**O'Loughlin, Mary Angela (2022)** ***Health care homes in Cairns: a mixed methods study exploring the experience of adults living with chronic conditions to inform the new model of primary health care.*** **PhD Thesis, James Cook University.**

# Health Care Homes in Cairns: a mixed methods study exploring the experience of adults living with chronic conditions to inform the new model of primary health care

**Thesis submitted by**

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May 2022

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# Acknowledgements

I would like to extend my immense gratitude and appreciation to my primary advisor Linton Harriss, who has provided unwavering guidance, support and friendship over the multiple years of this PhD project. Thank you, Linton, for sharing your exceptional expertise; always calmly, with patience and the highest professionalism.

To Jane Mills, my original PhD advisor: thank you for your unwavering support, even when you left our northern shores and headed south. You are an inspirational, extraordinary teacher and I am exceedingly grateful to have been guided by you.

To Robyn McDermott, thank you for sharing your extensive professional knowledge and talents. I have sincerely appreciated your guidance and support of my progress over these years.

Thank you to Caryn West for taking me on mid-way through my candidature. Your generosity of spirit, combined with your detailed, informed guidance has made a huge difference to my project. I am much more confident in my approach to research following your supervision.

To my husband, Simon, thank you for your incredible, dedicated support that has seen me through this journey. You have lived these years by my side, and I am looking forward to our post-PhD life together. To our children, I hope when you recollect your teenage years that I demonstrated (finally) that if you “just keep swimming” you can get there.

I am appreciative of the AITHM PhD Scholarship Program and the Australian Government Research Training Program Scholarship that supported this PhD study. Thank you to the Far North Queensland Hospital Foundation and the College of Public Health, Medical and Veterinary Sciences Higher Degree Research Enhancement Scheme for their helpful provision of funding.

I would like to acknowledge and thank the study participants, the original P3ED researchers and the FNQHAT research team for their contribution to this project. To my interview participants, a special thank you for sharing your time, thoughts and expertise. I sincerely appreciate your contribution to this project.

Finally, thank you to my JCU friends and colleagues for your understanding and support. I am looking forward to sharing another chapter with you.

# Statement of Contribution of Others

| ***Nature of Assistance*** | ***Contribution*** | ***Co-contributors*** |
|---|---|---|
| Intellectual support | The supervisory team contributed to the research proposal design; supported the development of the published papers; and proof-read the published papers and thesis. | Dr Linton Harriss,<br>James Cook University<br>Professor Robyn McDermott,<br>James Cook University<br>Professor Caryn West,<br>James Cook University<br>Professor Jane Mills,<br>La Trobe University |
| Data collection | Initial phone recruitment of participants for interview | Ms Sally McDonald,<br>Research Administration,<br>James Cook University |
| Data analysis | Supported dataset merging and data analysis | Dr Linton Harriss,<br>James Cook University<br>Fintan Thompson,<br>Data Manager,<br>James Cook University |
| Financial support | Tuition fee offset | Australian Government's Research Training Program Scholarship |
| | Stipend (2015-2018) | Australian Institute of Tropical Health and Medicine (AITHM) Postgraduate Research Scholarship,<br>James Cook University |
| | Provision of gift cards to interview participants and funding of | Far North Queensland Hospital Foundation, Research Grant |

| ***Nature of Assistance*** | ***Contribution*** | ***Co-contributors*** |
|---|---|---|
| | transcription services, to the value of $2,990 | |
| | Publication support for 1 x article publication charge, to the value of $3,000 | College of Public Health, Medical and Veterinary Sciences, Higher Degree Research Enhancement Scheme, James Cook University |
| In-kind support | Office space, photocopying | Centre for Chronic Disease Prevention (2015 to 2018),<br>College of Public Health, Medical and Veterinary Sciences (2019 to 2022),<br>James Cook University |

# Abstract

## Background, aim and scope

Person-centred care is a foundational goal of policymakers and service providers across the Australian health care landscape. This goal can only be achieved if the needs, values and preferences of the people that use health services are understood and used to drive service delivery. With chronic conditions being the leading cause of ill-health and death in the Australian population, improved approaches to care management for people living with chronic conditions are needed.

This research aimed to explore the experience of adults living with chronic conditions as they accessed health services; then use this knowledge to explain how the introduction of a new model of primary health care, the Health Care Homes model, might improve service delivery. The setting was Cairns, a regional city located in northern Queensland, Australia. Using a person-centred approach, local-dwelling adults living with chronic conditions voiced their perspectives on health service delivery and provided direction on ways to enhance model implementation.

## Methods

A two-phase, explanatory sequential mixed methods design was employed. In the first phase, quantitative exploration of local-area health service experiences was conducted, and data linkage undertaken. This data linkage connected an existing quantitative patient-experience survey with emergency department and hospital admissions administrative datasets. Quantitative analyses were undertaken using Stata 13.1 (Stata Corp, College Station, Texas, USA) to characterise the population; and to explore experiences and perspectives of health service delivery. In the second phase, a sample of people sourced from the quantitative patient-experience survey participated in twenty-one (21) semi-structured interviews to qualitatively explain the phase one findings; and to explore how elements of the Health Care Homes model were valued by the people that use health services. A modified grounded theory approach to analysis was applied, employing the methods of memoing; constant comparative analysis; concurrent data generation and analysis; and storyline thematic analysis. Data was managed using *NVivo* (Version 12, QSR International Pty Ltd.), *Microsoft Word 2016* and manual techniques. Finally, using the mixed method design, findings from the two phases were integrated to explain how implementation of the Health Care Home model might improve the delivery of health care services for people living with chronic conditions in Cairns.

## Results

Findings indicated that people living with uncommon, or difficult to manage, chronic conditions reported poorer care experiences and could potentially benefit from the implementation of a new care model. The need for people to be known by their care provider was highlighted by participants in this research. Formalising the commitment between a person and their general practitioner (GP), as part of the Health Care Homes model, could be advantageous to people living with uncommon chronic conditions. For people that live with common chronic conditions involving clear treatment plans, a change in the model of service delivery may not directly improve their experience of care. Those who felt the least understood and most disconnected from existing service provision may benefit the most from enrolment in Health Care Homes: by formalising their relationship with a GP and developing a shared care plan for ongoing action and review.

Uncertainties around the cost and delivery of service provision created confusion for people living with chronic conditions and deterred some from seeking care. Specifically, the current practice of GPs alternating between bulk-billed and fee-paying consultations created uncertainty. Clearly outlining the costs and processes of care, as part of enrolment in the Health Care Homes model, has the potential to promote the person-practitioner shared understanding of care delivery. Additionally, reduced demand on acute care services may result from people knowing if, and when, they will be bulk-billed for primary health care services.

The Health Care Homes model endeavours to share care delivery amongst key health professionals including regular GPs, other practice GPs and practice staff. The model design involves people committing to a practice for the management of their chronic condition needs. This research found that people living with chronic conditions make their commitment to an individual GP. Importantly, people were only willing to commit to a general practice organisation for the purpose of enabling access to their regular GP. Practice staff, including nursing staff, were not perceived by people to be central to the delivery of their care. Successful model implementation needs to consider this lack of commitment to the wider practice. Careful design of service delivery is indicated to support people’s care needs when their preferred GP is unavailable. Ignoring the importance of the primary person-practitioner relationship will challenge the model implementation. Measures to support this relationship while building connected, alternative care pathways into the system are essential.

Strategies to embed connected, alternative primary health care services within general practice are indicated, particularly for after-hours care provision. Beginning with an understanding that people strongly commit to their GP, but not to the practice, policymakers and service providers can consider ways to promote connectivity in primary care. Strategies to improve existing tools designed to share health information, such as My Health Record and shared care plans, would be helpful. Data collection and sharing needs to be with a person-centred focus, especially for regional-dwelling people who may experience privacy challenges related to living in communities with a limited number of services. Promoting the sharing of health information involves increasing people's health literacy and engagement with their own health records, to enable them to control data access and content. Continued work to promote accuracy in health service records promotes person-centred care, with reliable data supporting informed decision-making. This is of particular importance when people interact with health services to which they are not known.

**Conclusion:**

The successful delivery of person-centred care through the proposed Health Care Homes model involves understanding and prioritising the person-practitioner relationship. For people living with chronic conditions service delivery can be improved by supporting their preferred, regular GP relationship, and not assuming that this relationship extends to the practice organisation; removing uncertainty around costs and systems; providing alternate, connected care when their regular GP is unavailable; strengthening person-supported data sharing of health records; and prioritising the delivery of Health Care Homes enrolment to those least served by existing models of care, specifically those living with uncommon and difficult to treat chronic conditions. The Australian Health Care Homes model has the potential to improve health service delivery to people living with chronic conditions in Cairns, and across Australia, if the focus of the model is truly person-centred.

# Abbreviations

| | |
|---|---|
| ACCHO | Aboriginal Community Controlled Health Organisation |
| AMS | Aboriginal Medical Service |
| ABS | Australian Bureau of Statistics |
| AIHW | Australian Institute of Health and Welfare |
| CDM | Chronic Disease Management |
| CHF | Consumer Health Forum |
| CHHHS | Cairns and Hinterland Hospital and Health Service |
| COPD | Chronic obstructive pulmonary disease |
| CIs | Confidence intervals |
| EDs | Emergency departments |
| FNQHAT | Far North Queensland Hospital Avoidance Trial |
| FNQHREC | Far North Queensland Human Research Ethics Committee |
| GP | General practitioner |
| HCHs | Health Care Homes |
| JCU | James Cook University |
| JCUHREC | James Cook University Human Research Ethics Committee |
| MBS | Medicare Benefits Schedule |
| ORs | Odds ratios |
| P3ED | Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department |
| PCMH | Patient Centered Medical Home |
| PAGP-type | Potentially avoidable GP-type |
| PPHs | Potentially preventable hospitalisations |
| PHCAG | Primary Health Care Advisory Group |
| QHAPDC | Queensland Hospital Admitted Patient Data Collection |
| RQ | Research question |
| VPR | Voluntary patient registration |

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# Preface: Positioning of the researcher

In the years immediately preceding this thesis I had been working within the discipline of public health, with a focus on epidemiology; however, my earlier years of study and work were in the discipline of nursing which has historically aligned with both quantitative and qualitative approaches to research (Gerrish, Lathlean, & Cormack, 2015, p.26). In 2015, following interstate relocation to Cairns, I had the intention to further my research studies and was fortunate to be awarded an inaugural Australian Institute of Tropical Health and Medicine scholarship to undertake PhD studies at James Cook University. The scholarship was linked to the academic stream of chronic disease in tropical Australia, and it was through this scholarship process that I was introduced to Professors Jane Mills and Robyn McDermott; and Dr Linton Harriss. Professor Caryn West joined my advisory team in 2017.

I was privileged to be able to learn from highly esteemed research methodologists, with extensive experience working within the local region and across Australia. In addition, my advisors had previously been involved with two, independent research projects: the *Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department* (P3ED) project undertaken in 2014 and the *Far North Queensland Hospital Avoidance Trial* (FNQHAT), which had linked two Cairns Hospital administrative datasets for the period 2012 to 2014. These projects had been conducted separately, covering the same time period and the proposed idea for my PhD was to involve the linking of these datasets.

My first PhD challenge was to determine the purpose of the research. The P3ED project involved a quantitative patient experience survey undertaken in the Cairns Hospital ED, while the FNQHAT dataset was a previously merged dataset of patient medical records. With guidance from my advisory team, a consideration of these previous project features concluded that my PhD focus could be to explore the delivery of health service to people living with chronic conditions in Cairns: Why did people decide to visit the ED? What did they think of other health services? Were any patterns determinable when their reasons for attending the ED were linked with their actual hospital experience? How could we improve health service delivery using this person-perspective knowledge? Some of these ideas had already been considered in the original P3ED project, with the point of difference for my PhD research being the focus on adults living with chronic conditions.

While I was determining the purpose of my PhD project, the Australian Government's Primary Health Care Advisory Group released their 2016 report titled "*Better Outcomes for People with Chronic and Complex Health Conditions*" which recommended a new model of care, the Health Care Homes (Commonwealth of Australia Department of Health, 2016). In early 2016 it was uncertain if or how this model might be trialled or implemented in Australia, however it seemed like a unique opportunity to narrow the lens of the research; to consider, from the person-perspective, how this type of care model might improve health service delivery to people living with chronic conditions.

The next challenge was to determine the methodology and methods. As the project involved dataset linkage it was pre-determined that the methods would involve a quantitative approach, using statistical analyses. However, given that the project's purpose was to explore people's perspectives of health service delivery, a qualitative approach to understand their subjective experiences was important. A mixed methods approach, using both quantitative and qualitative investigations to explain and understand the phenomena, was methodologically suited for the task.

The idea of undertaking qualitative research, as part of the mixed methods approach, was initially confronting. Through my public health teaching I had a strong sense that the researcher should always be objective in their approach. Exploration of qualitative texts led me to the understanding that researcher subjectivity and reflexivity (Braun & Clarke, 2013) would challenge my existing beliefs. In my public health and nursing roles I had been trained to be objective; to maintain a professional stance; and to utilise evidence-based, best practice approaches which were scientifically derived (Gerrish et al., 2015). Including my own perspectives and acknowledging my own limitations was going to require effort, using techniques that I was unfamiliar with.

Initial reflection on the research process considered whether I was an insider or an outsider to the research; with insiders being people who identify with study participants, whereas outsiders are deemed to be separate to the group (Braun & Clarke, 2013). Initially I believed myself to be an outsider: an academically minded health professional who was interested in learning from the people who live with chronic conditions about their perspectives of health services. It was only several months into the project that I recognised I was in fact an insider as well. My father's life-long battle with chronic ill-health, had dominated my childhood and young adult life, until his death over 20 years ago. My childhood had been shaped by the limitations of his health: the inability to participate in common daily activities, such as driving or work; the constant visits to health practitioners and health services; and observing the effects of treatments which often caused complications. The impact of living with chronic conditions had influenced every aspect of my family life. As a child I did not recognise this was different to others, as I felt loved and cared for by my parents. Even as an adult, it was several months into this project before I realised that my father would have been an ideal participant. The understanding that I was an insider gave me confidence; I knew I would be able to empathise with my study participants. It is for this reason that my thesis is dedicated to my father, John, who lived with multiple, complex chronic conditions; and to my mother, Merle, whose life was guided by always caring for him.

# Chapter 1: Introduction

## 1.1 Introduction

Chronic disease presents a great challenge to the health of Australian people (Australian Institute of Health and Welfare [AIHW], 2014). Chronic diseases are differentiated from other health states as they are long-lasting, require ongoing care management and in general, cannot be cured (AIHW, 2014). The term *chronic conditions* is commonly used and recognises that the experience of chronic ill-health is not just the result of disease but includes other health states such as injury and some disabilities (AIHW, 2018a).

The impact of living with a chronic condition varies between individuals and often changes across time. Many people live with multiple chronic conditions, increasing their need for care and creating complexity in their care management (AIHW, 2020a). For people living with chronic conditions, the economic and social impact of managing their condition is significant (Stephen, Jan, Essue, & Leeder, 2012), with both the person and their family being affected by loss of income; increased personal expenditure (AIHW, 2012); and the potential for social isolation and mental ill health (Ellison, Gask, Bakerly, & Roberts, 2012).

There is an increasing occurrence of chronic conditions in Australia. Nearly half (47.3%) of the population had one or more chronic conditions in 2017-18. This was an increase on the proportion of people living with chronic conditions ten years earlier (2007-08: 42.2%) (Australian Bureau of Statistics [ABS}, 2018). Concomitantly, multimorbidity, where people live with two or more chronic conditions, increasingly impacts the Australian population (2014-15: 23%) (AIHW, 2018a). The cumulative effect of managing expanding and complex needs, challenges health services in the delivery of care for people living with chronic conditions.

Improving care management and preventing ill-health are key strategies that have been identified to support the health of Australian people in *Australia’s Long Term National Health Plan* (Australian Government Department of Health, 2019a). With more people living with chronic conditions there is an ever-increasing demand on the health care system (AIHW, 2014) and increased expenditure for the Australian community (AIHW, 2012). A planned approach is required to meet this demand. Effective care management in the primary health care setting has been identified as an important measure to prevent unnecessary hospitalisations and to reduce demand on acute care services, particularly in regional and remote areas (Reeve et al., 2015).

### *1.1.1 Health in regional Australia*

People living in regional and remote areas of Australia have an increased occurrence of chronic conditions when compared with metropolitan populations (AIHW, 2016; Productivity Commission, 2017), with chronic obstructive pulmonary disorder (COPD), diabetes, coronary heart disease and stroke having notably higher rates of occurrence in far north Queensland (Northern Queensland Primary Health Network, 2016). When compared with metropolitan communities, regional and remote Australians have high rates of risky behaviours, such as tobacco smoking and drinking alcohol, and experience poorer health outcomes including lower life expectancy and higher rates of disability (AIHW, 2018a, 2019).

Cairns is a large regional centre in far north Queensland which is unique in terms of population diversity and health service needs. As an outer regional community, geographical distance impacts health service delivery (AIHW, 2020a). When compared with those living in major cities, people living in outer regional areas experience poorer access to specialist medical services; are less likely to have a regular general practitioner (GP); and are more likely to attend the emergency department for care due to a lack of available GP services (AIHW, 2018b). The delivery of health services to the Cairns population is further challenged by the climatic influences of living in a tropical environment; a population which includes people living with high levels of socio-economic disadvantage, including communities of Aboriginal and Torres Strait Islander people; a significant overseas born population; and an insufficient and transient health workforce in some areas (Far North Queensland Medicare Local, 2014).

Alongside other regional Australian communities, people living in Cairns have notably higher rates of COPD and coronary heart disease. Presentations to the local area hospital emergency department for COPD and diabetes have substantially impacted health service delivery in Cairns (Far North Queensland Medicare Local, 2014; Northern Queensland Primary Health Network, 2016). A recent study estimated that approximately 20 per cent of presentations to the public hospital emergency department in Cairns were attributable to chronic conditions, with two-thirds of these being for circulatory diseases or mental/behavioural disorders (Harriss et al., 2016). These acute episodes of care are of interest to stakeholders, as some may be potentially preventable with appropriate management in primary health care (National Health Performance Authority, 2015). Enhancing the effective delivery of health services in regional areas of Australia, such as Cairns, is fundamental to improving population health and well-being.

### *1.1.2 Primary care and primary health care*

Given the significant challenge of delivering health services to people living with chronic conditions, a range of care models have been proposed, many of which have been situated in the primary care or primary health care setting (Commonwealth of Australia Department of Health, 2016). In Australia, primary care refers to community-based services provided by doctors, nurses and allied health practitioners, for the diagnosis, treatment and management of health conditions. Based on a medical model of health, general practice is the most common setting for primary care, with aged, disability and community care providers also delivering primary care services. As the first point of entry to the health system, primary care is the most commonly used health service in Australia (AIHW, 2020a; Keleher & MacDougall, 2016).

Although the labels are often used synonymously, a primary health care approach differs from that of primary care. Primary health care is based on a social model of health; it includes the provision of primary care services, as well as programs and services to address the wider societal factors that impact health. Principals of equity, acceptability, universalism, cultural competency and affordability are fostered in comprehensive primary health care, to promote the health of individuals and their communities (Keleher & MacDougall, 2016). Examples of this approach include Aboriginal Community Controlled Health Organisations (ACCHOs), which are culture-centred, local, community-based primary health care services that work to address the health needs of Aboriginal and Torres Strait Islander people (Backholer et al., 2021a). ACCHOs deliver comprehensive primary health care through linkages with wider societal organisations, including housing, employment and advocacy groups (Keleher & MacDougall, 2016).

When compared with primary care service providers, Australia has fewer primary health care organisations; and not all primary health care organisations are able to deliver a fully comprehensive approach. Selective primary health care involves an expanded general practice organisation that links to other services, including allied health. This type of primary health care uses a person-centred approach to address some of the underlying psycho-social influences on health, through an ongoing relationship between a person and their GP. In particular, behavioural risk factors are addressed with measures such as smoking cessation, nutrition education and exercise support (Keleher & MacDougall, 2016).

### *1.1.3 A person-centred approach*

With the support of the Australian Government, through a range of standards, frameworks and performance indicators, Australian health care organisations have attempted to provide a person-centred focus as part of their organisational strategy and service charter. The National Safety and Quality Primary and Community Healthcare Standards expound the importance of effective clinical governance and consumer partnerships, to support the delivery of safe, high-quality health care (Australian Commission on Safety and Quality in Health Care, 2021). However, actually incorporating the preferences, needs and values of people into health service delivery has proven to be challenging (Australian Commission on Safety and Quality in Health Care, 2011). Australia's health system is complicated, funding is complex, and data sharing between service providers is limited. There is a need for improved mechanisms to enable people to navigate the health system, understand their care options, and be involved in care decision-making. Although person-centred care is a goal of Australian health care organisations, in practice there has been limited understanding of how people with chronic conditions experience existing health care services and the value they place on these services.

The terms *patient-centred* or *person-centred* appear similar and are often used interchangeably, however they originate from different perspectives. Evolving from the traditional medical model of care, patient-centred care has been defined as "health care that is respectful of, and responsive to, the preferences, needs and values of patients" (Australian Commission on Safety and Quality in Health Care, 2011, p.1). A patient-centred approach acknowledges and supports the role of patients in making decisions about their own care, however the approach to care is founded on a paternalistic perspective, in which practitioners are the decision-makers, and patients comply with the plan for care. Contrastingly, the person-centred approach has been founded on a holistic model. This wider approach considers a person's social, emotional, spiritual and mental health needs, as well as the medical management of their condition. Person-centred care is a useful approach for people living with chronic conditions, as their health management needs are long-term, and their care management is ongoingly impacted by social determinants (Kumar & Chattu, 2018). It is for this reason that the term person-centred care is used in this thesis, except when the term patient-centred is specifically indicated.

### *1.1.4 Health Care Homes: a new model of primary health care*

By addressing the underlying determinants of health, a person-centred primary health care approach has the potential to better manage the care of those living with complex, chronic conditions (Backholer et al., 2021a). A range of care models have been proposed, and in 2016 the Australian Government commenced a trial of one of these models, the Health Care Homes (Australian Government Department of Health, 2020). The Health Care Homes model has a person-centred focus that focusses on working with people as partners to deliver high-quality care (Commonwealth of Australia Department of Health, 2016). The model provides a centralised "home" for health care needs for those living with a complex or chronic condition. This involves the person, agreeing to work in partnership with their preferred clinician, usually a GP or nurse practitioner, in an existing general practice setting, which may have a comprehensive or selective primary health care approach (Commonwealth of Australia Department of Health, 2016). Additional features of the Health Care Homes model include:

i. having medical records and the health care team all in one place;
ii. employing a team care approach to service provision;
iii. improved access to care services;
iv. improved methods of care coordination and communication;
v. improved methods of data collection and data sharing; and
vi. the use of evidence based best practice approaches and continuous quality improvement strategies (Commonwealth of Australia Department of Health, 2016).

#### *1.1.5 Data sharing between health services in Australia*

Features of the Health Care Homes model include having medical records all in one place, and improved methods of data collection and sharing. Data sharing of medical records between providers in the Australian health care system has been an ongoing challenge. General practices are run as independent businesses and use a range of stand-alone systems to manage their patient data. Historically, data management software has not been universally compatible between general or specialist practices, allied health or hospital providers. Further, the Australian population consistently raises privacy concerns around data collection and sharing (Pang et al., 2020). Poor data sharing has led to the ineffective and inefficient use of health services, such the duplication of pathology tests due to a lack of knowledge by practitioners of previous tests (Duckett, 2015).

In response to this issue of limited health information sharing across a diverse range of health service providers, a national digital health record system was established by the Australian Government. The My Health Record tool has been fully operational since 2019 for all Australians, using an approach in which people may opt-out of participation. It is not a fully comprehensive system and is reliant on individuals and practitioners to upload health information (Australian Digital Health Agency, 2022). Usage of the My Health Record system was an initial requirement for practices that were involved in the Health Care Homes trial, provided that the people enrolled in the Health Care Home provided their consent (Australian Government Department of Health, 2019b).

### *1.1.6 Australian health system funding, and the Health Care Homes model*

Alongside the challenge of poor data sharing between services, the Australian health care system is complex in terms of funding. Health care in Australia is primarily funded by the federal government through schemes such as Medicare, a universal health care scheme that includes funding for public hospital services, some private hospital services, some diagnostic services, and some components of primary health care. A combination of federal, state and territory governments jointly fund public hospitals, although the management of hospital care is mostly a state or territory government responsibility. In addition to funding Medicare, the federal government separately funds residential and community aged care, disability, and veteran's care. As well as public hospitals, state and territory governments fund community health, public health and patient transport services (AIHW, 2018c).

Private health insurance is encouraged by the government through taxation incentives, with more than half of the population being privately insured for private hospital care. In addition to private hospital insurance, people may choose an extras policy that includes varying levels of cover to support the costs of oral and allied health care. Worker's compensation insurers and motor vehicle accident insurers also contribute to funding health care costs. Increasingly, Australians are relying less on private health insurance and more on the Medicare funded public hospital system, and on their own individual contributions to care costs (AIHW, 2018c; Callander, Corscadden, & Levesque, 2017a).

In terms of primary health care, a majority of the payments for GP visits are comprised of a fee-for-service approach, whereby the person must visit the GP to initiate the payment mechanism (Duckett, 2015). Using a Medicare Benefits Schedule (MBS), funding is provided for GP visits up to a set scheduled fee. Any costs in excess of the scheduled fee are borne by the individual. The increasing cost of running a general practice organisation have not kept up with the government's stagnant schedule of fees, leading to pressure on individuals to pay additional, out-of-pocket costs for GP care (Callander, Larkins, & Corscadden, 2017b; Duckett, 2015).

Since 2005, the Chronic Disease Management (CDM) program has been supporting the care of people living with chronic conditions in Australia. It is funded through the MBS and promotes care planning through team-based primary health care. The CDM program supports the development of GP management plans, team care arrangements and care plan reviews. Further, under a CDM plan consumers may access up to five private allied health services per year (Welberry et al., 2019). This is important as most allied health services are not funded by the MBS. The CDM program supports the practice team and allied health to be involved in service delivery. As examples, practice nurses may undertake health assessments inside the general practice clinic; and consumers are given access to MBS funded physiotherapy services. Notably, the scheme requires a GP referral to activate the MBS CDM funding for these services (Australian Government Department of Health and Aged Care, 2022).

Funded by the federal government, an important characteristic of the Health Care Homes model is a change to the billing mechanism for providers. Under this model, general practice providers receive a monthly payment, determined by a risk stratification tool, to manage the care of the person's chronic condition(s). Unlike the existing fee-for-service model in Australian general practice, the Health Care Homes model aims to support flexible service delivery and encourage innovation. This includes fostering alternate workforce arrangements that encourage team-based care delivery, rather than the existing, in-room-only, GP-focussed consultation approach (Australian Government Department of Health, 2020; Commonwealth of Australia Department of Health, 2016).

### *1.1.7 Rationale for research*

The Australian Government's Health Care Homes was derived from an American model of primary care known as the Patient Centered Medical Home (PCMH) (Commonwealth of Australia Department of Health, 2016). Evaluations of the PCMH model have been published, particularly in terms of funding and efficiency, however there is little existing evidence on the person-perspective of the model (Aysola, Werner, Keddem, SoRelle, & Shea, 2015). Specifically, there is an absence of research that investigated if PCMH or Health Care Homes model implementation might make a difference to an individual's experience of health care. Further, Health Care Homes trials have been conducted across a range of metropolitan, regional and remote Australian communities; however, these did not include any communities in the far north Queensland region (Australian Government Department of Health, 2020). This absence of existing trial-sites provided an opportunity to prospectively examine whether this new model of care might make a difference to the delivery of health services, from the perspective of those who live with chronic conditions in Cairns.

## 1.2 Aim of the research

The aim of this research was to explore the experience of people living with chronic conditions in Cairns as they access local-area primary health care services; then use this knowledge to explain how the introduction of the Health Care Homes model might improve the delivery of health care services, from the perspective of the people who utilise these services.

## 1.3 Purpose of the research

The purpose of this research was to enable adults living with chronic conditions to inform on the Health Care Homes model of care, prior to implementation in the local Cairns region.

## 1.4 Research questions

The primary research question (***RQ***) was:

> How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?

This research question was supported by three (3) sub-questions:

> *Research Question 1 (**RQ1**):* What is the current experience of health care service for people living with chronic conditions in Cairns?
>
> *Research Question 2 (**RQ2**):* How are elements of the Health Care Homes model valued by people living with chronic conditions in Cairns?
>
> *Research Question 3 (**RQ3**):* Can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns? What factors will influence the implementation of this model of care?

## 1.5 Research design

The research approach was twofold:

i. to explore Cairns people’s experiences and perspectives of the health care services that they use for the management of their chronic condition; and then,
ii. to consider how the Health Care Homes model might improve health service delivery and identify factors that might influence the model’s implementation.

An explanatory sequential mixed method design was employed, where quantitative methods were followed by qualitative methods (Hesse-Biber, 2010). This mixed methods research design was selected for two reasons:

i. it best suited the sequencing of the data collection/analysis; and,
ii. integrating the data from one phase of data collection/analysis to the next, enables a deeper understanding of the phenomena (Schoonenboom & Johnson, 2017).

Specifically, an explanatory sequential design was used so that the knowledge attained in the quantitative phase could be used to inform the qualitative phase, and then the sequential mixed methods integration and analysis. An outline of the explanatory sequential mixed methods design is presented in *Figure 1*.

*Figure 1: Outline of explanatory sequential mixed methods design*

The project began with a literature review of the key concepts related to the Health Care Homes model. This included a scoping review to establish what was already known about the person-reported experience in the Patient-Centered Medical Home, which is the model of care that has been widely implemented across the United States and is the model from which the Australian Health Care Homes is derived.

Phase 1 of the project involved the quantitative investigation, where two existing datasets were linked. One of these datasets involved routinely collected hospital administrative data from the Cairns Hospital; the other comprised a quantitative, patient-perspective survey that explored people’s reasons for attending the Cairns Hospital emergency department and their perspectives on other health care services. Analyses of this new, linked dataset were used to examine the current experience of health care services for people living with chronic conditions in Cairns (*RQ1*).

Phase 2 of the project used a qualitative approach and involved interviews with people living with chronic conditions in Cairns. The data collection and analysis had a twofold aim:

i. to explore people's current experience of health care services (*RQ1*); and,
ii. to examine how elements of the Health Care Homes model are valued by people living with chronic conditions (*RQ2*).

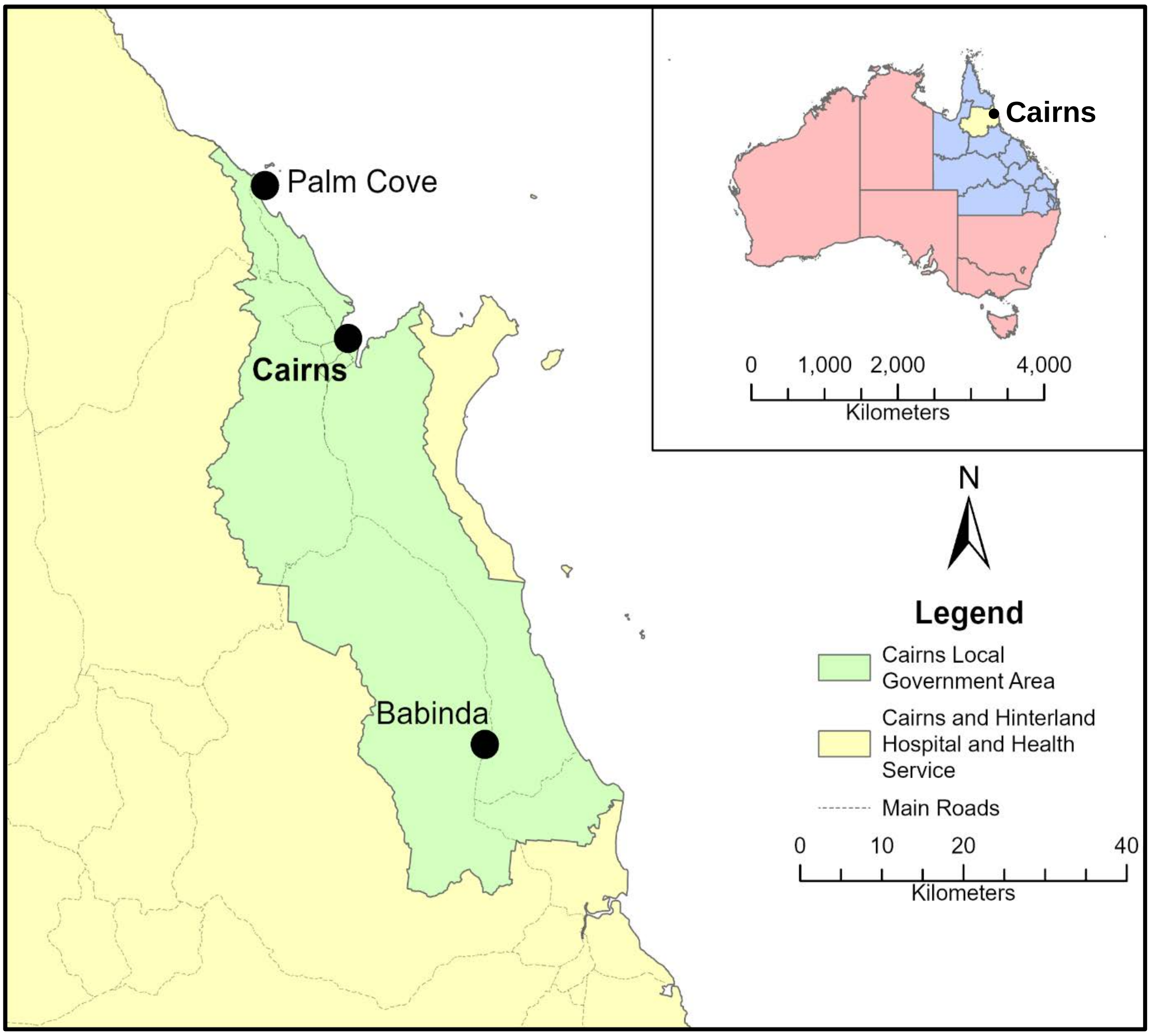
The qualitative phase engaged a sample of respondents from the Phase 1 patient-perspective survey. This approach was informed by the explanatory sequential mixed methods design that uses Phase 2 qualitative investigation to expand and explain findings from the first project phase (Creswell & Plano Clark, 2011).

