they presented for a physical health reason. There is also increasing interest to capture experiences of carers as they are recognised as a key support and also in need of support themselves (Goodwin and Happell, 2007) (Lavoie, 2018). Understanding provider experiences is important as well. They may have particular challenges dealing with mental health crises, involuntary admission, and substance use. Studies of their experiences include mention of the pressures of caring for mental health within targets for discharge time from ED (van Nieuwenhuizen et al., 2013).

Specifically, a key limitation regarding the quantitative analysis presented here is the under-representation of people with more serious mental health issues. The survey estimates only 11% with a self-reported condition compared to larger estimates based on research (20-30%) (Australian Bureau of Statistics, 2008, Fulbrook and Lawrence, 2015). The survey frame excludes people who were admitted for reasons related to self-harm or those later admitted to the hospital for mental health reasons. This limitation likely results in an underestimation of disparities for people with mental health conditions. In addition, the relatively low response rate for the survey (24%) may mean results could be biased. Despite this limitation the characteristics of the survey cohort population overall align well with the eligible population based on the ED administrative data.

Conclusion

In summary, people with mental health conditions face additional challenges when going to the emergency department irrespective of their primary reason for presentation. While most patients have positive experiences, there is room for improvement in emotional support, provision of information and respecting the preferences of patients with mental health conditions and their carers. Understanding and improving experiences of this group can help to reduce the readmissions that can occur when patients are not as engaged and supported in their care.

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Table 7.4 Percentage reporting the most positive response option, number of respondents, difference in experiences and adjusted odds ratio of reporting positive experiences for mental health condition group, NSW 2017–18

			Mental health condition		No condition		Disparities		
Dimension	Question	Response	N	%	N	%	Dif (%)	AOR	95%CI
Overall ratings	Overall, how would you rate the care you received while in the ED?	Very good	878	52	8646	60	-8	0.71	(0.62,0.81
	If asked about your experience in the ED by friends and family how would you respond?	Would speak highly	1018	62	10108	71	-9	0.69	(0.61,0.79)
	Were the ED staff you met on your arrival polite and courteous?	Yes, definitely	1170	76	11113	81	-5	0.76	(0.65,0.89)
	How would you rate how the ED health professionals worked together?	Very good	788	49	7744	56	-7	0.74	(0.65,0.84)
	Were the ED health professionals polite and courteous?	Yes, always	1207	79	11551	86	-7	0.64	(0.54,0.75)
	Overall, how would you rate the ED health professionals who treated you?	Very good	919	57	8991	66	-9	0.71	(0.62,0.81)
	Were the ED health professionals kind and caring towards you?	Yes, always	1159	76	11162	83	-7	0.68	(0.58,0.79)
Coordination /timeliness	Was the waiting time given to you by the ED staff you met on arrival about right?	Yes	304	73	3082	72	1	1.06	(0.8,1.39)
	From the time you arrived, how long did you wait before being triaged by a nurse?	within 15 min	979	69	9099	69	-0.2	1	(0.86,1.16)
	Did the ED health professionals introduce themselves to you?	Yes, all of them	978	70	9582	75	-5	0.78	(0.67,0.91)
	After triage, how long did you wait before being treated by an ED doctor or nurse? [Triage category 2]	Within 10 min	124	49	1197	64	-15	0.53	(0.37,0.76)
	After triage, how long did you wait before being treated by an ED doctor or nurse? [Triage category 3]	Within 30 min	304	58	2966	65	-7	0.75	(0.59,0.95)
	After triage, how long did you wait before being treated by an ED doctor or nurse? [Triage category 4]	Less than 1 hr	330	63	3570	69	-6	0.79	(0.62,1)
	Did you ever receive contradictory information about your condition or treatment from ED health professionals?	No	1176	78	10799	81	-3	0.89	(0.76,1.05)
	Was your departure from the ED delayed, before leaving the ED to go to a ward, home, or elsewhere?	No	1110	76	10724	84	-8	0.61	(0.53,0.72)
Emotional support/trust	Did you have confidence and trust in the ED health professionals treating you?	Yes, definitely	1044	67	10166	76	-9	0.68	(0.59,0.78)
	Did an ED health professional discuss your worries or fears with you?	Yes, completely	183	35	1448	43	-9	0.73	(0.58,0.92)
	In your opinion, did the ED nurses who treated you know enough about your care and treatment?	Yes, always	881	65	8854	73	-7	0.72	(0.62,0.84)
	While you were in the ED, did you feel threatened by other patients or visitors?	No	1379	90	12349	93	-3	0.73	(0.58,0.92)
	Treated unfairly in the ED (derived measure)	No	1371	90	12737	96	-6	0.39	(0.31,0.49)
Facilities/ safety	Was there a problem in finding a parking place near to the ED?	No problem	488	57	5458	58	-1	0.88	(0.74,1.05)
	Was the signposting directing you to the ED of the hospital easy to follow?	Yes, definitely	710	69	7807	75	-7	0.74	(0.62,0.88)
	How clean was the waiting area in the ED?	Very clean	475	50	4358	47	3	1.06	(0.9,1.24)
	Did you see ED health professionals wash their hands, or use hand gel to clean their hands, before touching you?	Yes, always	776	50	7536	56	-6	0.8	(0.7,0.91)
	How clean was the treatment area in the ED?	Very clean	1021	67	9209	68	-1	0.93	(0.81,1.06)
	While you were in the ED, did you see or hear any aggressive or threatening behaviour towards ED staff?	No	1190	84	11437	89	-5	0.73	(0.61,0.88)
Information and education	Did the ED staff you met on arrival give you enough information about what to expect during your visit?	Yes, completely	632	44	6932	52	-8	0.75	(0.65,0.86)
	Did the ED staff you met on arrival tell you how long you would have to wait for treatment?	Yes	452	39	4491	41	-2	0.92	(0.79,1.07)
	Did the ED health professionals explain things in a way you could understand?	Yes, always	1090	72	10812	81	-9	0.63	(0.55,0.73)
	How much information about your condition or treatment was given to you by ED health professionals?	Right amount	1084	78	11080	88	-10	0.57	(0.49,0.68)
Involvement of family/friends	If your family members or someone else close to you wanted to talk to the ED staff, did they get the opportunity to do so?	Yes, definitely	636	59	6502	69	-10	0.7	(0.59,0.82)
	How much information about your condition or treatment was given to your family, carer or someone else close to you?	Right amount	734	71	7875	84	-13	0.56	(0.47,0.67)
Physical comfort	Experienced issues with seating, safety, noise, temperature or odour in the waiting area	No	578	61	6528	70	-9	0.73	(0.62,0.87)
	Were you able to get assistance or advice from ED staff for your personal needs (e.g. for eating, drinking)	Yes, always	741	61	6943	71	-9	0.66	(0.56,0.77)

			Mental health condition		No condition		Disparities		
Dimension	Question	Response	N	%	N	%	Dif (%)	AOR	95%CI
	Do you think the ED health professionals did everything they could to help manage your pain?	Yes, definitely	472	53	4456	64	-11	0.64	(0.54,0.77)
	While you were waiting to be treated, did ED staff check on your condition? (coordination	Yes	630	72	5322	74	-2	0.9	(0.74,1.1)
Respect for preferences	Did you have enough time to discuss your health or medical problem with the ED doctors?	Yes, definitely	889	64	9402	74	-11	0.65	(0.56,0.75)
	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Yes, definitely	777	56	8369	67	-11	0.64	(0.56,0.74)
	Did you feel you were treated with respect and dignity while you were in the ED?	Yes, always	1160	76	11460	86	-10	0.56	(0.48,0.65)
	Did you stay until you received treatment?	Yes	1528	96	13275	97	-0.3	0.85	(0.59,1.2)
	Were you given enough privacy during your visit to the ED?	Yes, always	1076	70	10577	79	-9	0.65	(0.57,0.76)
	Were your cultural or religious beliefs respected by the ED staff?	Yes, always	443	88	4291	92	-4	0.56	(0.39,0.81)
Transition/ continuity	Did you feel involved in decisions about your discharge from hospital?	Yes, definitely	526	64	5835	73	-9	0.66	(0.55,0.79)
	Did an ED health professional tell you when you could resume your usual activities?	Yes, definitely	263	48	3003	58	-10	0.74	(0.6,0.91)
	Did the ED staff provide you with a document that summarised the care you received?	Yes	461	56	5031	60	-4	0.84	(0.71,0.99)
	Thinking about when you left the ED, were you given enough information about how to manage your care at home?	Yes, definitely	480	60	5973	73	-13	0.62	(0.52,0.74)
	Did ED staff take your family and home situation into account when planning your discharge?	Yes, definitely	313	63	3367	72	-9	0.7	(0.56,0.88)
	Thinking about when you left the ED, were adequate arrangements made by the hospital for any services you needed?	Yes, definitely	240	53	2547	63	-10	0.69	(0.54,0.87)
	Did ED staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes	614	81	6441	84	-3	0.94	(0.75,1.16)
	Did an ED health professional tell you about what signs or symptoms to watch out for after you went home?	Yes, completely	421	49	5244	61	-12	0.68	(0.58,0.81)
	Did an ED health professional explain the purpose of this medication in a way you could understand?	Yes, completely	216	81	2319	88	-7	0.59	(0.4,0.88)
	Did an ED health professional tell you about medication side effects to watch for?	Yes, completely	133	50	1430	54	-3	0.8	(0.59,1.07)
	Did you feel involved in the decision to use this medication in your ongoing treatment?	Yes, definitely	168	67	1744	71	-4	0.74	(0.53,1.02)

Note: People without a mental health condition are the reference group, such that negative percentage point difference values represent less positive experiences for people with a mental health condition, where differences are based on unrounded values. Significant differences are highlighted in grey were care experiences are statistically significantly less positive for people with mental health conditions after adjusting for age, sex, language and education (p<0.01). There were no differences where experiences were more positive. The average number of respondents are provided to demonstrate that not all patients answer all questions. For example, discharge related questions are only asked of patients who are not subsequently admitted to hospital.

Chapter 8: Experiences of maternity care in New South Wales

This chapter consists of a journal article:
Corscadden, L., Callander, E.J., Topp, S.M. et al. Experiences of maternity care in New South Wales among women with mental health conditions. BMC Pregnancy Childbirth 2020,20, 286.

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Experiences of maternity care in New South Wales among women with mental health conditions

L. Corscadden[1,2*], E. J. Callander[3], S. M. Topp[4] and D. E. Watson[2]

High quality maternity care is increasingly understood to represent a continuum of care spanning antenatal, labour and birth and postnatal phases that ensures a positive experience for mothers and families, and responds to their mental health needs. Mental health and maternity care are interconnected. Pregnancy and childbirth is a life changing period for women and their families, with many uncertainties and changes that may bring up new or existing mental health related needs. It is estimated more than one in ten mothers experience depressive episodes in the first months following birth (Gavin et al., 2005) with other studies suggesting as many as a quarter of women have depression or other mental disorders in early pregnancy (Howard et al., 2018). Mental health issues during and following pregnancy may have serious consequences for both mother and baby (Diego et al., 2004, Field et al., 2010).

In light of the importance of mental health in relation to the long-term outcomes of mother and child, consideration of mental health has become embedded within maternal health guidelines and policies. In early 2000, the World Health Organization (WHO) set out principles of perinatal care including a focus on ‘women-centred’ care which is culturally appropriate and provides women with information to make informed decisions (Chalmers et al., 2001). In Australia, guidelines for pregnancy care incorporate these WHO principles, and highlight guidelines for caring for population groups including women with serious mental illness (Department of Health, 2018). In New South Wales (NSW), one of the aims of the *Towards a Healthy Birth* framework is to develop, implement and evaluate strategies to support women to have a positive experience of pregnancy and birth (NSW Ministry of Health, 2019). At the same time, NSW's *First 2000 Days Framework* sets out guidelines to help improve opportunities for health intervention between pregnancy and the child's fifth birthday. It acknowledges the emotional needs of women can have an impact on both mothers' and babies' outcomes when they are not met (NSW Ministry of Health, 2019).

All women should have a positive pregnancy experience and at-risk women should have experiences that are responsive to their unique needs, if public health systems aim for high quality, equity and optimal outcomes for all mothers and families. These needs are encompassed in a global push for universal health coverage that 'leaves no one behind', and which is often defined equitable coverage of high quality care for all (World Health Organization, 2018). Despite the recognised importance of people's experiences with care and guidelines to ensure maternity care is responsive to mental health needs, literature on equity in care experiences has, to date, overlooked mental health. Studies from Scotland, England and Italy have explored equity in experiences of maternity care based on large representative patient surveys. These studies have shown women with: lower education (Tocchioni et al., 2018), from ethnic minority groups (Raleigh et al., 2010) younger women, and those from more deprived areas, and those with poorer health, had less positive experiences of care (Cheyne et al., 2019). We have found no study comparing maternity experiences of women with mental health conditions alongside more commonly assessed characteristics such as age, education, and parity.

The aim of this analysis is to answer the following questions:

- Do women with a long standing mental health condition have more or less positive experiences of care than other mothers?
- Is healthcare responsive to the particular or additional needs of women with mental health conditions from their perspectives?
- Which types of experiences reflect the most pronounced disparities in experiences for mothers with mental health conditions?

Methods

In 2017, more than 62,000 women gave birth in a New South Wales public hospital and all were eligible to participate in the Maternity Care Patient Survey. These women represent a majority of 97,000 deliveries in the state, where the remainder occur in private hospitals or out of hospital settings (Centre for Epidemiology and Evidence, 2018). Three months after birth, a stratified random sample of women in 71 public hospitals with more than 100 deliveries were invited to complete a paper or online survey. The survey excluded women who received inpatient psychiatric care, or who had a still birth. Nearly 5000 women over 18 years participated (n=4,787, response rate 35%). Women shared their experiences across four stages of antenatal care, care during labour and birth, care in hospital following birth and follow up care at home. The survey is largely based on a survey in England and modified for the Australian context (Todd et al., 2016) and is available on the Bureau of Health Information's website (http://www.bhi.nsw.gov.au) along with a technical supplement describing the survey methods, exclusions and representativeness. Responses were weighted to be representative of mothers who gave birth in public hospitals (Bureau of Health Information, 2018).

Mothers were considered as having a long-standing mental health condition based on their response when asked: 'Which, if any, of the following longstanding conditions do you have?'. Eight condition options are listed including 'A mental health condition (eg. depression)'. Women who responded 'yes' to that option are referred to in this analysis as having a mental health condition. We interpreted long-standing to mean these women had experienced mental health issues before their most recent pregnancy whether or not they had an acute episode of illness across the four stages of care.

Bivariate and multivariate analyses was conducted to assess differences in experiences by the presence of a self-reported longstanding mental health condition(s) for 64 measures including prenatal, perinatal and post-natal care. For each survey question, responses were dichotomised to focus on most positive response ('very good', 'always'), with all other response categories combined. Missing and not-applicable responses were excluded. This is consistent with published use of this survey data for public reporting (Bureau of Health Information, 2018). Analysis of a full set of survey measures is common in other equity focused analyses of survey results (Saunders et al., 2015, Cheyne et al., 2019).

Using logistic regression models, we compared the odds of positive experiences of care between women with and without a self-reported mental health condition for each of the 64 experience measures adjusting for age, remoteness, language spoken at home (English or non-English), parity, birth type and local health district of residence. Covariates were selected on the basis of univariate analyses and literature. In this analysis, differences in experiences that are associated with having a mental health condition, that are not related to other factors such as age, parity or location are referred to as disparities. Disparities are assumed to be amenable to improvement efforts.

In addition, experiences of women with and without mental health conditions were compared by calculating the percentage point difference in reporting the most positive response option. Where a negative percentage point differences suggests women with a mental health condition had less positive experiences.

To summarise responses, survey questions were mapped onto eight dimensions of patient experiences of care based on the literature (Jenkinson et al., 2002) including:

- overall impressions (e.g. overall ratings, courtesy of doctors),
- emotional support (e.g. discussion of fears, confidence and trust),
- respect for preferences (e.g. treated with respect and involved in decisions),
- information and education (e.g. provided information with clear explanations)
- involvement of family (e.g. family given information and opportunity to talk to professionals)
- physical comfort (e.g. pain management, assistance)
- coordination of care (e.g. organised, appointments on time, no conflicting information)
- continuity and transition (e.g. support in management of condition, know what to do next, told about side effects).

The full list of 64 measures and the domains they were mapped to is provided in the Appendix. In addition, within the larger list, two sub-groups of questions of interest were identified. First, we identified measures that have been identified in research and practice as being particularly important measures of patient experiences (Bureau of Health Information, 2019, Commission, 2019, Redshaw et al., 2019).

<u>Overall impressions</u>

- Overall, antenatal care was 'very good'
- Overall, hospital care during birth was 'very good'
- Overall, hospital care following delivery was 'very good'
- Overall, follow up care was 'very good'

<u>Emotional support</u>

- Professionals discussed worries and fears during antenatal care
- Professionals discussed worries and fears during labour
- Had confidence and trust in professionals during labour and birth

<u>Respect for patient preferences</u>

- 'Definitely' had input about pain relief during labour and birth
- 'Always' treated with respect and dignity during labour and birth
- 'Definitely' involved in decisions during labour and birth
- 'Definitely' involved in decisions about discharge

<u>Information and education</u>

- Received enough information about pain relief prior to the birth
- Professionals 'always' explained antenatal care clearly
- Midwives/doctors 'always' explained labour and birth clearly
- Professionals explained care following birth clearly
- Professionals gave enough information self-care after birth

<u>Physical comfort</u>

- Professionals did everything to help manage pain after birth

<u>Coordination</u>

- Antenatal care was 'very well organised'
- No conflicting information during labour and birth
- No conflicting information about self-care or care for baby

Second, we focused on experience measures that could serve as a proxy for guidelines for maternity care for women with mental illness and, therefore, where experiences would be expected to occur to ensure care is responsive to unique mental health needs. Therefore, a subset of five questions was identified as related to Australian guidelines for maternal care for women with mental health conditions, including questions about; emotional health, weight gain, and substance use as outlined to follow (Department of Health, 2018).

Survey questions	Related guidelines
• Did the health professionals give you advice about the risks of consuming alcohol while pregnant? • Did the health professionals give you advice about the risks of exposure to tobacco smoke while pregnant?	As part of providing ‘education about nutrition and ceasing smoking, substance use and alcohol intake in pregnancy'
• During a follow-up appointment, did a midwife or nurse ask you how you were feeling emotionally? • Did the health professionals ask you how you were feeling emotionally during your pregnancy? • After the birth, did the health professionals give you enough information about how to care for yourself?	As part of 'monitoring for early signs of relapse, particularly as medication is often ceased before or during pregnancy'

Results

Almost one in 10 women (7%, N=353) reported they had a mental health condition. These mothers tended to be younger, English speaking, born in Australia, have less formal education, and reside in rural areas (Table 8.1)

The factors associated with overall ratings of care at each stage of care are presented in Table 8.2. Overall, 63% of women rated their antennal care as ‘very good’ – this ranged from lows of 53% among women aged 18 to 24, and 55% among women with a mental health condition, to 74% of women from small hospitals. Similarly, for care during labour and birth and hospital care following birth, younger mothers and those who had mental health conditions were less likely to report high ratings. For follow up care at home, women from rural areas, giving birth in small hospitals, and those from high socio-economic status areas were more likely to rate the care received as ‘very good’ (Table 8.2).

Table 8.1 Characteristics of the respondents, by mental health condition group

		Percentage (%)			Number of respondents (n)		
		No condition group	Mental health group	Total	No condition group (n=4,315)	Mental health group (n=353)	Total (n=4,668)
Age*(p<0.001)	18-24	7	16	8	339	62	401
	25-29	24	22	24	1142	88	1230
	30-34	40	38	40	1682	127	1809
	35+	29	24	28	1152	76	1228
Language spoken at home* (p<0.001)	English	72	93	74	3540	338	3878
	Non-English	28	7	26	749	14	763
Born in Australia* (p<0.001)	Yes	55	83	57	2926	311	3237
	No	45	17	43	1389	42	1431
Education* (p<0.001)	Post graduate/higher degree	19	13	19	718	49	767
	Trade or technical certificate	24	26	24	1089	98	1187
	University degree	34	23	34	1439	73	1512
	Completed Year 12 or equivalent	14	23	14	643	73	716
	Less than Year 12 or equivalent	9	14	9	415	60	475
Socioeconomic status of postal code area (p=0.6757)	Quintile 1: Most disadvantaged	19	17	19	751	68	819
	Quintile 2	17	15	17	997	82	1079
	Quintile 3	24	22	24	1028	85	1113
	Quintile 4	22	26	22	816	69	885
	Quintile 5: Least disadvantaged	18	19	18	720	49	769
Rurality* (p<0.001)	Major cities	79	65	78	2282	140	2422
	Inner regional	16	27	17	1418	149	1567
	Outer regional, remote,very remote	5	8	5	614	64	678
Birth type (p=0.6087)	Vaginal birth	59	56	59	2637	206	2843
	Assisted vaginal birth	13	17	14	498	47	545
	Caesarean section (emergency)	14	14	14	591	51	642
	Caesarean section (planned)	14	13	14	568	48	616
Induced (p=0.6093)	No	57	59	57	2252	188	2440
	Yes	43	41	43	1442	116	1558
Given birth before (parity) (p=0.3356)	No	48	52	49	1995	183	2178
	Yes	52	48	51	2317	170	2487
Hospital size (p=0.0788)	Large and specialist	54	48	54	1035	63	1098
	Major	36	40	36	1718	153	1871
	Small	10	13	10	1562	137	1699
Provider of most antenatal care (p=0.7863)	Midwife(s)	61	62	61	2542	202	2744
	Obstetrician	17	16	17	657	52	709
	GP	16	14	15	850	71	921
	Other	6	7	6	266	28	294

Notes: * The distribution of characteristics for women with a mental health condition are significantly different than without a mental health condition (p ChiSq<0.001). Of all respondents, 7% self-reported a longstanding mental health condition. Missing responses excluded.

Comparing differences in experiences for selected measures

To determine if women with long standing mental health condition(s) have more or less positive experiences than other mothers - experience measures were compared between women with and without a mental health condition adjusting for age, language, education, parity, type of birth, and local health district. Across commonly reported measures of experiences, women with mental health conditions reported significantly less positive experiences for 16 of 20 measures (top part of Figure 8.1) For example, 76% of women with a mental health condition reported that they were 'always' being treated with respect, compared to 90% of women with no condition. Further, fewer than half of women with a mental health condition (48%) said they received enough information on pain relief, compared to 62% of women with no condition. Similarly, fewer than half of women with a mental health condition (48%) reported that they discussed worries and fears, compared to 63% of women with no condition.