Following Phases 1 and 2, the results from each of these phases were integrated to generate the mixed methods findings. This integration was guided by *RQ3:* to explain if, and how, the Health Care Homes model can improve the delivery of health service to people living with chronic conditions in Cairns; and to determine factors that might influence the implementation of this model of care.

## 1.6 Study setting

Cairns is a large, outer-regional city located in the far north of Queensland, Australia (Northern Queensland Primary Health Network, 2016). The setting for this study was the Cairns local area (see *Figure 2*).

*Figure 2: Location of Cairns and map of Cairns local government area*



*Note.* Map created with ESRI ArcGIS Pro using ABS (2016), Queensland Department of Resources (2020), and Australian Government Department of Industry, Science, Energy and Resources (2020) datasets under Creative Commons Attribution 4.0 International licence (CC BY 4.0).

With a population of over 150,000 in the local government area, Cairns has a higher proportion (9%) of people who identify as being Aboriginal and/or Torres Strait Islander when compared with state (4%) or national (2.8%) averages (ABS, 2020a).

The study was conducted with reference to the community serviced by the regional health service, the Cairns and Hinterland Hospital and Health Service (CHHHS), a Queensland Government, Queensland Health site. Although the CHHHS supports the health and well-being needs of a wide geographic community, including the Atherton Tablelands region, this present study was interested in the health service experiences of people who lived locally to the Cairns city and suburban areas. Consequently, the scope of the study setting was limited to the local government area of Cairns.

## 1.7 Outline of thesis

This thesis is comprised of seven chapters, beginning with this introductory chapter.

Chapter 2 describes the background to the project in the form of a review of the literature, which includes description of the Health Care Homes model of care. As part of this thesis process, manuscripts constructed from the research have been published in peer-reviewed journals. The initial project investigation involved a scoping review of the existing literature which described the patient-reported experience of the Patient Centered Medical Home model, which is the American model of care on which the Health Care Homes model is based. Chapter 2 includes this scoping review, which was published in the *Australian Journal of Primary Health* titled ‘Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes’.

Chapter 3 describes the project’s methodology and study design. This includes an outline of ethical approvals and a discussion of ethical considerations. The rationale for choosing a mixed method, explanatory sequential design is expounded. The use of modified grounded theory approaches to analysis within the mixed methods design are described and justified.

Chapters 4, 5 and 6 are the results chapters of this thesis. Chapters 4 and 5 relate to the two-phase mixed methods approach, with Chapter 4 describing the quantitative findings; and Chapter 5 presenting the qualitative findings. Chapter 6 integrates these findings to construct the mixed methods results and answer the primary research question: How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?

Manuscripts that have been published in peer-reviewed journals are included in these results chapters. In Chapter 4, three manuscripts are included. The article titled ‘Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study’ was published in *Emergency Medicine Australasia*; an article titled ‘Exploring the measure of potentially avoidable GP-type presentations to the emergency department in regional Queensland using linked, patient-perspective data’ was published in the *Australian Health Review; and* a research letter titled ‘Validating Indigenous status in a regional Queensland hospital emergency department dataset with patient-linked data’ was published in *The Medical Journal of Australia*. In addition, a draft report titled ‘Summary of the experience of Aboriginal and Torres Strait Islander people who participated in the CHHHS P3ED survey’ is included. Chapter 5 includes an article titled ‘Medical Homes and chronic care: consumer lessons for regional Australia’ which has been published in the *Australian Journal of Primary Health*.

Chapter 7 summarises and concludes the thesis, identifying recommendations that may support the introduction of the Health Care Homes model in the Cairns community. These recommendations have the potential to be relevant to other regional communities, as well as across the Australian health care landscape, in which people are increasingly informing on the models of care that deliver the health services that they need to manage the care of their chronic condition. Additionally, this chapter considers the strengths and limitations of this research and provides direction for future study.

### *1.7.1 Centred or Centered: a comment on spelling*

Throughout the thesis the American English spelling of the word ‘centered’ is used when referring to the name of the American model of care, the Patient-Centered Medical Home. At all other times the Australian English spelling of ‘centred’ is used.

## 1.8 Chapter summary

This chapter has provided an overview of the research project and introduced key study characteristics; including an introduction to study concepts; study aim and purpose; research questions; research design; and study setting. The chapter structure of the thesis was described and peer-reviewed manuscripts that have been incorporated into this thesis have been outlined.

The next chapter explores the literature that has informed the thesis and includes the first of the publications, which is a scoping review of patient-reported experience on the model of health care that is the focus for this thesis.

# Chapter 2: Literature Review

## 2.1 Introduction

This chapter explores the background to the study. This involves an appraisal of peer-reviewed journal articles and Australian Government publications to:

i. explore the impact of chronic conditions on the Australian population and health care system;
ii. identify existing models of primary health care for people living with chronic conditions; and,
iii. review the person-perspective evidence of the Patient-Centered Medical Home, which is the existing care model most similar to the Health Care Homes model.

The chapter includes the first publication from this thesis, a scoping review that was published in the *Australian Journal of Primary Health*, titled: ‘Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes’.

An understanding of the existing evidence is necessary to establish what is already known about the person-perspective of the care model. Identifying gaps in the existing knowledge provides the justification for the conduct of this study. Although there have been evaluations of the Patient-Centered Medical Homes model, most of these have been from a provider or funder perspective, not from the person-perspective (Aysola, Werner, et al., 2015). Australia’s health care service delivery aims to be person-centred (Australian Health Ministers’ Advisory Council, 2017). This aim can only be achieved if the needs, values and preferences of the people that use health services are understood and used to drive service delivery.

## 2.2 Health in the Australian population

Australian people are living longer, healthier lives with a health care system that compares favourably to many other countries of similar development (AIHW, 2018a). In 2017-18, over half of all Australians (56%) aged 15 years or more self-described their health status as 'very good' or 'excellent' (AIHW, 2020a). With a population of over 25 million, life expectancy has risen to 80.4 years for males and 84.6 years for females in 2016 (AIHW, 2018a). Although living longer, across the lifespan the number of years that an Australian person lives with ill-health has not changed since 2003 (AIHW, 2017b); with males and females expected to experience ill-health for 9.0 and 9.9 years of life respectively (AIHW, 2017b).

Disparities in health status are experienced by groups within the Australian population. People are more likely to experience ill-health in the later part of their lives, with aging and ill-health being directly correlated (AIHW, 2017b). When compared with those living in Australia's major cities, regional and remote dwelling Australians live shorter, less healthy lives; with increasing remoteness corresponding to declining health (AIHW, 2017b). Those living outside major cities may experience poorer access to health services; an increased occurrence of risky health behaviours (smoking and excessive drinking); and socioeconomic and educational disadvantages (AIHW, 2020a). Aboriginal and Torres Strait Islander people are notably impacted by socioeconomic disadvantage in Australia, leading to poorer health outcomes and shorter life expectancy (AIHW, 2017b, 2018a). People with disability may experience a higher occurrence of risky health behaviours (poor diet, insufficient exercise and smoking); an increase in mental-health challenges; and poorer overall health status, than those not living with disability (AIHW, 2020a).

It is clear that factors of age, regional/remote dwelling, socioeconomic disadvantage and disability, may increase the occurrence and impact of ill-health (AIHW, 2014, 2018a). These factors are not independent. As an example, those that live with chronic health conditions may experience challenges to employment opportunities; this can lead to increased socioeconomic disadvantage and impact the funding of their health care. Poorly managed health conditions can lead to further inability to access employment and an ongoing cycle of disadvantage (AIHW, 2020a).

### *2.2.1 Defining chronic conditions*

A wide range of disease states and health conditions can be described as chronic. For a health condition or disease to be defined as chronic it requires ongoing medical management; may be complex in aetiology; can have multiple risk factors; is often a permanent health state with no known cure; and may contribute to the development of further health conditions, leading to increased disability and reduced life expectancy (AIHW, 2011, 2012, 2014). Terminology is often used interchangeably, however the term ‘chronic condition’ is often preferred to ‘chronic disease’ as it includes not only disease states but incorporates health conditions that arise from genetic, injury and disability mechanisms (Australian Health Ministers’ Advisory Council, 2017). In this thesis the term ‘chronic disease’ is only used when disease-specific data is discussed.

### *2.2.2 Chronic conditions in the Australian population*

Chronic disease is the leading cause of ill-health and death in the Australian population (Australian Health Ministers’ Advisory Council, 2017; AIHW, 2012) with 90% of deaths having chronic disease as an underlying cause (AIHW, 2014). Over 75% of these deaths are attributable to four chronic diseases, specifically cardiovascular disease, cancer, COPD and diabetes. Prevalence estimates of the most common chronic conditions in the Australian population are described in *Figure 3*.

*Figure 3: Five most common chronic conditions in Australia*

| Common chronic conditions | Estimated Prevalence | Estimated Population |
|---|---|---|
| **Musculoskeletal conditions**<br>Including back problems and arthritis | 31.4% | 7.6 million |
| **Mental and behavioural conditions** | 20.1% | 4.8 million |
| **Respiratory diseases**<br>Including asthma and COPD | 13.7% | 3.3 million |
| **Diabetes mellitus** | 4.9% | 1.2 million |
| **Cardiovascular diseases** | 4.8% | 1.2 million |

*Note.* Sourced from ABS (2018)

Other conditions that significantly impact the health and well-being of Australian people include chronic kidney disease and cancer (ABS, 2018; AIHW, 2014).

Burden of disease analysis measures the impact of disease at a population level for both premature death (fatal burden) and ongoing illness (non-fatal burden) (AIHW, 2015b). Chronic disease has been identified as the leading cause of fatal burden of disease across both age and gender for the Australian adult population, with cardiovascular disease and cancer being the chronic diseases recognized as having the most significant impact (AIHW, 2015b). Concurrently, the non-fatal impact of chronic disease accounts for approximately 85% of the total burden of disease in the population (AIHW, 2014). Musculoskeletal disorders and mental and behavioural disorders have been identified as having a major impact on the non-fatal burden in the Australian population (AIHW, 2014). Since 1990, as a proportion of total burden, the non-fatal burden of chronic conditions has increased. This means that the impact on the Australian population of chronic disease is increasingly being experienced by those living with chronic disease rather than those dying prematurely from chronic disease (AIHW, 2014).

Many people suffer from multiple chronic conditions (AIHW, 2014). The 2017-18 National Health Survey estimated that nearly half of the Australian population (47.3%) had at least one chronic condition (ABS, 2018); with at least 20% of the population experiencing multiple chronic conditions (AIHW, 2020a). Living with multiple chronic conditions increases the complexity and cost of care management (Australian Health Ministers' Advisory Council, 2017). Older age people are more likely to experience multiple chronic conditions, with 29% of people aged over 65 years reporting that they have three or more chronic diseases (AIHW, 2016). This increased complexity of care often leads to poorer health outcomes with an increased occurrence of premature death. With Australia's population ageing, the number of people living with multi-morbidity is expected to rise, placing additional demand on Australia's health care system (Commonwealth of Australia Department of Health, 2016).

### *2.2.3 Measuring the cost and effectiveness of Australian health service delivery*

Chronic conditions exert an increasing financial pressure on the Australian community (AIHW, 2014); with the actual cost of care being unknown (AIHW, 2012). Total expenditure on health for the Australian population was estimated to be $185 billion in 2017-18, with a cost per person of $7,485 (AIHW, 2020a). Over the past decade expenditure on health has grown at a greater rate than the population size and has been consuming an increased proportion of the country's economic output (AIHW, 2018a). Costly disease groups include cardiovascular, oral, mental and musculoskeletal diseases, which together accounted for 36% of allocated health expenditure in 2008-09 (AIHW, 2014). Unallocated health expenditure, community and personal cost are difficult to estimate, with the combination of allocated and non-allocated costs having a significant and increasing impact on the Australian economy (AIHW, 2014).

Given the ongoing, substantial cost of managing chronic conditions, the Australian Government has established benchmarks to assess the performance of health service delivery (Council of Australian Governments, 2018). Under the Australian Health Performance Framework, health system effectiveness has been measured by a range of indicators including selected potentially preventable hospitalisations (PPHs) and potentially avoidable GP-type (PAGP-type) presentations to emergency departments (EDs) (AIHW, 2013, 2020b).

### *Potentially preventable hospital admissions*

Hospitals are key health service providers in Australia (AIHW, 2014; Lowthian et al., 2011). Chronic conditions impact on acute care hospital services by increasing the quantity and length of care episodes (AIHW, 2014; Lowthian et al., 2011). Potentially preventable hospitalisations "are those conditions where hospitalisation is thought to have been avoidable if timely and adequate non-hospital care had been provided" (AIHW, 2015a, p.89). The Australian Government measures PPHs in the acute care setting to determine the effectiveness of primary health care service delivery (Council of Australian Governments, 2015). Specifically, if a community is providing appropriate, timely and accessible GP, allied health and community health care, then hospitalisations arising from a range of conditions should be avoidable. Three broad categories of PPHs have been described:

i. conditions that could have been prevented by vaccination, such as influenza;
ii. conditions that require acute intervention, with examples of these being dental, urinary, ear, nose and throat infections; and,
iii. complications that arise from chronic conditions such as congestive cardiac failure, asthma, hypertension and complications from diabetes (AIHW, 2020c; Council of Australian Governments, 2015, 2018).

In Australia, the rate of PPHs for chronic conditions was 1,233 per 100,000 in 2017-18 (AIHW, 2020c). There were 343,500 PPHs identified as attributable to selected chronic conditions in Australian hospitals (both public and private) in 2017-18; with chronic obstructive pulmonary disease (COPD), congestive cardiac failure and type 2 Diabetes complications having the greatest impact (AIHW, 2020c). When examining rates of PPHs it is important to reflect that the measurement is complex. Changes in PPHs can be attributable to a range of factors; for example, PPHs will increase when there is an actual increase in the underlying disease, not just when primary health care services are lacking (AIHW, 2015a).

### *Potentially preventable emergency department presentations*

Alongside the potential increased demand for acute care hospital admissions, poor community-based coordination of chronic conditions may lead to an increase in emergency department presentations (Cameron, Joseph, & McCarthy, 2009). The National Healthcare Agreement indicator of PAGP-type presentations to EDs has been used to measure the availability and accessibility of Australian primary health and community services (AIHW, 2014, 2021). A PAGP-type presenter to the emergency department has been defined by the AIHW as a person who "was allocated a triage category of Semi-urgent or Non-urgent, and did not arrive by ambulance or by police or correctional vehicle, and at the end of the presentation, was not admitted to the hospital, was not referred to another hospital, and did not die” (AIHW, 2014, p.404). This current definition of a PAGP-type presentation to the ED is imprecise. Since 2012 the definition has been under review by the AIHW. Alternative definitions have been proposed, however agreement has yet to be reached on a preferred measure of this indicator of health service effectiveness (AIHW, 2014, 2021; Nagree, Gosbell, McCarthy, Moore, & Mountain, 2013). Using the existing AIHW definition of a PAGP-type presentation, an estimated 2.2 million presentations in 2012-13 were potentially avoidable to EDs in large Australian hospitals (AIHW, 2014, p. 404). It was estimated that this accounted for approximately 84% of emergency occasions of service in Australia (AIHW, 2014). With the increasing demand for chronic care, improved care management in the primary health care setting has the potential to reduce costly acute episodes of care in Australian hospitals and EDs and improve population health and well-being.

### *2.2.4 Managing chronic conditions in the Australian health care system*

For many people living with chronic conditions there is no cure, with ongoing health care management required. Managing complex ill-health, over a continuous, unending period requires access to multiple health professionals and health service providers. The impact of living with a chronic condition is borne by the individual, however it also may substantially impact their family and carers (AIHW, 2014).

Chronic care health service providers in Australia include acute care public and private hospitals; emergency health services, including hospital emergency departments and ambulance services; primary care and primary health care services, including general medical practices, ACCHOs and Aboriginal Medical Services (AMSs); community health services; Allied health services including radiology, pathology and pharmacy; and, a range of specialist private and public health clinics (AIHW, 2014).

While there are a range of health care services for people living with chronic conditions, the Australian health system is complicated and people with chronic conditions are required to negotiate this complex health care system while already being disadvantaged by their own ill-health. A need for improved support to assist people living with ill-health to navigate the health care system has been identified (Consumers Health Forum of Australia, 2010). Common challenges for people living with chronic conditions include “dealing with symptoms, disability, emotional impacts, complex medication regimens, difficult lifestyle adjustments, and obtaining helpful medical care” (E. H. Wagner, Austin, Davis, & Hindmarsh, 2001, p.65). For people living with chronic conditions in Australia, the challenge of “obtaining helpful medical care” is of particular importance with GPs commonly being their main source of medical advice and the gatekeepers to other health services. GPs frequently identify the occurrence of a chronic condition, coordinate care with other health professionals and facilitate access to support services such as disability support, psychosocial support and, in some circumstances, financial support. As discussed by E. H. Wagner et al. (2001), to address the needs of people living with chronic conditions, mechanisms that support GPs to provide “helpful” medical care are needed.

In 2015 the Australian Government established the Primary Health Care Advisory Group (PHCAG) to investigate a long-term strategy for the management of chronic conditions. The report of the PHCAG in December 2015 outlined the importance of managing chronic care in the primary health care setting. There was an acknowledgement that chronic condition-related usage of acute care health services was sometimes unavoidable; however, where possible, individuals, the community and funders could benefit from improved management of chronic care in the non-acute care setting (Commonwealth of Australia Department of Health, 2016).

## 2.3 ‘Patient-Centered Medical Home’ and ‘Health Care Homes’ Models of Chronic Care

Given the significant and increasing economic and personal impact of chronic conditions, prevention and management is a principal goal for the Australian health care system, with an integrated and coordinated approach required to maximise resources (AIHW, 2014). To effectively meet the challenge of chronic care service delivery a shift in the approach to care management has been recognised. Health services have historically focussed on episodes of acute injury and illness, but different approaches are needed to address the needs of people living with chronic conditions. E. H. Wagner et al. (2001) assert that even if already hard-working health professionals continue to extend their efforts and expertise, if they remain within an approach to care, which is based on treating acute care illnesses, then they will never be able to effectively treat chronic conditions. A new model of care is indicated and a range of frameworks for models of care have been developed to improve the delivery of chronic care services with the principal focus being on improving primary health care.

Research has been undertaken to determine models of care which address the health needs of people living with chronic conditions. A systematic literature review identified five principal chronic illness models of care:

i. The Chronic Care Model;
ii. Improving Chronic Illness Care;
iii. Innovative Care for Chronic Conditions;
iv. The Stanford Model; and,
v. The Community based Transition Model (Grover & Joshi, 2015, p.210).

Each of these care models include a range of elements which aim to improve health service delivery by engaging patients, direct care providers and the health system organisation as partners in care provision.

### *2.3.1 Patient-Centered Medical Home Model*

Of particular interest to the Australian health care sector was a care model developed in the United States of America and derived from the Chronic Care Model: the Patient-Centered Medical Home (PCMH) (Green, Wendland, Carver, Hughes Rinker, & Mun, 2012). The model design was expounded in the “Joint Principles of the Patient-Centered Medical Home” document, which was published in 2007 (American Academy of Family Physicians, 2008). The original idea of a ‘medical home’, in which people have a home-base for the management of their health care needs, can be traced to the American Academy of Pediatrics which advocated for the centralisation of special needs children’s medical records by practitioners in

1967 (American Academy of Family Physicians, 2008). Since 2007 PCMHs have been used to support the primary care medical needs of a range of population groups including Veterans and safety-net or disadvantaged populations (van den Berk-Clark et al., 2018). The PCMH model is characterised by:

i. each patient having a primary care physician who fosters a supportive patient-physician relationship to deliver whole-person, co-ordinated health care;
ii. the physician being located as part of a wider practice team who work collaboratively to support the physician-patient partnership;
iii. patients who are encouraged to be actively engaged in their own care;
iv. enhanced access to available and accessible care, for example out of hours or at short notice;
v. care delivery that is integrated with other health providers, including allied health professionals, acute and primary health care services and culturally appropriate community services; and,
vi. care co-ordination focussed on using technology to support health information exchange (American Academy of Family Physicians, 2008).

The PCMH model requires ongoing quality and safety assurance in the delivery of health services. It advocates a payment structure that recognises the value-added services delivered to the patient, whether these services are provided by the primary physician or other practice staff. Under the PCMH model of care remuneration should also be available to reward positive health outcomes such as reduced hospitalisations resulting from improved primary health service delivery (American Academy of Family Physicians, 2008). In 2014 a supplement to the Joint Principles of the PCMH was endorsed by a range of American primary care organisations to include behavioural health care as part of the PCMH model of care (Baird et al., 2014). This supplement to the PCMH care model is a response to the recognition of the importance of the whole of person care advocated in the original Joint Principles; and provides an additional focus on the mental and social wellbeing of patients involved the PCMH model of care (Baird et al., 2014).

### *2.3.2 Health Care Homes Model*

The Patient-Centered Medical Home model of care has been implemented widely across the United States and generated discussion on the potential advantage of this care model for Australia (Australian Medical Association, 2015; Ernst & Young, WentWest Limited, & Menzies Centre for Health Policy, 2015; Jackson, 2012; Janamian, Jackson, Glasson, & Nicholson, 2014). In 2016, resulting from the recommendations of the Primary Health Care Advisory Group, the Australian Government announced a trial of a Health Care Homes (HCHs) model of care (Commonwealth of Australia Department of Health, 2016). The trial initially aimed to involve 65,000 people living with complex or chronic conditions, across 200 general medical practices or ACCHOs, over a 2-year period commencing in July 2017 (Turnbull & Ley, 2016). The actual HCHs trial commenced in October 2017 and was planned to run for nearly 4 years, until June 2021. The trial began with a staged roll-out. Actual uptake of the trial was substantially less than initially planned, with approximately 10,000 people enrolled across 129 practices or ACCHOs (Australian Government Department of Health, 2020).

The HCHs model is derived from the PCMH model, with features adapted for the Australian context. Key characteristics of the HCHs model include:

i. voluntary patient enrolment with an accessible general practice or ACCHO, to be the person's nominated "home" to manage the care of their chronic condition, with their health care team and medical records being in one place;
ii. care management is funded through a capitation model, using a stratification tool to fund a three-tiered, needs-based payment model;
iii. nomination by the person of their preferred leading clinician, most commonly a GP but the model does allow for a nurse practitioner;
iv. enhanced access to care;
v. improved care coordination;
vi. improved communication approaches for person with the health care team;
vii. increased data collection and data sharing, to improve communication across the health system;
viii. promotion of patients and their families/carers as partners in care; and,
ix. a commitment to continuous quality improvement and use of evidence based best practice approaches to care provision (Australian Government Department of Health, 2019b; Commonwealth of Australia Department of Health, 2016).

As part of the implementation of the HCHs model, nurse practitioners and general practice nurses have an expanded role. Nurse practitioners are experienced registered nurses who have been endorsed to provide an extended, independent clinical role. In the HCH, nurse practitioners may be the lead clinician, diagnosing and treating people living with chronic conditions (ANMJ Staff, 2021). Practice nurses are registered nurses who work as part of the primary health care team. The HCH model involves practice nurses better supporting people's access to care via secure telephone and email communications; and promoting care coordination through better monitoring of care needs. These approaches may benefit GPs through an increased sharing of the practice workload and are of particular importance to regional Australian communities such as Cairns, that are experiencing GP workforce shortages (Northern Queensland Primary Health Network, 2019). Expanding the role of nurses in general practice promotes the delivery of high-quality primary health care service by improving people’s experiences of care; enhancing coordination to improve health outcomes; improving efficiency through better staff management; and improving health practitioner experience (Australian Government Department of Health, 2019b).

## 2.4 Person-perspectives of the care model

Changing approaches to managing care requires an understanding of the values, needs and preferences of people living with chronic conditions to maximise the acceptability of service delivery to the participant group (Janamian, Crossland, & Wells, 2016). To understand what was already known about the person-reported experience of the PCMH in published literature, a scoping review of international, peer-reviewed literature pertaining to the patient experience of the PCMH was undertaken. Previously, there had been evaluations of the PCMH model of care, but the majority of these were from a practitioner or health policy perspective, with patient experience only examined in a limited number of studies (Aysola, Rhodes, & Polsky, 2015).

The scoping review examined the existing evidence on the care model, from the patient perspective, as well as how the patient perspective has been measured in previous research. The research approach was informed by two leading scoping review theorists: Arksey and O'Malley (2005) and The Joanna Briggs Institute (2015). The review found that there was limited existing, reliable knowledge of the patient-reported experience in the PCMH, indicating a gap in current understanding of people’s perspectives on the model of care.

The following article is the scoping review of the literature that explores the patient-reported experience in the PCMH care model. The article was published in the *Australian Journal of Primary Health* (2017*)* and is titled ‘Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes’. Following acceptance, the *Australian Journal of Primary Health* advised that the article was to be published under an open access licence at no cost to the authors.

### *2.4.1 Manuscript*

O'Loughlin, M., Mills, J., McDermott, R., & Harriss, L. (2017). Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes. *Australian Journal of Primary Health, 23*(5), 429-439. https://doi.org/10.1071/PY17063

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 2 | O'Loughlin, M., Mills, J., McDermott, R., & Harriss, L. (2017). Review of patient-reported experience within Patient-Centered | Developed the initial idea, undertook the data collection; | O'Loughlin, M. |

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|---|---|---|---|
| | Medical Homes: insights for Australian Health Care Homes. *Australian Journal of Primary Health, 23*(5), 429-439. doi:https://doi.org/10.1071/PY17063<br>Accepted for publication: 24 July 2017<br>Published: 20 September 2017 | analysed the data; wrote the article. | |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | Mills, J. |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | McDermott, R. |
| | | Assisted with the development of the initial idea; assisted with article selection and data analysis; assisted with writing and editing. | Harriss, L. |

CSIRO PUBLISHING
*Australian Journal of Primary Health*
https://doi.org/10.1071/PY17063

Review

# Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes

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**Abstract.** Understanding patient experience is necessary to advance the patient-centred approach to health service delivery. Australia's primary healthcare model, the 'Health Care Home', is based on the 'Patient-Centered Medical Home' (PCMH) model developed in the United States. Both these models aim to improve patient experience; however, the majority of existing PCMH model evaluations have focussed on funding, management and quality assurance measures. This review investigated the scope of evidence reported by adult patients using a PCMH. Using a systematic framework, the review identified 39 studies, sourced from 33 individual datasets, which used both quantitative and qualitative approaches. Patient experience was reported for model attributes, including the patient–physician and patient–practice relationships; care-coordination; access to care; and, patient engagement, goal setting and shared decision-making. Results were mixed, with the patient experience improving under the PCMH model for some attributes, and some studies indicating no difference in patient experience following PCMH implementation. The scope and quality of existing evidence does not demonstrate improvement in adult patient experience when using the PCMH. Better measures to evaluate patient experience in the Australian Health Care Home model are required.

**Additional keywords:** healthcare evaluation, health services research, quality of health care.

Received 10 March 2017, accepted 24 July 2017, published online 20 September 2017

## Introduction

Managing the healthcare needs of people living with chronic conditions is an ongoing challenge, with many people suffering from multiple conditions. A coordinated approach to care management is needed, although for people already disadvantaged by ill-health, the challenge of navigating a complex healthcare system increases the burden on individuals, their families and carers. Derived from the Chronic Care Model (Green *et al.* 2012), the concept of patients having a Medical Home to manage their primary healthcare needs has been widely supported across the United States through the Patient-Centered Medical Home (PCMH) model (Peikes *et al.* 2012). Australia's Health Care Home model has been adapted from the PCMH to address the complex healthcare needs of people living with chronic conditions within a different fiscal environment (Commonwealth of Australia 2016).

Key attributes of the PCMH model include: (i) each patient has a primary care physician responsible for fostering a supportive relationship to deliver whole-person, coordinated health care; (ii) the physician is located as part of a wider practice team working collaboratively to support the primary physician–patient partnership; (iii) care is coordinated, with a focus on using technology to support health information exchange; (iv) care is available and accessible as required; and (v) patients are actively encouraged to participate in healthcare decisions (American Academy of Family Physicians 2008). Fig. 1 shows the PCMH model. Although paediatric Medical Homes were developed in the 1960s, Medical Homes for adult populations have only been widely established after 2007, following endorsement of the PCMH by leading American physician organisations (Baird *et al.* 2014).

Both the PCMH and Health Care Home models aim to deliver sustainable health care and improve patient outcomes and experience (American Academy of Family Physicians 2008; Commonwealth of Australia 2016). Since endorsement in 2007, evaluations of the PCMH have primarily been instigated by insurers to appraise service funding or by practice managers as part of quality improvement strategies. Although understanding patient experience is a crucial part of the continuous quality improvement cycle of PCMHs, very few studies have specifically focussed on examining this in detail (Aysola *et al.* 2015). There have been some evaluations in

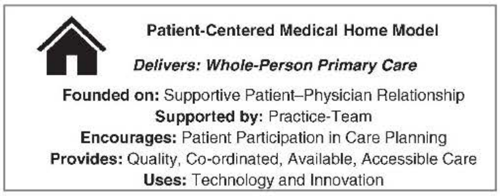

**Fig. 1.** Patient-Centered Medical Home (PCMH) model of care.

paediatric populations; however, the experience of adults living with chronic conditions differs from this cohort.

A search of PROSPERO in May 2016 for systematic reviews of patient experience in the PCMH identified nil results. Searches using Medline, CINAHL and Scopus identified several reviews of the implementation of the PCMH, some of which examined patient experience as part of a range of influencing factors, but none of which specifically scrutinised the adult patient experience in the Medical Home. Our review was conducted to address this knowledge gap, by assessing the scope of literature in which adult patients have reported their experiences of using a PCMH model of care.

## Methods

A five-step methodological framework was used for this scoping review (Arksey and O'Malley 2005; Levac *et al.* 2010; The Joanna Briggs Institute 2015).

### *Step 1. Identify research question*

The primary research question was: what is the adult patient-reported experience of using the Patient Centered Medical Home model?

### *Step 2. Search literature; and Step 3. Select studies*

The strategy for article inclusion is outlined in Box 1. Using these strategies, 631 articles were identified for review. Fig. 2 outlines the selection process for articles.

### *Step 4. Extract data*

Data were extracted for each study using a charting table. Information recorded included: author(s); year of publication; study aim; population of interest; methods including study design, sample size, data collection instrument; study outcome; and, study strengths and limitations.

### *Step 5. Compile results*

Results were collated and summarised to address the research question, then examined to determine if the individual PCMH model attributes had been measured or described. A thematic approach derived from individual PCMH model attributes was used to describe patient-reported experience within PCMHs.

## Results

The majority of studies were classified as quantitative ($n=29$), followed by qualitative ($n=8$) and mixed methods ($n=2$) (Table 1). Quantitative studies collected data from patients using a mix of validated ($n=24$) and non-validated survey tools ($n=5$) (Table 1). Validated tools included the Consumer Assessment of Healthcare Providers and Systems Clinician & Group (CAHPS-CG) (Agency for Healthcare Research and Quality 2017) and Press Ganey surveys (Press Ganey 2017). The quantitative studies included a mix of descriptive only and comparative study designs (Table 1), with comparisons being made pre-post PCMH implementation ($n=3$) (Coleman *et al.* 2010; Kern *et al.* 2013; Carrillo *et al.* 2014); between PCMH and non-PCMH sites ($n=3$) (Christensen *et al.* 2013; Maeng *et al.* 2013); and both pre-post implementation, PCMH and non-PCMH sites, using a quasi-experimental study design ($n=6$) (Reid *et al.* 2009, 2010; Jaén *et al.* 2010*a*; Nutting *et al.* 2010; Fishman *et al.* 2012; Heyworth *et al.* 2014). Analyses from existing large-scale survey datasets were also undertaken ($n=6$) (Beal *et al.* 2009; Solberg *et al.* 2011; Thygeson *et al.* 2012; Lebrun-Harris *et al.* 2013; Nelson *et al.* 2014; Reddy *et al.* 2015). There were 23 independent data sources identified, as some articles used the same research investigation technique, specifically, studies that examined the Group Health Medical Home pilot ($n=4$) (Reid *et al.* 2009, 2010; Coleman *et al.* 2010; Fishman *et al.* 2012); evaluations conducted as part of the

**Box 1. Strategy for article inclusion**

**Databases**
MEDLINE, CINAHL, Scopus and Informit.

**Key terms**
('Patient-Centered Medical Home' OR 'PCMH' OR 'Patient Centered Medical Home' OR 'Patient-Centred Medical Home' OR 'Patient Centred Medical Home' OR 'medical home' OR 'health home' OR 'health care home' OR 'health-care home' OR 'Patient-Centered Medical Homes' OR 'Patient Centered Medical Homes' OR 'Patient-Centred Medical Homes' OR 'Patient Centred Medical Homes' OR 'medical homes' OR 'health homes' OR 'health care homes' OR 'health-care homes') AND ('Attitude to Health' OR 'Patient Attitude' OR 'patient perception' OR 'Patient Attitudes' OR 'patient perceptions' OR 'patient preference' OR 'patient preferences' OR 'Patient Satisfaction' OR 'patient experience' OR 'patient experiences' OR 'patient perspective' OR 'patient satisfaction' OR 'patient perspectives' OR 'patient feelings').

**Inclusion criteria**
- English language
- Published from January 2007 (Medical Homes for adult populations have been established post 2007) to May 2016
- Primary research publications
- Adult populations
- Patient responses from within existing PCMH

**Exclusion criteria**
- News and commentary articles
- Examination of stakeholder perception of patient response, such as provider perception of patient experience
- Examination of patient experience using health service utilisation data

Study selection undertaken by two academic clinicians using a consultative approach.
Bibliographic details from PCMH review were articles checked to ensure inclusion of all relevant studies.

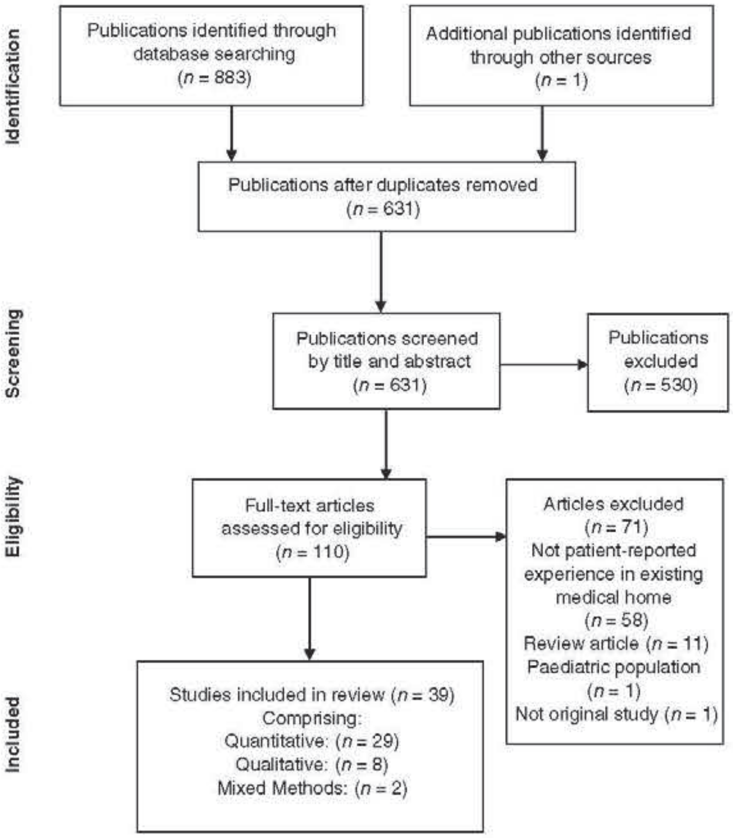

**Fig. 2.** Flow diagram illustrating process for article inclusion.

National Demonstration Project ($n = 2$) (Jaén *et al.* 2010*a*; Nutting *et al.* 2010); studies that examined Medical Home implementation in Florida ($n = 2$) (Cook *et al.* 2015, 2016); and studies from Health Partners Medical Group ($n = 2$) (Solberg *et al.* 2011; Thygeson *et al.* 2012). The majority of quantitative studies examined patient experience as part of a broader evaluation of PCMH implementation.

Attributes derived from the Joint Principles of the Patient-Centered Medical Home model were identified within each study. Table 2 identifies each attribute and outlines the study designs used to measure patient experience of the attribute.

### *Patient–provider relationship*

Although a significant portion of studies investigated the patient–provider relationship in the PCMH (Table 2), the results were mixed. Four studies reported a slightly higher level of satisfaction among patients regarding the care they received from their physician following implementation of the Medical Home model (Solberg *et al.* 2011; Carrillo *et al.* 2014; Hall *et al.* 2014; Heyworth *et al.* 2014). One study reported an improvement in patient satisfaction after 12 (Reid *et al.* 2009) and 24 months (Reid *et al.* 2010) of PCMH care; however, this improvement in doctor–patient interaction diminished over time. Three studies that examined improvement in patients' perception of their relationship with a primary care physician found no change following implementation of the PCMH model (Jaén *et al.* 2010*a*; Kern *et al.* 2013; Reddy *et al.* 2015).

Other studies reported a high level of patient satisfaction with their provider in the PCMH model, although these studies reported on satisfaction with care at only one point in time (Day *et al.* 2013; Kennedy *et al.* 2013; Lebrun-Harris *et al.* 2013; Cook *et al.* 2015, 2016; Wagner *et al.* 2015) with no comparison to a non-PCMH site or to any change in the care model over time.

Two studies comparing the experience of patients in a PCMH with traditional care sites reported a slightly better patient experience of provider communication in the Medical Home (Beal *et al.* 2009; Christensen *et al.* 2013). A study of the Geisinger Health System, ProvenHealth Navigator, PCMH model found no improvement in the patient–provider relationship between the PCMH and non-PCMH sites, although this was measured using a non-validated survey tool (Maeng *et al.* 2013).

Some investigations that examined influencing factors in the patient–physician relationship found that personal physician engagement and communication with patients significantly improved post implementation (Christensen *et al.* 2013;

**Table 1. Summary characteristics of studies included in this review ($n = 39$)**

PCMH, Patient-Centered Medical Home; MEPS, Medical Expenditure Panel Survey; RN, Registered Nurse; CAHPS-CG, Consumer Assessment of Healthcare Providers and Systems Clinician & Group; PACIC, Patient Assessment of Chronic Illness Care; PCAS, Primary Care Assessment Survey; ACES-SF, Ambulatory Care Experiences Survey; ACGME, American Council for Graduate Medical Education; SHEP, Survey of Healthcare Experiences of Patients; CPCI, Components of Primary Care Index; DDSM-QM, Diabetes Disease State Management Questionnaire

| Reference | Study aim | Study design | Study outcome | Validated tool |
|---|---|---|---|---|
| Quantitative studies ($n = 29$) | | | | |
| Bastian *et al.* (2014) | Patient perception of PCMH-designated Veterans women's health providers. | Comparative within PCMHs, single measure postal survey. | Patient experience improves in women's only PCMH. | Yes |
| Beal *et al.* (2009) | Determine if racial disparities affect access to PCMH. | Large-scale survey analysis using MEPS. | Within Latino subgroup: unequal access to PCMH. For patients with access to PCMH: improved access to preventative care and a better patient experience. | Yes |
| Biernacki *et al.* (2015) | Patient satisfaction with RN coordinating care in PCMH. | Comparative within PCMHs survey. | High satisfaction for integration of RN into team. | No |
| Carrillo *et al.* (2014) | Patient experience following implementation of PCMH in a poor community. | Comparative pre-post survey. Press Ganey survey tool. New York Regional Health Collaborative. | Improvement in patient satisfaction for all measures pre-post PCMH implementation. | Yes |
| Carvajal *et al.* (2014) | Comparing patient experiences at teaching or non-teaching PCMH practices. | Descriptive face-to-face survey. CAHPS-CG and PACIC survey tools. | Better patient experience overall at teaching sites. Accessing care was poorer at teaching sites. No difference for provider communication or reception courtesy between sites.<br>Patient engagement better at teaching site. | Yes |
| Christensen *et al.* (2013) | Veteran patient satisfaction comparative PCMH and traditional care model. | Comparative PCMH and non-PCMH, postal survey. CAHPS-CG, Insignia Health Patient Activation Measure and the PCAS tools. | Increased satisfaction for chronic-condition patients across all areas in PCMH. | Yes |
| Coleman *et al.* (2010) | Patient experience when reassigned to a new physician in PCMH. | Comparative pre-post, postal survey. ACES-SF and PACIC survey tools. Group Health medical home pilot. | No difference in patient satisfaction after reassignment to a new physician. | Yes |
| Cook *et al.* (2015) | Patient experience in PCMH. | Descriptive face-to-face survey. Modified CAHPS-CG survey tool. Florida PCMHs. | High level of positive experience in PCMH for practice–patient relationship; quality of care from primary care provider; and, reminders and administration. Moderate level of positive experience for setting goals and test follow up. Limited level for access to care and very limited for recommendation for education to improve own health. | Yes |
| Cook *et al.* (2016) | Patient experience of access and coordination of care in PCMH, underserved population. | Descriptive face-to-face survey. Modified CAHPS-CG survey tool. Participatory research methodology. Florida PCMHs. | Patients with chronic conditions that require more than three visits per year reported better coordination and service experience than patients who attended less frequently. High level of positive experience in PCMH for practice–patient relationship and care coordination. Limited level for access to care. | Yes |
| Day *et al.* (2013) | Patient satisfaction in the PCMH. | Descriptive email survey. Press Ganey survey tool. | Overall satisfied, with high satisfaction for clinician interaction. Poor satisfaction for in-clinic waiting time. | Yes |
| Fishman *et al.* (2012) | Experience of seniors in PCMH. | Comparative pre-post PCMH and non-PCMH postal survey. ACES-SF and PACIC survey tools. Group Health medical home pilot. | Improved experience with continuity of care, access to care and shared decision-making, compared to controls, for seniors in PCMH. | Yes |

| | | | | |
|---|---|---|---|---|
| Heyworth *et al.* (2014) | Change in experience post implementation of PCMH. | Comparative pre-post PCMH and non-PCMH postal survey. Press Ganey survey tool. | Higher satisfaction post intervention compared with controls.<br>Personal physician engagement and communication improved. Access and care coordination did not improve. | Yes |
| Jaén *et al.* (2010*a*) | Evaluate change in patient experience during transformation to PCMH. | Comparative pre-post PCMH and non-PCMH survey. ACES-SF and ACGME Survey tools. National Demonstration Project. | No improvement in patient experience. | Yes |
| Jubelt *et al.* (2014) | Effect of case manager on PCMH patient satisfaction. | Retrospective study using repeated, post-only postal survey data. Adapted from CAHPS-CG survey tool. Geisinger Health System, ProvenHealth Navigator. | Good case management improves patient satisfaction with care. | Yes |
| Kern *et al.* (2013) | Patient experience in the PCMH. | Comparative pre-post telephone survey. CAHPS-CG and additional survey tools. | Improved access to care. Mixed results for patient–practitioner and patient–practice relationship. No improvement in care coordination. | Yes |
| Lebrun-Harris *et al.* (2013) | Patient ratings of PCMH, vulnerable population. | Descriptive large-scale survey analysis, using Health Center Patient Survey. Range of tools. | Excellent or very good quality of service in PCMH for vulnerable population. Access and communication influence positive satisfaction ratings. | Yes |
| Maeng *et al.* (2013) | Experience of adults with chronic conditions in PCMH. | Comparative PCMH and non-PCMH postal survey. Geisinger Health System, ProvenHealth Navigator. | Improvements for PCMH patients in terms of quality of care, care coordination and service delivery. No improvement for access to care and patient perception of physician performance. | No |
| Thygeson *et al.* (2012) | Measure quality in PCMHs. | Survey analysis, using fuzzy set technique. Existing data on patient satisfaction from postal surveys: Picker Survey and Consumer Choice insurer satisfaction survey. Health Partners Medical Group. | Good provider–patient communication improves patient experience. | Yes |
| Moran *et al.* (2011) | Patient satisfaction with nurse diabetes educator in PCMH. | Descriptive survey. | Patients highly satisfied with nurse educator care. | No |
| Nelson *et al.* (2014) | Index measure of patient satisfaction in Veteran PCMHs. | Descriptive large-scale survey analysis. CAHPS-CG and SHEP surveys. | Higher level of PCMH clinic implementation associated with higher patient satisfaction. | Yes |
| Nocon *et al.* (2014) | Safety-net patient perception of support for patient activation in the PCMH. | Descriptive postal survey. PACIC and CAHPS-CG survey tools. | For patients with poor or fair health, PCMH was associated with patient perception of increased clinic support for patient activation. | Yes |
| Nutting *et al.* (2010) | Patient experience with implementation of PCMH model. | Comparative pre-post PCMH and non-PCMH survey. ACES-SF, CPCI and additional Likert scale survey tools. National Demonstration Project. | Patient experience of care diminished during implementation period for both facilitated and self-directed PCMH implementation sites. | Yes |
| Reddy *et al.* (2015) | Veteran experience with implementation of PCMH model. | Large-scale survey analysis using SHEP survey tool. | No difference in patient experience. | Yes |
| Reid *et al.* (2009) | Patient experience in the PCMH. | Comparative pre-post PCMH and non-PCMH postal survey. ACES-SF and PACIC survey tools. Group Health medical home pilot. | At 12 months: PCMH patients reported better care experience on six of seven scales, especially care coordination access and patient activation. | Yes |
| Reid *et al.* (2010) | Patient experience in the PCMH. | Comparative pre-post PCMH and non-PCMH postal survey. ACES-SF and PACIC survey tools. Group Health medical home pilot. | At 24 months: PCMH patients continue to have better experience for three scales: co-ordination, access and goal setting; some improvement in physician–patient interaction and patient involvement. Diminishment in rate of improvement over time. | Yes |

(*continued next page*)

**Table 1.** *(continued)*

| Reference | Study aim | Study design | Study outcome | Validated tool |
|---|---|---|---|---|
| Schmidt *et al.* (2013) | Effect of uptake of PCMH improvements on patient experience, safety-net population. | Descriptive face-to-face survey. | Positive rating for accessibility of care and poor rating for care coordination. Increased PCMH uptake improves care coordination. | No |
| Shawn McFarland *et al.* (2014) | Patient satisfaction with pharmacist in veteran PCMH. | Descriptive postal survey. Modified DDSM-QM survey tool. | 'Very satisfied overall' with clinical pharmacy specialist in PCMH. | Yes |
| Solberg *et al.* (2011) | Patient experience during transformation to PCMH. | Large-scale survey trend analysis using Picker Survey and Consumer Choice insurer satisfaction survey. Health Partners Medical Group. | Small increase in patient satisfaction. | Yes |
| Wennerstrom *et al.* (2015) | Evaluation of Community Health Workers in PCMH. | Descriptive survey. | High satisfaction with Community Health Workers for education and self-management support. | No |
| Qualitative studies ($n = 8$) | | | | |
| Aysola *et al.* (2015) | Patient experience of PCMH. | Comparative PCMH and less-PCMH-orientated clinics. Semi-structured telephone interviews and Likert scale questions. Grounded theory approach. | Relationship with primary physician is the most important factor, issues with team-based coordination not as important.<br>From patient perspective, no change with or without PCMH care model. Lack of awareness of PCMH adoption. Patients did not recognise care model. | |
| Fix *et al.* (2014) | Determine if Veterans in HIV clinics receive care aligned with PCMH model. | Comparative PCMH and less-PCMH-orientated clinics. Semi-structured face-to-face interviews. Methodology not identified. Convenience sample. Sample size pre-determined. | Patients working with care teams reported improved relationship with provider and care experience. | |
| Janiszewski *et al.* (2015) | Patient experience of diabetes self-management education program in PCMH. | Focus groups. Convenience sample. Constant comparative analysis, coding and thematic determination. | Access to care and support the most prominent themes, with the program being identified as useful. | |
| Kangovi *et al.* (2015) | High-risk patient perceptions of PCMH. | Semi-structured face-to-face interviews. Modified grounded theory approach. Convenience sampling, based on inclusion criteria. Interview guide based on PCMH model of care. Member checking. | Patients reported: limited computer literacy, which prevented use of electronic communication; preference for a continuous relationship with one primary care provider; and a trade-off between continuity of care and access to care, due to physician limitations. | |
| Kennedy *et al.* (2013) | Patient experience within PCMH. | Cognitive interviews using validated face-to-face, patient experience survey. Instrument not specified. Focus groups using Nominal Group Technique. Non-validated exit survey. | Patients perceive inadequacies for access to care. Positive experience for quality of care. | |
| Kennedy *et al.* (2015) | Patient experience within PCMH. | Cognitive interviews using validated face-to-face, patient experience survey, across three MHs. Instrument not specified. Focus groups using Nominal Group Technique. Non-validated exit survey. | Patients wanted improvement in access to care, increased staff numbers and increased range of services. | |
| Kozminski *et al.* (2011) | Patient attitude to pharmacist in PCMH. | Non-validated, written survey tool. Brief, structured face-to-face interviews, across four MHs. Convenience sample until data saturated. Coding and thematic analysis. Triangulation. | Pharmacist is valued in the PCMH. | |

| | | | |
|---|---|---|---|
| Takane and Hunt (2012) | Patient perception of PCMH during transition. | Qualitative, focus groups. Sample based on practice recommendation. Thematic analysis. | Patients identified the importance of the practitioner–patient and practice–patient relationships; the need for self-management of care. Challenges identified included: access to care and concern about confidentiality in small community. |
| Mixed-method studies ($n = 2$) | | | |
| Hall *et al.* (2014) | Experience in different PCMHs for adults with diabetes. | Comparative PCMH and less-PCMH-orientated clinics, validated telephone survey. ACES-SF survey tool.<br>Interviews to determine adherence to PCMH principles. | Higher ratings of care across all domains for clinic with greatest adherence to PCMH principles. |
| Wagner *et al.* (2015) | Veteran patient satisfaction with dimensions of PCMH care model. | Descriptive validated survey and face-to-face interview.<br>SHEP survey tool. Interviews: purposeful sampling from survey cohort. Coding and identification of core themes. | Patients satisfied with provider communication and shared decision-making. Mixed results for access to care and care coordination. Qualitative findings included: difficulty with accessing care when needed. Patients' value good communication with provider and care that is well-coordinated. |

Heyworth *et al.* 2014; Cook *et al.* 2015). Contrastingly, another study found that patient–provider communication did not improve and overall physician rating did not improve with implementation of the PCMH model (Kern *et al.* 2013). Patients reported an improvement in their perception of the time spent in consultation with the physician in the PCMH model (Kern *et al.* 2013), and a positive correlation was observed in several studies for physician continuity and patient satisfaction in the PCMH (Fishman *et al.* 2012; Takane and Hunt 2012; Day *et al.* 2013; Wagner *et al.* 2015).

The importance of the patient–provider relationship was explored in qualitative studies, with a range of positive experiences reported (Takane and Hunt 2012; Fix *et al.* 2014; Aysola *et al.* 2015; Wagner *et al.* 2015). If patients had a positive relationship with their physician, this was seen to be of greater importance than any challenges encountered when accessing care (Aysola *et al.* 2015).

### *Patient–practice relationship*

There was insufficient evidence to determine if implementing the PCMH model improves patient experience with practice staff. Two studies demonstrated an increase in patient satisfaction with office staff within the PCMH model compared with the traditional model of care (Christensen *et al.* 2013; Hall *et al.* 2014). Other researchers described a high level of positive patient experience in the PCMH when it came to practice staff providing respectful, helpful care (Cook *et al.* 2015, 2016) and in terms of friendly, helpful staff (Kennedy *et al.* 2015). Contrastingly, two independent cross-sectional studies, using the traditional care model as the comparative group, found no difference in the helpfulness of practice staff between the groups (Reid *et al.* 2009; Maeng *et al.* 2013). In a study that measured the change in patient experience over time, the perceived helpfulness of office staff improved; however, across a 15-month timeframe, overall patient experience with office staff did not improve (Kern *et al.* 2013).

### *Care coordination and integration*

Current evidence indicates that the PCMH may improve care coordination, although the results are mixed. Several studies reported an improvement in the patient experience of care coordination in PCMHs (Reid *et al.* 2009, 2010; Maeng *et al.* 2013; Schmidt *et al.* 2013; Carrillo *et al.* 2014; Hall *et al.* 2014). However, it is worth noting that two of these studies did not use validated survey tools.

In contrast, five other studies identified no improvement in patient satisfaction with care coordination in the PCMH model (Jaén *et al.* 2010*a*; Nutting *et al.* 2010; Kern *et al.* 2013; Heyworth *et al.* 2014; Reddy *et al.* 2015). There was no improvement for the patient experience of follow up of test results in the PCMH following implementation (Kern *et al.* 2013) or when compared with a non-PCMH site (Maeng *et al.* 2013).

For studies that described patient experience, one study reported no patient concern relating to care coordination in the PCMH (Aysola *et al.* 2015), whereas other studies had mixed results for care coordination (Fix *et al.* 2014; Wagner *et al.* 2015). Patients reported very positive experiences in the PCMH model for provision of reminders and administration (87 and 93.7%

agreement) (Cook *et al.* 2015, 2016) and for support provided by health navigators (Janiszewski *et al.* 2015). A more moderate level of positive experience was reported for test follow up (83.9 and 78.6% agreement) (Solberg *et al.* 2011; Cook *et al.* 2016). Patients with chronic conditions that required more than three visits per year reported better coordination and service experience than patients who had fewer visits (Cook *et al.* 2016).

### *Access to care*

Accessing service in the Medical Home is a priority for patients (Janiszewski *et al.* 2015) and there was some evidence to suggest that the PCMH model can improve patient access to care. Along with care coordination, access to care was the most commonly investigated attribute of the PCMH model across the range of studies included in this review (Table 2). Kern *et al.* (2013) observed that access to care had the least patient satisfaction at baseline and the most potential for improvement under the PCMH model.

A range of studies reported improvement in patient perceived access to care in the PCMH (Reid *et al.* 2009, 2010; Solberg *et al.* 2011; Fishman *et al.* 2012; Christensen *et al.* 2013; Kern *et al.* 2013; Schmidt *et al.* 2013; Carrillo *et al.* 2014; Hall *et al.* 2014; Jubelt *et al.* 2014). Specific areas of improvement were: ease of appointment scheduling; access to routine appointments; ability to obtain urgent appointments; and, reduced in-office waiting time. In the Group Health studies, better access to care was observed at 12 months (Reid *et al.* 2009), with continuing improvement in access to care at 24 months (Reid *et al.* 2010). This is in direct contrast with the patient–provider relationship model attribute, which in these studies, was shown to improve, albeit at a diminishing rate over time. Another study reported overall positive ratings (63%) for patient experience in accessing care across 26 safety-net clinics. Safety-net clinics deliver care to vulnerable populations, and there was a positive association for increased access to care to small- and medium-sized clinics when compared with larger clinic sites (Schmidt *et al.* 2013).

Although a range of studies demonstrated that the PCMH care model can enhance patient access to care, there were also a collection of studies that found no significant improvement (Jaén *et al.* 2010*a*; Nutting *et al.* 2010; Solberg *et al.* 2011; Maeng *et al.* 2013; Schmidt *et al.* 2013; Heyworth *et al.* 2014; Aysola *et al.* 2015; Reddy *et al.* 2015). Two studies of PCMHs in Florida using the same cohort reported limited access to care, both in and out of hours (Cook *et al.* 2015, 2016). Patients reported poor satisfaction for in-clinic waiting time (Day *et al.* 2013); getting an appointment (Kennedy *et al.* 2013, 2015); and no improvement in patient satisfaction for post-appointment access to care in the Medical Home (Solberg *et al.* 2011). Patients provided mixed results for timely access to care in the Veterans Woman's PCMH (Wagner *et al.* 2015).

Descriptive studies examined a range of characteristics related to access to care in the PCMH. Access to care was an important component of improving patient satisfaction and patient perception of care quality (Lebrun-Harris *et al.* 2013). Patients identified that improvements in appointment scheduling and reduced in-clinic wait time would improve their experience in the PCMH model (Kennedy *et al.* 2013, 2015).

### *Patient engagement, activation and shared decision-making*

There was limited investigation into the patient engagement, activation and shared decision-making model attribute. A military population study that compared PCMH with non-PCMH sites found a higher level of patient activation in the PCMH (Christensen *et al.* 2013). The Group Health PCMH evaluation identified improvements in patient activation, involvement and goal setting at 12 months (Reid *et al.* 2009). At 24 months, the improvement continued for patient activation and goal setting (Reid *et al.* 2010), and although patient involvement was still improving, it was at a diminishing rate (Reid *et al.* 2010). Senior patients in the Group Health's PCMH study reported an improved experience with shared decision-making, when compared with controls (Fishman *et al.* 2012).

By contrast, most patients in 24 safety-net clinics did not identify that patient activation improved under the PCMH care model; however, for the cohort of patients experiencing the poorest level of health, there was an association between an increased uptake of the PCMH model and perceived clinic support for patient activation (Nocon *et al.* 2014). This result is important as it signals the potential for the PCMH model to promote patient activation in underserved minority groups.

**Table 2. Investigation of Patient-Centered Medical Home (PCMH) model attributes, by study type**

Data are presented as *n* (%)

| PCMH model attribute | (i) Patient–provider relationship | (ii) Patient–practice relationship | (iii) Care-coordination and integration | (iv) Access to care | (v) Patient engagement |
|---|---|---|---|---|---|
| Quantitative studies ($n=23$)[A] | | | | | |
| Studies that investigated attribute | 15 (65%) | 10 (43%) | 16 (70%) | 17 (74%) | 10 (43%) |
| Of which: | | | | | |
| Demonstrated improvement | 6 | 1 | 4 | 6 | 2 |
| Demonstrated no improvement | 4 | 3 | 4 | 4 | 0 |
| Qualitative studies ($n=8$) | | | | | |
| Studies that investigated attribute | 6 (75%) | 5 (63%) | 8 (100%) | 7 (88%) | 5 (63%) |
| Mixed method studies ($n=2$) | | | | | |
| Studies that investigated attribute | 2 (100%) | 1 (50%) | 2 (100%) | 2 (100%) | 1 (50%) |
| Of which: | | | | | |
| Demonstrated improvement | 1 | 1 | 1 | 1 | 0 |

[A] Twenty-nine studies identified using only twenty-three separate datasets.

Aspects of patient activation were explored in a survey of patients enrolled in five Florida PCMHs, and a moderate level of positive experience was described for patient goal setting. Very few patients, however, reported that they received recommendations on education to improve their own health (23.6%) (Cook *et al.* 2015). Patients were satisfied with their opportunities for shared decision-making in the Veterans Woman's PCMH (Wagner *et al.* 2015). In a qualitative investigation, most participants identified the importance of a supportive patient–doctor relationship to promote shared decision-making (Aysola *et al.* 2015).

## Discussion

Overall, this review found mixed evidence that the PCMH model improves adult patient-reported experience across the five attributes described in the 'Joint Principles of the Patient-Centered Medical Home' (American Academy of Family Physicians 2008). The importance of the primary patient–physician relationship was supported, but the extent to which PCMH implementation affects this relationship is unclear. Evidence suggests that some aspects of care coordination and access may improve for patients in the PCMH. Results for all model attributes are limited by the scope of existing evidence, with the patient–practice relationship and patient engagement, activation and shared decision-making attributes being the least investigated.

A lack of discernible effect on patient experience following PCMH implementation may be attributable to the model structure. Some approaches, such as improvements in care coordination, are in the background to service delivery. These strategies may not directly affect patient's perceptions of their experience of care. Further, patients who currently utilise practices with high levels of service delivery may not be notably affected by changes resulting from PCMH implementation (Maeng *et al.* 2013). This observation has the potential to affect patient experience evaluation of the Health Care Home, as practice site participation is voluntary, indicating a willingness by the practice to participate in strategies that aim to improve quality of service.

This review was conducted using a structured framework reflecting a leading methodological approach; a comprehensive search strategy was used and references were checked in the identified literature. Given, however, that 'patient satisfaction' and 'patient experience' are terms not clearly defined, there is potential for literature to exist and not have been included in this review. Similarly, although the search strategy for the 'Patient-Centered Medical Home' was detailed, there is the potential for derivatives of the terminology to have been missed.

Research that examines the experience of patients as they interact with healthcare services is difficult to assess with consistency. The measurement of patient experience is subject to potential bias, as it is based on a perception of care not an objective measure of care delivery, generating ongoing debate on ways to measure patient experience (Berkowitz 2016). Further, our study found there was an absence of quantity and rigor when evaluating the patient experience in the PCMH. A significant portion of quantitative studies used descriptive, single-measure designs generating commentary, but without the ability to determine the effect of model implementation. Identifying a paucity of investigation into patient experience in the PCMH is consistent with previous studies (Nocon *et al.* 2014; Aysola *et al.* 2015), although this is the first review to specifically quantify the evidence for individual PCMH model attributes.

Using validated measuring tools enables comparison across populations and within populations and has the potential to promote consistency in evaluation. In Australia, the validated Patient Partnership in Care (PPiC) tool (Powell *et al.* 2009), which incorporates patient-reported experience and outcome, is indicated to evaluate trials of the Health Care Home. Examining patient experience within the Australian primary healthcare context is challenged, however, by a lack of publicly available survey instruments, the limited publication of survey responses and a corresponding absence of independent review (Gardner *et al.* 2016). Australian policymakers have the opportunity to learn from international experience. In the United States, patient experience is measured as part of the quality improvement cycle of PCMH accreditation (Quigley *et al.* 2015). A standard survey tool used to measure patient experience is the freely available Consumer Assessment of Healthcare Providers and Systems (CAHPS) instrument, which includes a subset of PCMH-specific questions (Agency for Healthcare Research and Quality 2017). Results from the CAHPS surveys are publicly available, enabling practices to benchmark their performance and providing the opportunity for comparative evaluation. In the United Kingdom, patient experience is measured annually by the large-scale GP Survey, with the results being utilised to inform patient decision-making through an easily accessed consumer website (NHS England, see https://gp-patient.co.uk/practices-search, accessed 19 July 2017).

It is worth appraising survey measures to ensure they are population-appropriate and that variability between practices is considered. Given that the Health Care Home trial sites include practices in metropolitan, regional and remote communities, as well as Aboriginal Community-Controlled Health Services, there is a need to tailor the evaluation to include a diverse range of patient experiences. Several study authors have espoused the use of mixed-methods approaches to measure patient experience in the Medical Home (Jaén *et al.* 2010*b*; Goldman *et al.* 2015), combining qualitative investigation, to determine contextual detail from the distinctive patient group, with quantitative investigation, using rigorous, validated survey methods to promote generalisability of results to the wider population.

## Conclusion

Improving patient experience has been identified as one of the key reasons to implement the PCMH care model by primary care physicians in the United States. This is the first study to explore the patient-reported evidence for each attribute of the PCMH model.

Our results suggest that the patient experience of their relationship with providers and access to care in the Medical Home were the most commonly investigated model attributes, with some positive findings for implementation of the care model. Patient engagement, activation and shared decision-making, along with patient experience with practice staff and other team-care health professionals were model attributes that had a significantly limited scope of existing evidence. Generally, all model attributes lacked rigorous, detailed investigation, and an increased research agenda is proposed to determine whether implementation of the Health Care Home model can improve the patient experience of health service.

## Conflicts of interest

The authors declare that they have no conflicts of interest.

## Acknowledgements

This research was conducted with the support of the Australian Institute of Tropical Health and Medicine (AITHM), Centre for Chronic Disease Prevention, James Cook University, Australia and the Australian Government's Research Training Program Scholarship.

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### *2.4.2 Summary of the manuscript*

This scoping review, undertaken in 2016, determined there was a lack of evidence of person-reported experiences of the PCMH model. Existing studies lacked rigour in methods; did not clearly demonstrate improvement in key areas of the model; or lacked detail in people's perceptions of the care model. This lack of evidence strengthened the need for this research.

## 2.5 Chapter summary

This chapter defined the term chronic conditions and identified the prevalence of common chronic conditions in the Australian population. The impact of chronic conditions on Australia's health care system was discussed, including the cost of care. The need for a new model of care management was established; and the Patient Centered Medical Home and Health Care Homes models were described. Existing knowledge of the person-perspective of the care model was explored, with areas of uncertainty identified.

The next chapter explores the methodological approach of this research. It includes justification for the mixed methods application and explains the study design and methods.

# Chapter 3: Theoretical Framework, Design and Methods

## 3.1 Introduction

This chapter explores the methodological approach to the study, the study design and methods. It begins with a consideration of ontology, epistemology and axiology (Creswell, 2016) and includes a discussion of pragmatism, which is the philosophy that underpins the research. Informed by this pragmatic stance and using the theory of partnership models of consumer value co-creation, the study design is elucidated. Specifically, the **quan → QUAL** mixed methods explanatory sequential design variant is justified and described. Approaches to the quantitative data linkage and analyses; the qualitative data collection and analyses; and mixed methods integration, are detailed. The use of modified grounded theory methods within the qualitative approach is discussed.

## 3.2 Background to the methodological framework

### *3.2.1 Ontology and epistemology: reality and knowledge construction*

Methodology is the framework which guides and supports the research (Braun & Clarke, 2013). Understanding and situating the research in a methodological framework was one of the early challenges in the planning of this thesis. This involved an exploration of a range of theoretical perspectives (Braun & Clarke, 2013; Charmaz, 2011; Corbin & Strauss, 2008; Creswell, 2014; Creswell & Plano Clark, 2011; Hesse-Biber & Leavy, 2008; Lincoln, Lynham, & Guba, 2011; Marecek, 2003; Mills & Birks, 2014; Morse & Niehaus, 2009; Pihlström, 2011; Saldaña, 2009; Saldana, Leavy, & Beretvas, 2011; Tashakkori & Teddlie, 2010; Yvonne Feilzer, 2010) to determine the approach that might best address the research question.

The journey to situate the thesis methodology began with an exploration of my own thoughts and perspectives on the ontological concept of reality (Corbin & Strauss, 2008; Mills & Birks, 2014). Methodological texts posed a range of questions: can reality be measured? Is there one objective reality? Or multiple realities? Or multiple perspectives on an individual reality? (Braun & Clarke, 2013; Corbin & Strauss, 2008; Mills & Birks, 2014). For the author of this thesis there are some aspects of life in which there is only one objective reality. Juliet Corbin confirms this ontological view, describing the existence of “external events, such as a full moon, a war, and an airplane crashing into a building” (Corbin & Strauss, 2008, p.13). However, although a singular reality may be objectively defined in some instances, my belief is that some realities can only ever be interpreted; that each person has a different perspective on their own reality; that each person assigns a different value to their reality; that a person’s perspective has the potential to change their reality; and that perspectives on reality may change over time. This perspective aligns with the relativist ontology of multiple realities (Braun & Clarke, 2013; Denzin & Lincoln, 2018).