Importantly, women with mental health conditions offered high ratings of care for measures that we expected, prospectively, to see same or better experiences due to the presence of guidelines for maternity care for women with mental illness. Furthermore, there were no significant differences between women with and without mental health conditions across six experience measures selected to serve as a proxy for guidelines (bottom of Figure 8.1). About nine in ten women in both groups were asked how they were feeling emotionally during antennal check-ups – 89% of those with a mental health condition and 93% of women with no condition. Nearly all women said they were asked how they were feeling emotionally during follow-up care (97% and 98%).

Comparing differences across domains and stages of care

To assess disparities in experiences across domains and stages of care, Table 8.3 summaries differences between women with and without mental health conditions across 64 measures. The number of measures where there were significant differences between groups across the domains and stages of care are presented (Table 8.3 a) as well as the percentage point differences between these two groups across eight domains and four stages of care (Table 8.3 b)

Women with mental health conditions had significantly less positive experiences for 41 of 64 measures, and only more positive on one measure. For example, women with mental health conditions were less positive across seven of nine overall experience measures – one overall measure in relation to antenatal care, two overall measures of care during delivery and four overall measures of hospital care following birth. At the same time, women with mental health conditions were less positive of antenatal care across seven experience measures – one overall measure, two measures of emotional support, two measures related to information and education and two questions regarding coordination of care. Across stages of maternity care, experiences were significantly less positive for women with mental health conditions for 7 of 17 antenatal measures, 13 of 18 birth-related measures, 19 of 23 measures about hospital care following birth, and 2 of 6 measures of follow up at home. Experiences were significantly more positive for one measure (i.e. information on safe sleeping). In relation to the magnitude of differences between women with and without mental health conditions, the percentage point differences were most pronounced during hospital care following birth, with an average adjusted difference of -11. There were differences of 8 percentage points or more on average across all dimensions of care in that stage.

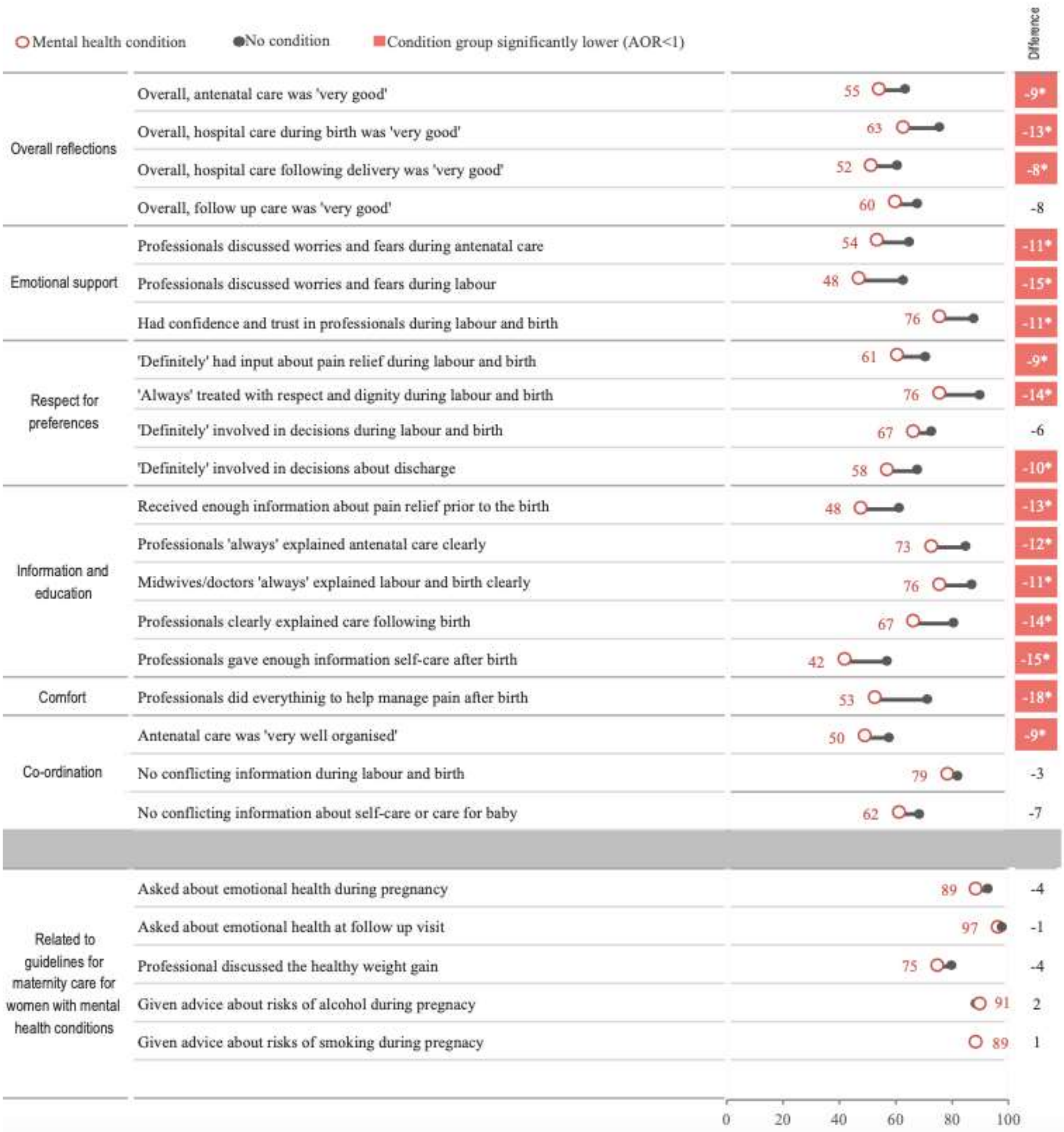
Across experience dimensions, the differences between women with and without a mental health condition, were most pronounced for experiences about comfort (average percentage point difference: -11) and overall impressions of care and emotional support (average percentage point difference was -10 for both measures). For example, 76% of women with a mental health condition said they 'always' had confidence and trust in doctors and midwives providing care during labour, compared to 88% of women with no condition (percentage point difference: -12). Results for all 64 experience measures are available in the Technical Appendix (Table 8.4).

Table 8.2: Percentage of women rating care as ‘very good’ by stage of care and patient characteristics

		Antenatal	Labour and birth	Hospital following birth	Follow up at home
New South Wales (NSW)		63	75	60	67
Age	18-24	**53**	**64**	**50**	**61**
	25-29	64	74	58	66
	30-34	63	77	62	69
	35+	65	76	62	68
Immigrant	Born in Australia	66	77	60	68
	Not born in Australia	59	72	60	66
Language spoken at home	Non-English	65	77	60	68
	English	57	70	59	66
Mental health condition	No (self-reported)	64	76	60	68
	Yes (self-reported)	**55**	**63**	**52**	**60**
Socio-economic status of area	Quintile 1: Most disadvantaged	58	68	59	66
	Quintile 2	60	76	60	63
	Quintile 3	65	75	58	**72**
	Quintile 4	63	75	60	66
	Quintile 5: Least dis.	**70**	**81**	63	69
Rurality	Major cities	62	74	59	68
	Inner regional	67	76	62	66
	Outer regional and remote	69	80	**67**	61
Education	Post graduate/higher degree	66	76	60	68
	University degree	62	74	59	67
	Trade or technical certificate	63	77	61	67
	Completed Year 12 or equivalent	62	72	60	66
	Less than Year 12 or equivalent	62	77	59	69
Survey mode	Hardcopy	64	76	60	68
	Online	61	73	60	67
Baby spent time in intensive care	No	64	77	61	68
	Yes	58	67	57	63
Type of birth	Assisted vaginal birth	59	69	57	67
	Caesarean section(emergency)	59	67	56	62
	Caesarean section	62	78	65	68
	Vaginal birth	65	78	60	69
Induced	No	65	76	61	69
	Yes	61	73	57	66
Given birth before (parity)	No	63	73	56	64
	Yes	64	77	63	**71**
Who provided	Midwives	66	77	61	70
	Obstetrician	61	72	52	61
	GP	56	72	63	65
Hospital size	Large, or specialist hospitals	61	75	59	67
	Major hospitals	63	73	59	68
	Smaller district hospitals	**74**	**82**	**72**	67

Note: Descriptive results where green shading denotes the highest two ratings in a column and red shading denotes the lowest two ratings.

Figure 8.1: Percentage reporting the most positive response for selected questions by condition group



Notes: Selected questions include experiences that matter most (20 questions) or related to guidelines (5 questions). Women without a mental health condition are the reference group, such that negative percentage point difference values represent less positive experiences for women with a mental health condition. Percentage point differences are shaded were care experiences are statistically significantly less positive for women with mental health conditions after adjusting for age, language, education, parity, birth type, and local health district.

Table 8.3 Number of significant disparities, and average difference in experiences by dimension and stage of care

	Stage of maternity care				
Experience domain	Antenatal (17 questions)	During birth (18 questions)	Hospital following birth (23 questions)	Follow up at home (6 questions)	Summary or average across domain
a) Number of measures where there were significant disparities for women with mental health conditions*					
Overall impression	1	2	4		7 of 9
Emotional support	2	2	1		5 of 7
Physical comfort		2	6		8 of 9
Information and education	2	1	3		6 of 11
Involvement of friends and family		1	1		2 of 2
Respect for patient preferences		4	2	2	8 of 11
Continuity and transition			1		1 of 3
Coordination of care	2	1	1		4 of 12
Total (64 questions)	7	13	19	2	41 of 64
b) Average percentage point difference between women with and without a mental health condition					
Overall impression	-7	-10	-12	-8	-10
Emotional support	-9	-13	-13	-1	-10
Physical comfort		-13	-10		-11
Information and education	-5	-11	-12	2	-8
Involvement of friends/ family		-9	-8		-8
Respect for patient preferences		-7	-9	-8	-7
Continuity and transition			-10	2	-6
Coordination of care	-2	-4	-9		-4
Total (64 questions)	-5	-8	-11	-3	-8

Note: Women without a mental health condition are the reference group, such that negative percentage point difference values represent less positive experiences for women with a mental health condition. Percentage point differences are counted were care experiences are statistically significantly **less positive** for women with mental health conditions after adjusting for age, language, education, parity, birth type, and local health districts.
*Women with mental health conditions had significantly more positive experiences on only one measure for information and education, at follow up at home about safe sleeping for the baby, and is not noted in this table counts of significant disparities. See Appendix A for results for all 64 measures.

Discussion

A majority of women reported positive overall ratings of antenatal care, care during labour and birth, hospital care following birth and follow up care at home. In addition, the vast majority of women, including those with self-reported longstanding mental health conditions, give very high ratings to experience measures related to guidelines for maternity care related to mental illness. Australian guidelines that can be measured from mothers' perspectives include, provision of information about how to care for themselves if they need it (e.g. provide psychoeducation, advise about the benefits of support groups, advice on benefits of counselling), monitoring weight gain and substance use for example. This confirmed our hypothesis that women with mental health conditions would have the same or ideally more positive experiences on measures related to these guidelines. Australian guidelines recommend women are asked about their emotional health (Department of Health, 2018).

About nine in ten women both with and without mental health conditions said they were asked about emotional health during antennal check-ups (89% and 93%), follow-up care (97% and 98%). Internationally, most women recalled being asked about their emotional health during pregnancy (82%) and in the postnatal period (90%) (Redshaw and Henderson, 2016). However, this is the first study we are aware of to look at questions related to emotional well-being by mental health condition group.