Epistemology involves understanding how knowledge is constructed, with a researcher’s ontological stance impacting their perspective or worldview (Saldana et al., 2011). Aligning with my ontological position of some objective realities combined with multiple subjective realities, for this thesis I am interested in constructing knowledge from a range of perspectives. I am interested in objective facts; in the statistics that are recorded, which can be summarised and analysed to describe the health service events that have occurred. Concomitantly I am interested in seeking knowledge directly from individuals living with chronic conditions; to understand their views on health care service provision and to explore if the service met their own, perceived need.

### *3.2.2 Pragmatism and mixed methods research*

The development of the philosophy of pragmatism began with debate. Early writings by William James (1842-1910) and Charles Sanders Peirce (1839-1914) identified that the purpose of the pragmatic method was to "Make Our Ideas Clear" (Pihlström, 2011, p. 49). While Pierce asserted that ideas needed to only be conceivable in a practical form, James required the ideas be actualised in practice (Pihlström, 2011). John Dewey (1859-1952) extended the thinking of these earlier writers, expounding the need for "action and opportunity [to] justify themselves only to the degree in which they render life more reasonable and increase its value" (Dewey, as cited in Pihlström, 2011, p. 77). Dewey's instrumentalism has substantially influenced the modern understanding of pragmatism. Pragmatism has been defined as using what works to find a solution to a problem. Using this approach, pragmatists focus on the research problem to determine which methods are most useful to address the research question (Creswell, 2014).

Philosophical debate continues today, with ongoing tensions amongst pragmatists and disunion on the boundaries of the pragmatic approach (Creswell & Plano Clark, 2011; Pihlström, 2011; Yvonne Feilzer, 2010). Consensus does exist in some areas. Debates about reality are discouraged (Creswell, 2014; Long, 2002), with pragmatists asserting that individuals can have a known objective truth and an internal subjective truth (Creswell, 2014). Concurrently pragmatists do not assert a single, fixed truth but believe that truth is reflective of the current knowledge (Corbin & Strauss, 2008), and an "absolute truth will be determined at the end of history" (Tashakkori & Teddlie, 2010, p.131). There is an acceptance that social and cultural factors impact people's perspectives. This has led to pragmatists drawing on both quantitative and qualitative approaches to problem-solve (Creswell, 2014; Tashakkori & Teddlie, 2010).

Although scholars have identified a wider range of philosophical stances (Creswell & Plano Clark, 2007), Teddlie, Tashakkori, and Johnson (2008) argue that three mixed methods research communities can be defined based on their epistemological and ontological view. These philosophical groupings comprise of postpositivists, constructivists and mixed methodologists.

i. Quantitatively orientated postpositivists aim for a singular truth, while recognising that this may never be found. They acknowledge that researchers are impacted by their context; that the search for accurate knowledge may be impacted by subjective influences; and efforts to control these influences may assist in an improved understanding of the truth (Braun & Clarke, 2013; Creswell, 2014).

ii. Constructivists assert there is no singular truth, contending that people construct knowledge and truth from perspectives derived from their own experiences (Mills & Birks, 2014). It is the role of the researcher to reconstruct an understanding of the truth based on the research data which includes a consideration of people's social and cultural contexts (Braun & Clarke, 2013).

iii. Meanwhile, mixed methodologists acknowledge that there are both singular and multiple realities, however they focus their inquiry on solving real-world challenges (Yvonne Feilzer, 2010). Guided by pragmatism, researchers apply the best research solution to the problem utilising quantitative and qualitative approaches (Creswell, 2014; Teddlie et al., 2008).

Given my ontological position, this thesis combines dual perspectives; the side that requires an objective, measurable, postpositivist approach to gain knowledge of the delivery of health services; and the side that recognises the constructivist, diverse nature of people. This thesis is based on the premise that for a thorough investigation of health systems a combination approach is optimal. By combining the knowledge obtained from health service statistics with the person-perspectives of health service delivery; using a pragmatic, mixed methods approach; this thesis aims to inform on the delivery of health services for people living with chronic conditions.

### *3.2.3 Axiology: my own values and bias*

Coming from a public health/postpositivist background, my plan for undertaking quantitative research appeared clear; the methods would involve utilising and developing statistical analytic skills. Although my personal philosophical position aligned strongly with the qualitative paradigm, to understand people's perspectives from their subjective experience (Braun & Clarke, 2013), for me, the idea of undertaking qualitative research was challenging.

Qualitative research aims to explore the meaning of the data (Braun & Clarke, 2013). Knowledge within the qualitative paradigm is contextual, being situated in the environment from which it is obtained; it is therefore subjective and should be viewed through the lens of both the participants and the researcher (Braun & Clarke, 2013). This involves a reflexive approach, in which the researcher critically examines their own perspectives and biases, to determine how their subjective view may impact the process of sourcing, gathering, analysing and representing the data (Mills & Birks, 2014).

Reflection on the research process involved a consideration of my own subjective biases. I recognised that throughout my nursing and public health work I had, in the majority and without question, accepted the medical model of care as the truthful model. Although a supporter of the notion that individual perspectives vary, I had a strong sense that the researcher should only be objective in their approach. Undertaking the qualitative phase of this thesis required the development of new skills to identify and understand my own subjective perspectives; and to recognise the impact this might have on the research process.

### *3.2.4 Existing datasets impacted the methodology*

A methodological framework is informed by ontological and epistemological positions and is used to guide the methods of a study (Mills & Birks, 2014). Study methods are best determined after the methodological framework has been identified (Braun & Clarke, 2013); however, in reality some of the methods of this thesis were pre-determined. Specifically, the foundation idea for the thesis came from the intention to merge two existing datasets:

i. A patient experience survey dataset that was sourced from *The Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department (P3ED)* project, which was a mixed methods study led by James Cook University (JCU) researchers in 2014. Part of this project had involved a structured, face-to-face survey undertaken with people during their presentation to the Cairns Hospital emergency department, in the period 13 March to 11 April 2014.

ii. A linked dataset involving two hospital administrative datasets that had been sourced and developed as part of the *Far North Queensland Hospital Avoidance Trial (FNQHAT).* The two datasets were the Cairns Hospital Queensland Hospital Admitted Patient Data Collection (QHAPDC) and Cairns Emergency Department Information System (EDIS). The FNQHAT project was led by a different group of JCU researchers to those involved in the P3ED study. The FNQHAT datasets were sourced from the Cairns Hospital; were for the period 1 July 2012 to 30 June 2014, incorporating the P3ED study period; and involved the same population as the P3ED study.

The intent to merge these existing datasets guided the methods of this thesis; that is the methods were required to include a quantitative data linkage of the P3ED and FNQHAT datasets. This dataset linkage placed a restriction on the temporality of the study design, as there was existing data to be analysed and limited opportunity to gather further information from the study population. This is important as it influenced the research question, research methodology and methods for this thesis.

## 3.3 Theoretical framework: A mixed methods, person-centred approach

The aim of this research was to explore the experience of people living with chronic conditions in Cairns as they access local-area primary health care services; then use this knowledge to explain how the introduction of the HCHs model might improve the delivery of health care services.

Health service utilisation research, using administrative datasets, is commonly conducted by clinicians and administrators to assess service outcomes in order to satisfy funding bodies and service regulators (Da Silva, Contandriopoulos, Pineault, & Tousignant, 2011). The research is usually undertaken using quantitative approaches, measuring health service delivery by volume. Examples of this include number of episodes of care, deaths, illnesses or complications; and estimates of the costs of care provision. A recognised limitation of this approach is the absence of any detail or explanation for any differences observed in the statistical findings (Da Silva et al., 2011). In this study, given the existence of the FNQHAT administrative datasets, quantitative data analyses were indicated. While this could provide evidence of the volume of peoples' interactions with health providers, further investigation was needed in this study to understand the person-perspective of the service and to identify opportunities to improve service delivery.

### *3.3.1 Explanatory sequential mixed methods design*

Mixed methods research uses both quantitative and qualitative approaches to "investigate the same underlying phenomenon" (Leech & Onwuegbuzie, 2009, p.265). The data collection, analysis and interpretation are undertaken using more than one method, to generate an understanding of the phenomena that is more expansive and valid than using one method alone (Schoonenboom & Johnson, 2017).

The design for this project used quantitative strategies to investigate existing service use and nominal experiences, however these inquiries were not independently capable of satisfying the study aim. Specifically, additional investigation was needed to gather people's perspectives on health services and to inform the HCHs model of care. Qualitative methods are indicated for a mixed methods study to access the "part of the phenomena of interest that cannot be accessed by the use of the first method alone" (Morse & Niehaus, 2009, p.9). In this study, the specific phenomena that required qualitative investigation were the needs, preferences and values of people who live with chronic conditions.

Guided by the paradigm of pragmatism, methods that best addressed the research question were used. An explanatory sequential mixed methods design was employed (Creswell & Plano Clark, 2011; Hesse-Biber, 2010). Explanatory designs involve two distinct phases:

i. the first phase involves quantitative data collection and analysis; and,
ii. the second phase builds on the phase-one study results by using qualitative methods to explain and expand the findings from the quantitative phase (Creswell & Plano Clark, 2011).

An explanatory design suited the study aim, to explain how and why the HCHs model might improve the delivery of health service to people living with chronic conditions.

The sequencing in this study was influenced by the use of existing datasets. As acknowledged, the quantitative data collection existed prior to the development of the study design. The sequential design enabled the knowledge attained from the linkage and analyses of the existing quantitative datasets to be used to inform the qualitative data collection and analyses. This is an essential characteristic of the explanatory sequential mixed methods design: that the qualitative investigation builds from the results of the quantitative study (Hesse-Biber & Leavy, 2008).

### *3.3.2 Eclecticism, integration and theoretical drive*

Mixed methods research is valuable when the researcher recognises that a range of methods are possible to address the research question, but that some methods are better suited than others. Teddlie and Tashakkori (2011) describe this as methodological eclecticism, asserting that a knowledgeable researcher considers the range of available methods and chooses the methods best able to answer the research question.

Mixed methods researchers need to demonstrate that the methods chosen can be coalesced to form an integrated body of research (Morse & Niehaus, 2009). Mixed methods research is not simply a compilation of standalone, independent research methods, although each component of mixed methods research needs to be rigorously conducted (Creswell & Plano Clark, 2011; Morse & Niehaus, 2009; Teddlie & Tashakkori). An alternative design that was considered for this study was the multiple-methods or multimethod study which, like mixed methods, involves employing more than one approach to answer the research question. Some authors have argued that multi-methods studies involve either the use of more than one quantitative approach; or more than one qualitative approach; and that a mix of quantitative and qualitative approaches is a mixed methods approach (Schoonenboom & Johnson, 2017; Tashakkori & Teddlie, 2010). Others have a different view, allowing multiple-methods study designs to be solely quantitative, qualitative, or a mix of both quantitative and qualitative approaches, as long as there is more than one approach (Anguera, Blanco-Villaseñor, Losada, Sánchez-Algarra, & Onwuegbuzie, 2018). They distinguish multi-methods from mixed methods designs based on the process of integration in the study. Integration has been described as the most important feature of mixed methods research (Schoonenboom & Johnson, 2017). For a mixed methods study, the findings of each of the methods are integrated during the conduct of the research and at the end of the research process; whereas in a multi-methods study the convergence of the independent approaches only occurs at the study end (Anguera et al., 2018). This study is of a mixed methods not a multi-methods design for three reasons:

i. it employs both quantitative and qualitative approaches;
ii. integration occurs during the conduct of the study, as quantitative findings are used to inform the qualitative data collection; and,
iii. quantitative and qualitative findings are integrated in the results point of integration to answer the research question (Schoonenboom & Johnson, 2017).

Morse and Niehaus (2009) expound the importance of understanding the theoretical drive or the overall conceptual direction of mixed methods research. The conceptual direction of this study is inductive: as it seeks to determine an optimal HCH model of care derived from an understanding of individual level experiences of having a chronic condition and accessing health care services. The study focuses on both service-level and person-level data. The study is sequentially quantitative to qualitative, with the quantitative findings informing the qualitative approach. The quantitative investigation in this study situates the qualitative research: by exploring the current experience of health care services for people living with chronic conditions in Cairns; and by identifying areas that required further explanation for investigation in the qualitative phase.

### *3.3.3 Person-centred care: a partnership model to improve service delivery*

Fostering a person-centred approach has the potential to promote equitable, sustainable, high-quality health services (World Health Organization, 2016). Across Australia, health care organisations aim to deliver person-centred care (Productivity Commission, 2017). Co-design, or co-production, in health service planning is necessary for this person-centred approach (World Health Organization, 2016). However, despite rhetoric around person-centred or patient-centred care delivery for more than a decade (Consumers Health Forum of Australia, 2010; Productivity Commission, 2017), it has only been in recent years that consumer perspectives have been meaningfully integrated into the process of improving health services (Janamian et al., 2016).

Co-creation with consumers needs to be purposefully designed. The sequential nature of this research, involving an emphasis on the qualitative findings, focusses the inquiry on the person-perspective which exemplifies the Nambisan and Nambisan (2009) partnership model of consumer co-creation. The theory of partnership models of consumer value co-creation was developed for health service organisations and applies well to this research. A partnership model involves the organisation or researcher leading the project; with consumers contributing to new knowledge creation as experts in their experiences. This model differs from other models of co-creation that are led by consumers. The partnership model is researcher-led; combining the knowledge sourced from consumers, with existing knowledge, to develop or improve service delivery (Nambisan & Nambisan, 2009). It is important to note that this is not a co-design project, as consumers were not involved in all stages of the research process (Slattery, Saeri, & Bragge, 2020).

By using quantitative and qualitative investigations in a two-phase mixed methods approach, knowledge of how people living with chronic conditions in Cairns currently use health services, and their perspectives on service delivery, is obtained from consumers. Integration of the Phases 1 and 2 findings, to consider how these person-perspectives might influence implementation of the HCHs model, is an example of researcher-led inquiry working in partnership with consumers to consider the direction of future health service delivery.

As part of study recruitment, Braun and Clarke (2013) describe the need to consider hidden populations which may be hard to engage in research activity. In this study the hidden population includes those who have limited engagement with health service research. A strength of this study design is the recruitment of participants from the ED. This differs from studies that invite participation from the wider general population, such as the ABS Patient Experiences in Australia (ABS, 2020b); or use people who have a keen interest in research and have previously nominated themselves to be consumer health research participants. Policymakers and service providers are interested in understanding the health-seeking behaviour of people whose presentation to the emergency department can be characterised as potentially avoidable (Cheek, Allen, Shires, Parry, & Ruigrok, 2016). PAGP-type presenters to the ED are an example of a hidden population whose research participation may be improved through their direct recruitment from the ED, which is the approach undertaken in this study.

### *3.3.4 Summary of the background and theoretical framework*

In summary, the theoretical framework for this thesis uses the paradigm of pragmatism: to employ the methods that best address the research question. An explanatory, sequential mixed methods study design has been identified as the optimum approach to explain the phenomena being studied. The theoretical drive of the research is inductive, using person-level data to generate person-perspectives of the HCHs model, based on the partnership model of consumer co-creation.

Through the creation of a linked dataset, sourced from existing datasets, the quantitative investigation provides the unique opportunity to build on the efforts of earlier researchers. The use of the explanatory sequential mixed methods design enables learnings from the first phase quantitative investigation to inform the data collection of the second phase qualitative inquiry, and the subsequent overall interpretation of the integrated findings.

## 3.4 Research design, methods and analysis

In this section the research questions will be identified and linked to the study methods. Each of the study methods will be identified, described and justified. The structure of this section is determined by the explanatory sequential mixed methods design: first the quantitative methods are described, then the qualitative methods, and finally the mixed methods approach.

### *3.4.1 Research questions and study design*

The primary research question for this thesis was:

> ***How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?***

To support the primary research question, three sub-questions were constructed:

*Research sub-question 1 (RQ1)*

> ***What is the current experience of health care service for people living with chronic conditions in Cairns?***

*Research sub-question 2 (RQ2)*

> ***How are elements of the Health Care Homes model valued by people living with chronic conditions in Cairns?***

*Research sub-question 3 (RQ3)*

> ***Can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns? What factors will influence the implementation of this model of care?***

The primary research question and sub-questions were explored throughout different stages of the mixed methods study design.

*Table 1* connects the mixed methods study phases to the research questions and key study procedures.

*Table 1: Overview of the study design linked to the research questions*

| | |
|---|---|
| **Phase 1**<br>**RQ1** | **Quantitative investigation of the person-perspective of current health services using existing datasets and data linkage.** |
| | Data Linkage of P3ED Survey dataset participants with FNQHAT QHAPDC and EDIS datasets to characterise the population and describe health care service utilisation for people living with chronic conditions in Cairns. |
| | For people living with chronic conditions in Cairns: analyses of the linked dataset for variables related to their perspectives and experiences of health services. |
| **Phase 2**<br>**RQ1, RQ2, RQ3** | **Qualitative exploration of the person-perspective of current health services and the HCHs model elements.** |
| | Recruitment of a subset of P3ED survey participants for interview. |
| | Semi-structured interviews, informed by the Phase 1 findings and elements of the HCHs model. |
| | Grounded theory approaches of data generation and analysis. |
| **RQ3** | **Mixed methods integration of findings from Phases 1 and 2 to determine if/how the HCHs model can improve care.** |

### *3.4.2 Phase 1: Quantitative Investigation: Existing Datasets*

*RQ1: What is the current experience of health care service for people living with chronic conditions in Cairns?*

Phase 1 of the study used descriptive, comparative analyses of existing datasets to investigate the existing service usage and nominal experiences of people living with chronic conditions in Cairns. The datasets were sourced from two independent, previous projects undertaken by

JCU researchers (see *section 3.2.4 Existing datasets impacted the methodology*). Three existing datasets were examined, as outlined in *Table 2***.**

*Table 2:* Existing datasets used for data linkage

| Project source | Dataset | Time Period |
|---|---|---|
| **Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department (P3ED)** | P3ED Survey dataset | March 13 - April 11 2014 |
| **Far North Queensland Hospital Avoidance Trial (FNQHAT)** | Emergency Department Information System (EDIS) dataset: Presentations to the Cairns Hospital Emergency Department | July 2012 - June 2014 |
| **Far North Queensland Hospital Avoidance Trial (FNQHAT)** | Queensland Hospital Admitted Patient Data Collection (QHAPDC) dataset: Admissions to Cairns Hospital | July 2012 - June 2014 |

The P3ED Survey dataset was sourced from a cross-sectional, patient experience survey undertaken with people who presented to the ED of the Cairns Hospital, 24-hours/day, 7-days per week during the one-month study period. This survey focused on reasons for attendance to the ED and considered a range of variables related to the access and acceptability of primary health care services in Cairns. The survey instrument comprised of 52 items, with questions derived from four previous studies (Chalder et al., 2007; Durand et al., 2012; Jukka, Hollins, Hollins, & Beaton, 2013; Steele, Anstett, & Milne, 2008). Clinical and research team members refined the survey tool, which was piloted (n=144) and amended prior to full deployment (Mills et al., 2014). The P3ED researchers did not report further checks for validity as part of the survey process (Creswell, 2014; Mills et al., 2014). This is an acknowledged limitation of using this survey dataset in the present research. An outline of key variables sourced from the P3ED Survey dataset is provided (see *Table 3*). The P3ED Survey questions are included at Appendix .

*Table 3: List of P3ED Survey variables*

| |
|---|
| **Demographic characteristics of cohort** |
| Gender/Age/English language/Education level/Occupational status/Ethnicity |
| Non-resident presentations; Cairns resident presentations |
| **Presentation to Emergency Department** |
| Timing of presentation to ED (time of day/day of week; business hours/weekends) |
| Mode of arrival to ED |
| Self-referred or health professional referred to ED, from patient perspective |
| If self-referred, primary reason for choice of ED rather than other health service |
| **Utilisation of health services** |
| Has a regular GP |
| Previous contact with other health care service for presenting complaint |
| Usual choice of health care service |
| Patient preferred health care service |
| Attributes and facilities patients value in health care services |
| Patient perception of GP service availability |
| Patient awareness and acceptability of alternate health services (eg. 13-Health) |

For this thesis, the existing P3ED dataset was examined with a focus on a sub-cohort of survey participants who:

i. were adults (≥18 years of age);
ii. gave consent during the P3ED Survey project to access their Medical Record;
iii. self-identified as being a local Cairns resident; and,
iv. self-identified as having a long-standing or chronic condition.

The rationale for this approach was primarily determined by the HCHs model of care. Although children were not ineligible to be enrolled in the HCHs trials, it was anticipated that the majority of people living with chronic conditions would be older than 45 years (Australian Government Department of Health, 2020). The study was restricted to local Cairns residents, as the HCHs model had been designed to support people's needs in their local community. Cairns is a tourist centre and a considerable portion of interstate, intrastate and international visitors attend the Cairns Hospital and ED each year (Harriss, Dey, Thompson, & McDermott, 2015). Further, people's self-report of having a long-standing or chronic condition was used to determine inclusion for two reasons: i) to align with the person-centred approach in which the person living with a chronic condition is central to the research; and ii) the occurrence of a chronic condition may not be captured in the existing hospital administrative data record, which was collected to address the presenting health concern.

The FNQHAT EDIS and QHAPDC datasets comprised of hospital administrative data, detailing emergency department presentations and hospital admissions for the Cairns Hospital. The FNQHAT research team had previously developed these datasets. As part of this previous investigation, the researchers had identified that approximately 20% of all ED presentations during the July 2012 to June 2014 period were for chronic conditions. These presentations were generated by 11,936 local-dwelling individuals (Harriss et al., 2016). Characteristics of presentations in the FNQHAT datasets included age, gender, presentation time and day, arrival by ambulance, presentation type, final diagnosis, length of stay, discharge direction, frequency of presentation within the past 12 months and admission details.

Importantly, the time period for data collection for the P3ED Survey dataset was within the same time-period as the data contained in the FNQHAT datasets. Although these projects were separate in origin, this overlapping time period was essential for investigation in this current study, as the source population was common to all three datasets.

The data linkage of these existing datasets was used to inform the research question (*RQ1*), by exploring how people living with chronic conditions had experienced contact with primary and acute care services, and their perspectives on the current model of care delivery. Linkage of these existing datasets provided an opportunity to build on the efforts of the earlier FNQHAT and P3ED researchers; and to further inform on the health service experience of people living with chronic conditions in Cairns.

### *3.4.3 Phase 1: Data Linkage of P3ED Survey dataset participants with FNQHAT EDIS and QHAPDC datasets*

Data linkage is an increasingly utilised technique that involves connecting existing administrative datasets to examine the health experiences of individuals across time. A major benefit of data linkage is that it allows researchers to access large-scale samples without the cost and intrusiveness of undertaking additional research activity, such as the implementation of a large-scale population-based survey (Boyd et al., 2015). Data linkage studies are an efficient way of using existing datasets as a resource for understanding and potentially improving health systems.

Addressing concerns around privacy and ethics are integral to the design and conduct of data linkage studies (Emery & Boyle, 2017). Issues of data quality are of concern; with known issues of incomplete and inaccurate records contained within datasets that were designed for administrative, not research, purposes (Boyd et al., 2015). Despite these challenges, world-wide, the advantages of ethically conducted, high-quality, linked data studies have been recognised. Supported by government, policymakers, practitioners and consumers, data linkage studies are increasingly being undertaken in Australia to generate new knowledge and understanding (Emery & Boyle, 2017; Queensland Government, 2020b).

Data linkage was used in this study as the primary method of collecting the quantitative data for analysis. Although the data collection had been undertaken by previous researchers, the process in this study created a new linked dataset by merging the existing P3ED and FNQHAT datasets.

Data linkage in this study entailed connecting survey participants from the P3ED project to the FNQHAT datasets. This involved using P3ED Survey participants unique Medical Record Numbers (MRNs) to identify ED presentations and episodes of hospital care for the P3ED participants within the FNQHAT datasets.

Data linkage was undertaken using Stata 13.1 (Stata Corp, College Station, Texas, USA). Following ethical approvals (see *section 3.5 Ethical considerations*), the process for dataset merging was as follows:

i. the P3ED dataset was reviewed; missing or incomplete variables were identified and updated. This process involved validating participant characteristics in the P3ED Survey dataset with a separate logbook that had been used, as part of the P3ED study, to record MRNs and key participant characteristics;
ii. P3ED Survey participants who identified as being non-local (international, interstate and intrastate visitors) were removed from the P3ED dataset;
iii. identification of local resident P3ED Survey participants' MRNs (all ages: children and adults): all ages were included in the initial merging to capture and validate all survey participants;
iv. local resident P3ED Survey participant MRNs were merged with the variable for EDIS presentation within the FNQHAT dataset;
v. local resident P3ED Survey participants who were unable to be linked to the EDIS dataset were removed (n=14) from the P3ED group for analysis; this included removal of a survey participant (n=1) who had not provided consent to access their Medical Record as part of the original P3ED Survey study (see *section 3.5 Ethical considerations*);
vi. validation of age and gender for local resident P3ED Survey participants between the P3ED and EDIS datasets;
vii. identification of the ED visit that corresponded to completion of the P3ED Survey;
viii. P3ED-EDIS linked dataset merged with the variable for QHAPDC hospital admission within the FNQHAT dataset;

ix. validation of MRN, age and gender for local resident P3ED Survey participants with the QHAPDC dataset; and,

x. validation of those that were: admitted to hospital from the ED; admitted directly to hospital (not from ED) and had presented to ED on the same day; and who were admitted to hospital twice on the same day.

*Figure 4* displays the data linkage of the local resident P3ED survey participants (n=1,370, all ages) to the FNQHAT EDIS dataset; and identifies the number of ED presentations over the 2-year period (July 2012 to June 2014) for the P3ED group (n= 5,016 ED presentations).

*Figure 4: Merge of EDIS and P3ED Datasets: ED Presentations for local resident P3ED Survey Participants (n=1,370, all ages), over 2-year period (July 2012 to June 2014)*

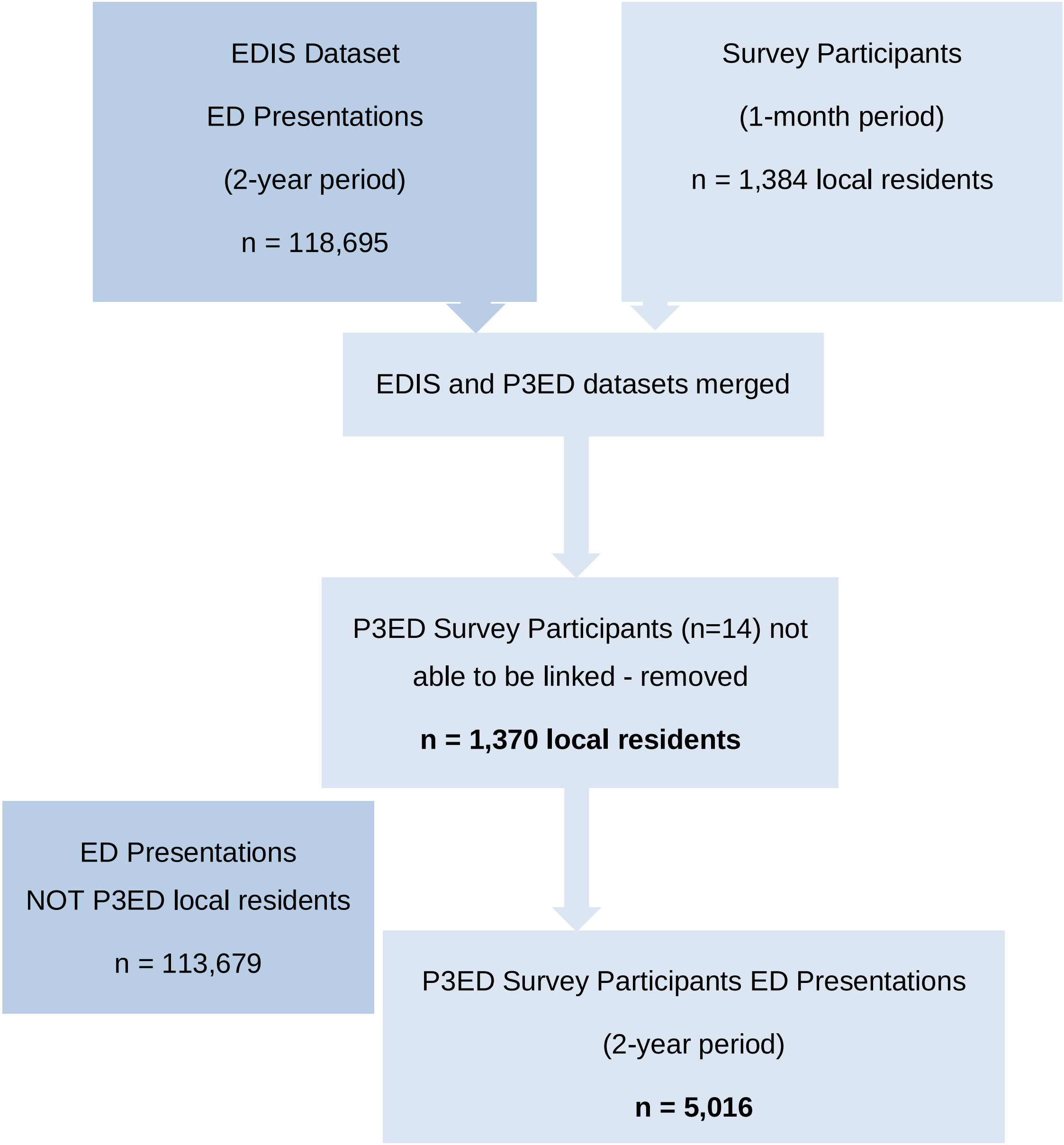
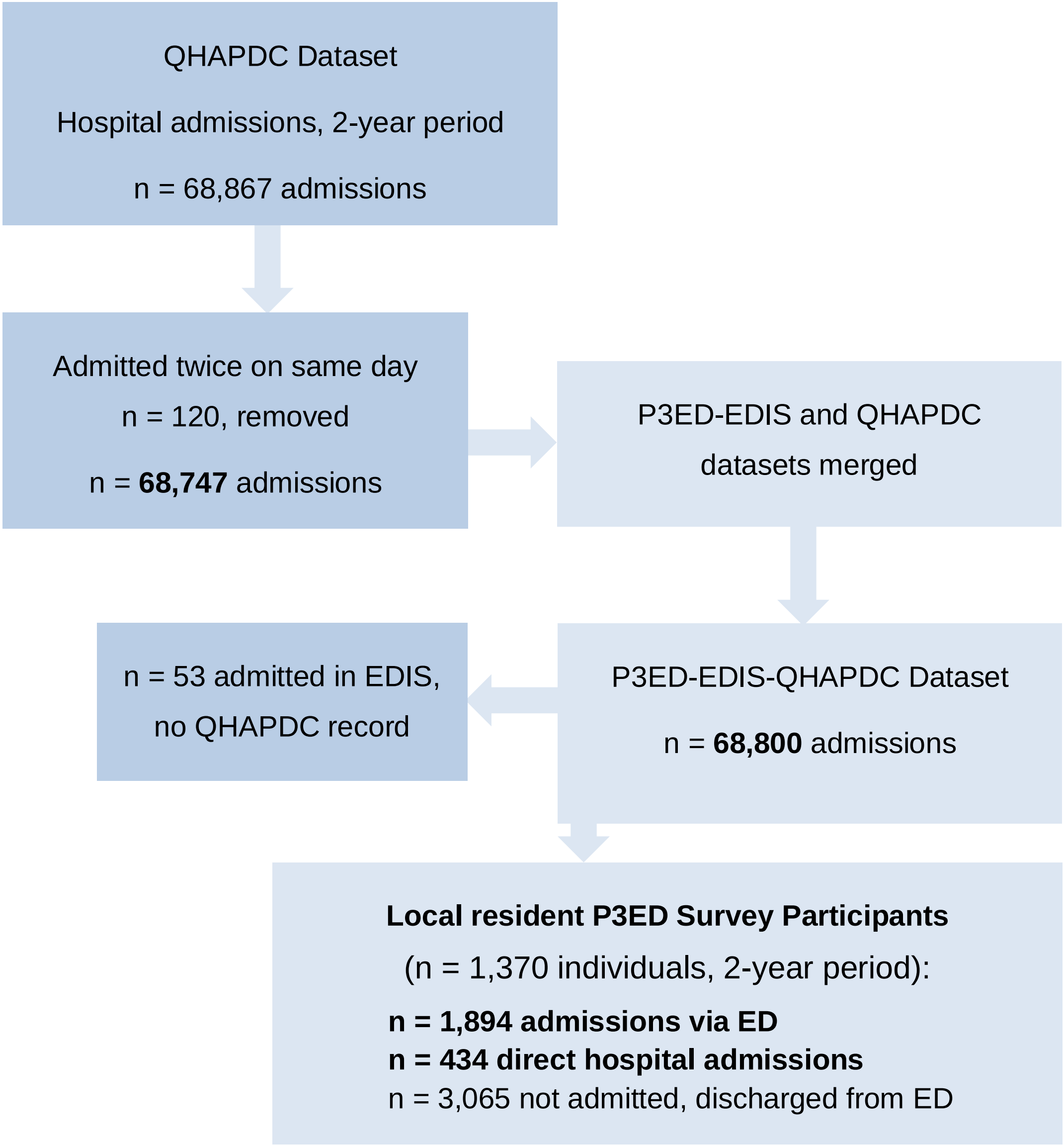


*Figure 5* depicts the data linkage of the P3ED-EDIS dataset to the FNQHAT QHAPDC dataset; and ascertains the number of hospital admissions over the 2-year period (July 2012 to June 2014) for the local resident P3ED Survey participants (n=2,328, with n=53 unable to be linked from ED to hospital admission records).