While women who have a mental health condition reported positive experiences related to guidelines, they reported less positive experiences with care across all eight experiences domains and all four stages of care compared to women with no condition. Women with mental health conditions were less positive about experiences for 41 of 64 measures, and only more positive on one, after adjusting for age, language and birth type among other factors. Disparities for the mental health group were most pronounced for experience dimensions related to comfort, emotional support, respect for preferences, and overall reflections of care. Across stages of maternity care, differences were most pronounced during hospital care following birth. In contrast, for questions about continuity and coordination, and care during antenatal and follow up stages of care there were fewer significant differences. Consistent with this finding, analysis of maternity care in Scotland showed that women reporting poorer health, also reported less positive experiences in most domains of care including pain relief, communication, involvement in decisions, confidence and overall ratings (Cheyne et al., 2019).

A New South Wales Ministry of health report notes, “Preparing mothers emotionally for birth, and promoting the mental health of parents and carers in pregnancy, can make a dramatic difference to how parents and carers experience birth, and how they cope in their transition from pregnancy to parenthood” (NSW Ministry of Health, 2019). This analysis brings to light several areas of women’s experiences of maternity care where care could be improved for mothers with mental health conditions. Findings build on a state report that showed women in New South Wales with mental health conditions had less positive experiences of care than those with no condition for a subset of measures (Bureau of Health Information, 2019). While women offer positive ratings of maternal care and very high ratings on experience measures identified as proxies for guidelines, women who report having mental health conditions offer less positive ratings on many domains of care critically important to clinical quality and outcomes including, for example, emotional support, respect for preferences, information and education and pain management.

This study adds to the evidence that despite universal care in Australia, vulnerable women do not experience the same complete and quality access to maternity care that has been posed elsewhere (Sutherland et al., 2012). The current study suggests, women with mental health conditions which may be among those most in need of support during and following pregnancy can be less likely to get it. This was also true for experiences related to emotional support, where it would be expected that those with mental health conditions should report better experiences than those with no mental health conditions. Where other studies on disparities in experiences have focused on young mothers, from diverse or low income backgrounds (Cheyne et al., 2019), this current study demonstrates that mothers with mental health conditions need more support in terms of overall maternal care and care for mental health needs.

Ensuring women with mental health related needs get access to mental health care during and after their pregnancy is a part of providing good continuity of care. There is evidence that some models of care, such as those providing continuity of care, can have benefits particularly for vulnerable groups (Homer, 2016). However, there are barriers that may prevent women from seeking mental health treatment including: stigma, a fear of losing parental rights, negative experiences with health professionals, and a perceived lack of skills among professionals to help them (Byatt et al., 2013). Professionals themselves may not feel prepared to deal with mental health needs. A study of midwives suggests they do not feel well equipped to deal with mental health issues (Mccauley et al., 2011). In this study, it was not possible to consider how possible differences in staff or service settings may enable patient-provider relationships or responsive care to mothers with mental health conditions.

Maternity experience surveys and monitoring experiences for mothers from vulnerable groups may help draw attention to these needs more regularly and show where they differ regionally. Currently in Australia, indicators and regular reporting on maternity care exclude experiences and do not focus on intersections with mental health (AIHW, 2018). Monitoring, transparency and regular reporting is important to help the general public and providers understand the variation in experiences. Further, data linkage between guideline related experiences and outcomes, could help to substantiate the degree to which better experiences lead to better outcomes. This may help improve the evidence base to include patient experiences as part of practice guidelines.

Limitations

This secondary analysis of cross-sectional data cannot be used to determine if the mental health condition was present before birth or would have been considered only after birth. The survey likely underrepresents mothers with serious mental health conditions as the survey excludes women who spent any time in a psychiatric unit, had a history of self-harm or expressed suicide ideation. There were too few Aboriginal women represented in the survey to consider their experiences as a group in this analysis. Other analysis suggests, some minority groups not included due to lower representation (Cheyne et al., 2019), and postal or paper surveys may not be the right method to capture their experiences. The survey response rate of 35% may also introduce sources of bias that were not possible to determine from a review of the evidence of representativeness outlined in the survey technical supplement.

Analysis findings may be sensitive to methods used. There are different findings in the literature for link between experience and age or parity and experience for example. The analysis of the most positive category may not be sensitive to the fact that some groups may have reporting tendencies that avoid extreme responses. Some analyses use scored responses that include all response categories. With survey data alone it is not possible to establish meaningful differences. Using linked data in future analysis may help demonstrate possible clinical significance of different experiences of care. However, in this analysis the focus is an aspirational goal of ensuring all women have positive experiences.

Conclusions

Women with mental health conditions offer high ratings on a small selection of experience measures identified as proxies for guidelines, but otherwise report substantially less positive experiences of care than women without conditions across all domains and stages of the maternal care journey. They represent a unique and important population group to consider who have particular needs that must be better understood and addresses. Hospital care following birth, emotional support and respect for patient preferences are key areas for improvement of experiences for women with mental health conditions, where there were pronounced disparities. There are also opportunities for better data collection and monitoring of experiences of screening for mental health issues, whether or not people are getting help when women identify that they are in need of help with mental health conditions.

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Table 8.4 Percentages, difference and adjusted odds of reporting positive experiences, women with compared to those without, a mental health condition

Dimension	Stage	Question	Response	MHC (n)	MHC (%)	No MHC (%)	GAP	AOR	AOR 95% CI
Overall	1	#Overall, how would you rate the antenatal care you received during your pregnancy?	Very good	341	55	64	**-9***	0.69	(0.51,0.94)
	1	Were the health professionals providing your antenatal care polite and courteous?	Yes, always	345	84	90	-6	0.67	(0.43,1.05)
	2	#Overall, how would you rate the care you received in the hospital during your labour and birth?	Very good	351	63	76	**-13***	0.55	(0.4,0.76)
	2	Were the midwives or doctors kind and caring towards you? [during labour and birth]	Yes, always	352	82	89	**-7***	0.58	(0.39,0.86)
	3	#Overall, how would you rate the care you received in the hospital after your baby was born?	Very good	350	52	60	**-8***	0.72	(0.53,0.97)
	3	If friends and family asked about your maternity experience at the hospital where you gave birth, how would you respond?	Would speak highly	352	70	81	**-11***	0.57	(0.41,0.8)
	3	After the birth of your baby, were the health professionals taking care of you kind and caring?	Yes, always	352	63	78	**-14***	0.5	(0.36,0.7)
	3	Looking back, do you feel that the length of your stay in hospital was…?	About right	352	71	84	**-13***	0.49	(0.34,0.69)
	4	#Overall, how would you rate the care you received in the first two weeks after arriving home from the hospital?	Very good	353	60	68	-8	0.75	(0.55,1.02)
Emotional	1	(MH) Did the health professionals ask you how you were feeling emotionally during your pregnancy?	Yes	334	89	93	-4	0.67	(0.4,1.11)
	1	#Did the health professionals discuss your worries or fears with you? [at antenatal check-ups]	Yes, completely	240	54	65	**-11***	0.67	(0.46,0.97)
	1	Did you have confidence and trust in the health professionals providing your antenatal care?	Yes, always	345	71	83	**-11***	0.54	(0.39,0.76)
	2	#Did you have confidence and trust in the midwives or doctors taking care of you during your labour and birth?	Yes, always	352	76	88	**-11***	0.48	(0.33,0.69)
	2	#Did a midwife or doctor discuss your worries or fears with you? [during labour and birth]	Yes, completely	214	48	63	**-15***	0.54	(0.37,0.78)
	3	Shortly after the birth, did a health professional talk to you about how the birth had gone?	Yes	353	62	75	**-13***	0.55	(0.41,0.76)
	4	(MH) During a follow-up appointment, did a midwife or nurse ask you how you were feeling emotionally?	Yes	337	97	98	-1	0.63	(0.29,1.39)
Information	1	(MH) Did the health professionals give you advice about the risks of consuming alcohol while pregnant?	Yes	324	91	89	2	1.19	(0.68,2.09)
	1	(MH) Did the health professionals give you advice about the risks of exposure to tobacco smoke while pregnant?	Yes	329	89	88	1	1.04	(0.61,1.75)
	1	(MH) Did the health professionals discuss the importance of healthy weight gain with you? [at antenatal check-ups]	Yes	321	75	80	-4	0.77	(0.53,1.11)
	1	#Did the health professionals providing your antenatal care explain things in a way you could understand?	Yes, always	346	73	85	**-12***	0.51	(0.35,0.74)
	1	#Did you receive enough information about pain relief options prior to the birth?	Yes, definitely	314	48	62	**-13***	0.58	(0.42,0.8)
	2	#During your labour and birth, did the midwives or doctors explain things in a way you could understand?	Yes, always	352	76	87	**-11***	0.49	(0.34,0.71)
	3	#(MH) After the birth, did the health professionals give you enough information about how to care for yourself?	Yes, completely	344	42	57	**-15***	0.56	(0.41,0.75)
	3	#After the birth of your baby, did the health professionals explain things in a way you could understand?	Yes, always	352	67	81	**-14***	0.51	(0.37,0.71)
	3	After the birth, did the health professionals give you enough information about how to care for your baby?	Yes, completely	304	38	56	**-18***	0.48	(0.35,0.66)
	3	Did midwives in the hospital work with you to show you a good position for breastfeeding your baby?	Yes	305	88	91	-3	0.74	(0.43,1.29)
	4	At any point during your pregnancy or after the birth, were you shown or given information about safe sleeping for your baby?	Yes	343	99	96	2*	2.69	(1.27,5.7)
Respect	2	#Were you involved, as much as you wanted to be, in decisions during your labour and birth?	Yes, definitely	346	67	73	-6	0.76	(0.56,1.04)
	2	#Did you feel you were treated with respect and dignity during your labour and birth?	Yes, always	352	76	90	**-14***	0.37	(0.25,0.54)
	2	During your labour, were you able to move around and choose the position that made you most comfortable?	Yes, most of the time	280	60	67	**-7***	0.7	(0.49,0.99)
	2	Were you offered the option of being in a bath during labour?	Yes	226	50	53	-3	0.85	(0.58,1.25)
	2	#Did you have enough say about your pain relief during your labour and birth?	Yes, definitely	351	61	71	**-9***	0.66	(0.49,0.89)
	2	Were you given enough privacy in the birth room or theatre?	Yes, always	351	84	90	**-6***	0.62	(0.41,0.93)
Respect	2	Did you have skin to skin contact with your baby shortly after the birth?	Yes	308	97	96	0	1.04	(0.46,2.35)