*Figure 5: Merge of QHAPDC and P3ED-EDIS Datasets: Hospital Admissions for local resident P3ED Survey participants (n=1,370, all ages), over 2-year period (July 2012 to June 2014)*



### *3.4.4 Phase 1: Analyses of the linked dataset*

Analyses were undertaken using Stata 13.1 (Stata Corp, College Station, Texas, USA) to characterise the population and to inform on the experience of health care service for people living with chronic conditions in Cairns. Standard statistical methods were employed, as appropriate, including Pearson's Chi-squared test of equal proportions for binary categorical variables (Pearson, 1900); two-sample Wilcoxon rank-sum (Mann–Whitney) test for variables with a non-parametric distribution (Mann & Whitney, 1947); and Fisher's exact test used for small sized cells (n<5) (Fisher, 1922). Confidence limits were set at the 95% level and two-sided P values presented. P values of <0.05 were regarded as statistically significant. Logistic regression analyses involving Odds Ratios (ORs) with 95% confidence intervals (95%CIs) were used to explore model associations; with model estimates of goodness-of-fit calculated using the Hosmer-Lemeshow test (Hosmer, Lemeshow, & Sturdivant, 2013).

Analyses of the linked data to address *RQ1* by exploring the current experience of health care service for people living with chronic conditions in Cairns, were:

i. comparison of characteristics of P3ED Survey participants and non-participants in the FNQHAT datasets for the 1-month P3ED study period (March 2014 to April 2014). These analyses were to identify potential limitations to the generalisability of findings to the wider ED population, related to the characteristics of the P3ED Survey sample;
ii. comparison of characteristics; health service perspectives and experiences, of the P3ED Survey participants who self-identified as having a chronic condition to those without a chronic condition, for the 1-month P3ED study period;
iii. age stratified analyses of health service perspectives and experiences of the P3ED Survey participants who self-identified as having a chronic condition, for the 1-month P3ED study period; and,
iv. comparison of characteristics, including self-reported chronic condition status; health service perspectives and experiences of Aboriginal and Torres Strait Islander P3ED Survey participants to all other P3ED Survey participants, for the 1-month P3ED study period.

Additional investigations were undertaken following the data linkage, when the merged dataset analyses indicated differences between some of the person-reported data and the hospital administrative datasets. People who participated in the face-to-face P3ED Survey were linked in this study to their corresponding ED presentation episode of care. It was anticipated that the hospital administrative data variables for the care episode would align directly with the person-reported survey variables. However, this did not occur for several variables prompting additional investigation to explore the inconsistency.

A recognised limitation of using administrative heath data is the potential for inaccuracy in the dataset (Boyd et al., 2015). Differences between the hospital administrative data record and the person-perspective in this study required further investigation. The linked dataset provided a unique opportunity to explore the person-perspective of their own medical record and highlight issues that might impact further health service research that relies on the accuracy of administrative datasets. This approach aligns with the thesis purpose: to enable people who access health services to inform on the delivery of the service; and supports understanding of *RQ1* by enhancing understanding of people's current experience of health care services.

Analyses of the linked dataset to address *RQ1* by exploring inconsistency between the person-reported experience of health care services and the administrative dataset records, for people living with chronic conditions in Cairns, were:

i. validation of Indigenous status using sensitivity, specificity, and overall accuracy measures; and
ii. comparison of measure elements of two measures of PAGP-type presentations to the ED (see *section 2.2.3 Measuring the cost and effectiveness of Australian health service delivery*).

### *3.4.5 Phase 2: Qualitative Investigation*

*RQ1: What is the current experience of health care service for people living with chronic conditions in Cairns?*

*RQ2: How are elements of the Health Care Homes model valued by people living with chronic conditions in Cairns?*

Phase 2 of the study involved a qualitative exploration with two key aims:

i. to inform on the person-perspective of existing health services; and,
ii. to determine how the HCHs model elements were valued by the participant group.

The inquiry involved semi-structured interviews, which were informed by the Phase 1 study results. The participant group was sourced from the P3ED Survey study population. Twenty-one (21) interviews were conducted from September 2017 to November 2018. The qualitative exploration used inductive and deductive approaches, viewed through the lens of the HCHs model elements.

### *3.4.6 Phase 2: Recruitment to interview*

A sample of people from the original P3ED study were recontacted and invited to participate in semi-structured interviews to investigate how elements of the Health Care Homes model were valued by the participant group. As part of the previous study, the P3ED Survey respondents had provided their contact details directly to the researchers as either a landline telephone number, mobile phone number or email address.

Potential interview participants were identified using the P3ED Survey dataset. Survey respondents who had provided their contact details (n=329) were detected within the dataset. Recruitment was restricted to:

i. P3ED Survey participants who had previously consented to be contacted for future research;
ii. local resident, adults (aged over 18 years); and
iii. those who had identified as living with a long-standing or chronic condition.

In total, n=124 people were identified as potential interview participants. Of these n=41 provided an email address; n=55 gave a mobile phone number; and n=29 supplied a landline phone number. One of these participants (n=1) had provided both mobile phone and email details. Using this existing group reflects the explanatory mixed methods design to engage participants from the quantitative phase of the project, to generate a more detailed explanation of the results and to develop further explanation in the qualitative phase (Creswell & Plano Clark, 2011).

Purposive sampling is used in qualitative investigation to deliberately choose participants that have experience of the phenomena under investigation; to add range and depth to the understanding of the phenomena; and to source those with diverse perspectives (Braun & Clarke, 2013; Creswell, 2014; Creswell & Plano Clark, 2011). Initial sampling for interview participants began with stratification of the eligible P3ED Survey respondents by age, gender and type of chronic condition, to promote range and diversity in the study sample (Braun & Clarke, 2013). Informed by the Phase 1 study results, people who had repeated presentations to acute care services were identified and sampled purposively in the initial recruitment stage.

Eleven (n=11) people responded to the initial recruitment stage (August to October, 2017) and agreed to potentially participate in an interview. Additional recruitment was undertaken in March, June, August and November 2018.

At the commencement of the study, it was intended that the number of interview participants would be decided by employing the process of theoretical sampling and the techniques of coding, analysis and concurrent data generation (see *section 3.4.7 Phase 2: Semi-structured* interviews) until data saturation was achieved for the research questions (Birks & Mills, 2015; Corbin & Strauss, 2008). Theoretical sampling is a grounded theory method in which decisions made about collecting data are guided by previous data collection and analysis within the study; the gaps in understanding are purposefully identified; and new participants to the study are recruited to inform on the development of these ideas (Birks & Mills, 2015; Braun & Clarke, 2013). Saturation in data collection occurs when enough data has been collected to saturate or sufficiently inform understanding of the phenomena of interest: meaning that the collection of additional data does not add any new information to the emerging categories and themes (Braun & Clarke, 2013; Corbin & Strauss, 2008; Morse & Niehaus, 2009).

However, following initial recruitment in this study, it was established that a proportion of phone numbers were disconnected, some messages to mobile numbers failed to send, some people were deceased, and some people declined the opportunity to participate in the research. Corbin and Strauss (2008) have recognised the need to sometimes accept that only limited data sources may be available for inclusion in a study. For this study, the recruitment process was driven by the need to maximise the variation in the sample (Creswell & Plano Clark, 2011). Additionally, a key feature of the explanatory sequential mixed methods design involved participants from the quantitative investigation explaining the Phase 1 results through the Phase 2 qualitative inquiry (Creswell & Plano Clark, 2011). For these reasons, using a pragmatic approach, all eligible P3ED Survey respondents were approached for interview participation. The final sample for the interviews comprised of all respondents who met the study inclusion criteria and agreed to interview, with the total final number of interviews undertaken being twenty-one (n=21). *Table 4* characterises those who agreed to participate in an interview and those that were unable to be contacted or declined.

*Table 4: Recruitment to interview from P3ED Survey: Outcomes from recruitment invitation (n=124)*

| **All eligible P3ED Survey respondents n = 124** | | | **Reason did not participate** | | |
|---|---|---|---|---|---|
| | **Agreed to interview n = 21 n (%)** | **Did not participate n =103 n (%)** | Declined, withdrawn or unsuitable n = 7 | Contact details not current n = 37 | No response n = 59 |
| Age | | | | | |
| **Young-adults (18-44 year)** | 4 (19%) | 22 (21%) | 2 | 4 | 16 |
| **Middle-aged adults (45-64 years)** | 11 (52%) | 44 (43%) | 2 | 12 | 30 |
| **Older-aged adults (≥65 years)** | 6 (29%) | 37 (36%) | 3 | 21 | 13 |
| Gender | | | | | |
| **Female** | 11 (52%) | 59 (57%) | 4 | 19 | 36 |
| **Male** | 10 (48%) | 44 (43%) | 3 | 18 | 23 |

|  | **Agreed to interview n = 21 n (%)** | **Did not participate n =103 n (%)** | Declined, withdrawn or unsuitable n = 7 | Contact details not current n = 37 | No response n = 59 |
|---|---|---|---|---|---|
| Indigenous |  |  |  |  |  |
| **Aboriginal and/or Torres Strait Islander** | 1 (5%) | 11 (11%) | - | 5 | 6 |
| Contact method |  |  |  |  |  |
| **Landline telephone** | 4 (19%) | 25 (14%) | 4 | 21 | - |
| **Text message to mobile phone** | 10 (48%) | 44 (43%) | 2 | 11 | 31 |
| **Email** | 7 (33%) | 34 (33%) | 1 | 5 | 28 |
| Self-reported chronic condition* |  |  |  |  |  |
| **Complete or serious hearing impairment** | 2 (10%) | 7 (7%) | - | 5 | 2 |
| **Complete or partial vision impairment** | 3 (14%) | 7 (7%) | - | 4 | 3 |
| **Long-standing physical condition (example arthritis, chronic pain)** | 5 (24%) | 40 (39%) | - | 12 | 25 |
| **Mental health condition** | 1 (5%) | 18 (17%) | 1 | 8 | 9 |
| **Long-standing illness (example cancer, diabetes)** | 17 (81%) | 71 (69%) | 6 | 29 | 36 |

* P3ED Survey self-reported chronic condition; could choose more than one chronic condition

### *3.4.7 Phase 2: Semi-structured interviews*

The interview method of data collection is ideal for research questions that involve an understanding of people's experiences, perceptions and beliefs (Braun & Clarke, 2013). In this study, face-to-face interviews were undertaken using a structured interview schedule to guide the conversation. Although unstructured interviews by experienced practitioners may produce deep, rich data (Corbin & Strauss, 2008); a semi-structured interview approach, using a prepared interview schedule, is useful for guiding the conversation (Mills & Birks, 2014). Given that the researcher was a relative novice to conducting interviews, and that specific HCHs model elements were to be examined, a semi-structured approach to interview was employed in this study.

Semi-structured interviews allow the researcher to guide the exploration, while enabling participants to raise their own ideas and concerns as part of the conversation (Braun & Clarke, 2013). For this study a semi-structured interview schedule was prepared using guidelines outlined by Braun and Clarke (2013). These included a consideration of the opening and closing questions to set the tone of the interview, invite participation and promote the sharing of participant insights; careful sequencing and wording of questions; the addition of prompts to initiate and highlight discussion; and reflection on the style of wording to ensure that it would be acceptable to the participant group (Braun & Clarke, 2013). The interview schedule was reviewed and tested with the research team and trusted colleagues, prior to undertaking the initial interviews. Some of those who contributed to the piloting had chronic conditions, however people living with chronic conditions were not intentionally recruited as part of the interview schedule testing. Following the initial interviews, the interview schedule was amended, with further amendments as part of the process of concurrent data generation and analysis (Birks & Mills, 2015).

To maximise the potential for success, interviews should be undertaken in an environment in which both participants and researchers feel safe and comfortable (Braun & Clarke, 2013). In this study participants were asked to nominate their preferred place to interview. Some offered to travel to the university campus and meet in a conveniently located classroom (n=10); others chose their home environment (n=7); some chose a workplace (n=3); and one was a long-term caravan park resident (n=1). Researcher safety was considered for the interview sites, particularly those conducted off-campus. A safety buddy procedure was implemented that involved the researcher checking-in with an ethically approved member of the research team, who was provided with details on the interview location, the time and contact details of the participant (Braun & Clarke, 2013). For those conducted on-campus, paid parking and filtered water were provided to participants; with the on-campus interviews being conducted in a private, booked, on-campus classroom space that was easily accessible. Interviews varied in duration, from 25 to 75 minutes.

The initial schedule for the semi-structured interviews was informed by:

i. the HCHs model elements; and,
ii. findings from the quantitative Phase 1 investigation, which was an essential component of the explanatory sequential mixed methods design (Creswell & Plano Clark, 2011).

Participants were asked to respond to specific HCHs model features to explore experience, preference and need for health service delivery for people living with chronic conditions. This included views on GP practitioners and practices; care co-ordination, care planning, data sharing and decision making; and recommendations for service improvement. Phase 1 findings informed the interview schedule, specifically around having a regular GP; experience of alternative service providers to the GP; barriers and facilitators that impact access to GP care; and explanation of the concept of 'high-quality' care. The initial interview schedule is included in Appendix B - Interview Schedules.

Following reflection on the initial interviews (n=2), the interview schedule was modified slightly, with minor changes to the schedule continuing across the range of interviews. The interview schedule was adjusted across the study period in response to the interview experience, participant input and the evolving data analysis (Braun & Clarke, 2013). Additional interview schedules are included in Appendix B - Interview Schedules.

With participant consent, interviews were audio-recorded. Initial interviews were reviewed and transcribed by the researcher (n=3: Participants 1, 2 and 5). The audio files of the remaining interviews were reviewed by the researcher, participant identifying details were removed, and the audio files were professionally transcribed. Following professional transcription, interview transcripts were reviewed by the researcher for accuracy. To protect privacy, as part of the interview process, participants were asked to avoid referring to health professional staff by name. However, some continued to use staff and service names, and these were removed prior to undertaking the data analysis.

### *3.4.8 Phase 2: Grounded theory approaches to data generation and analysis in mixed methods research*

Analysis of the interview data involved inductive and deductive approaches, with the process guided by the grounded theory approaches of memoing; constant comparative analysis; concurrent data generation and analysis; and storyline (Birks & Mills, 2015, 2019). The purpose of this research was to enable local people living with chronic conditions to inform on the delivery of health service provided by the HCHs care model. Grounded theory approaches aim to describe a process that is grounded in the data (Mills & Birks, 2014). Even though the aim of this study was predominantly exploratory, the use of selected grounded theory methods was deemed to be valuable for this research, to support data generation that was directly derived from participant understanding. This modified grounded theory approach to analysis did not aim to generate a grounded theory. The application of grounded theory methods was guided by the overarching mixed methods design, employing a pragmatic stance to be "instrumentally effective in gathering information … to inform the practical problem at hand" (Tashakkori & Teddlie, 2010, p.139).

Braun and Clarke (2013) describe the need to begin qualitative analysis by *noticings,* that is by collating and responding to a researchers' thoughts and ideas at the initial stage of immersion in the data. In this study, observations immediately following the interviews were recorded by the researcher as fieldnotes. These fieldnotes were primarily used to remind the researcher of the informal conversations or contextual information that was observed during the research process (Birks & Mills, 2015). The fieldnotes were reviewed across the analysis process to remind the researcher of important noticings. An example of a fieldnote is included as follows:

> *A very different interview – very well-informed participant – who is a member of the HC [Health Care] community and so her experience is likely to be different as she has existing relationships with her HC team.*

As the researcher reviewed the transcripts and became more familiar with the data, a series of memos were created detailing researcher observations and insights. Some of these memos were contained in the *NVivo 12* (QSR International Pty Ltd.) files; while others were in a paper-based note-book. Often thoughts would arrive at inconvenient times: such as when driving the car or on waking in the night. In these instances the researcher would jot down a note at the earliest opportunity; or voice-memo on a mobile phone and email to herself. Memoing has been described as a fundamental process in grounded theory research; where insights into the developing analysis are recorded (Birks & Mills, 2015). An example of a memoing is included below:

> *When asked about their chronic conditions [initially], many people mentioned one or two primary health concerns. As the interview progressed it was common for the person to remember additional health concerns which were significant determinants of their health. Examples of this: … mental health … history of alcoholism … child abuse … substance use.*

### Coding and analysis

Coding is a technique used for analysing qualitative data to identify patterns and concepts (Birks & Mills, 2015). It involves the grouping, labelling and organising of ideas to generate understanding (Creswell & Plano Clark, 2007). Coding is the method that captures the “essence” of the data, whereas categorisation is the connection of the captured data (Saldaña, 2009, p.8). Complete coding involves “identify[ing] anything and everything” in the data that could be used to answer the research question (Braun & Clarke, 2013, p.206). The first-round, or initial coding, of interview data was undertaken line-by-line, using a complete coding approach to organise the coded data into categories (Saldaña, 2009). Data collected from the interview transcripts was imported into *NVivo 12* (QSR International Pty Ltd.) software for this initial analysis.

Braun and Clarke (2013) assert that researcher-derived coding is useful when exploring a conceptual framework. The participant may not actually say that they are describing the phenomena, however their response is directly addressing a key component of the framework. For this research, the HCHs model elements provided the conceptual framework. This was necessary to address *RQ2: How are elements of the Health Care Homes model valued by people living with chronic conditions in Cairns*? Questions on the model elements were included in the interview schedule and it was the participant responses to these questions that informed the pre-determined data categories. Stemmed from the HCHs model, these categories were participant experiences of: GP care, practice care, care co-ordination, shared decision making, data sharing and access to care. In addition to these researcher-derived categories, data-derived coding was generated by participant responses (Braun & Clarke, 2013). In vivo coding was used, where the precise participant words were employed in the labelling of the coded concepts (Creswell & Plano Clark, 2007). Structural coding was undertaken, involving the data-derived classification of ideas and concepts that had relevancy to the research questions (Saldaña, 2009).

Coding commenced following the first two interviews and utilised the grounded theory method of constant comparative analysis, which involves consistently comparing data to data, data to incident, and incident to incident (Birks & Mills, 2015). As new ideas and thoughts were identified in the interview data, the researcher re-reviewed the earlier interview data to examine the data from multiple perspectives and build understanding of the meaning of the data as an entire whole. In this study initial coding included identifying and organising the range of participant views; identifying and observing patterns in the data; and reflecting on how participant views were consistent or different from each other. Constant comparative analysis involved ongoing review of the interview data, to determine if the identified patterns might be consistent or divergent across the particpant group; and to elucidate factors that might have impacted the diversity of viewpoints (Birks & Mills, 2015). In this research, constant comparative analysis was used across all of the interview data to build-up an understanding of participants' perspectives of the HCHs model.

A key feature of the grounded theory approach to data collection and analysis used in this mixed methods study, was that analysis commenced in the early stages of data collection. Concurrent data generation and analysis involves using the learnings from the earlier data analysis to drive the direction of the ongoing data collection and analysis (Birks & Mills, 2015). Theoretical sampling is an important component of concurrent data generation and analysis to identify "issues that require expansion, clarification or confirmation" (Birks & Mills, 2015, p.68). As described in *section 3.4.6 Phase 2: Recruitment to interview*, it was the intention of the researcher to use theroretical sampling to guide the recruitment of particpants to the study. For pragamatic reasons, this approach to data collection was unable to be undertaken. However, theoretical sampling was employed in this research as learnings from earlier interview analysis informed the direction of future data collection (Birks & Mills, 2015). Specifically, during the research, some of the questions for interview were amended to explore new ideas. As an example, early interview analysis indicated that some participants asserted that their GP had provided them with specific instructions on how to gain access to an urgent appointment at their regular GP's practice. Knowledge of this structured, but informal approach to accessing care was identified in the initial coding. This knowledge was used to add an additional question to the interview schedule to inquire from other participants if their GP had advised them on ways to access urgent care.

As part of the method of constant comparative analysis, categories were expanded, merged and reorganised in an ongoing process to organise the data into a structure that could answer the research questions (Birks & Mills, 2015). At the completion of the initial coding of the interview transcripts, coding was reviewed to check for accuracy and the categorisation was refined. Ongoing memoing informed the development of the data analysis, providing insight to understanding of the data and identifying areas for further investigation (Creswell & Plano Clark, 2011).

Participant attributes were coded using *NVivo 12* (QSR International Pty Ltd.). This classification process enabled interview data to be analysed by variables including age, gender and type of chronic condition. Attribute coding is useful for data management and facilitates data review to support the developing analysis and interpretation (Saldaña, 2009).

To address *RQ2* involving people's perspectives of the HCHs model elements, in the next stage of data analysis, the coded data was exported from *NVivo 12* (QSR International Pty Ltd.) and printed. Using a deductive approach, the coded data was manually assigned to elements of the HCHs model of care. As described by Saldaña (2009), manual coding was advantageous in this part of the coding process to help the researcher identify the “smaller pieces of the larger puzzle” (p.22). Using *Microsoft Word 2016* software, further coding and analysis was undertaken to refine the data and build-up understanding of participant perspectives of the HCHs model elements.

At this later stage of analysis it was necessary to identify the key messages, or the “story” of the data. Storyline is “an advanced analytical technique used in grounded theory research for the purpose of both integrating and articulating theory” (Birks & Mills, 2019, p.2). Birks and Mills (2019) assert that the method is useful for researchers in the later stage of constant comparative analysis, who may be overwhelmed by the quantity of data but highly engaged or immersed in the process. Storyline is not simply a retelling of the data story. It is a formative approach that conceptualises and organises the data analyses. It involves connecting the emerging categories to integrate and summatively construct key messages from the data (Birks & Mills, 2019). The approach to storyline analysis in this research involved reflecting on the coded data that described people’s perspectives of health care services to identify “patterns of connectivity” (Birks & Mills, 2019, p.3). The HCHs model elements continued to be used to organise the storyline structure, with reflection on the emerging messages from the categorised data being informed by the initial fieldnotes and the ongoing memoing. Following this, the storyline was reviewed and refined, to identify the value of the HCHs model elements from the perpective of people living with chronic conditions (*RQ2*).

### *3.4.9 Mixed Methods Integration and Interpretation*

*RQ3: Can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns? What factors will influence the implementation of this model of care?*

In keeping with the mixed methods approach, findings from Phases 1 and 2 were integrated. The aim of this mixed methods integration was two-fold:

i. to determine if the Health Care Homes model of care can improve the delivery of health services to people living with chronic conditions in Cairns; and,
ii. to explore what factors might influence the implementation of this model of care.

Integration in mixed methods research uses findings from earlier study phases to build something new. For explanatory sequential mixed methods designs, the approach involves considering how the Phase 2 qualitative inquiry helps to explain the Phase 1 quantitative results (Creswell & Plano Clark, 2011).

### *3.4.10 Key mixed methods design concepts: interaction, priority, timing and mixing*

Creswell and Plano Clark (2011) describe key decisions to consider in the design of mixed methods research. Each of these four concepts were considered in the design of this research.

i. **Interaction** considers if the study phases are conducted independently, or if they interact (Creswell & Plano Clark, 2011). In this research the phases interacted in two ways: firstly, results from the Phase 1 quantitative analyses were used to inform the interview schedule for the Phase 2 qualitative semi-structured interviews; and secondly, the source population for recruitment to the Phase 2 interviews involved participants from the Phase 1 P3ED Survey who had indicated that they were local-dwelling and had a chronic condition.

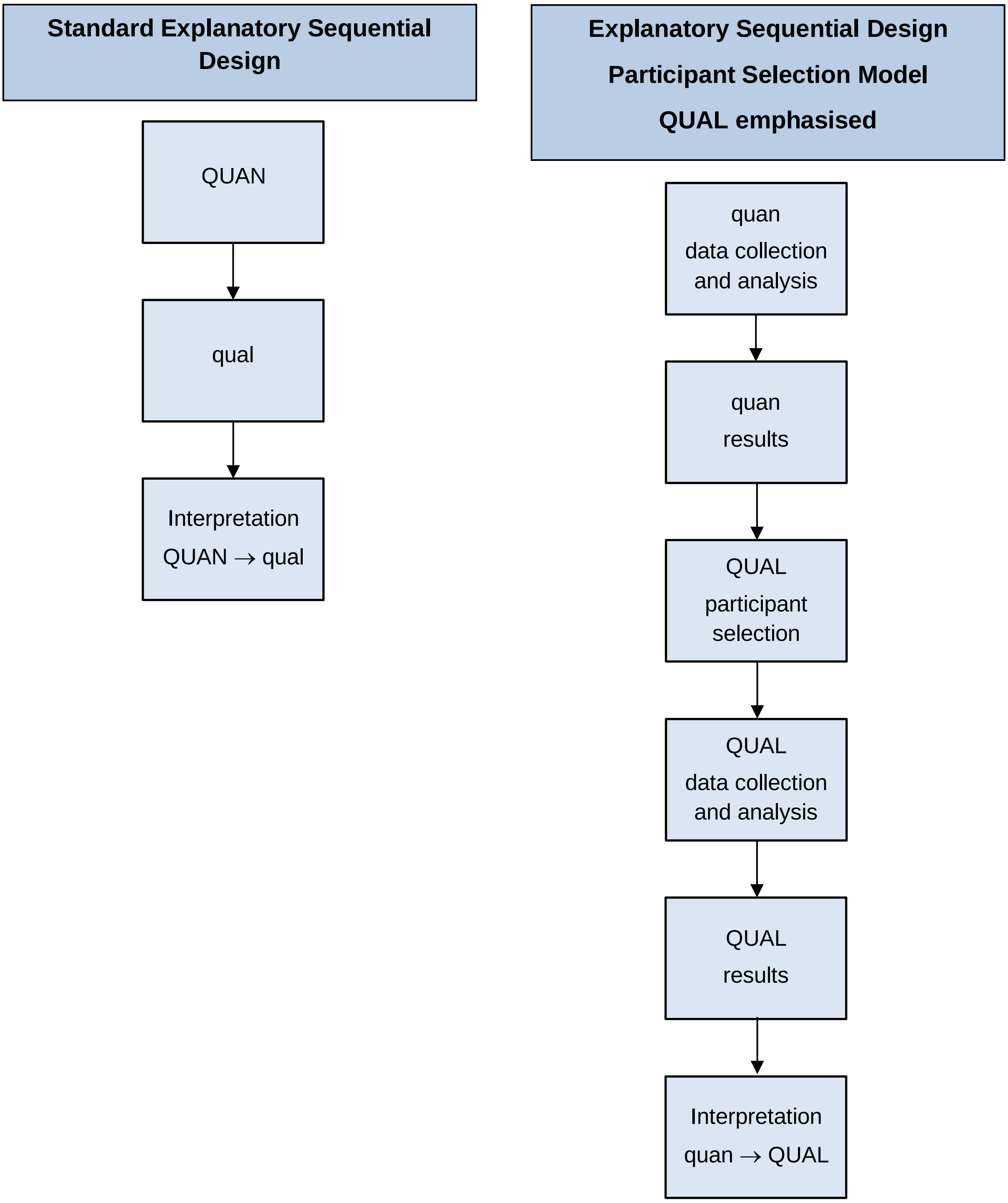
ii. **Priority** considers which study phase has priority, or is the most important, to answer the research question. That is, does the quantitative or the qualitative investigation best address the primary research question? Using a notation system, mixed methods designs are commonly described with the priority or core phase in uppercase letters, the supplementary phase in lowercase letters and notations such as an arrow to indicate the direction of inquiry (Creswell & Plano Clark, 2011; Morse & Niehaus, 2009; Natasi, Hitchcock, & Brown, 2010). In this research the qualitative phase directly answers the primary research question. The Phase 1 quantitative investigation does not independently address the primary *RQ: How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?* The notation for this study is therefore described as:

    **quan → QUAL**

    It is important to acknowledge that prioritising the qualitative phase differs from the typical study typology of ‘signature’ explanatory mixed methods designs. Some authors assert that the priority phase must occur initially in a sequential design (Morse & Niehaus, 2009). Others assert that ongoing controversy exists around definitions used in the signature mixed methods designs. They observe that as an evolving field diversity is common between mixed methodologists (Natasi et al., 2010). Indeed, Leech and Onwuegbuzie (2009) assert that in one methodological textbook, 35 mixed methods research designs were presented. Mixed methods researchers are in a continuous process to clarify the methodology (Leech & Onwuegbuzie, 2009; Natasi et al., 2010; Teddlie & Tashakkori, 2012). Schoonenboom and Johnson (2017) assert that a ‘hybrid’ design type should be added to the existing signature mixed methods designs, to describe complex combinations of mixed methods design typologies. They observe that in practice many mixed methods designs are not of the typical typologies and that researchers should be guided by the research question to construct an appropriate mixed methods design (Schoonenboom & Johnson, 2017).

Although there are acknowledged differences between mixed methodologists around study typologies, Creswell and Plano Clark (2007) maintain that the **quan → QUAL** variant of the explanatory sequential design may be useful; particularly in situations where quantitative investigation is used to purposefully select participants for qualitative inquiry. This was the planned approach for this study: participants in the Phase 2 qualitative interviews were to be sourced from the Phase 1 quantitative dataset. This planned process involved purposefully selecting participants for interview based on attributes sourced from the linked dataset such as age, gender, frequency of presentation to the ED and type of chronic condition. This design has been described as the participant-selection variant of the explanatory design (Creswell & Plano Clark, 2007, 2011). Hesse-Biber (2010) confirms the use of the **quan → QUAL** explanatory sequential design, identifying that qualitative inquiry can be used to validate and/or compare quantitative findings. This was the approach in this study, as Phase 1 quantitative findings were explored and clarified in the Phase 2 qualitative interviews. *Figure 6* describes and compares the typical explanatory sequential **QUAN → qual** design with the **quan → QUAL** variant.

*Figure 6: Comparative of typical explanatory design and the* ***quan → QUAL*** *variant*



*Note.* Adapted from Creswell and Plano Clark (2007, p.73)

iii. **Timing** is the third of the four key decisions to be considered in the design of a mixed methods study. As stated earlier, the quantitative datasets were already in existence prior to study commencement. This meant that decisions around the timing of the study were restricted: the quantitative phase needed to either occur alongside the qualitative phase in a concurrent design; or prior to the qualitative phase in a sequential design (Creswell & Plano Clark, 2011). In order to use the knowledge gained in the Phase 1 data linkage analysis to inform on the Phase 2 qualitative data collection, a sequential design was indicated and utilised.

iv. **Mixing** involves the approach to combining the findings from each study phase. It encompasses more than just reporting findings sequentially, as findings from each of the phases are conceptually integrated. Mixing may occur at different temporal points in the study design. In this study mixing occurred in the data collection process, when the results of the Phase 1 quantitative analyses informed part of the interview schedule for the Phase 2 qualitative data collection. This process of connection assisted in the building of the overall results and is integral to the explanatory mixed methods approach. In addition, mixing in this study occurred after the completion of both Phases 1 and 2. At this stage of the study, the findings from each phase were identified, described and compared. This process focussed on how the earlier Phase 1 quantitative findings were expanded, clarified and explained by the Phase 2 qualitative inquiry, with the aim of interpreting the integrated findings to address the research questions (Creswell & Plano Clark, 2011).

Procedural diagrams are commonly used to display the mixed methods research process (Creswell & Plano Clark, 2011; Plano Clark & Ivankova, 2016). The **quan → QUAL** variant of the explanatory sequential mixed methods design, incorporating the data linkage approach in the first phase, is displayed as *Figure 7*. This figure describes the **quan → QUAL** phases of the research; summarises the activities undertaken in each part of the study; and outlines the product from each of these activities.

*Figure 7: Procedural display of the* ***quan*** *→* ***QUAL*** *variant of the explanatory sequential mixed methods design*

| Phase | Procedure | Product |
|---|---|---|
| Quan<br>Data Linkage | Linkage of P3ED Survey Dataset with QHAPDC and EDIS Datasets. | New, linked dataset. |
| Quan<br>Data Analysis | Binary categorical analysis using Pearson's Chi-squared ($\chi^2$) statistic; Wilcoxon rank-sum (Mann-Whitney) for non-parametric variables; Fisher's exact test for small sized cells (n<5). Sensitivity, specificity and accuracy calculations with 95% confidence intervals (CIs). Univariate and multivariate logistic regression using Odds Ratios (95% CIs); Hosmer-Lemeshow test for model goodness-of-fit. | Descriptive and inferential statistics. |
| Purposive Sampling<br>Interview Schedule | Purposive sampling of P3ED Survey respondents for recruitment to interview. Findings from quantitative data analysis informed interview schedule. | Local resident people living with chronic conditions for interview (n=21).<br>Interview schedule. |
| QUAL<br>Data Collection | Semi-structured, face-to-face interviews (n=21). | Interview transcripts. |
| QUAL<br>Data Analysis | Coding; constant comparative analysis; concurrent data generation and analysis; theoretical sampling; and storyline analysis. | Codes and themes relevant to HCHs model elements.<br>Comparative of people living with uncommon and common chronic conditions. |
| Integration of Quantitative and Qualitative Findings | Integration, interpretation and explanation of quantitative and qualitative findings. | Integrated results display.<br>Discussion. |

## 3.5 Ethical considerations

### 3.5.1 Ethical Approvals

This research was undertaken following the principles and responsibilities outlined in the *Australian Code for the Responsible Conduct of Research* (National Health and Medical Research Council, Australian Research Council, & Universities Australia, 2007, 2018a) and the *National Statement on Ethical Conduct in Human Research* (National Health and Medical Research Council, Australian Research Council, & Universities Australia, 2018b).

Ethical approvals for this study were obtained from the *Far North Queensland Human Research Ethics Committee* (FNQHREC) and the *James Cook University Human Research Ethics Committee* (JCUHREC*).* Ethical approval letters are included in Appendix C - Ethics and Research Approvals.

### 3.5.2 Waiver of consent

A waiver of the requirement for participants to consent to participation in this study was required for the process of data linkage. The data linkage involved two existing FNQHREC approved studies: P3ED (HREC/14/QCH/9887 LR) and FNQHAT (HREC/13/QCH/131880). Consent in the previous studies impacted this current data linkage study:

i. for the P3ED Survey dataset: as part of the earlier P3ED study, participants gave consent to provide the survey responses and participate in the research. Each of these participants gave consent for P3ED researchers to access their electronic medical record concerning their Emergency Department visit. Participants in the P3ED study had agreed to let researchers extract information from the Emergency Department Information System (EDIS) and match it with their survey results. P3ED Survey participants who did not give consent to access and link their medical record were removed from this current study; and,
ii. for the FNQHAT datasets: a waiver of consent had been previously granted for this project; and there was no additional risk perceived for participants by this current data linkage.

The waiver of consent for this study was approved as part of the FNQHREC ethics application (see Appendix C - Ethics and Research Approvals).

### 3.5.3 Public Health Act (PHA) Approval

This project involved using data sourced from Queensland Health administrative datasets. This data involved health information that was identifiable or potentially re-identifiable. Under the Queensland Government Public Health Act 2005 (PHA), approval for the release of this data was required (Queensland Government, 2020a). PHA approval for this research was obtained and has been included in Appendix C - Ethics and Research Approvals.

### *3.5.4 Site Specific Assessment*

This project involved engaging the Queensland Government Cairns and Hinterland Hospital and Health Service (CHHHS) as a research site. Site Specific Assessment (SSA) was required to ensure that that the research site could support and deliver the resources required for the project, as part of the Queensland Government Financial Accountability Act 2009 (Queensland Health, 2010) and the Code for the Responsible Conduct of Research (National Health and Medical Research Council et al., 2007). This research governance activity was approved by the CHHHS and the approval has been included in Appendix C - Ethics and Research Approvals.

### *3.5.5 Recruitment to interview*

For the Phase 2 qualitative approach, recruitment of participants to interview was needed. In this study, potential participant contact details were sourced from previous P3ED Survey participants who had agreed to being contacted about future participation in research. Contact details were not sourced from the administrative datasets. Dataset details were used, however, as part of the preselection process whereby potential participants were theoretically sampled for self-reported chronic condition status, reason for ED presentation, age, gender and ethnicity.

The process of recruitment to interview was constructed to support the participation of only those P3ED Survey participants that might have an interest in the current research. To ensure previous participation in the P3ED study did not impair participants' free and voluntary consent, the methods of contact for invitation were carefully considered.

P3ED Survey respondents had provided a landline telephone number, mobile phone number or email address to the P3ED research team. Recruitment for this present study involved:

i. for respondents who had provided a mobile phone number: contact was made using an SMS to enquire if they might be interested in participating in an interview. Participants were asked to respond to indicate an interest in participating in the current study;
ii. for respondents who provided a landline phone number: contact was made by a Research Assistant to enquire if they might be interested in participating in an interview. A Research Assistant was engaged to minimise any potential perceived coercion to participate, which might have occurred if initial contact was made by a researcher involved in the project. If the respondent indicated an interest, they were

advised that a JCU researcher would contact them to provide further information about participating in the interview; and,

iii. for respondents who provided an email address: contact was made to enquire if they might be interested in participating in an interview. Participants were asked to respond via email or phone to indicate an interest in participating in the current study.

Contact via email and SMS text clearly advised that participants only make contact with the research team if they had an interest in finding out more about the study. The same message was left for those that had a landline phone answering service. The recruitment invitation has been included in Appendix D – Interview Documents.

### 3.5.6 Informed consent and project participation

Participants in this project were invited to interview and only participated if they indicated interest in the project and provided their informed consent. Prior to interview all participants received a Participant Information Sheet for review and Consent Form and these have been included in Appendix D – Interview Documents.

The Participant Information Sheet detailed key project information. Participants were required to review the Participant Information Sheet and were offered the opportunity to ask questions, prior to being asked to sign the Consent Form.

All those willing to participate in the study were asked to provide written, signed consent prior to interview, indicating that they had understood the project information. All participants for interview were over 18-years of age. In addition, participants who agreed to participate in the interviews were able to exit the study at any time, with clear details on the process for doing this provided to participants.

Taking part in the interview was completely voluntary and participants were advised that they could stop taking part in the interview or the study at any time, without giving a reason. The Participant Information Sheet included contact details for the Principal Researcher, the Supervisor and the FNQHREC, so that these could be used for any queries that participants might have about the study.

Participant well-being was considered. If a participant was to become upset at any time during the interview, the interviewer was to remind them of the opportunity to suspend and/or withdraw from the interview; and to provide the contact details for a local telephone counselling service, if wanted.

### 3.5.7 Privacy and confidentiality

Common to all studies involving human research, there is a potential risk of harm to participants if privacy and/or confidentiality is breached (National Health and Medical

Research Council et al., 2018b). For this study, privacy involved ensuring that participant information could not be reviewed by anyone outside of the ethically approved study team; and confidentiality involved the obligation to only use the participant data for the approved study purposes (National Health and Medical Research Council et al., 2018b). Efforts made to ensure privacy and confidentiality in this study included:

i. quantitative investigation, including the data linkage and analysis, was restricted to authorised study personnel only;
ii. for the linked dataset analyses and reporting, participants remain de-identified;
iii. for the qualitative investigation, participant identifying details were removed prior to transcription and analysis of the audiotaped interviews;
iv. for the qualitative analyses and reporting, participants remain de-identified;
v. all data generated during the study was password protected and stored in a secure environment within JCU. Access to data was restricted to authorised study personnel only.
vi. participant consent forms were stored securely at the JCU site; and,
vii. at the conclusion of the study all study records will be stored securely to maintain confidentiality and will be kept for a minimum of 5 years, as per JCU policy.

## 3.6 Far North Queensland Hospital Foundation Grant

In 2016, following ethical approval from the FNQHREC, an application for grant funding was made to the Far North Queensland Hospital Foundation. The funding request was to support the conduct of the study in two ways:

i. for the supply of transcription services for some of the interviews; and,
ii. to provide interview participants with a $50 gift-card (Coles-Myer) in recognition of their contribution of time and effort to the study.

The approval for this funding has been included in Appendix E – Research Grants. Interview participants were asked to sign a register indicating their receipt of a gift-card. This register was stored securely at the JCU site.

Receipt of this funding meant that updates were required to the ethical approvals for the conduct of the study. Final ethical approvals are included in Appendix C - Ethics and Research Approvals.

## 3.7 Chapter summary

This chapter described the methodological approach to the research; justifies the use of the mixed methods design; and outlines the limitations and benefits of using existing datasets. The quantitative and qualitative approaches were described, justified and detailed. This included a description of the data linkage, data collection, data analyses and ethical considerations. The approach to the mixed methods integration and interpretation was specified.

The next chapter explores the findings from the quantitative investigations. It includes three publications that address the first research question. Using the linked dataset, these publications examine the current experience of health care service for people living with chronic conditions in Cairns. Additionally, a draft report provided to the CHHHS Aboriginal and Torres Strait Islander Community Consultation Committee is included that describes health service perspectives and experiences of Aboriginal and Torres Strait Islander P3ED Survey participants.

# Chapter 4: Quantitative Findings

## 4.1 Introduction

This chapter describes the findings from the Phase 1 quantitative investigations. Using the linked dataset analyses, the current experience of health care service for people living with chronic conditions in Cairns is explored (*RQ1*). Further, the person-reported experiences of health care services were compared with their administrative records, providing insight into the impact that inaccuracy in the recording of patient records can have on understanding of the person experience. Three published articles are included in this chapter. Alongside these publications, a draft report on the health service experiences of Aboriginal and Torres Strait Islander people who participated in the P3ED Survey is presented. This report was undertaken at the request of the local hospital and health service Aboriginal and Torres Strait Islander Community Consultation Committee.

## 4.2 Factors that influence adult presentation to the emergency department: an exploration of the person-perspective of primary and acute health care services

The first of three published journal articles examined people's experiences and perspectives of existing primary and acute health care services. Using the linked dataset, the study focussed on the local resident, adult, Cairns population. The following article was published in *Emergency Medicine* Australasia (2019) and is titled 'Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study'. The article addresses *RQ1*, which considers the current experience of health care service for people living with chronic conditions in Cairns and presents the major findings of the quantitative Phase 1 investigation.

Comparison and discussion of the representativeness of the P3ED Survey participant group with all other ED attendees (≥18 years; for the one-month P3ED study period) can be found in this article.

### *4.2.1 Manuscript*

O'Loughlin, M., Harriss, L., Thompson, F., McDermott, R., & Mills, J. (2019). Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study. *Emergency Medicine Australasia, 31*(1), 67-75. doi:10.1111/1742-6723.13094

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 4 | O'Loughlin, M., Harriss, L., Thompson, F., McDermott, R., & Mills, J. (2019). Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study. *Emergency Medicine Australasia, 31*(1), 67-75. doi:10.1111/1742-6723.13094 | Developed the initial idea, planned and undertook the data linkage and statistical analyses; wrote the article. | O'Loughlin, M. |
| | | Assisted with the development | Harriss, L. |

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| | Accepted for publication: 4 April 2018<br>Published: 31 May 2018 | of the initial idea; assisted with the plan for data linkage and statistical analyses; assisted with writing and editing. | |
| | | Assisted with the data linkage; assisted with the statistical analyses; assisted with writing and editing. | Thompson, F. |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | McDermott, R. |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | Mills, J. |

Emergency Medicine Australasia

*Emergency Medicine Australasia* (2018) doi: 10.1111/1742-6723.13094

ORIGINAL RESEARCH

# Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study

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## Abstract

***Objective***: Explore factors that influence presentation at a regional hospital ED and identify opportunities to reduce attendance, particularly for adults with chronic conditions.

***Methods***: Cross-sectional survey of ED attenders, for 1 month period (March to April 2014), with linkage of survey data to administrative data sets.

***Results***: A total of 1000 adults completed the survey of which 549 (54.9%) self-identified as living with a chronic condition. Over half ($n = 572$, 57.2%) had their presenting problem for less than 24 h prior to attending the ED and 56.8% ($n = 568$) attended the ED outside working hours. Most ED presentations were recorded in the administrative data set as self-referred ($n = 933$, 93.3%); however, 29% ($n = 290$) of survey participants reported being referred to the ED by a medical practitioner. The majority of adults had a regular general practice ($n = 863$, 86.3%) with 30% ($n = 258$) visiting their practice in the week prior to presentation at the ED. Awareness of services such as the 13-Health telephone advice line was generally low ($n = 370$, 37%) and most did not consider alternative health services as suitable for their care. High-quality care, co-location of diagnostic services and extended hours of service were important to patients.

***Conclusion***: Despite being connected to a general practice, people focussed their health-seeking behaviour on the ED in the immediate period prior to presentation. Patients reported a limited awareness of alternative health services and opportunities exist to potentially reduce ED attendance, particularly for young and middle-aged adults with chronic conditions.

**Key words:** *attitude to health, chronic disease, health services research, primary health care, quality of health care.*

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*Accepted 4 April 2018*

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## 4.3 Exploring potentially avoidable general practitioner-type presentations to the emergency department

An interesting finding from the linked dataset analysis involved people's reports of being referred to the ED by their GP. A comparison between the person-report of self-referral to the ED and the hospital administrative record for the same visit, identified that the record of doctor-referral to the ED was higher in the patient survey (n=290, 29%) than in the administrative dataset (n=67, 6.7%). Importantly, over one-third (n=49, 35.3%) of younger-aged people (18-44 years) living with self-identified chronic conditions reported that they were directed to attend the ED by a medical practitioner (O'Loughlin, Harriss, Thompson, McDermott, & Mills, 2019). This inconsistency in the findings led to the second of the quantitative, Phase 1 publications which explored potentially avoidable GP-type (PAGP-type) presentations to the ED. The analysis demonstrated that people living with chronic conditions were less likely to be classified as PAGP-type presenters to the ED, indicating that people living with chronic conditions attended the ED for health needs that required ED care, not just because attending the ED was convenient or cost-saving (O'Loughlin, Mills, McDermott, & Harriss, 2021). This finding enhanced understanding of the current experience of health care service for people living with chronic conditions in Cairns (*RQ1*).

The article was published in the *Australian Health Review* (2021) and is titled 'Exploring the measure of potentially avoidable general practitioner-type presentations to the emergency department in regional Queensland using linked, patient-perspective data'. Publication support was received for this article following a successful application to the competitive JCU, College of Public Health, Medical and Veterinary Sciences, Higher Degree Research Enhancement Scheme Grants scheme (see Appendix E – Research Grants). The article was accepted for publication prior to the *Australian Health Review* being advised of the authors' intention to apply for publication under an open access licence. The open access licence was attained by using the Research Enhancement Scheme funds to pay for the author publication fee.

### *4.3.1 Manuscript*

O'Loughlin, M., Mills, J., McDermott, R., & Harriss, L. R. (2021). Exploring the measure of potentially avoidable general practitioner-type presentations to the emergency department in regional Queensland using linked, patient-perspective data. *Australian Health Review, 45*(1), 90-96. doi:https://doi.org/10.1071/AH19210

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 4 | O'Loughlin, M., Mills, J., McDermott, R., & Harriss, L. R. (2021). Exploring the measure of potentially avoidable general practitioner-type presentations to the emergency department in regional Queensland using linked, patient-perspective data. *Australian Health Review, 45*(1), 90-96. doi:https://doi.org/10.1071/AH19210<br>Accepted for publication: 12 May 2020<br>Published: 30 October 2020 | Developed the initial idea, planned and undertook the statistical analyses; wrote the article. | O'Loughlin, M. |
| | | Assisted with the development of initial idea; assisted with writing and editing. | Mills, J. |
| | | Assisted with the development of initial idea; assisted with writing and editing. | McDermott, R. |
| | | Assisted with the development of the initial idea; assisted with the plan for statistical analyses; assisted with writing and editing. | Harriss, L. |

**CSIRO** PUBLISHING

*Australian Health Review*
https://doi.org/10.1071/AH19210

# Exploring the measure of potentially avoidable general practitioner-type presentations to the emergency department in regional Queensland using linked, patient-perspective data

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**Abstract.**

**Objective.** To explore measures of potentially avoidable general practitioner (PAGP)-type presentations to the emergency department (ED) of a large regional hospital in northern Queensland.

**Methods.** Linkage of an ED administrative dataset to a face-to-face patient survey of local residents ($n = 1000$); calculation of Australian Institute of Health and Welfare (AIHW) and Australasian College of Emergency Medicine (ACEM) measures of PAGP-type presentations to the ED; and exploration of these measures with patient-perspective linked data.

**Results.** PAGP-type presenters to the ED were younger in age (median age in years: total cohort: 49; AIHW 38, $P < 0.001$; ACEM 36, $P < 0.001$); with the odds of having a chronic condition being less likely for AIHW PAGP-type presenters than other ED presenters (OR (95% CI) 0.54 (0.38–0.77): $P = 0.001$)) after adjustment for age. PAGP-type presenters nominated reasons of convenience rather than urgency as their rationale for attending the ED, irrespective of measure. The number of PAGP-type presentations to the ED identified by the AIHW measure was more than three-fold higher than the ACEM measure (AIHW: $n = 227$; ACEM: $n = 67$). Influencing factors include the low proportion of ED attendees who had a medical consultation time of <1 h at this hospital site (1-month survey period: 17.8%); and differences between the patient self-report and ED administrative record for 'self-referral to the ED' (Self-referred: Survey 71% vs EDIS 93%, $P < 0.001$).

**Conclusions.** Identification of PAGP-type presentations to the ED could be enhanced with improvements to the quality of administrative processes when recording patient 'self-referral to the ED', along with further consideration of hospital site variation for the length of medical consultation time.

**What is known about the topic?** PAGP-type presentations to the ED are an Australian National Healthcare Agreement progress indicator. Methods of measuring this indicator have been under review since 2012 and debate remains on how to accurately determine the measure.

**What does this paper add?** By using patient perspective-linked data to explore different measures of PAGP-type presentations to EDs, this paper identifies issues with measure elements and suggests ways to improve these measures.

**What are the implications for practitioners?** Measure elements of patient 'self-referral to the ED' and 'medical consultation time' require further consideration if they are to be used to measure PAGP-type presentations to the ED.

Received 13 September 2019, accepted 12 May 2020, published online 30 October 2020

## Introduction

Of interest to Australian health service providers and policy-makers is the measure of potentially avoidable general practitioner (PAGP)-type presentations to the emergency department (ED). This indicator of health service effectiveness[1] estimates the number of presentations to the ED that could have potentially been treated in primary care.[2,3] In 2017–18, 2.9 million PAGP-type presentations were recorded in Australian public hospital EDs.[4] Although not a measure of hospital performance, the number of PAGP-type presentations is used to indicate the accessibility and affordability of primary health care.[3] Debate remains on how to accurately define PAGP-type presentations to the ED.[5] This debate is particularly important to resolve in regional and remote areas for planning appropriate health service delivery. In these areas, the relative scarcity of diagnostic and primary care services generally results in public hospitals becoming the default provider,[6] with subsequently higher rates of PAGP-type emergency presentations in regional and remote hospitals compared with hospitals in metropolitan areas.[7]

### Australian Institute of Health and Welfare measure

Methods of measuring PAGP-type presentations to the ED have been under review by the Australian Institute of Health and Welfare (AIHW) since 2012.[8] After several years of reporting as an interim indicator, recent AIHW publications have chosen to exclude selected PAGP-type presentations due to limitations in the existing methodology.[9,10] As a progress measure of the Australian public healthcare system, this indicator is currently described as needing significant work to improve accountability,[1] with the main criticism being that the current AIHW measure (Table 1) overestimates the proportion of true PAGP-type presentations to the ED.[11] One element of the AIHW's measure is the Australasian Triage Scale category,[12] and some authors have argued that it is a scale of perceived urgency, not complexity, and consequently is not useful to inform on PAGP-type presentations to the ED.[5]

### Alternate measures

Alternate measures of PAGP-type presentations to the ED have been developed by others; for example, the Australasian College of Emergency Medicine (ACEM) measure (Table 1) is commonly used[5] and may provide a more useful estimate of PAGP-type presentations in rural[13] and metropolitan populations.[11] However, a recent study found several models, including the ACEM measure, to be inaccurate in a specialised paediatric cohort.[14] Other proposed measures include the Sprivulis method which uses discharge rates;[15] and the Diagnosis method that relies on a list of defined diagnoses that are suitable for GP management.[11] Although demonstrating general consistency with the ACEM approach,[11] these other measures involve increased complexity and are challenging to use when compared with the AIHW and ACEM measures.

### Study objectives

The study aimed to explore elements of the AIHW and ACEM measures of PAGP-type presentations to the ED and to inform on ways to improve these measures using person-perspective data linked to hospital administrative records.

**Table 1. Elements of Australian Institute of Health and Welfare (AIHW) and Australasian College of Emergency Medicine (ACEM) definitions for potentially avoidable general practitioner (PAGP)-type presentations to the emergency department (ED)**

AIHW definition of PAGP-type presentation to ED = (Australasian Triage Scale category 4 or 5) + (Not admitted, not referred to another hospital, not deceased) + (Did not arrive by ambulance, police or corrections vehicle). ACEM definition of PAGP-type presentation to ED = (Did not arrive by ambulance, police or corrections vehicle) + (Self-referred) + (Medical consultation time less than 1 h)

| Element of measure | AIHW | ACEM |
|---|---|---|
| Australasian Triage Scale category 4 or 5[A] | X | |
| Not admitted, not referred to another hospital, not deceased | X | |
| Did not arrive by ambulance, police or corrections vehicle | X | X |
| Self-referred | | X |
| Medical consultation time <1 h | | X |

[A] Maximum waiting time for medical assessment and treatment. Category 4: within 60 min; Category 5: within 120 min.[9]

## Methods

### Approvals

Far North Queensland Human Research Ethics Committee Research (FNQHREC) approval was obtained for *The Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department (P3ED)* patient survey (HREC/14/QCH/9–887 LR). This approval included the requirement for informed consent to be obtained from survey participants for the completion of the questionnaire and to access their medical record. Additional ethics approvals were obtained from the FNQHREC for the Far North Queensland Hospital Avoidance Trial (FNQHAT) administrative Emergency Department Information System (EDIS) dataset (HREC/13/QCH/131–880); and for the linkage and analysis of the patient survey and administrative dataset (HREC/16/QCH/81–1068).

### Study population and setting

The setting was a large, regional, public hospital in north Queensland over a 1-month period in 2014 (13 March to 11 April). Recruitment was undertaken in the ED 24 h per day, 7 days per week for the study period. Potential participants were identified by hospital staff as suitable for approach. Research assistants obtained informed consent and facilitated the face-to-face survey, which was undertaken using iPad tablets. The 28-question instrument explored factors associated with ED attendance. Analyses of this patient survey have been reported elsewhere.[16]

In the study period, 3229 individual adults (aged ≥18 years) attended the ED including international, inter-state and intra-state visitors. For this present study, only adults who agreed to participate in the survey and self-identified as residing locally were included in the data linkage ($n = 1014$). The exclusion of non-local people from the study was due to a high transient population in the region; with our research focus for PAGP-type presenters being local-dwelling individuals.

### *Data linkage*

Responses from adults who completed the survey were linked to the EDIS dataset for a 2-year period (July 2012 to June 2014). Linkage was undertaken using Medical Record Numbers, with removal of those unable to be linked ($n - 14$). Datasets were merged using Stata 13.1 (Stata Corp, College Station, TX, USA). The final study sample for analysis comprises all local resident, adult survey respondents who were able to be linked to their own administrative data record ($n - 1000$).

### *Analysis*

PAGP-type presentations to the ED were estimated using two approaches: the AIHW and ACEM measures (Table 1). Characteristics were independently compared between AIHW and non-AIHW PAGP-type presenters; and ACEM and non-ACEM PAGP-type presenters. Analyses were conducted using Pearson's Chi-squared ($\chi^2$) statistic for categorical variables, with Fisher's exact test used for small-sized cells ($n < 5$); and Wilcoxon rank-sum (Mann–Whitney U-test) for non-parametric variables.

The association between having a chronic condition and being an AIHW or ACEM PAGP-type presenter was explored using logistic regression. Odds ratios (ORs) with 95% confidence intervals (OR (95%CI)) were calculated using logistic regression to explore the association between having a chronic condition and each PAGP-type. Model 1 used univariate logistic regression with chronic condition as the independent variable and Model 2 used multivariate logistic regression with further adjustment for age, gender, Indigenous status, arrival out-of-hours and having a regular GP. Two-sided $P$ values of <0.05 were regarded as significant. Model estimates of goodness-of-fit were calculated using the Hosmer–Lemeshow test, with Stata 13.1 being used for all analyses.

## **Results**

### *Characteristics of PAGP-type presenters*

The AIHW measure classified significantly more PAGP-type presenters than the ACEM measure ($n - 227$ vs 67, $\chi^2 - 51.6$, d.f. $- 1$, $P < 0.001$), with 39 individuals being identified by both measures (Fig. 1, Table 2). Compared with all other survey respondents, both the AIHW and ACEM PAGP-type presenters were significantly younger (Mann–Whitney U-test: median age: AIHW 38 vs 52 years, z $- 6.515$, $P < 0.001$; ACEM 36 vs 49 years, z $- 3.931$, $P - 0.001$).

### *Comparison of existing measures of PAGP-type presentations to the ED*

Nearly three-quarters of those identified by the ACEM measure had the mandatory AIHW elements 'Australasian Triage Scale 4 or 5' ($n - 49$, 73%) and 'Not admitted, not referred to another hospital, not deceased' ($n - 48$, 72%). Seventeen percent ($n - 39$) of those identified by the AIHW measure had the mandatory ACEM element 'Medical consultation time less than 1 h' (Table 2).

### *Comparison of EDIS and self-reported referral to the ED*

EDIS records indicated that 93% ($n - 933$) of the cohort were self-referred to the ED, compared with only 71% ($n - 710$) of survey participants who reported that they were self-referred ($\chi^2 - 21.332$, d.f. $- 1$, $P < 0.001$) (Table 2).

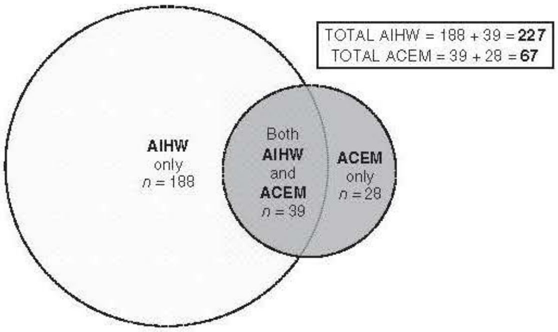

**Fig. 1.** Comparison of Australian Institute of Health and Welfare (AIHW) and Australasian College of Emergency Medicine (ACEM) potentially avoidable general practitioner (PAGP)-type presentations to the emergency department (ED). For $n = 1000$ local adult residents responding to a survey in a 1-month study period (13 March to 11 April 2014).

### *Reasons PAGP-type presenters attend the ED*

Survey respondents were asked to nominate their main reason for attending the ED. Across the study sample, the most common reason was that their problem was urgent, or that the ED was the best place for their problem ($n - 320$, 32%). Irrespective of measure, PAGP-type presenters were less likely to nominate this reason (AIHW: $\chi^2 - 15.901$, d.f. $- 1$, $P < 0.0001$; ACEM: $\chi^2 - 5.237$, d.f. $- 1$, $P - 0.022$). The second most common reason was the self-report of being sent to the ED by a doctor or specialist ($n - 290$, 29%), with ACEM PAGP-type presenters being less likely to identify this reason (ACEM: $\chi^2 - 8.452$, d.f. $- 1$, $P - 0.004$). When compared with the wider survey cohort, both measures of PAGP-type presenters nominated that they were more likely to attend the ED because: the service was open 24 h (AIHW: $\chi^2 - 7.418$, d.f. $- 1$, $P - 0.006$; ACEM: $\chi^2 - 8.817$, d.f. $- 1$, $P - 0.003$); and it was quicker than getting a GP appointment (AIHW: $\chi^2 - 11.010$, d.f. $- 1$, $P - 0.001$; ACEM: $\chi^2 - 7.679$, d.f. $- 1$, $P - 0.006$). AIHW PAGP-type presenters were more likely to attend the ED because services such as pathology and radiography were co-located ($\chi^2 - 7.566$, d.f. $- 1$, $P - 0.006$); whereas the convenient location of the ED increased the likelihood of ED attendance by ACEM PAGP-type presenters ($\chi^2 - 6.705$, d.f. $- 1$, $P - 0.01$) (Table 3).

### *Patient factors that influence PAGP-type presentation measures*

The odds of having a self-reported chronic condition was ~60% less for both AIHW and ACEM PAGP-type presentations than for other ED presentations (OR (95% CI)); AIHW: 0.39 (0.29–0.53: $P < 0.001$); ACEM: 0.38 (0.22–0.64: $P < 0.001$). After adjusting for age and other potential confounders, the association between chronic conditions and both PAGP-type presentations weakened slightly and lost statistical significance with the ACEM presentations, possibly due to a smaller sample size (AIHW: $n - 227$; ACEM: $n - 67$) (Table 4).

**Table 2. Characteristics of 1000 adult survey participants presenting to the emergency department in 2014, comparing two definitions for PAGP-type presentation**

Data are presented as *n* (%) unless otherwise stipulated. Data sourced from administrative datasets unless otherwise indicated. Local residents only. *P* values that are significant at <0.05 are indicated in bold. AIHW, Australian Institute of Health and Welfare; ACEM, Australasian College of Emergency Medicine; ED, emergency department; PAGP, potentially avoidable general practitioner; *P* diff., *P* difference; s.d., standard deviation; IQR, interquartile range.

| Characteristics | All survey respondents | AIHW PAGP-type | Non-AIHW PAGP-type | *P* diff | ACEM PAGP-type | Non-ACEM PAGP-type | *P* diff |
|---|---|---|---|---|---|---|---|
| ED attendees (≥18 years) | 1000 | 227 | 773 | | 67 | 993 | |
| Male | 493 (49.3) | 109 (48.0) | 384 (49.7) | 0.66 | 32 (47.8) | 461 (49.4) | 0.79 |
| Female | 507 (50.7) | 118 (52.0) | 389 (50.3) | | 35 (52.2) | 472 (50.6) | |
| Age, median (IQR)[A] | 49 (32,63) | 38(28,54) | 52(36,65) | **<0.0001** | 36(25,55) | 49(33,63) | **0.0001** |
| Indigenous[B] | 114 (11.6) | 20 (9.2) | 94 (12.3) | 0.20 | 7 (10.9) | 107 (11.7) | 0.86 |
| Arrived out of hours[C] | 568 (56.8) | 137 (60.4) | 431 (55.8) | 0.22 | 35 (52.2) | 533 (57.1) | 0.44 |
| AIHW element: | | | | | | | |
| Triage category 4 or 5 | 419 (41.9) | 227 (100) | 192 (24.8) | **<0.0001** | 49 (73.1) | 370 (39.7) | **<0.0001** |
| Not: admitted, referred to another hospital, deceased | 572 (57.2) | 227 (100) | 345 (44.6) | **<0.0001** | 48 (71.6) | 524 (56.2) | **0.01** |
| Both AIHW and ACEM element: | | | | | | | |
| Not: arrived by ambulance, police or corrections | 621 (62.1) | 227 (100) | 394 (51.0) | **<0.0001** | 67 (100) | 554 (59.4) | **<0.0001** |
| ACEM element: | | | | | | | |
| Self-referred (not doctor-referred) to ED | 933 (93.3) | 222 (97.8) | 711 (92.0) | **0.002** | 67 (100) | 866 (92.8) | **0.02** |
| Medical consultation time <1 h | 88 (8.8) | 39 (17.2) | 49 (6.3) | **<0.0001** | 67 (100) | 21 (2.6) | **<0.0001** |
| Patient reports: self-referred (not doctor-referred) to ED[D] | 710 (71.0) | 169 (74.5) | 541 (70.0) | 0.19 | 58 (86.6) | 652 (69.9) | **0.004** |
| Patient reports: self-identified chronic condition[D] | 549 (54.9) | 84 (37.0) | 465 (60.2) | **<0.0001** | 22 (32.8) | 527 (56.5) | **<0.0001** |
| Patient reports: has regular GP[D] | 863 (86.3) | 189 (83.3) | 674 (87.5) | 0.10 | 51 (76.1) | 812 (87.3) | **0.01** |
| *If has regular GP* visited in previous 7 days[D] | 258 (30.0) | 53 (28.0) | 205 (30.5) | 0.51 | 12 (23.5) | 246 (30.4) | 0.30 |
| *If has regular GP* has bulk-billing[D] | 658 (76.4) | 133 (70.4) | 525 (78.1) | **0.03** | 36 (70.6) | 622 (76.8) | 0.31 |
| *If has regular GP* difficult to get urgent appointment[D] | 244 (28.4) | 55 (29.1) | 189 (28.2) | 0.80 | 14 (27.5) | 230 (28.4) | 0.88 |

[A] *P* difference by two-sample Wilcoxon rank-sum (Mann–Whitney U-test) non-parametric test.

[B] Indigenous status based on 980 people with known status.

[C] Out of hours: 1800–0800 hours weekdays, weekends excluding 0800–1200 hours Saturday.

[D] Data sourced from patient survey.

Multivariable analysis demonstrated a consistent, slight association between younger age and PAGP-type presentation across both measures (AIHW: 0.98 (0.97–0.99: $P < 0.001$); ACEM: 0.98 (0.96–0.99: $P = 0.007$)). Gender, Indigenous status, arrival to the ED out of hours and having a regular GP did not affect the likelihood of being an AIHW or ACEM PAGP-type presenter (Table 4).

## Discussion

In our study, the AIHW measure identified more than three-times the number of PAGP-type presentations to the ED than the ACEM measure. Nearly three-quarters of those identified by the ACEM measure were consistent with the AIHW model elements of triage category (ACEM 73%) and non-admission/referral/deceased (ACEM 72%); the other AIHW model element of non-arrival by ambulance/police/corrections was common to both measures. The ACEM measure element of self-referral to the ED was consistent for those identified by the AIHW measure (AIHW 98%); however, there was a notable difference between a person's self-report of being referred to the ED and their administrative data record. Having a medical consultation of <1 h in the ED, part of the ACEM measure, was not common for those identified by the AIHW measure (17%) (Table 2).

Consistent with previous studies, both AIHW and ACEM PAGP-type presenters were younger than other ED survey respondents.[17] Irrespective of measure, PAGP-type presenters nominated reasons of convenience rather than urgency as their rationale for attending the ED (Table 3). Although over half of all survey respondents ($n = 549$, 55%) identified that they had one or more chronic conditions, AIHW PAGP-type presenters were less likely to have a chronic condition when influencing factors, such as age, were considered (Table 4).