Dimension	Stage	Question	Response	MHC (n)	MHC (%)	No MHC (%)	GAP	AOR	AOR 95% CI
	3	#Did you feel involved in decisions about your discharge from hospital?	Yes, definitely	349	58	68	**-10***	0.62	(0.46,0.85)
	3	Were your decisions about how you wanted to feed your baby respected by the health professionals?	Yes, always	347	74	82	**-7***	0.66	(0.46,0.95)
	4	In general, did you feel that the midwife or nurse listened to you? [at follow-up appointment]	Yes, always	342	83	92	**-9***	0.48	(0.31,0.74)
	4	In general, did you have enough time with the midwife or nurse to ask questions or discuss any concerns? [at follow-up]	Yes, definitely	342	84	91	**-7***	0.55	(0.35,0.86)
Involvement	2	During your labour and birth, was your birthing companion involved as much as they wanted to be?	Yes, definitely	347	79	88	**-9***	0.56	(0.38,0.82)
	3	Were the visiting times convenient for your friends and family?	Yes, definitely	340	66	74	**-8***	0.66	(0.47,0.92)
Physical comfort	2	Do you think the midwives or doctors did everything reasonable to help you manage your pain during your labour and birth?	Yes, definitely	350	66	77	**-11***	0.57	(0.42,0.79)
	2	Were you able to get assistance from midwives or doctors when you needed it? [during labour and birth]	Yes, always	345	67	83	**-16***	0.43	(0.31,0.61)
	3	#Do you think the health professionals did everything they could to help you manage your pain after the birth of your baby?	Yes, definitely	274	53	71	**-18***	0.46	(0.33,0.65)
	3	After the birth of your baby, were you able to get assistance or advice from health professionals when you needed it?	Yes, always	351	54	70	**-16***	0.51	(0.37,0.68)
	3	How clean were the wards or rooms you stayed in after the birth of your baby?	Very clean	350	63	70	**-7***	0.7	(0.51,0.97)
	3	How clean were the toilets and bathrooms you used after the birth of your baby?	Very clean	351	60	67	**-7***	0.69	(0.51,0.95)
	3	Bothered by noise, lack of privacy, lack of security or lighting during stay in hospital	Not bothered	349	38	44	**-7***	0.71	(0.52,0.95)
	3	How would you rate the hospital food?	Very good	344	14	17	-3	0.78	(0.51,1.19)
	3	Did the hospital provide access to food when you needed it?	Yes, always	330	49	61	**-12***	0.62	(0.46,0.85)
Coordination	1	#How well organised was the antenatal care you received at your check-ups?	Very well organised	345	50	58	**-9***	0.71	(0.53,0.95)
	1	How many weeks pregnant were you when you had your first appointment for antenatal care?	Less than 14 weeks	339	43	40	3	1.16	(0.85,1.57)
	1	How much of this time did you usually spend waiting to be seen? [antenatal]	Under 30 minutes	345	54	55	-1	0.86	(0.64,1.16)
	1	Do you think the amount of time you waited was...? [antenatal]	About right	342	57	56	0	0.94	(0.69,1.27)
	1	Was there any time when the health professionals needed access to your medical history and it was not available?	No	344	67	75	**-8***	0.66	(0.48,0.92)
	1	Were you provided with a personal antenatal card, where information about your antenatal check-ups was recorded?	Yes	339	94	96	-3	0.6	(0.31,1.15)
	1	Did the health professionals update your personal antenatal card at every check-up?	Yes	316	98	97	1	1.47	(0.76,2.85)
	2	#Did midwives or doctors ever give you conflicting information during your labour and birth?	No	351	79	82	-3	0.83	(0.56,1.22)
	2	Had you previously met any of the midwives or doctors who cared for you during your labour and birth?	Yes	348	49	49	0	0.92	(0.68,1.25)
	2	Did the midwives or doctors who you did not already know, introduce themselves to you during your labour and birth?	Yes, always	327	76	85	**-9***	0.54	(0.37,0.79)
	3	#After the birth, did you ever receive conflicting information from health professionals about how to care for yourself/your baby?	No	353	62	69	-7	0.76	(0.56,1.03)
	3	Did you ever receive conflicting advice about feeding your baby from the health professionals?	No	346	57	69	**-12***	0.64	(0.47,0.87)
Continuity	3	Before leaving hospital, were you given enough information about caring for yourself and your baby at home?	Yes, completely	335	45	64	**-19***	0.45	(0.34,0.61)
	3	Did hospital staff tell you who to contact if you were worried about your health or your baby's health after you left hospital?	Yes	335	93	95	-2	0.8	(0.41,1.56)
	4	In the first 2 weeks after arriving home, had a follow-up appointment with a midwife or nurse?	Yes at home	352	89	86	2	1.28	(0.85,1.93)

Note: Adjusted Odds Ratio (AOR) of positive experience for women with compared without a mental health condition after adjusting for age, language, education, type of birth, parity, and local health district of residence are denoted by "*" where significant at p<0.05.Stage 1: Antenatal, stage 2: Labour and birth, stage 3: hospital care following birth, stage 4: follow up care. Mental health condition group (MHC), no condition group (no MHC), Gap=percentage point difference MHC group minus no MHC group results. Question text denoted by (MH) were questions identified as proxy measures related to guidelines for maternity care for women with mental illness.

Chapter 9: Final thoughts

This chapter provides a discussion of the key findings from work presented in Sections I to III of this thesis, describing how the aims were addressed, strengths and limitations, and opportunities for future work.

Discussion

In high performing health systems, care is accessible, patient-centred as well as equitable (Kruk and Pate, 2020, Nuti et al., 2017). While healthcare in Australia ranks highly among international systems, not all Australians have the same opportunities to access care. People with mental health conditions experience additional challenges in accessing mental health care, and when using other health care services. This thesis presents evidence of disparities in experiences of access to care for Australians with mental health conditions.

To the candidate's knowledge chapters of this thesis contributed to some of the first work to analyse experiences of access to care focusing on people with self-reported mental health conditions. This has provided new evidence for the first time attempting to see accessing care through the eyes of people with self-reported mental health conditions. Patient-centred access and experiences of care are considered through multi-dimensional frameworks, which help to highlight key areas of disparities for people with mental health conditions. Findings point to areas of stark disparities in experiences of access to care across 11 countries, with a more in depth focus on Australia. Results showed that Australians with mental health conditions face interconnected challenges with particular barriers with affordability of care, getting conflicting or not enough information for themselves or their family, or being treated with respect. Further, looking at the characteristics of Australians who experience mental health conditions, showed they often face additional social and economic challenges such as higher out-of-pocket costs and lower income.

In terms of mental health care, analysis in Chapter 3 highlighted that an estimated one in 10 people who experienced emotional distress (12%) reported unmet need for services in Australia between 2013 and 2016. Factors associated with unmet need included: higher out of pocket costs for healthcare, lower income, lower education and poorer health. These factors were similar in both Australia and Canada, with stronger associations for high out of pocket costs and lower income with unmet need in Australia. In both countries people with unmet need for mental health care were also more likely to say they had to forego any healthcare due to cost. More than four in 10 of people who had experienced emotional distress (42%) said they skipped a consultation for health services in the year prior. These findings addressed the first aim of this thesis, to assess the factors associated with unmet need for mental health care, in other words to look at disparities in unmet need and compare patterns internationally (aim 3).

When exploring experiences of healthcare more broadly, analyses presented in this thesis showed people with mental health conditions were more likely to face barriers across all stages of accessing care compared to those with no condition in the 2016 Commonwealth Fund International Health Policy Survey. For Australian adults accessing primary, specialist and hospital care, people with mental health conditions were more likely to experience barriers for 24 of 33 measures, with barriers that were nine percentage points higher than those with no condition on average – the largest among international comparators. Yet, there were no disparities in Australia and most other countries for other measures such as those related to affiliation with a regular care provider and chronic disease care, or medication information at discharge from hospital. The largest disparities between those with and without mental health conditions in Australia were in terms of affordability (i.e skipping care due to cost) respect from professionals (i.e. doctors and nurses showed courtesy and respect) and receiving conflicting information from health professionals. These analysis, presented in chapters 4 and 5 address aims 2, 3 and 4: Do people with mental health conditions in Australia face barriers to accessing care; how do disparities compare internationally; and for which types of care are disparities most pronounced in various sectors.

To go deeper into the access dimensions of affordability, a targeted analysis of Australians aged 65 years and over was considered in Chapter 6. Results highlighted that more than one quarter of older adults with mental health conditions said they had to forego care due to cost (25%) and they had trouble paying medical bills (27%) – levels higher than those with no conditions, one physical condition or two or more physical health conditions. High out-of-pocket healthcare costs and lack of private insurance were key factors contributing to greater odds of affordability barriers for all older Australians, with particular impact for those with mental health conditions. This analysis added additional evidence using another data set, and focused on a specific population to demonstrate that affordability issues are pronounced for people with mental health conditions in particular, contributing to aims 2 and 4.

In addition, analysis of maternity and emergency department in Chapters 7 and 8 care also point to disparities for people with mental health conditions. In New South Wales, people with a self-reported mental health condition using emergency care for any reason had less positive experiences on 40 of 53 measures in 2017–18. There were similar findings for analysis of maternity care experiences in 2017 in NSW. Experiences of maternity care for women with mental health conditions were less positive for 41 of 64 measures and more positive for one (information on safe sleeping). In both sectors, disparities were pronounced for overall ratings of care, physical comfort such as pain management, information provision (clear communication), respect for patients, and emotional support and trust. There were fewer disparities for measures related to the facilities and the physical environment. Of particular note, for measures related to aspects of care for which there are existing guidelines for maternity care for women with mental illness (e.g. discussions of emotional health, alcohol, weight gain) there were smaller or no differences in experiences. These findings contributed further evidence to aim 4, demonstrating large disparities in experience in other sectors and in particular, but not all, dimensions of experience.

Findings across chapters 4 to 8 point to persistent and large disparities in experiences accessing care for people with mental health conditions. However, important areas where there are no disparities, such as affiliation with a regular GP, chronic disease care, experiences with facilities and guideline-related measures of maternity care suggest that disparities are not inevitable. Analysis point to priority areas for action to improve experiences of care for Australians with mental health conditions.

Strengths

This thesis has built on strengths of existing methods and data sources in two key ways. First by examining access and experiences through existing frameworks to consider a broad range of experiences of care across a comprehensive set of dimensions. Second by looking through an equity lens from the perspective of people with mental health conditions. The analyses have encompassed international, national and state levels and several sectors highlighting similarities in patterns of disparities in experiences across sectors and places. It has built on disparities analysis that tend to focus only on an association or a difference between groups, and taken a step further to demonstrate the need to consider of both the size of disparities and ‘levels’ of barriers or experiences. Priorities for addressing disparities should include this consideration of how many people are affected by access barriers, thus considering the absolute size of the problem.

A second key area of strengths is the translational aspect of this work as it connects with performance reporting and healthcare policy. Through analysis of regularly conducted surveys, findings point to opportunities for monitoring disparities for performance measurement to inform quality improvement efforts. Further, by demonstrating the absence of disparities for some survey measures related to guidelines in maternity care and chronic disease care, the findings show that policy efforts may help to address disparities.

Table 9.1 Summary of disparities in experiences of access to care for Australians with mental health conditions

Population, Survey, Chapter	**Largest percentage point differences**	**Smallest percentage point differences**	**Significant Disparities, average gap**
Australian Adults, Commonwealth Fund International Health Policy Survey 2016 **Adults aged 18+** **(and 10 country comparators),** **Chapter 5**	1.Doctors and nurses show courtesy and respect (-24, -26) 2. Conflicting information (-22) 3. Skipped consultation, test, medication due to cost (-21)	1. Written plan for chronic condition (8) 2. Discussion of treatment options for condition (3) 3. Medication information when leaving hospital (0)	24 of 33 access measures for Australia Average=-9 (largest among all countries)
Australians aged 65+ years, Commonwealth Fund International Health Policy Survey older adults 2017, Chapter 6	Skipped test, meds, consultation due to cost (-15) Problems paying bills (-12)		2 of 2 affordability measures Average=-14
New South Wales, patients all ages Emergency Department Patient Survey 2017-18, Chapter 7	1. Information for family/carer (-13) 2. Information to manage care at home(-12) 3. What to watch for when went home (-12)	1.How clean was the waiting area (3) 2. Right waiting time provided (1) 3. Triaged in 15 minutes (0)	40 of 53 experience measures Average=-7
New South Wales, mothers Maternity Care Survey 2017, Chapter 8	1.Information for caring for self/baby at home (-19) 2. Pain management (-18) 3. Information to care for baby after delivery	1.First antenatal appointment 14 weeks (3) 2. Risks of consuming alcohol (2) 3. Safe sleeping for baby	41 of 64 experience measures Average=-8

Note: for ED After triage, how long did you wait before being treated by an ED doctor or nurse? [Triage category 2] was the largest disparity -15, but was stratified further by triage, and there were not significant differences for all triage categories.

Limitations and challenges

A limitation in the analysis is identifying people with mental health conditions in general surveys. Ensuring that survey cohorts are representative of vulnerable population groups is a challenge for all large scale surveys. The percentage of people who self-reported being diagnosed with a mental health condition is somewhat lower in the general surveys in this analysis than what would be expected from mental health specific survey instruments, therefore it is likely those with serious illness are underrepresented in the results. This may also be due to the questions asking about 'long-standing' or asking if people are 'currently treating' their health conditions . Overall, the survey data sources used in this analysis build on large-scale, representative and robust data sources that have demonstrated consistency over time or alignment with other survey data sources (Appendix A - Appendix E). It also appeared that people born outside Australia, are less likely to self-report having a mental health condition. Stigma associated with mental illness or fear regarding material consequences of a diagnosis may be more pronounced in some cultural, gender or age groups. Testing and refining of the survey questions regarding mental health conditions with different focus groups could help improve data collection in the future.

There are also methodological limitations and challenges in comparing people's experiences. Patient perspectives, expectations and response tendencies are important to consider to ensure fair comparisons in performance reporting. For example, men and older people tend to respond more positively to patient experience surveys. Therefore, comparisons of experiences by mental health condition group are adjusted for these characteristics. An argument might then be that people with mental health conditions simply tend to be less positive in general hence reporting less positive experience. However, each analysis presented in this thesis included examples of measures with no disparities by condition group, or examples where those with mental health conditions had more positive experiences than other groups. In these cases, there was often a plausible policy-related explanation, such as the presence of additional supports in place for those with a mental health condition as compared to those with none (e.g. having a regular doctor, having emotional needs considered in maternity and emergency department experiences). These examples suggest that people with a mental health condition are not less positive, and disparities are amenable to improvement. Regardless, a key part of the patient-centred access framework highlights the needs to consider people's ability and capacities. If people with mental health conditions do not feel that care is accessible, and they don't feel comfortable to seek it, then it is not fully accessible to them. Understanding the perspectives of people with mental health conditions may help to reorient health services, and challenges to ensure care is perceived as more accessible.

Patient-centred access reflects cumulative experiences of care. A possible limitation of this analysis is that it explored disparities in measures that reflect a single or specific type of experience. While measures were considered across a range of experience dimensions, it is important to consider how barriers to accessing care can accumulate. Groups, such as those with mental health conditions may experience barriers in multiple ways. Additional disparities analysis would be improved by taking a cumulative approach to understand the profiles of barriers different groups may face across a range of health and social sectors. While composite measures present challenges for directing action in quality improvement or performance reporting, analysis to better understand they layers of barriers people with mental health conditions face could be better expanded on in the academic literature to further ‘build a case’ for action to improve access experiences for this group.

Opportunities for evolution of healthcare performance reporting in Australia

There is an impetus for healthcare performance reporting in Australia to evolve in order to address the essential elements of patient-centredness and equity in care. International comparisons outlined here in this thesis point to affordability challenges for Australians with mental health conditions that are more pronounced than those in other countries. This was a ‘red flag’ highlighting a need for monitoring and targets to improve equity and action around perceived affordability of care for people with mental health conditions in particular. More broadly, the literature review in this thesis has identified examples from other countries including the United Kingdom, Canada, and the United States where disparities in healthcare are quantified in regular reporting (Agency for Healthcare Research and Quality, 2016, Schneider, 2017, Canadian Institute for Health Information, 2018, Canadian Institute for Health Information, 2016, Health Quality and Safety Commission, 2019). Building on these examples to summarise disparities, evidence presented in Chapter 5 demonstrated the importance of simultaneously considering relative size of populations affected in addition to the size of disparities in order to identify places or populations most disadvantaged and prioritise areas for action. There is an opportunity to better monitor and measure equity from the perspective of a range of population groups. Particularly there is growing evidence, including empirical evidence presented here, of the importance of considering people with mental health conditions as a priority population, and regularly reporting disparities in their experiences of care.

Ensuring care is patient-centred means patient perspectives of care must be reflected in efforts to monitor quality of care. The literature outlined in Chapter 2 also suggested an absence of patient reported measures in exploring access to care. In Sections II and III, the importance of patient perspectives on accessing care was presented, highlighting that patients are often best placed to report on how accessible or patient-centred their care is. With an increasing focus of healthcare providers toward ‘value based care’ (Woolcock et al., 2019, Canadian Foundation for Healthcare Improvement, 2020) , there is greater attention on connecting spending to outcomes that matter to patients, rather than focusing only on volumes of services that may or may not achieve those outcomes. Therefore, it would appear that in years to come performance frameworks and reporting such as those discussed in the introduction and literature review by the Australian Institute for Health and Welfare or the Productivity Commission (Australian Institute for Health and Welfare, 2019) (Productivity Commission, 2019) need to include more patient reported measures to be able to reflect what matters most to patients. Currently, measures of access to care focus on use of services, with an exception of note being a measure of patients reporting foregone care due to cost. There is an annual survey of patient experiences of care in Australia, and state level surveys of hospital experiences that could be better leveraged for use in regular reporting to include patients’ perspectives.

Finally, there is an opportunity to improve reporting of experiences of unmet need for mental health care in terms of the frequency of collecting and reporting information. The most recent survey in Australia to capture information about mental health services was the 2007 Mental Health and Well-being Survey, conducted by the Australian Bureau of Statistics (ABS) (Australian Bureau of Statistics, 2008). This 13 year-old survey remains regularly cited in literature on mental health and mental health care in Australia. The ABS conducts an annual survey of patient experience collecting general information about unmet need for primary, specialist, hospital care (Australian Bureau of Statistics, 2016). There is an opportunity to add a question about mental health care specifically to this general survey, which may also help to normalize the idea of mental health care alongside other types of care. The analysis presented in Chapter 3 points to potential options. The Commonwealth Fund Survey questions on unmet need for mental health care showed alignment with more complex survey instruments in the 2007 survey, suggesting it is possible to ask simple questions about mental health care and get meaningful results.

Extensions of analysis

Access and experiences are cumulative. These experiences cannot easily be captured in one survey or a single point in time. Further reflecting on the cumulative nature of patient-centred access, analysis of experiences of mental health services and other sectors such as cancer care experiences or other disease related care experiences would help to better complete the picture of patients’ experiences of care. Linked data or mixed methods studies may be better able to capture these experiences, to provide more depth in understanding of disparities in patient experiences of access to care. Including perspectives of people with lived experience of mental illness who have tried seeking care would be essential to better understand how to act to reduce disparities in access and experiences, which would hopefully lose the gap in life expectancy for people with mental illness.

Conclusion

This thesis provides evidence of the types and extent of disparities in experiences of access to care for people with mental health conditions. Opportunities to improve the measurement of disparities in patient-reported measures in healthcare performance reporting have also been demonstrated. Four aims were addressed in this thesis, via 6 publications (4 published, 1 accepted awaiting publication, and 1 under review). Using various sources of data, this thesis provides novel and compelling evidence demonstrating that people with mental health conditions are more likely to experience barriers accessing healthcare and have poorer experiences across a wide range of services including primary care, inpatient care, emergency department and maternity care compared to people with no condition. International comparisons revealed that disparities in access to care were more pronounced in Australia than in other countries including the United States. Yet, in some countries and within Australia particularly for measures related to policy guidelines there were no differences in experiences for people with and without mental health conditions. Therefore disparities are not certain or simply due to more negative response tendencies of people with mental health conditions, they are amenable to change. Monitoring efforts to track and compare disparities are essential toward addressing disparities in access and experiences and hopefully, eventually reducing disparities in health outcomes as well.

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Appendix A Commonwealth Fund Survey 2013

The Commonwealth Fund International Health Policy Survey 2013 was a telephone survey conducted in 11 countries. Analysis for Chapter 3 included respondents for Australia and Canada. The tables in this section provide more information on the survey and respondents for these two countries and levels of missing responses for key measures used in the analysis.

Table A.1 Survey characteristics, number of respondents and response rates, Australia and Canada, 2013

	Language(s)	Average length in minutes	Landline respondents	Cell phone	Total respondents	Response rates
Australia	English	19	1,703	497	2,200	30%
Canada	English, French	22 (16)	4,444	968	5,412	24%

Table A.2 Respondent and target population characteristics, Australia, 2013

	Unweighted	Weighted	Target total
Male	48%	49%	49%
Female	52%	51%	51%
18-24	12%	13%	12%
25-34	17%	18%	18%
35-49	28%	28%	28%
50-64	24%	24%	24%
65+	19%	18%	18%
High School or Less	43%	46%	47%
Some Post-Secondary	29%	30%	31%
University Degree or more	25%	22%	22%
Major City	60%	70%	70%
Cell Phone Only	8%	24%	25%
NSW	69%	32%	32%
Victoria	12%	25%	25%
Queensland	9%	20%	20%
South Australia	3%	8%	8%
Western Australia	4%	10%	10%
Tasmania	1%	2%	2%
Northern Territory	1%	1%	1%
Australian Capital Territory	1%	2%	2%

Notes: the *Unweighted column* reflects the characteristics of the respondents to the survey, the *Total column* reflects the target population characteristics from the known population (i.e Census), the Weighted column reflects the weighted survey cohort, weighted to reflect the target population.

Table A.3 Respondent and target population characteristics, Canada, 2013

	Unweighted	Weighted	Target -total
Male	41%	48%	48%
Female	59%	52%	52%
18-24	5%	11%	12%
25-34	11%	16%	16%
35-49	24%	30%	30%
50-64	34%	25%	25%
65+	27%	18%	17%
High School or Less	32%	44%	45%
Some Post-Secondary	36%	30%	29%
University Degree or More	30%	24%	23%
English Only	70%	69%	68%
French Only	9%	12%	13%
Both English/French	20%	19%	19%
Cell Phone Only	6%	13%	14%
Newfoundland	5%	1%	1%
PEI	5%	<1%	<1%
Nova Scotia	5%	3%	3%
New Brunswick	5%	2%	2%
Quebec	19%	23%	23%
Ontario	29%	39%	39%
Manitoba	5%	4%	4%
Saskatchewan	5%	3%	3%
Alberta	19%	11%	11%
British Columbia	5%	13%	13%
Territories	<1%	<1%	<1%

Notes: the Unweighted column reflects the characteristics of the respondents to the survey, the Total column reflects the target population characteristics from the known population (i.e Census), the Weighted column reflects the weighted survey cohort, weighted to reflect the target population.

Table A.4 Percentage and number of missing values for the main study variables, Canada, 2013

	Australia	Canada
In the past two years, have you experienced emotional distress such as anxiety or great sadness which you found difficult to cope with by yourself?	<1% (n=15)	<1% (n=26)
When you experienced emotional distress and it was difficult to cope by yourself were you able to get help from a professional?	<1% (n=6)	2% (n=17)

Aligning international survey results to other national surveys

The prevalence of unmet need for mental health services based on the 2013 and 2016 surveys was approximately 3% in each country (Australia 21%*12%, Canada 25%*11%). These estimates of population level unmet need are in line with, other reports on perceived unmet need for mental health services of 3-5% (Roll et al., 2013, Sunderland and Findlay, 2013) [Chapter 3 and Table 3.1].