### *Self-referral to the ED*

Our study identified differences between the patient report of self-referral to the ED and the ED administrative dataset (Patient survey self-referred: 71% vs EDIS self-referred: 93%) (Table 2). Other patient perspective studies have identified a similar proportion of self-referrals to the ED as those reported in our study (~30% referred by healthcare practitioner).[18,19] A notable strength of our study design was the data linkage that enabled a direct comparison between individual patient report and their

**Table 3. Patient-reported reason for attending the ED, by AIHW and ACEM definitions for PAGP-type presentation**

Data are presented as *n* (%) unless otherwise stipulated. Data sourced from patient survey. Local residents only. AIHW, Australian Institute of Health and Welfare; ACEM, Australasian College of Emergency Medicine; ED, emergency department; PAGP, potentially avoidable general practitioner; *P* diff., *P* difference. *P* difference by Chi-squared test. For cell *n* <5, *P* difference was detected by using Fisher's exact test. *P* values that are significant at <0.05 are indicated in bold. '–' indicates no responses for these variables

| Reported reason for attending the ED | All survey respondents | AIHW PAGP-type | Non-AIHW PAGP-type | *P* diff | ACEM PAGP-type | Non-ACEM PAGP-type | *P* diff |
|---|---|---|---|---|---|---|---|
| ED attendees (≥18 years) | 1000 | 227 | 773 | | 67 | 933 | |
| Patient perceives ED is best place for their needs | | | | | | | |
| Best place for problem/urgent problem | 320 (32.0) | 48 (21.1) | 272 (35.2) | **<0.0001** | 13 (19.4) | 307 (32.9) | **0.022** |
| Perceives hospital admission is needed | 26 (2.6) | 3 (1.3) | 23 (3.0) | 0.24 | 1 (1.5) | 25 (2.7) | 1.00 |
| Perceives specialist care is needed | 2 (0.2) | 1 (0.4) | 1 (0.1) | 0.40 | – | 2 (0.2) | 1.00 |
| Return post hospital discharge | 2 (0.2) | 1 (0.4) | 1 (0.1) | 0.40 | – | 2 (0.2) | 1.00 |
| Patient reports being directed to attend ED | | | | | | | |
| By doctor or specialist | 290 (29.0) | 58 (25.6) | 232 (30.0) | 0.19 | 9 (13.4) | 281 (30.1) | **0.004** |
| Was sent by another health professional | 22 (2.2) | 4 (1.8) | 18 (2.3) | 0.80 | 3 (4.5) | 19 (2.0) | 0.18 |
| Was sent by 13HEALTH telephone advice line | 4 (0.4) | 1 (0.4) | 3 (0.4) | 1.00 | 1 (1.5) | 3 (0.3) | 0.24 |
| An organisational requirement to attend ED | 2 (0.2) | 1 (0.4) | 1 (0.1) | 0.40 | – | 2 (0.2) | 1.00 |
| Asked to return by hospital doctor or nurse | 2 (0.2) | – | 2 (0.3) | 1.00 | – | 2 (0.2) | 1.00 |
| Sent by someone, not health professional | 43 (4.3) | 5 (2.2) | 38 (4.9) | 0.09 | 3 (4.5) | 40 (4.3) | 0.76 |
| Patient reports range of services/hours of service | | | | | | | |
| Services in one location, example: X-ray, bloods | 116 (11.6) | 38 (16.7) | 78 (10.1) | **0.006** | 9 (13.4) | 107 (11.5) | 0.63 |
| Open 24 h | 46 (4.6) | 18 (7.9) | 28 (3.6) | **0.006** | 8 (11.9) | 38 (4.1) | **0.003** |
| Patient reports reassurance/second opinion | | | | | | | |
| Feels reassured by ED staff | 16 (1.6) | 7 (3.1) | 9 (1.2) | **0.043** | 1 (1.5) | 15 (1.6) | 1.00 |
| Wants a second opinion | 12 (1.2) | 5 (2.2) | 7 (0.9) | 0.12 | 4 (6.0) | 8 (0.9) | **0.006** |
| Always comes to hospital for care | 12 (1.2) | 3 (1.3) | 9 (1.2) | 0.74 | – | 12 (1.3) | 1.00 |
| Very happy with the care received in the past | 8 (0.8) | 2 (0.9) | 6 (0.8) | 1.00 | 1 (1.5) | 7 (0.8) | 0.43 |
| Patient reports convenience/cost/preference | | | | | | | |
| Quicker than getting a GP appointment | 32 (3.2) | 15 (6.6) | 17 (2.2) | **0.001** | 6 (9.0) | 26 (2.8) | **0.006** |
| Convenient location | 26 (2.6) | 9 (4.0) | 17 (2.2) | 0.14 | 5 (7.5) | 21 (2.3) | **0.01** |
| Would be a shorter wait | 8 (0.8) | 3 (1.3) | 5 (0.1) | 0.39 | 3 (4.5) | 5 (0.5) | **0.013** |
| Did not want to bother GP | 2 (0.2) | 1 (0.4) | 1 (0.1) | 0.40 | – | 2 (0.2) | 1.00 |
| ED is cheaper than a GP visit | 2 (0.2) | 2 (0.9) | – | 0.05 | – | 2 (0.2) | 1.00 |
| Does not have a GP | 2 (0.2) | – | 2 (0.3) | 1.00 | – | 2 (0.2) | 1.00 |
| To see someone who does not know me | 1 (0.1) | 1 (0.4) | – | 0.23 | – | 1 (0.1) | 1.00 |
| Unhappy with GP services | 1 (0.1) | – | 1 (0.1) | 1.00 | – | 1 (0.1) | 1.00 |
| Needed Panadol | 1 (0.1) | – | 1 (0.1) | 1.00 | – | 1 (0.1) | 1.00 |
| Unable to be determined | 2 (0.2) | 1 (0.4) | 1 (0.1) | 1.00 | – | 2 (0.2) | 1.00 |

own hospital record. Given that the ACEM measure of PAGP-type presentations and other proposed alternate measures, such as the Sprivulis and Diagnosis methods, use self-referral as a key data element,[11] the difference between patient report and hospital record of 'self-referral to the ED' warrants further consideration.

The difference between patient report and their administrative record may indicate inadequacy in mechanisms to facilitate information sharing between health professionals, including primary care providers, to the ED. In addition to medical practitioners, participants in our study reported being referred to the ED by other health professionals such as a dentist or pharmacist ($n = 22$, 2.2%), the Australian Government's 13HEALTH telephone advice service ($n = 4$, 0.4%); and other organisational requirements to attend an ED ($n = 2$, 0.2%) (Table 3). These referral pathways are consistent with other studies that have reported an even greater effect of non-medical (doctor or specialist) health professionals referring patients to the ED than found in our study.[18,19]

There is an opportunity for policymakers and service providers to enhance our understanding of health system functioning by identifying pathways taken by patients to attend the ED. Systems could be strengthened with improved mechanisms to record the patient's nominated health professional who referred them to the ED; to establish routine recording of presentations that are an organisational requirement to attend the ED; and to develop a mechanism to link a person's 13HEALTH consultation with their ED presentation. These approaches could provide

**Table 4. Odds ratios (95% CIs) for the association between chronic conditions and other demographic and patient-perspective variables for AIHW and ACEM PAGP-type presentation measures**

Data sourced from administrative datasets unless otherwise indicated. Local residents only. Model 1: using univariate logistic regression with chronic condition as the independent variable. Model 2: using multivariate logistic regression further adjusting for age, gender, Indigenous status, arrival out-of-hours and having a regular GP. AIHW, Australian Institute of Health and Welfare; ACEM, Australasian College of Emergency Medicine; PAGP, potentially avoidable general practitioner; OR, odds ratio; CI, confidence interval; s.e., standard error. *P* values that are significant at <0.05 are indicated in bold

| | OR (95% CI) | s.e. | z | *P* |
|---|---|---|---|---|
| AIHW PAGP-type, *n* = 227 | | | | |
| *Model 1* | | | | |
| Chronic condition, *n* = 84 | 0.39 (0.29–0.53) | 0.06 | −6.06 | **<0.0001** |
| *Model 2*[A] | | | | |
| Chronic condition, *n* = 84 | 0.54 (0.38–0.77) | 0.10 | −3.45 | **0.001** |
| Age | 0.98 (0.97–0.99) | 0.01 | −4.42 | **<0.0001** |
| Gender | 1.05 (0.76–1.43) | 0.17 | 0.27 | 0.78 |
| Indigenous, *n* = 20 | 0.68 (0.40–1.15) | 0.18 | −1.44 | 0.15 |
| Arrived out of hours[B], *n* = 137 | 1.14 (0.83–1.57) | 0.19 | 0.82 | 0.41 |
| Patient reports: has a regular GP[C], *n* = 189 | 1.11 (0.71–1.74) | 0.25 | 0.46 | 0.65 |
| ACEM PAGP-type, *n* = 67 | | | | |
| *Model 1* | | | | |
| Chronic condition, *n* = 22 | 0.38 (0.22–0.64) | 0.10 | −3.64 | **<0.0001** |
| *Model 2*[D] | | | | |
| Chronic condition, *n* = 22 | 0.61 (0.34–1.11) | 0.19 | −1.61 | 0.11 |
| Age | 0.98 (0.96–0.99) | 0.01 | −2.70 | **0.007** |
| Gender | 1.05 (0.62–1.78) | 0.28 | 0.20 | 0.85 |
| Indigenous, *n* = 7 | 0.86 (0.37–1.98) | 0.37 | −0.35 | 0.73 |
| Arrived out of hours[B], *n* = 35 | 0.70 (0.42–1.18) | 0.19 | −1.34 | 0.18 |
| Patient reports: has a regular GP[C], *n* = 51 | 0.68 (0.36–1.31) | 0.23 | −1.15 | 0.25 |

[A] Hosmer–Lemeshow goodness of fit for AIHW PAGP-type Model 2, *P* = 0.72.

[B] Out of hours: 1800–0800 hours weekdays, weekends excluding 0800–1200 hours Saturday

[C] Data sourced from patient survey.

[D] Hosmer–Lemeshow goodness of fit for ACEM PAGP-type Model 2, *P* = 0.53.

the currently missing detail that helps to explain why people attend EDs.

### Medical consultation time in the ED

In previous studies, the ACEM measure of PAGP-type presentations estimated approximately half the number of PAGP-type presentations as the AIHW measure,[11,17] whereas in our study, it was less than one-third. An influencing factor is the small proportion of survey respondents who had a medical consultation time of <1 h (All survey respondents: $n = 88$, 8.8%) (Table 2). Additional analysis of the total ED cohort ($n = 3229$) for the month-long survey period demonstrated that 17.8% ($n = 575$) of the entire ED cohort had a medical consultation time <1 h (data not shown), indicating that this may be a characteristic of our hospital site.

A recent New South Wales study found an increased proportion of PAGP-type presentations to the ED for regional and remote centres when compared with major Australian cities, irrespective of the measure used (AIHW, ACEM or Sprivulis) or the length of consultation time used in the ACEM measure (15, 30, 60 or unlimited minutes).[17] This previous study estimated that for inner-regional hospitals, ~30% of all presentations to the ED were PAGP-type, using the ACEM measure with a 1-h medical consultation time.[17] Our study was conducted in a regional hospital setting with considerably longer medical consultation times in the ED, indicating variation between hospital sites. Accordingly, if the element of medical consultation time is to be used in the measure of PAGP-type presentations to the ED, then further consideration of hospital site variability is warranted.

### Limitations

Our study was limited in several ways; the study sample was sourced from the ED waiting room; when compared with the wider ED cohort, earlier research indicated that this sample was typical for gender but slightly older in age;[16] study respondents were more likely to have arrived by ambulance and to be discharged home;[16] the patient survey was a piloted, but non-validated tool that had previously been used by health services;[16] and our study involved one hospital and further investigation is indicated to inform on other sites.

Data inaccuracies within the EDIS dataset have been previously documented by Queensland Health[20] and have the potential to bias study results, although this is likely to be non-differential misclassification. Ongoing efforts to improve ED administrative data quality are supported by the findings of this study.

## Conclusion

Our study linked patient-reported experience from a face-to-face survey with an administrative EDIS dataset from a large regional emergency department in northern Queensland. Our main results demonstrated some consistency between the AIHW and ACEM measures of PAGP-type presentations, with the ACEM model element of length of medical consultation time in the ED being a notable exception. Further, the current recording of a patient's 'self-referral to the ED' in the administrative dataset does not accurately reflect the actual person-reported experience. This finding, in addition to longer medical consultation times in our dataset, affected the measures of PAGP-type presentation to the ED. As such, we recommend improving clerical methods on the ground to record 'self-referral to the ED' and propose further consideration of the length of medical consultation time, to more accurately determine measures of PAGP-type presentations to the ED.

## Competing interests

The authors declare they have no competing interests.

## Acknowledgements

This present research was conducted with the support of the Australian Institute of Tropical Health and Medicine (AITHM), James Cook University, Australia and an Australian Government Research Training Program Scholarship; but did not receive any specific funding. The original P3ED study was funded by Far North Queensland Medicare Local and the Cairns and Hinterland Hospital and Health Service. The authors thank members of the original P3ED study team; members of the original FNQHAT study team; and patients and staff of the Cairns Hospital for their support of this project.

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## 4.4 Validating Indigenous status: the difference between person-reported status and the administrative dataset record

As part of the dissemination of the Phase 1 quantitative findings, local area health professionals demonstrated an interest in the project's progress. Two Aboriginal and Torres Strait Islander health organisations communicated that findings specific to Aboriginal and Torres Strait Islander people were of interest to them. In 2018, presentations on the Phase 1 findings were shared with the Apunipima Cape York Health Council journal club and the Cairns and Hinterland Hospital and Health Service (CHHHS) Aboriginal and Torres Strait Islander Community Consultation Committee. Discussions with these organisations led to further project outputs.

The Apunipima Cape York Health Council staff indicated an interest in the difference between the self-reported data and the ED administrative dataset for Indigenous status. Resulting from this discussion, a validation study was published as a Research Letter in the *Medical Journal of Australia* (2019). The Research Letter, titled 'Validating Indigenous status in a regional Queensland hospital emergency department dataset with patient-linked data', identified differences for Indigenous status between the person self-report in the P3ED Survey and the ED administrative dataset. When utilising administrative datasets for health services research, data discrepancies have the potential to influence understanding of people's experiences of health care services (*RQ1*).

### *4.4.1 Manuscript*

O'Loughlin, M., Harriss, L., Mills, J., Thompson, F., & McDermott, R. (2020). Validating Indigenous status in a regional Queensland hospital emergency department dataset with patient-linked data. *Medical Journal of Australia, 212*(5), 230-231. doi:10.5694/mja2.50401

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 4 | O'Loughlin, M., Harriss, L., Mills, J., Thompson, F., & McDermott, R. (2020). Validating Indigenous status in a regional Queensland hospital emergency department dataset with | Developed the initial idea, Planned and undertook the statistical | O'Loughlin, M. |

| | | | |
|---|---|---|---|
| | patient-linked data. *Medical Journal of Australia, 212*(5), 230-231. doi:10.5694/mja2.50401<br>Accepted for publication: 6 August 2019<br>Published: 10 November 2019 | analyses; wrote the research letter. | |
| | | Assisted with the plan and undertaking of the statistical analyses; Assisted with writing and editing. | Harriss, L. |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | Mills, J. |
| | | Assisted with the undertaking of the statistical analyses; Assisted with writing and editing. | Thompson, F. |
| | | Assisted with the development of the initial idea; assisted with writing and editing. | McDermott, R. |

# Validating Indigenous status in a regional Queensland hospital emergency department dataset with patient-linked data

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doi: 10.5694/mja2.50401

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## 4.5 Health care service experiences of Aboriginal and Torres Strait Islander people

At the request of the CHHHS Aboriginal and Torres Strait Islander Community Consultation Committee a draft report was prepared to provide additional information on the experience of Aboriginal and Torres Strait Islander P3ED Survey participants whose responses were not separately described in the initial 2014 P3ED study (Mills et al., 2014) or the other Phase 1 publications.

This draft report focussed on all Aboriginal and Torres Strait Islander P3ED Survey participants: both those who did, and did not, self-identify as having a chronic condition. The draft report continued the exploration of the current experience of health care service for people living in Cairns (*RQ1*). Cairns has a higher proportion of people who identify as being Aboriginal and Torres Strait Islander when compared with the wider Australian population (Cairns 9%; Australia-wide 2.8%) (ABS, 2020a); and nearly 60% of P3ED Aboriginal and Torres Strait Islander P3ED Survey participants self-identified as having a chronic condition.

The draft report is titled '*Summary of the experience of Aboriginal and Torres Strait Islander people who participated in the CHHHS P3ED Survey*'. It was provided to the CHHHS Aboriginal and Torres Strait Islander Community Consultation Committee in June 2018.

### *4.5.1 Manuscript*

O'Loughlin, M., Harriss, L., Mills, J., McDermott, R., & West, C. (2018). *Summary of the experience of Aboriginal and Torres Strait Islander people who participated in the CHHHS P3ED Survey.* Unpublished report. James Cook University. Cairns, Australia.

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 4 | O'Loughlin, M., Harriss, L., Mills, J., McDermott, R., & West, C. (2018). *Summary of the experience of Aboriginal and Torres Strait Islander people who participated in the CHHHS P3ED Survey.* Unpublished | Developed the initial idea, Planned and undertook the statistical analyses; wrote the report. | O'Loughlin, M. |

| | | | |
|---|---|---|---|
| | report. James Cook University. Cairns, Australia. | Assisted with writing and editing.<br>Reviewed draft report. | Harriss, L. |
| | | Reviewed draft report. | Mills, J. |
| | | Reviewed draft report. | McDermott, R. |
| | | Reviewed draft report. | West, C. |

# Summary of the experience of Aboriginal and Torres Strait Islander people who participated in the CHHHS P3ED Survey

| | |
|---|---|
| Author<br>PhD Supervisors | Mary O'Loughlin, AITHM PhD Candidate, James Cook University<br>mary.oloughlin@my.jcu.edu.au<br>Dr Linton Harriss, Prof Jane Mills, Prof Robyn McDermott, A/Prof Caryn West |
| Description | Results from the 2014 CHHHS P3ED study for Aboriginal and Torres Strait Islander survey respondents |
| Key Points | • Many Aboriginal and Torres Strait Islander people described being well-connected to a General Practice/Health Service.<br>• Around 20% of Aboriginal and Torres Strait Islander people reported a lack of connection to primary healthcare services, focussing on the ED for their healthcare needs.<br>• Access to high-quality ED care was valued by all participants.<br>• There was a lack of awareness and/or acceptability of alternative health services, particularly the 13-Health telephone service.<br>• Inaccuracies in the administrative data for Indigenous status and self-referral to the ED have the potential to influence decision making. |

This summary has been prepared for the CHHHS Aboriginal and Torres Strait Islander Community Consultation Committee at the Committee's request. It provides additional information on the experience of Aboriginal and Torres Strait Islander survey participants whose responses were not separately described in the original 2014 P3ED report or the published study:
O'Loughlin, M., Harriss, L., Thompson, F., McDermott, R., & Mills, J. (2018). Exploring factors that influence adult presentation to an emergency department in regional Queensland: A linked, cross-sectional, patient perspective study. *Emergency Medicine Australasia*. https://doi.org/10.1111/1742-6723.13094

**Background**

*The Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department (P3ED)* mixed-methods project was conducted in 2014 to examine patient-reported reasons for ED attendance.

*P3ED Survey*
A cross-sectional survey was undertaken 24 hours per day, 7 days per week for a one-month period, 13 March to 11 April 2014, covering people presenting to the ED. Using an iPad, research assistants implemented the face-to-face survey, which comprised of a 28-question, 52-item instrument.

*Data Linkage*
Survey responses were linked to a combined Emergency Department Information System (EDIS)/Queensland Hospital Admitted Patients Data Collection (QHAPDC) dataset for the two-year period 1 July 2012 to 30 June 2014. This dataset had previously been developed by James Cook University researchers as part of a separate project. The EDIS/QHAPDC dataset included a variable

indicating an individual's frequency of presentation to the ED, which was a count of the maximum number of ED presentations per individual in any one-year period between July 2012 and June 2014.

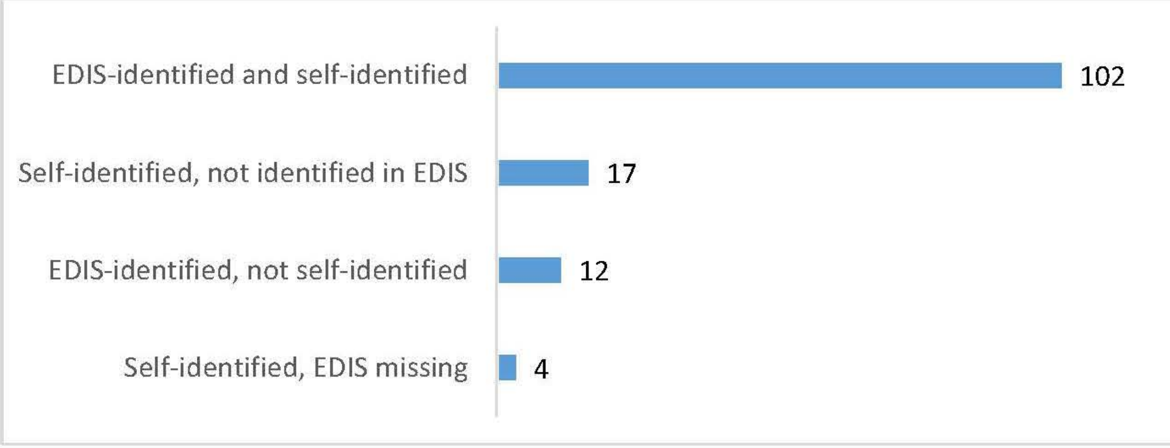
*Research Approvals*
Research approvals were obtained from the Far North Queensland Human Research Ethics Committee for the original P3ED survey (approval HREC/14/QCH/9-887 LR); for the Far North Queensland Hospital Avoidance Trial (FNQHAT) EDIS and QHAPDC linked dataset project (approval HREC/13/QCH/131-880); and for the present study involving data linkage and analysis of the P3ED survey and FNQHAT dataset (approval HREC/16/QCH/81-1068).

### Results for Aboriginal and Torres Strait Islander survey participants

In the one-month survey period (March to April 2014) 3,229 individual people attended the Cairns Hospital ED. Of these, 566 people (17.5%) were recorded in the EDIS as being Aboriginal and/or Torres Strait Islander.

The original P3ED study included interstate/overseas visitors and children. This current analysis was limited to adult ED attendees (18 years or over) who self-identified as being a local resident of Cairns (n=1,000). Of these, 135 (13.5%) were identified as being Aboriginal and/or Torres Strait Islander using the EDIS or by participant self-report (see Figure 1).

**Figure 1: Aboriginal and Torres Strait Islander people identified from the administrative (EDIS) data set and by participant self-report (n=135)**



Aboriginal and Torres Strait Islander people who participated in the P3ED survey ***differed*** from other ED attendee survey participants as follows:

- More Aboriginal and Torres Strait Islander women participated in the survey than men (61% vs 39%).
- Aboriginal and Torres Strait Islander participants were younger in age than other survey participants (mean age 42 vs 47 years).
- Aboriginal and Torres Strait Islander people had a higher frequency of visiting the ED in any one-year period (4 or more visits in any one-year period: 36.3% vs 23.1%).
- Aboriginal and Torres Strait Islander people were less likely to report having a regular general practice when compared to all other survey participants (80.6% vs 87.5%).

- Aboriginal and Torres Strait Islander people were more likely to nominate the ED as their 'usual place' of healthcare service when compared to all other survey participants (11.9% vs 2.4%).
- For Aboriginal and Torres Strait Islander people that did have a regular general practice, the practice was more likely to offer bulk-billing services when compared to all other survey participants (93.5% vs 73.8%).
- For those that did have a regular general practice, Aboriginal and Torres Strait Islander people reported less difficulty in obtaining an urgent appointment when compared to all other survey participants (16.7% vs 30.1%).
- Aboriginal and Torres Strait Islander people were less likely to have preferred to attend a local GP for their presenting problem (7.4% vs 14.4%).
- Compared to the total ED group, a similar proportion of people self-identified as living with a chronic condition (59% vs 54%)), however the type of condition differed. More Aboriginal and Torres Strait Islander survey participants reported having a long-standing illness, such as diabetes, cancer, heart disease (77.5% vs 70.8%) and fewer people reported a long standing physical condition such as arthritis or chronic pain (22.5% vs 42.0%).

Aboriginal and Torres Strait Islander survey participants ***did not*** differ from the wider ED group for factors such as:

- Arriving to the ED outside of normal working hours.
- Arriving by ambulance to the ED.
- Being recorded as self-referred to the ED in the administrative data set.
- Being discharged home from the ED (ie. not admitted).
- Triage category (indicating urgency of need for care).
- Over half (55.6%) had their presenting complaint for less than 24 hours and 37.8% had consulted another health practitioner about this complaint.
- Nearly one-third had visited their regular general practice in the week prior to attending the ED.
- 28.2% reported being referred by a medical practitioner to attend the ED, however only 7.4% were identified as Doctor-referred in the EDIS.
- Half of survey participants identified high quality care as being the most important factor for any alternative service to the ED.
- There was a low level of awareness of the 13-Health telephone advice service.
- Few people considered using alternative services to the ED for their presenting complaint.

### Summary for Aboriginal and Torres Strait Islander survey participants

Many Aboriginal and Torres Strait Islander people who participated in the P3ED survey described being well-connected to a General Practice/Health Service and reported being able to receive regular, bulk-billing care and access to urgent appointments. Concurrently, around 20% of Aboriginal and Torres Strait Islander people reported a lack of connection to primary healthcare services and this group had an increased focus on ED care to manage their healthcare needs.

Aboriginal and Torres Strait Islander people reported a similar experience to the wider group of ED attendees for many factors related to their ED presentation. Access to high-quality ED care was valued by all participants. Study participants reported a lack of awareness and/or acceptability of alternative health services designed to reduce ED attendance, particularly the 13-Health telephone service. A shortage of south-side services (Edmonton, Gordonvale, White Rock), Kuranda services, mental health services and access to specialist care was identified by participants. For Wuchopperen, extended hours of care (some suggested late night, some till 7pm) and on-site pharmacy were specifically mentioned as ways to improve services by Aboriginal and Torres Strait Islander survey participants.

Inaccuracies in the administrative data set have the potential to influence health service decision making. This study identified disparities between a person's reported experience and the EDIS record, particularly for Indigenous status and self-referral to the ED. Measures to improve the accurate recording of administrative data warrant further investigation.

Compared to the local resident Cairns population, the proportion of Aboriginal and Torres Strait Islander people who participated in this study was broadly representative (13.5%). Nonetheless, this report represents the views of a relatively small number of people (n=135). Future work is warranted for a more detailed understanding of Aboriginal and Torres Strait Islander people's perspectives on the delivery of healthcare service in this local region.

**Acknowledgements**

This present research was conducted with the support of the Australian Institute of Tropical Health and Medicine (AITHM), Centre for Chronic Disease Prevention, James Cook University, Australia and the Australian Government's Research Training Program Scholarship. The P3ED study was funded by Far North Queensland Medicare Local and the Cairns and Hinterland Hospital and Health Service. Members of the original study team included Prof Jane Mills, A/Professor Kerrianne Watt, Dr Neil Beaton, Dr Michael Wilson, Ms Nicky Neighbour, Dr Scott Davis, Ms Annette Panzera, Dr Richard Stone, Dr Ben Rose, Mr Jarred Brose, Dr Robyn Cant, Mr Murray Towne, Ms Marnie Hitchins, Ms Anna Groth, Dr Don Wyatt, Mr Luke Croker, Mr Vishal Sharma, Ms Amanda Hand and Ms Jane Hollins. The author thanks the patients and staff at the Cairns Hospital for their support of this project.

## Table 1. Characteristics of adult attendees to Emergency Department during one-month period, March - April 2014[†]

† Data sourced from EDIS
‡ Local Cairns resident adult (≥ 18 years) survey participants
¶Binary categorical data were analysed using Pearson's Chi-square statistic. *P* values (two-sided) <0.05 were considered statistically significant (significant values in bold)
††P difference by two-sample Wilcoxon rank-sum (Mann-Whitney) non-parametric test
‡‡ Out-of-hours: 6pm-8am weekdays, weekends excluding 8am-12noon Saturday
*P* diff, *P* difference; SD, standard deviation; IQR, interquartile range

| Characteristics | Aboriginal and Torres Strait Islander survey participants[‡] n (%) | All other survey participants[‡] n (%) | *P* diff[¶] | All ED attendees in one-month n (%) |
|---|---|---|---|---|
| ED attendees | 135 | 865 | | 3,229 |
| Male | 53 (39.3) | 440 (50.9) | **0.012** | 1,642 (50.8) |
| Female | 82 (60.7) | 425 (49.1) | | 1,587 (49.2) |
| Age, mean(SD) | 42.0(15.6) | 49.6(19.3) | | 47.1(19.2) |
| median(IQR) [††] | 43(28,53) | 50(33,64) | **<0.001** | 45(31,61) |
| Out-of-hours[‡‡] | 78 (57.8) | 490 (56.7) | 0.80 | 1,819 (56.3) |
| Frequency of visits in any one-year | | | | |
| 1 to 3 visits | 86 (63.7) | 665 (76.9) | **0.001** | 2,515 (77.9) |
| 4 to 9 visits | 34 (25.2) | 154 (17.8) | **0.041** | 535 (16.6) |
| 10 or more visits | 15 (11.1) | 46 (5.3) | **0.009** | 179 (5.5) |
| Arrived by Ambulance | 54 (40.0) | 324 (37.5) | 0.57 | 1,385 (42.9) |
| Referred by self/family/friend | 125 (92.6) | 808 (93.4) | 0.72 | 2,860 (88.6) |
| Triage Category 1, 2, 3 | 81 (60.0) | 500 (57.8) | 0.63 | 1,801 (55.8) |
| Discharged home from ED | 70 (51.9) | 482 (55.7) | 0.40 | 1,652 (51.2) |

## Table 2. Aboriginal and Torres Strait Islander ED attendees experience of health services (n=1,000)

†Binary categorical data were analysed using Pearson's Chi-square statistic. *P* values (two-sided) <0.05 were considered statistically significant (significant values in bold).
*P* diff, *P* difference.

| Reported experience | Aboriginal and Torres Strait Islander survey participants n (%) | All other survey participants n (%) | *P* diff † |
|---|---|---|---|
| ED attendees (≥ 18 years) | 135 | 865 | |
| Main reason chose to attend ED: | | | |
| no choice / urgent problem | 44 (32.6) | 311 (36.0) | |
| best place for problem | 39 (28.9) | 211 (24.4) | |
| services in one location | 15 (11.1) | 101 (11.7) | |
| open 24 hours | 6 (4.4) | 40 (4.6) | |
| Patient reported arrival by Ambulance | 56 (41.5) | 330 (38.2) | 0.46 |
| If by Ambulance, the reason: | | | |
| Urgent/significant health problem | 47 (83.9) | 299 (90.1) | |
| No other transport available | 7 (12.5) | 33 (9.9) | 0.50 |
| Referred by a medical practitioner to the ED | 38 (28.2) | 252 (29.1) | 0.82 |
| Length of presenting complaint: | | | |
| less than 24 hours | 75 (55.6) | 497 (57.5) | |
| 24 to 72 hours | 18 (13.3) | 111 (12.8) | |
| 3 to 7 days | 19 (14.1) | 105 (12.1) | |
| 1 week or more | 23 (17.0) | 152 (17.6) | |
| Consulted another health professional about presenting complaint | 51 (37.8) | 368 (42.5) | 0.30 |
| If seen another health professional, when: | | | |
| less than 24 hours | 31 (60.8) | 210 (57.1) | |
| 1 to 7 days | 10 (19.6) | 90 (24.5) | |
| more than 1 week | 10 (19.6) | 65 (17.7) | |
| Usual place of healthcare service: | | | |
| General Practice | 100 (74.1) | 812 (94.3) | |
| Aboriginal Medical Service | 13 (9.6) | 0 (0.0) | |
| Emergency Department | 16 (11.9) | 21 (2.4) | |
| Has a regular general practice | 108 (80.6) | 755 (87.5) | **0.030** |
| Regular general practice offers bulk-billing | 101 (93.5) | 557 (73.8) | **<0.001** |
| Last visit to regular general practice: | | | |
| less than 1 week | 34 (31.5) | 224 (29.7) | |
| 1-4 weeks | 23 (21.3) | 249 (33.0) | |
| 1-3 months | 24 (22.2) | 150 (19.9) | |
| more than 3 months | 27 (25.0) | 130 (17.2) | |
| Difficult to get urgent appointment at regular general practice | 18 (16.7) | 226 (30.1) | **0.004** |

| | | | |
|---|---|---|---|
| If had difficulty, told practice matter was 'Urgent' | 11 (61.1) | 135 (59.7) | 0.91 |
| Attended ED as unable to get urgent appointment with regular general practice in previous 12 months | 9 (8.3) | 57 (7.6) | 0.78 |
| Preferred to have attended a local GP for presenting problem | 10 (7.4) | 124 (14.4) | **0.027** |
| Priority factors for alternative service to ED: any preference (ranked 1, 2 or 3 of 10) | | | |
| High quality care | 69 (51.1) | 427 (49.4) | 0.71 |
| Pathology/medical imaging on-site | 50 (37.0) | 316 (36.5) | 0.91 |
| Extended or 24-hour service | 44 (32.6) | 292 (33.8) | 0.79 |
| Bulk-billing: any preference | 37 (27.4) | 212 (24.5) | 0.47 |
| Easy to get appointment | 26 (19.3) | 178 (20.6) | 0.72 |
| Convenient location | 14 (10.4) | 155 (17.9) | **0.030** |
| Has self-identified chronic condition(s) | 80 (59.3) | 469 (54.2) | 0.27 |
| Type of self-identified condition(s): | | | |
| Long standing illness (examples: cancer, diabetes, heart disease) | 62 (77.5) | 332 (70.8) | |
| Long-standing physical condition (examples: arthritis, chronic pain) | 18 (22.5) | 197 (42.0) | |
| Mental health condition | 14 (17.5) | 67 (14.3) | |
| Significant vision impairment | 2 (2.5) | 40 (8.5) | |
| Significant hearing impairment | 5 (6.3) | 38 (8.1) | |
| Aware of 13-Health service for telephone health advice | 41 (30.4) | 329 (38.1) | 0.09 |
| If aware, had used previously | 20 (48.8) | 145 (44.1) | 0.57 |
| If aware, considered using for presenting complaint | 5 (12.2) | 30 (9.2) | 0.53 |
| Aware of bulk-billing, walk-in, after-hours, local, general practice clinic | 94 (69.6) | 628 (72.7) | 0.46 |
| If aware, had used previously | 78 (83.0) | 490 (78.0) | 0.27 |
| If aware, considered using for presenting complaint | 22 (23.4) | 119 (19.0) | 0.31 |
| Aware of Dial a Doctor service for home visit | 115 (85.2) | 758 (87.7) | 0.41 |
| If aware, had used previously | 51 (44.3) | 330 (43.7) | 0.89 |
| If aware, considered using for presenting complaint | 12 (10.4) | 80 (10.6) | 0.95 |

## 4.6 Chapter summary

This chapter presented the findings from the Phase 1 quantitative investigations. Three published articles and one draft report have been included in this chapter. Key results that described the current experience of health care services for people living with chronic conditions in Cairns (*RQ1*) were:

i. The P3ED Survey population was broadly representative of all ED attendees for gender, but slightly older in age (median age 49 vs 44 years, *P*=0.001). Aboriginal and Torres Strait Islander people, and people with mental and behavioural conditions were under-represented in the P3ED Survey cohort.
ii. People living with chronic conditions were more likely than other ED attendees to: frequently present to the ED (10 or more visits in 1 year: 9.7% vs 6.1%, *P*<0.001); arrive by ambulance (49.4% vs 37.8%, *P*<0.001); and be triaged at a higher urgency of care category (Triage Category 1,2,3: 63.6% vs 58.1%, *P*<0.001). They were less likely to be discharged home (45.5% vs 55.2%, P<0.001). Although older-age was a likely confounder of these results, people living with chronic conditions demonstrated a strong need for acute health care services.
iii. Many people living with chronic conditions reported reasons of urgency or need as their rationale for attending the ED. Over half of people living with chronic conditions (56%) arrived at the ED after-hours; nearly one-third (29%) reported difficulty gaining an urgent appointment at their regular GP practice; and only a small proportion (12%) asserted that they would have preferred to attend a local GP for their presenting health issue.
iv. People living with chronic conditions were less likely to experience episodes of ED care that were potentially avoidable when measured by the AIHW indicator of PAGP-type presentations to the ED (adjusted for age: *P*=0.001).
v. Most people living with chronic conditions had a regular GP (94%) and approximately one-third (32%) of these visited their GP in the week preceding their ED presentation.
vi. There was a higher use of primary and acute health care services by young-aged adults living with chronic conditions. This may be impacted by a higher occurrence of mental health conditions.
vii. A lack of access to bulk-billing may influence middle-aged people's access to primary health care and result in an increased demand on acute care services.
viii. Although many were aware of alternative services such as doctor to the home and bulk-billing, after-hours GP clinics, most did not consider using these services for the presenting health issue.

ix. For people living with chronic conditions, there was a notable difference between self-report and the hospital administrative data record of doctor referral to the ED (29% vs 6.9%). Enhanced methods to record the pathways taken by people to attend the ED could improve understanding of the person-experience of health care services.
x. Continued efforts to improve the recording of Indigenous status in hospital administrative datasets may support better understanding of people's experiences of health services. Reducing dataset inaccuracy is necessary so that researchers and policymakers can rely on the data sources that are used to make decisions on health service delivery, particularly for identified population groups.