Appendix B Commonwealth Fund Survey 2016

The Commonwealth Fund International Health Policy Survey for 2016 was a telephone survey conducted in 11 countries. Analysis for Chapter 3, 4 and 5 included respondents for Australia and other countries. The tables in this section provide more information on the survey and Australian respondents and levels of missing responses for key measures used in the analysis.

Table B.1 Survey characteristics, number of respondents and response rates, by country, 2016

Country	Average Length (minutes)	Landline respondents	Cell phone respondents	Number of respondents	Response rate
Australia	21	3,052	2,196	5248	25%
Canada	20	3,317	1,230	4547	21%
France	25	763	340	1103	25%
Germany	22	636	364	1000	27%
Netherlands	19	783	444	1227	32%
New Zealand	19	646	354	1000	31%
Norway	18	277	816	1093	11%
Sweden	21	2,697	4,427	7124	17%
Switzerland	24/25	119	99/ 1302 online)	1520	47%
United Kingdom	17	656	344	1000	22%
United States	20	800	1,201	2001	18%

Representativeness and alignment of results with local surveys

Survey sampling and weighting methodology is used to create nationally representative samples of respondents aged 18 and over. An example of the alignment of the weighted survey respondents and the total population in Australia is provided in Table B.2.

In addition, in Chapter 4, findings were presented that align the prevalence of mental health related estimates from the survey with local results. Based on the international survey, 14% of Australians self-reported having a mental illness and 20% said they had experienced emotional distress. The combined prevalence of people who had either been diagnosed or recently distressed was 23% in Australia (Table 4.1). These estimates align reasonably well with national prevalence estimates. In 2007, 20% of Australian adults had a mental illness based on the Mental Health and Well-Being Survey (Australian Bureau of Statistics, 2008). In 2014-15, 18% had a mental health condition (Australian Institute for Health and Welfare, 2016). [See Chapter 4 for reference details]

Table B.2 Respondent and target population characteristics, Australia, 2016

	Unweighted sample cohort	Weighted	Total Adults - Target
Age/Sex			
Male 18-24	4%	7%	6%
Male 25-34	9%	10%	10%
Male 35-49	15%	14%	13%
Male 50-64	12%	11%	12%
Male 65+	9%	8%	9%
Female 18-24	4%	7%	6%
Female 25-34	10%	10%	9%
Female 35-49	14%	13%	13%
Female 50-64	13%	11%	12%
Female 65+	11%	9%	10%
Education			
High School or Less	33%	47%	47%
Some Post-Secondary	26%	27%	28%
University Degree or more	41%	26%	25%
Urban Status			
Major City	58%	71%	70%
Not Major City	42%	29%	30%
Phone Status			
Cell Phone Only	8%	29%	29%
Region/Strata			

Notes: the unweighted column reflects the characteristics of the respondents to the survey, the Total column reflects the target population characteristics from the known population (i.e Census), the weighted column reflects the weighted survey cohort, weighted to reflect the target population.

Table B.3 Percentage of missing values by question and country, 2016

	Australia	Canada	France	Germany	Netherlands	New Zealand	Norway	Sweden	Switzerland	United Kingdom	United States
Conflicting information	1	1	1	0	0	0	1	1	0	0	1
Do not have professional support needed to help manage your condition	1	2	0	0	2	1	1	4	0	0	1
Doctors did not always treat you with courtesy and respect	1	2	0	0	1	1	2	2	0	0	0
Five days or more to get GP appointment	0	0	0	0	0	0	0	0	0	0	0
GP was not up-to-date following hospital care	9	4	0	5	15	4	4	10	1	3	3
GP was not up-to-date following specialist care	8	6	1	0	11	3	9	27	1	5	5
GP/place does not explain things clearly	0	0	0	0	0	0	2	2	0	0	1
GP/place does not involve you in decisions	2	1	0	0	1	1	5	6	1	1	1
GP/place does not know medical history	5	2	0	0	1	1	6	11	0	2	2
GP/place does not spend enough time	1	1	0	0	0	0	2	2	0	1	1
Had problems paying medical bills	1	1	0	0	1	0	0	11	2	0	1
Had problems with insurance payment	3	2	0	0	1	2	2	2	3	1	1
Hospital did not arrange follow-up care	2	2	0	1	2	1	3	2	0	1	0
Last emergency department visit could have been treated by GP	0	0	0	0	0	0	0	0	0	0	0
Medical care received was fair/poor	0	0	0	0	0	0	1	1	0	0	1
No discussion of goals for chronic condition treatment	0	1	1	0	1	1	2	2	0	1	1
No discussion of treatment options for chronic condition	2	1	1	0	1	0	2	2	0	1	2
No regular GP	0	0	0	0	0	0	0	0	0	0	0
No written information at discharge about managing care at home	3	2	0	8	2	1	2	3	0	1	0
No written plan for managing care at home	2	1	1	0	1	1	1	2	0	1	2
Not confident about managing health problem	4	1	0	0	2	0	2	2	1	1	1
Not involved in decisions about treatment in hospital	3	2	0	0	2	1	2	5	0	2	2
Nurses did not always treat you with courtesy and respect	0	1	0	0	0	1	0	1	0	0	0
Our health care system has so much wrong with it / completely rebuild it	5	2	0	0	4	2	2	3	0	3	5
Place of care sometimes/rarely never coordinates care	2	1	0	0	3	1	6	4	0	2	2
Purpose of medication not discussed before hospital discharge	4	2	1	3	2	2	3	2	0	0	2
Quality of medical care in this country is fair/poor	1	2	0	0	2	1	1	3	0	2	5
Results or records unavailable at time of appointment	1	1	1	0	1	1	4	8	0	1	2
Skipped consultation due to cost	0	0	0	0	0	0	1	0	0	0	1
Skipped consultation, test or prescription due to cost	2	0	0	0	3	0	0	7	13	2	0
Skipped dental check-up due to cost	1	0	0	0	0	0	0	0	0	0	0
Skipped medication or doses due to cost	0	0	1	0	0	0	0	0	0	0	0
Skipped test, treatment or follow up due to cost	0	0	0	0	0	0	0	0	0	0	0
Sometimes/rarely/never get response from GP clinic the same day	0	2	0	0	0	0	2	1	0	0	1
Specialist did not have information from regular GP	5	2	1	0	5	1	4	14	1	1	2
Spent a lot of time on paperwork related to medical bills	2	1	0	0	1	1	0	11	3	0	1
Very difficult to get out-of-hours care	6	3	1	0	2	3	9	8	0	5	6
Waited two months or longer to see a specialist	6	4	0	1	7	3	8	7	1	9	5

Appendix C Commonwealth Fund Survey 2017

The Commonwealth Fund International Health Policy Survey for 2017 was a telephone survey conducted in 11 countries. Analysis for Chapter 6 included respondents for Australia. The tables in this section provide more information on the respondents' characteristics and levels of missing responses for key measures used in the analysis. There were 5,248 respondents in Australia and the response rate was 25%.

Table C.1 Respondent and target population characteristics, Australia, 2017

	Unweighted	Weighted	Total -Adults
Gender by Age			
Male 65-69	20%	16%	15%
Male 70-74	12%	12%	11%
Male 75+	14%	19%	19%
Female 65-69	21%	16%	15%
Female 70-74	15%	12%	12%
Female 75+	18%	26%	27%
Education			
High School or Less	37%	65%	66%
Some Post-Secondary	30%	24%	24%
University Degree or more	32%	11%	11%
Urban Status			
Major City	60%	66%	65%
Not Major City	40%	34%	35%
Region/Strata			
NSW	47%	34%	34%
Victoria	45%	25%	25%
Queensland	4%	19%	19%
Western Australia	2%	9%	9%
South Australia	2%	9%	9%
Tasmania	1%	3%	3%
Australian Capital Territory	0%	1%	1%
Northern Territory	0%	0%	0%

Representativeness and alignment of results with local surveys

In the survey, 48% of Australians aged 65 years and over reported having two or more chronic conditions. The prevalence of the sample reporting a chronic condition was lower than an estimated 60% of adults aged 65 years and over with two or more conditions based on an Australian Institute of Health and Welfare report (Australian Institute for Health and Welfare, 2016). The Commonwealth Fund Survey respondents were asked about nine specific conditions and also given an option to say they 'no longer treating' the condition [See Chapter 7].

Table C.2 Percentage and number of missing responses for selected questions, Australia, 2017

	N	%
During the past 12 months, was there a time when you skipped: a consultation, a test or follow up, or medication or doses, due to cost? (derived)	19	1%
In addition to government funded health services, are you currently covered by any private health insurance that you or your family pays for or that an employer or association provides?	13	1%
In the past 12 months, about how much of your own money have you and your family spent for medical treatments or services that were not covered by Medicare or private insurance?	123	5%
In the past 12 months, did you have problems paying or were unable to pay any medical bills?	18	1%
How often in the past 12 months would you say you were worried or stressed about having enough money to buy nutritious meals, would you say?	13	1%
How often in the past 12 months would you say you were worried or stressed about having enough money to pay your rent or mortgage, would you say?	57	2%
How often in the past 12 months would you say you were worried or stressed about having enough money to pay for other monthly bills, like electricity, heat, and your telephone, would you say?	8	0%
During the past 12 months, was there a time when you did not fill/collect a prescription for medicine, or you skipped doses of your medicine because of the cost?	50	2%
During the past 12 months, was there a time when you had a medical problem but did not consult with/visit a doctor because of the cost?	41	2%
During the past 12 months, was there a time when you skipped a medical test, treatment, or follow-up that was recommended by a doctor because of the cost?	53	2%

Appendix D Emergency Department Patient Survey 2017–18

The Emergency Department Patient Survey in New South Wales for 2017–18 was survey mailed out to patients following care received in an emergency department. Analysis for Chapter 7 included respondents to this survey. It reflects the experiences of 15,995 adults and children. Table D.1 provides more information on the respondents' characteristics in the survey and the sampling frame demonstrating the representativeness of the survey cohort in that the weighted cohort reflects the patient population based on the administrative data (see also Table 7.1 in the Chapter). More information is provided on the percentage of missing and 'don't know' responses (Table D.2), where nearly all measures have less than 5% missing.

The survey has been conducted annually since 2013-14, where there is strong consistency in results over time (http://www.bhi.nsw.gov.au),

Table D.1 Respondent and target population characteristics, emergency departments patients, New South Wales, 2017–18

	Percentage in patient population	% in eligible population	Percentage of respondents (unweighted)	Percentage of respondents (weighted)
Under 18	25	25	22	25
18–49	38	38	35	38
50+	37	37	43	37
Admitted Emergency	28	25	37	25
Non-admitted Emergency	72	75	63	75
Male	51	n/a	47	47
Female	49	n/a	53	53
Central Coast	5	5	4	5
Far West	1	1	1	1
Hunter New England	14	13	15	13
Illawarra Shoalhaven	6	6	5	6
Mid North Coast	5	4	6	4
Murrumbidgee	3	3	4	3
Nepean Blue Mountains	5	4	4	4
Northern NSW	7	7	8	7
Northern Sydney	9	9	10	9
South Eastern Sydney	9	9	8	9
South Western Sydney	11	11	8	11
Southern NSW	4	4	4	4
St Vincent's Health Network	2	2	2	2
Sydney	6	6	6	6
Sydney Children's Hospitals Network	4	4	4	4
Western NSW	5	4	7	4
Western Sydney	7	7	6	7

Source: Bureau of Health Information. *Technical Supplement: Emergency Department Patient Survey, 2017–18.* Sydney (NSW); BHI; 2019.

Table D.2 Percentage of don’t know and missing responses by question

Question	Don’t know	Missing
Were the ED staff you met on your arrival polite and courteous?	0.9	2.5
Did the ED staff you met on arrival give you enough information about what to expect during your visit?	1.1	5.8
Did the ED staff you met on arrival tell you how long you would have to wait for treatment?	1.5	9.9
Was the waiting time given to you by the ED staff you met on arrival about right?	2.3	4.7
Did you experience any of the following issues when in the waiting area? [with seating, safety, noise, temperature or odour in the waiting area]	6.9	
How clean was the waiting area in the ED?	1.3	
From the time you first arrived at the ED, how long did you wait before being triaged by a nurse - that is, before an initial assessment of your condition was made?	2	5.4
After triage (initial assessment), how long did you wait before being treated by an ED doctor or nurse?	3.2	6.8
While you were waiting to be treated, did ED staff check on your condition?	1.2	5.8
Did the ED health professionals introduce themselves to you?	2.6	5.1
Did the ED health professionals explain things in a way you could understand?	2.8	
Did you have enough time to discuss your health or medical problem with the ED doctors?	2.6	2.6
How much information about your condition or treatment was given to you by ED health professionals?	3	
Were you involved, as much as you wanted to be, in decisions about your care and treatment?	2.7	
If your family members or someone else close to you wanted to talk to the ED staff, did they get the opportunity to do so?	2.7	3.1
How much information about your condition or treatment was given to your family, carer or someone else close to you?	3	4.8
Were you able to get assistance or advice from ED staff for your personal needs (e.g. for eating, drinking, going to the toilet, contacting family)?	2.8	
How would you rate how the ED health professionals worked together?	2.6	
Did you have confidence and trust in the ED health professionals treating you?	2.6	
Were the ED health professionals polite and courteous?	2.7	
Overall, how would you rate the ED health professionals who treated you?	2.5	
Did you ever receive contradictory information about your condition or treatment from ED health professionals?	3.6	
Were the ED health professionals kind and caring towards you?	2.6	
Did you feel you were treated with respect and dignity while you were in the ED?	2.5	
Were you given enough privacy during your visit to the ED?	2.9	
Were your cultural or religious beliefs respected by the ED staff?	3.6	
Did you have worries or fears about your condition or treatment while in the ED?	3.2	
Did an ED health professional discuss your worries or fears with you?	4.1	
In your opinion, did the ED nurses who treated you know enough about your care and treatment?	3.2	3.3
Were you ever in pain while in the ED?	3.4	
Do you think the ED health professionals did everything they could to help manage your pain?	2.7	
How clean was the treatment area in the ED?	3.3	
While you were in the ED, did you feel threatened by other patients or visitors?	3	
While you were in the ED, did you see or hear any aggressive or threatening behaviour towards ED staff?	2.9	3.7
Did an ED health professional explain the test, X-ray or scan results in a way that you could understand?	2.3	
Did you feel involved in decisions about your discharge from hospital?	1.9	
Thinking about when you left the ED, were you given enough information about how to manage your care at home?	1.7	
Did ED staff take your family and home situation into account when planning your discharge?	2.1	4.1
Thinking about when you left the ED, were adequate arrangements made by the hospital for any services you needed?	1.8	

Question	Don’t know	Missing
Did ED staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	2.1	11.2
Thinking about your illness or treatment, did an ED health professional tell you about what signs or symptoms to watch out for after you went home?	2.5	
Were you given or prescribed any new medication to take at home?	2	
Did an ED health professional explain the purpose of this medication in a way you could understand?	2.1	
Did an ED health professional tell you about medication side effects to watch for?	2.6	
Did you feel involved in the decision to use this medication in your ongoing treatment?	2.4	
Did an ED health professional tell you when you could resume your usual activities, such as when you could go back to work or drive a car?	2.7	
Was your departure from the ED delayed - that is, before leaving the ED to go to a ward, another hospital, home, or elsewhere?	4.3	
Did a member of staff explain the reason for the delay? [in discharge]	4.7	
What were the main reasons for the delay? [in discharge]	4.7	4.9
Overall, how would you rate the care you received while in the ED?	1.7	
If asked about your experience in the ED by friends and family how would you respond?	2.1	
Did the care and treatment received in the ED help you?	2	
In total, how long did you spend in the ED?	2.5	7.1
Were you ever treated unfairly for any of the reasons below?	5.8	

Appendix E Maternity Care Survey 2017

For the 2017 Maternity Care Survey, 13,811 surveys were mailed and 4,787 responses were returned. Analysis for Chapter 8 included respondents to this survey. Completeness was high overall, with respondents answering, on average, 91 out of the 99 of the questions. The response rate was 35%. Table E.1 below highlights the representativeness of the survey where the survey cohort reflects the regional and age distribution of the eligible population in the sample frame. Table E.2 provides information on the percentage of missing and 'don't know' responses.

The survey was initially conducted in 2015, and showed consistency in results over time (http://www.bhi.nsw.gov.au)

Table E.1 Respondent and target population characteristics, women receiving maternity care, New South Wales, 2017–18

	% in patient population	**% in eligible population**	**% in respondents (unweighted)**	**% in respondents (weighted)**
Central Coast	4	4	3	4
Far West	0	0	1	0
Hunter New England	12	12	14	12
Illawarra Shoalhaven	5	5	4	5
Mid North Coast	3	3	6	3
Murrumbidgee	3	3	6	3
Nepean Blue Mountains	7	7	6	7
Northern NSW	4	4	6	4
Northern Sydney	8	9	12	9
South Eastern Sydney	11	11	7	11
South Western Sydney	16	16	8	16
Southern NSW	2	2	7	2
Sydney	10	10	4	10
Western NSW	4	4	8	4
Western Sydney	11	11	5	11
Age: 18-24 years	16	.	10	9
Age 25-29	29	.	28	26
Age 30-34	33	.	38	40
Age 35-39	18	.	19	20
Age 40-44	4	.	4	4
Age 45+	0	.	0	0
Not Aboriginal	95	.	98	98
Aboriginal/Torres Strait Islander	5	.	2	2

Source: Bureau of Health Information. *Technical Supplement – Maternity Care Survey 2017*. Sydney (NSW); BHI; 2018.

Table E.2 Percentage of don't know and missing responses by question

Question	Don't know	Missing
How many weeks pregnant were you when you had your first appointment for antenatal care?	3.8	0.7
How much of this time did you usually spend waiting to be seen? [at antenatal check-ups]	0.4	1.5
Do you think the amount of time you waited was...? [at antenatal check-ups]	0.6	1.3
How well organised was the antenatal care you received at your check-ups?		0.9
Did the health professionals providing your antenatal care explain things in a way you could understand?		0.8
Did you have confidence and trust in the health professionals providing your antenatal care?		0.9
Were the health professionals providing your antenatal care polite and courteous?		1.1
Was there any time when the health professionals needed access to your medical history and it was not available?	10	1.1
Were you provided with a personal antenatal card (e.g. a Yellow Card), where information about your antenatal check-ups was recorded?	1.7	1
Did the health professionals update your personal antenatal card at every check-up?	0.3	1
Did the health professionals give you advice about the risks of consuming alcohol while pregnant?	6.6	1.2
Did the health professionals give you advice about the risks of exposure to tobacco smoke while pregnant?	6	1.2
Did the health professionals discuss the importance of healthy weight gain with you? [at antenatal check-ups]	6.5	1.2
Did the health professionals ask you how you were feeling emotionally during your pregnancy?	2.3	1.2
Did the health professionals discuss your worries or fears with you? [at antenatal check-ups]		0.9
Did you receive enough information about pain relief options prior to the birth?		1.4
Overall, how would you rate the antenatal care you received during your pregnancy?		1.5
During your labour, were you able to move around and choose the position that made you most comfortable?		1
Were you offered the option of being in a bath during labour?	2.5	1.4
Did you have enough say about your pain relief during your labour and birth?		0.7
Do you think the midwives or doctors did everything reasonable to help you manage your pain during your labour and birth?		0.8
Had you previously met any of the midwives or doctors who cared for you during your labour and birth?	1.2	0.5
Did the midwives or doctors who you did not already know, introduce themselves to you during your labour and birth?	2.5	0.8
Were you able to get assistance from midwives or doctors when you needed it? [during labour and birth]		0.3
During your labour and birth, did the midwives or doctors explain things in a way you could understand?		0.3
Did midwives or doctors ever give you conflicting information during your labour and birth?		0.6
Were you involved, as much as you wanted to be, in decisions during your labour and birth?		0.5
During your labour and birth, was your birthing companion (e.g. your partner, the baby's father, doula or family member) involved as much as they wanted to be?	0.4	0.3
Did you have confidence and trust in the midwives or doctors taking care of you during your labour and birth?		0.4
Were the midwives or doctors kind and caring towards you? [during labour and birth]		0.4
Did a midwife or doctor discuss your worries or fears with you? [during labour and birth]		0.9
Did you feel you were treated with respect and dignity during your labour and birth?		0.3
Were you given enough privacy in the birth room or theatre?		0.5
Did you have skin to skin contact with your baby shortly after the birth?		0.5

Question	Don't know	Missing
Overall, how would you rate the care you received in the hospital during your labour and birth?		0.5
Shortly after the birth, did a health professional talk to you about how the birth had gone?	10.4	0.2
After the birth of your baby, did the health professionals explain things in a way you could understand?		0.3
After the birth, did the health professionals give you enough information about how to care for yourself		0.2
After the birth, did the health professionals give you enough information about how to care for your baby?		0.4
After the birth of your baby, did you ever receive conflicting information from health professionals about how to care for yourself or your baby?		0.4
Do you think the health professionals did everything they could to help you manage your pain after the birth of your baby?		0.9
After the birth of your baby, were you able to get assistance or advice from health professionals when you needed it?		0.2
After the birth of your baby, were the health professionals taking care of you kind and caring?		0.1
Were the visiting times convenient for your friends and family?		0.3
How clean were the wards or rooms you stayed in after the birth of your baby?		0.8
How clean were the toilets and bathrooms you used after the birth of your baby?		0.6
During your stay in hospital, were you ever bothered by any of the following?		1.7
How would you rate the hospital food?		0.4
Did the hospital provide access to food when you needed it?	4.4	0.6
Were your decisions about how you wanted to feed your baby respected by the health professionals?		0.4
Did you ever receive conflicting advice about feeding your baby from the health professionals?		0.5
Did midwives in the hospital work with you to show you a good position for breastfeeding your baby?		0.4
Did you feel involved in decisions about your discharge from hospital?		0.5
Looking back, do you feel that the length of your stay in hospital was…?		0.6
Before leaving hospital, were you given enough information about caring for yourself and your baby at home?		0.7
Did hospital staff tell you who to contact if you were worried about your health or your baby's health after you left hospital?	4.1	0.3
Overall, how would you rate the care you received in the hospital after your baby was born?		0.4
In the first 2 weeks after arriving home, did you have a follow-up appointment with a midwife or nurse?		0.3
During a follow-up appointment, did a midwife or nurse ask you how you were feeling emotionally?	1.9	0.3
In general, did you feel that the midwife or nurse listened to you? [at follow-up appointment]		0.2
In general, did you have enough time with the midwife or nurse to ask questions or discuss any concerns?		0.2
At any point during your pregnancy or after the birth, were you shown or given information about safe sleeping for your baby?		0.6
Overall, how would you rate the care you received in the first two weeks after arriving home from the hospital?		0.5
If friends and family asked about your maternity experience at the hospital where you gave birth, how would you respond?		0.8