These findings from Phase 1 informed the Phase 2 data collection and analysis: specifically, the recruitment approach, interview schedule, and data analysis. The next chapter describes the findings from the Phase 2 qualitative investigations. It includes a manuscript that focusses on exploring the value of the HCHs model elements to people living with chronic conditions *(RQ2)*; and considers factors that might impact the model implementation *(RQ3).*

# Chapter 5: Qualitative Findings

## 5.1 Introduction

In chapter 5 the Phase 2 qualitative findings are presented. It is in this chapter that people living with chronic conditions in Cairns describe their perspectives on, and preferences for, health care service delivery, through the lens of the HCHs model. Employing the explanatory sequential mixed methods approach, this Phase 2 inquiry helps to explain and explore Phase 1 quantitative findings.

Research questions that guided the qualitative phase were:

> How are elements of the HCHs model valued by people living with chronic conditions in Cairns (*RQ2*)?
>
> Can the HCHs model improve the delivery of health services and what factors might influence the implementation of this model of care (*RQ3*)?
>
> Additionally, understanding of people's experiences of chronic condition health care services (*RQ1*) was enhanced in this chapter.

A published manuscript is included. This manuscript details the data collection and analysis methods undertaken in this phase, involving twenty-one (21) semi-structured interviews with people who live with chronic conditions in Cairns. It includes a summary of participant characteristics. Findings deepen understanding of the person-perspective of the HCHs model elements *(RQ2)* and factors that may influence model implementation *(RQ3)*. Given the need for brevity in manuscripts, additional learnings are presented in the later sections of this chapter. These learnings further explore the research questions *(RQ2; RQ3)* and expand on the Phase 1 findings *(RQ1)*.

## 5.2 The HCHs model: person perspectives

The following manuscript has been published by the *Australian Journal of Primary Health*. It is titled: ‘Medical Homes and chronic care: consumer lessons for regional Australia’. The manuscript addresses *RQ2* and *RQ3*, exploring the HCHs model elements from the person-perspective. It presents the major findings of the qualitative Phase 2 investigation.

### *5.2.1 Manuscript*

O'Loughlin, M., West, C., & Mills, J. (2022). Medical homes and chronic care: consumer lessons for regional Australia. *Australian Journal of Primary Health*, -. doi:https://doi.org/10.1071/PY21020

**Declaration of Authorship:**

| Chapter | Publication Details | Author Contribution | Signature |
|---|---|---|---|
| 4 | O'Loughlin, M., West, C., & Mills, J. (2022). Medical homes and chronic care: consumer lessons for regional Australia. *Australian Journal of Primary Health*, -. doi:https://doi.org/10.1071/PY21020<br>Accepted for publication: 4 November 2021<br>Published online: 1 February 2022 | Developed the initial idea, planned and undertook the data collection and analyses; developed the findings; wrote the article. | O'Loughlin, M. |
| | | Supported data collection; supported the data analyses and development of findings; assisted with writing and editing. | West, C. |
| | | Assisted with the development of the initial idea; | Mills, J. |

| | | | |
|---|---|---|---|
| | | guided data analysis methods; supported the data analyses and development of findings; assisted with writing and editing. | |

**CSIRO** PUBLISHING
*Australian Journal of Primary Health*
https://doi.org/10.1071/PY21020
**Research**

# Medical homes and chronic care: consumer lessons for regional Australia

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**Abstract.** Medical home models of care, including Australia's Health Care Homes, have the potential to improve health service delivery. This qualitative study explored the primary healthcare experience of people living with chronic conditions in a regional community. The study aim was to use consumer perspectives to inform the further development of a medical home-type model for regional Australia. Participants were recruited from the emergency department of a north Queensland hospital. Twenty-one adults (aged ≥18 years) participated in interviews, using a semi-structured schedule. Inductive, deductive and abductive analyses were guided by grounded theory methods. Participants were committed to an individual GP, rather than a practice organisation. This finding has implications for medical homes, as individuals may choose not to access team-based practice care. Most participants perceived they currently received high-quality GP care, although challenges were identified. These challenges included disconnected after-hours care and uncertainty around the cost of care. Those living with complex, uncommon, chronic conditions felt the most disenfranchised from existing care models, and could benefit from increased engagement with a medical home-type model. Strengthening the continuity of care between GPs both within and outside the practice may enhance service delivery. Involving consumers in the design of care models supports health services that are fit-for-purpose.

**Keywords:** general practice, Health Care Homes, patient experience, primary care, rural, voluntary patient registration.

Received 2 February 2021, accepted 4 November 2021, published online 1 February 2022

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## 5.3 Further learnings on elements of the Health Care Homes model

In addition to the results described in the manuscript, the Phase 2 qualitative inquiry generated knowledge that further informed the research questions. These findings are detailed in this section, broadening insight into the person-perspective of the HCHs model elements.

### *5.3.1 Committing to a regular GP in a regional community*

The HCHs model involves a formalised commitment between an individual and their GP practice for the care management of their chronic condition. The experience of living in a regional community may influence this commitment. Specifically, several participants reported personal relationships with GPs outside of the practice setting. These relationships impacted their experience of care by facilitating access to their regular GP outside of the usual practice mechanisms:

> *He's actually a good friend of mine [the GP] … reception … puts me in straightaway. It doesn't matter when it is. Doesn't matter if they're full or not* (P19).

> *We're friends on Facebook … I'll just message her … "I need to see you", and she's like, "oh, come and see me tomorrow; I'll fit you in at this time"* (P12).

### *5.3.2 Involving practice nursing and administrative staff in care delivery*

Establishing a medical home-base for care in the HCHs model involves GP practice nursing staff being active members of a person's health care team. Many participants described positive experiences with practice nursing staff. Continuity of nursing staff within the practice team was highly regarded by participants:

> *There has been one change with one nurse since I have been seeing that practice. They keep their nurses … the nursing staff there are fantastic … they knew my history* (P1).

Concurrently, interruptions to the operation of the practice team, due to leave-taking and a high staff turnover, negatively impacted participant experiences of care:

> *They have … a weekly meeting and you come up, but both of the people [nursing staff] that speak on my behalf are not there …they're absent* (P3).

There were reports of diversity in the nursing staff within the same practice and between practices:

> *There's one nurse there who's brilliant, and then the nurse who's been there for the whole time I've been there … she needs to go* (P12).

This difference in the perceived quality of nursing staff impacted participant's willingness to have nursing staff involved in their care and to view their medical records:

> *Not with her, no. No. With that other nice nurse, definitely, give her everything, because you'd walk in, and you'd feel almost loved* (P12).

Overall, there was mostly a positive consensus on the role of nurses in care coordination and delivery, which aligns with the HCHs model element of team-based care delivery. Similar to the views described in the manuscript on using alternative GPs within the regular GPs practice, individual characteristics influenced participant perspectives on the involvement of practice nursing staff in their care.

Other practice staff, specifically reception and administration staff, were largely viewed as having a service role, with their primary function being to facilitate access to the GP.

> *I hope it's [Name], on reception … Because [Name] puts me in straightaway. It doesn't matter when it is. Doesn't matter if they're full or not* (P19).

There were some participants who considered the reception and administrative practice staff to be integral to their care delivery:

> *They're working together with my GP (*P9).

Concurrently, others perceived reception and administration staff to be uninvolved in their care:

> *Friendly … But I don't think they're decision makers* (P4).

As gatekeepers to care, reception and administrative staff were strongly valued. However, as partners in care, there was very limited support for the wider practice staff team to be involved in participant care, with the decision to attend the practice not being governed by experiences with the practice staff:

> *I don't go there to see the reception staff … you only see them for about two seconds anyway* (P12).

### *5.3.3 Pharmacists, physiotherapists and psychologists as partners in care*

Experiences with pharmacists varied widely, in terms of the style of interaction and the extent to which GPs and pharmacists collaborated to deliver care. Transactional-style interactions with pharmacists were reported by some participants. Others described pharmacists as necessary to their care: providing medication advice and a detailed understanding of health conditions:

> *Probably more helpful than GPs at times … They know a lot about the drugs you're taking, and they know a lot about the disease that you have* (P18).

Interactions between GPs and pharmacists were described. Few participants reported an active, collaborative approach to care involving their GP and pharmacist working together. A small number observed that some crosschecking of medications did appear to be undertaken. Others perceived that their pharmacist was substantially independent of their GP: with limited or no interaction with their regular GP and no knowledge of the person's plans for care. Notably, participants described how pharmacists could be effective in their role as supportive health care practitioners without having any known connection, or direct communication, with the regular GP.

Similar findings were identified for communication and care coordination between the regular GP and physiotherapists. There were several reports of referral to physiotherapists by the regular GP. However, although participants valued the contributions made by physiotherapists to their care, ongoing engagement between physiotherapists and GPs was not identified as an essential next step in that process.

Communications and care coordination between a person's GP and psychologist were more active.  Reports of a team-care approach and consistent communication between the regular GP and treating psychologist were described:

*I usually try to see [Psychologist name] for the first visit and then see [GP name] after that …*
*She [the GP] got me to start seeing [Psychologist name], my psychologist, as well.*
*They've been working together on my behalf for all this time.*
*People say to me, "why do you go all the way up there to see your doctor?"*
*I say, "mate, I've got a good relationship with them.*
*I don't want to start from scratch with someone else"* (P21).

As noted in the manuscript, some participants did not want their regular GP and psychologist to interact:

*I'm a bit worried that he [the psychologist] is going to tell her [the GP] ...*
*I said to him, "you know, I don't want you to"* (P18).

### *5.3.4 Coordinating care delivery*

A fundamental reason for the HCHs model implementation is to improve the coordination of care for people living with chronic conditions. The communication of pathology test results to participants lacked uniformity across practices. Some GP practices required participants to schedule a return visit irrespective of the test result; and other practices only required a visit if there was an abnormal result. Participants reported the frustration of attending an appointment to be told that there was nothing wrong with their test result:

*I've come all this way for that?* (P2).

Similarly, there was exasperation expressed around the need to travel and have a GP consultation to obtain a repeat prescription:

> *We’ve got to actually make an appointment to go in and just get her 5 minutes*
> *to write out a script for us and I feel that’s wrong, not on her behalf,*
> *but on the system’s behalf, I feel that’s wrong.*
> *Especially when you’ve been seeing them for so long*
> *and she knows what you’re on and what you can’t have and what you can have,*
> *so she’s not about to write you out a script for something that you’re not supposed to have*
> *… all of us are suffering because, like I said,*
> *even she’s suffering because she [the GP] is having to like book a 15-minute appointment*
> *for us when it’s been solved in 5 minutes* (P9).

### *5.3.5 Information sharing*

Reports on the process of information sharing between health practitioners was mixed. Helpful communications from GPs to other health practitioners were described. Communications from hospital clinics, pathology providers, allied health professionals and the local private hospital to GPs were perceived to be mostly good. There were mixed reports of effective communication from medical specialists to GPs. Several participants reported that communication from the public hospital to their GP was limited, and that they kept their own records to support information flow between the services. Although there were a few positive reports, overall post-hospital discharge communication was identified as an area of particular concern, with multiple reports of absent or delayed information sharing:

> *He’s always angry [the GP] when I go to the ED and no letter gets sent to him.*
> *And I keep on telling them to do that, but they don’t do it for some reason.*
> *There must be a communication gap there* (P19).

### *5.3.6 Person-activated care management*

Many participants reported an existing active role in managing their own care. A range of person-activated care management approaches were described including researching health conditions and treatment options; querying proposed treatment plans; investigating and identifying GPs to connect with practitioners that best addressed care needs; collating and sharing health information; and coordinating care between health service providers.

Participants described maintaining their own personal health records management systems, which they routinely updated and shared with their health practitioners. Commonly these systems involved collections of physical documents kept in files and boxes.

> *I’ve got a box with all my paperwork and tablets in it, which I take in whenever I go*
> *so that he can vary my medications, he knows what I have used,*
> *especially on painkillers, he can monitor that.*

*He also goes through all the paperwork that I present for him to go through*
*and he knows what I've brought to him which he marks on his computer* (P11).

As part of maintaining their own records and to facilitate communication between their health providers, participants described routinely requesting copies of reports and documents to share with their health practitioners:

*Each time I've gone there and said, "can you please get a copy of your report to my GP",*
*quite often I'll wait for it and they'll give to me and I deliver it* (P11).

When participants experienced episodes of poorer health, they identified a reduced ability to be active in their own care management and an increased reliance on health practitioners to guide their care.

*You go looking for another doctor … you've got to keep trying …*
*I can be thankful that we are able to do that.*
*But there may come a time when we can't. So, while you are able, you've got to do it*
*and then hope that your doctor sticks around* (P4).

### *5.3.7 Flexible approaches to care delivery*

Participants valued face-to-face consultations with GPs:

*I like face-to-face because I like to be able to read a person too,*
*because anyone can put anything on over the phone* (P14).

Routine measures, such as blood pressure monitoring, were seen as a necessary part of the face-to-face interaction.

*I feel better when you see them and you're talking to them face-to-face*
*and they take your blood pressure, they do your weight* (P17).

Flexible care approaches using technology were identified as useful to some:

*Skype's good … I like to look at people and see, gauge their reactions* (P12).

*I walk away from the GP … and it has taken me two and half hours to get that referral all up:*
*travel time, waiting time … when I could have done it over the phone or Skype* (P1).

Older participants (age >65) reported concern with non-face-to-face care.

*Not for older patients …*
*a lot of my friends are clueless, absolutely clueless about computers* (P4).

Established relationships enhanced the effectiveness of online interactions. One participant described how they would feel if they did not already know the health professional in an online medical appointment:

> *I probably would be … not myself, and it would be weird* (P12).

The use of email was also seen as advantageous for two purposes: firstly, for routine care management, such as the provision of repeat prescriptions and appointment reminders; and secondly, as a follow-up for complex information:

> *If you could cut and paste your notes and just put it in an email,*
> *it would be so helpful for me, because my memory is quite unreliable …*
> *it would be so much more considerate* (P3).

### *5.3.8 Changing care providers: complexity matters*

The challenge of accessing GP care for people living with complex uncommon chronic conditions was described in the manuscript. Barriers identified included the difficulty of finding a GP willing to manage the care of people living with complex chronic conditions.

> *You've got to explain it all again … when you're swapping GPs there's a lot to say* (P18).

Participants with complex conditions perceived they were too difficult for practitioners to take on as clients:

> *She was like the new girl there and I got fobbed off to her … that's how it felt …*
> *Because I was in the too-hard-basket … no-one knew what to do with me* (P18).

This barrier to accessing care was heightened with the addition of potential out-of-pocket costs for GP care. Specifically, participants who wanted to change from their current GP were hesitant or unable to take action due to the cost of initial appointments:

> *When I rang [GP name] to make an appointment … it could be over $100 ...*
> *for your first appointment … it is preventing me* (P18).

## 5.4 Further understanding of key Phase 1 findings

Employing the explanatory sequential mixed methods approach, inquiry in this chapter expands the Phase 1 study results. In addition to the learnings on elements of the HCHs model, two key Phase 1 findings were explored in Phase 2. These findings enhance understanding of people's experiences of health care services (*RQ1*) and involve:

i. self-referral to the ED; and,
ii. the concept of 'high-quality care'.

### *5.4.1 Self-referral to the ED*

A key finding from the quantitative investigation was a difference in the person-report and the hospital dataset record for self-referral to the ED. Nearly a third of people living with chronic conditions reported being referred to the ED by a doctor, however this was not captured in their hospital data record of doctor referral to the ED (29% vs 6.9%).

Referral mechanisms to the ED were explored with interview participants. Several participants reported long-standing instructions from their regular GP to directly attend the ED when they had an acute exacerbation of their chronic condition. These participants did not attempt to access GP care when their health deteriorated, and contended that they were following their regular GP's direction to present to the ED.

> *If I have any troubles [GP name] has just told me, present yourself to the ED, just go straight to the ED because you don't muck around* (P5).

As these episodes of care bypassed the GP practice, they were unable to be captured in the ED referral statistics, however participants clearly asserted that they were referred by a doctor to attend the ED because of the established direction from their GP.

The nature of the chronic condition impacted these directions to attend the ED, with acute conditions such as cardiac and diabetic complications being identified as requiring an immediate need to present to the ED without attempting to access primary care services. However, this was not always the case. One participant perceived that their GP unnecessarily directed them to seek care at the ED when they had an acute exacerbation of their complex chronic condition [liver condition]. They reasoned that their care could potentially be managed by their GP, but that the GP preferred for them to attend the ED:

> *It's embarrassing going into the hospital all the time, you go in wasting their time and all the rest of it, they've got more urgent cases going on* (P15).

### *5.4.2 High-quality care*

In the Phase 1 investigation, having ‘high-quality care’ was the highest ranked priority factor for alternative services to ED (n=278, 50.6%). However, it was unclear what the concept of ‘high-quality care’ meant to the P3ED Survey participants.

Interview participants were asked to consider what ‘high-quality care’ meant to them in the context of managing their chronic health condition. Key characteristics of high-quality care for participants were:

i. that the GP was a good listener and effective communicator, who cared about the person’s well-being and explained concepts clearly and truthfully;
ii. that the GP was effective in their professional scope of practice and willing to persevere to identify and treat the health condition;
iii. that the GP followed through on their investigations and advised of treatment options; and,
iv. that GP care was available and accessible.

As described by one participant:

> *High-quality care is an understanding of the problem that you are suffering and a willingness to … find a proper solution not just a Band-Aid solution* (P1).

## 5.5 Chapter summary

This chapter presented the findings from the Phase 2 qualitative inquiry and included an article that has been accepted for publication in a peer-reviewed journal. In this chapter, participant perspectives on elements of the HCHs model were explored (*RQ2*); factors that might influence the implementation of this model of care were identified (*RQ3*); and understanding of participant experiences of chronic condition health care services was enhanced (*RQ1*).

Key findings for participants were:

i. For many, the commitment was to a regular GP for the management of their chronic condition. This commitment did not necessarily extend to the practice organisation, or to pharmacy and other allied health practitioners.
ii. For some, specialist medical practitioners, not GPs, were identified as the preferred care providers. Specifically, diabetes and cardiac conditions were commonly managed by medical specialists and their associated care teams.
iii. Accessible and acceptable alternatives to regular GP care were limited.
iv. A high turnover of GP practice staff negatively impacted experiences of service delivery.
v. Uncertainty in the costs and processes within practices created confusion for people with chronic conditions. The provision of bulk-billed services was a notable area of concern.
vi. The use of shared care plans for managing chronic health care needs was limited.
vii. Shared data management systems within practices were well-supported. Data sharing between health service providers was impacted by poor knowledge and usage of existing systems, including My Health Record. When system functioning was poor, participants reported self-initiated methods of sharing data between practitioners and services involved in the delivery of their care.
viii. Existing, face-to-face GP care was highly valued. Flexible approaches to care delivery were valued by some.
ix. Those living with uncommon, complex chronic conditions reported unmet needs for care following engagement with the existing care model.
x. Living in a regional community, in which people are known to their care providers, may both enhance and inhibit their experiences of care delivery.
xi. Many GP referrals to attend the ED are not captured in existing administrative datasets because the direction from the GP is long-standing.

xii. The concept of what constituted ‘high-quality care’ varied. Key features included being known, understood and cared for by the health practitioner. Using evidence based best-practice approaches was a fundamental part of care delivery.

The next chapter integrates findings from Phases 1 and 2 to build the mixed insights. The connection between the two study phases is illustrated, demonstrating how the major quantitative findings informed the qualitative approach and subsequent findings. The chapter considers if, and how, the HCHs model of care might improve the delivery of health services to people living with chronic conditions in Cairns (*RQ3*).

# Chapter 6: Mixed Methods Integration of Results and Discussion

## 6.1 Introduction

Chapters 4 and 5 presented the quantitative and qualitative findings of the thesis. This chapter presents the integration of these findings. As explained in *Chapter 3,* a sequential mixed methods approach is used when the findings from a single quantitative or qualitative study phase are not independently sufficient for the purpose of answering the mixed methods research question. The explanatory sequential mixed methods approach strengthens the study results by connecting and building on the Phase 1 quantitative findings in the Phase 2 qualitative inquiry (Creswell & Plano Clark, 2011; Schoonenboom & Johnson, 2017). This approach was necessary for this project as the quantitative findings identified key areas of interest to answer the research questions, however they did not generate a comprehensive understanding of the phenomena under investigation. It was through the qualitative inquiry that people living with chronic conditions in Cairns were able to provide the detailed explanations that were required to inform the mixed methods research question(s):

> Can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns? What factors will influence the implementation of this model of care *(RQ3*)?

This chapter describes the process of integration undertaken in this research. Phases 1 and 2 study participants are compared; and the connection between the Phase 1 findings and the Phase 2 inquiry is elucidated. The integrated mixed methods findings are presented using a joint display and narrative approach. The chapter concludes with a discussion which is informed by the primary research question:

> How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?

## 6.2 Mixed methods integration process

In *Chapter 3* the process of mixed methods integration for this research was described (see *section 3.4.9 Mixed Methods Integration and Interpretation*). Two main types of interaction between the study phases were identified:

i. Phase 2 interview participants were sourced from the Phase 1 study population; and,
ii. important Phase 1 findings informed the Phase 2 inquiry.

In this section the characteristics of study participants in Phases 1 and 2 are compared. Key quantitative findings are identified and linked to the qualitative interview questions used for the Phase 2 data collection. A description of these interactions is necessary to demonstrate the validity of the mixed methods data analysis (Creswell & Plano Clark, 2011).

### *6.2.1 Comparative of Phases 1 and 2 study participants*

The source population for Phase 2 qualitative interview participation comprised of respondents from the Phase 1 P3ED Survey. This approach was used to minimise potential threats to validity by selecting inappropriate participants and/or participants who are unable to explain the Phase 1 quantitative findings (Creswell & Plano Clark, 2011).

*Table 5* compares characteristics of Phase 1 and 2 participants. For an explanatory mixed methods design, a display that links the demographic characteristics is useful to identify differences between the groups (Creswell & Plano Clark, 2011). Specifically, *Table 5* demonstrates that people who identified as Indigenous, and those reporting mental health conditions were underrepresented in the interview participant group.

*Table 5: Characteristics of adult P3ED Survey participants with chronic conditions, and interview participants*

| | **Adult survey participants with chronic conditions‡ n (%)** | **Interview participants¶ n (%)** |
|---|---|---|
| **ED attendees (≥18 years)†** | 549 | 21 |
| **Female†** | 287 (52.3) | 11 (52.4) |
| **Male†** | 262 (47.7) | 10 (47.6) |
| **Young-aged adults** (18-44 years)† | 139 (25.3) | 4 (19.0) |
| **Middle-aged adults** (45-64 years)† | 217 (39.5) | 11 (52.4) |
| **Older-aged adults** (≥65 years)† | 193 (35.2) | 6 (28.6) |

| | Adult survey participants with chronic conditions[‡] n (%) | Interview participants[¶] n (%) |
|---|---|---|
| **Indigenous**[†] | 74 (13.7) | 1 (4.8) |
| **Self-identified chronic condition***  | | |
| *Long-standing illness (example diabetes)* | 394 (71.8) | 17 (81.0) |
| *Long-standing physical condition (example arthritis)* | 215 (39.2) | 5 (23.8) |
| *Mental health condition* | 81 (14.8) | 1 (4.8) |
| *Complete or serious hearing impairment* | 43 (7.8) | 2 (9.5) |
| *Complete or partial vision impairment* | 42 (7.7) | 3 (14.3) |

[‡] Local resident adult (≥18 years) P3ED Survey participants who attended emergency department during 1-month period, March to April 2014.
[¶] Recruited to interview following P3ED Survey participation.
[†] Data sourced from EDIS.
*Self-identified a pre-existing chronic condition in P3ED Survey; could choose more than one chronic condition.

### *6.2.2 Following up Phase 1 findings with Phase 2 inquiry*

Connecting the data between the phases in an explanatory sequential mixed methods design involves identifying the key Phase 1 quantitative findings and devising interview questions from these findings to be used in the Phase 2 qualitative data collection (Creswell & Plano Clark, 2011). A side-by-side display is a useful tool to demonstrate the process of integrating Phase 1 findings into the Phase 2 data collection strategy (McCrudden & McTigue, 2019). *Table 6* describes how the Phase 1 quantitative findings informed the interview questions used in the Phase 2 qualitative data collection. Guided by the mixed methods research question (*RQ3),* the side-by-side display includes the rationale for using each of the questions to advance the qualitative inquiry.

*Table 6: Quantitative findings linked to interview schedule*

| | **Quantitative finding for people living with chronic conditions** | **Interview question** | **Rationale for the question** |
|---|---|---|---|
| **Regular GP care** | Most have a regular general practice (n=516, 94.3%), with approximately one-third (32.3%) of these visiting their GP in the week preceding their ED presentation. | Do you have a regular GP practice? A regular GP?<br>If NO: Why not?<br>If YES: How long have you been going to the practice/GP? Is it easy to get to the practice from your home?<br>What is your experience of care at this practice/GP?<br>Why do you choose to go to this practice/practitioner? What do you like/dislike about your practice/GP?<br>Thinking about your GP practice, what is your experience with the practice staff? Do they work | To explore people's current experience of GP care for managing chronic conditions.<br>To elicit understanding of how the current model of GP care is valued by people living with chronic conditions. |

| | Quantitative finding for people living with chronic conditions | Interview question | Rationale for the question |
|---|---|---|---|
| | | together to support your care with the GP? | |
| **Access to care** | Middle-aged adults (45-64 years) reported least access to bulk-billing services at regular GP practice (n=148, 73.6%). | Do you have a regular GP practice? A regular GP?<br>If YES: Fees? | To explore access to bulk-billing GP services at the regular GP practice. |
| **ED attendance to manage chronic care needs** | More likely than other ED attendees to: frequently present to the ED (10 or more visits in 1 year: 9.7% vs 6.1%, P<0.001); arrive by ambulance (49.4% vs 37.8%, P<0.001); and be triaged at a higher urgency of care category (Triage Category 1,2,3: 63.6% vs 58.1%, P<0.001). Less likely to be discharged home (45.5% vs 55.2%, P<0.001).<br>Less likely to experience episodes of ED care that were | Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. hospitals, clinics, specialists …) | To explore experiences of hospital health care services for managing chronic care needs.<br>To enhance insight into perspectives on using hospital services to manage chronic care needs. |

| | Quantitative finding for people living with chronic conditions | Interview question | Rationale for the question |
|---|---|---|---|
| | potentially avoidable when measured by the AIHW indicator of PAGP-type presentations to the ED (adjusted for age: *P*=0.001). | | |
| **Access to urgent GP care** | Over half (n=308, 56.1%) arrived at the ED after-hours<br>Nearly one-third (n=144, 29%) reported difficulty gaining an urgent appointment at their regular GP practice. | Thinking about getting access to health services such as GPs, what has been your experience of accessing health services in-hours? Out-of-hours? For … Urgent health needs?<br>Can you think of any approaches that might improve your access to care? (eg. available hours, in-person consultations, telephone, email, videoconference …) | To explore experiences of accessing urgent GP care.<br>To elucidate potential ways to improve access to urgent GP care. |
| **Self-referral to the ED** | Difference between self-report and the hospital administrative | Thinking about getting access to health services such as GPs, what has been your experience | To explore rationale for self-referral to the ED and consider |

|  | Quantitative finding for people living with chronic conditions | Interview question | Rationale for the question |
|---|---|---|---|
|  | data record of doctor referral to the ED (29% vs 6.9%). | of accessing health services … For … Urgent health needs? | factors that may be influencing self-referral. |
| **Alternative GP care services** | Some awareness of alternative GP care services – Telephone advice service (n=198, 36.1%); Bulk-billing, walk-in, after-hours GP clinic (n=376, 68.5%); Doctor to home service (n=481, 87.6%).<br>Most did not consider using these services for their presenting health issue – Telephone advice service (n=15, 7.6%); Bulk-billing, walk-in, after-hours GP clinic (n=65, 17.3%); Doctor to home service (n=48, 10%).<br>Only a minority (n=71, 12.9%) preferred to attend a local GP for | Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. bulk-billing clinic, telephone advice, home visit doctor, …) | To explore experiences of alternative GP care services.<br>To elucidate if/how services might be used as alternatives to regular GP care. |

|  | Quantitative finding for people living with chronic conditions | Interview question | Rationale for the question |
|---|---|---|---|
|  | their presenting health issue instead of the ED. |  |  |
| **Understanding ‘high-quality care’** | ‘High-quality care’ was the highest ranked priority factor for any alternative services to ED (n=278, 50.6%) | In our earlier research a majority of people said that if there was an alternative health service to the Hospital Emergency Department then it would need to offer ‘high-quality care’. Thinking about your health and your health care needs, what does ‘high-quality care’ mean to you? | To expand understanding of what ‘high-quality care’ means to people who use health services. |
| **Access to diagnostic medical information** | Having “Pathology/medical imaging on-site” was the second highest ranked priority factor for any alternative services to ED (n=197, 35.9%) | Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? (eg. follow up of test results) | To explore experiences of care coordination, specifically access to diagnostic medical information. |
| **Connecting care providers** | Nearly half (n=236, 43%) consulted another health | What has been your experience of health professionals collecting | To explore existing mechanisms of communication and data |

|  | Quantitative finding for people living with chronic conditions | Interview question | Rationale for the question |
|---|---|---|---|
|  | professional about the presenting complaint prior to attending the ED | and sharing data or information about your health?<br>How do feel about the sharing of your health information within the GP/AMS practice? With other health services? (eg. hospital, allied health)<br>Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? (eg. co-ordination with specialists, allied health (physio, pharmacist), hospital)<br>What types of approaches could you suggest to improve the co-ordination of your care? | sharing between health professionals.<br>To elucidate understanding of the person-perspective of health information sharing and care co-ordination between health professionals. |

## 6.3 Integrated findings

To address the research questions using an explanatory sequential mixed methods design, the quantitative and qualitative findings are integrated in the results (Plano Clark & Ivankova, 2016; Schoonenboom & Johnson, 2017) or the "point of interface" (Morse & Niehaus, 2009, p.25). This integration expounds the explicit relationship between the Phases 1 and 2 findings to demonstrate how the Phase 2 qualitative findings confirmed or expanded understanding of the Phase 1 quantitative results (Plano Clark & Ivankova, 2016). Creswell and Plano Clark (2011) describe this process as drawing meta-inferences to directly address the mixed methods research question (*RQ3*).

Joint displays are useful tools to demonstrate how findings from each of the study phases have been combined (Creswell & Plano Clark, 2011; Fetters, Curry, & Creswell, 2013). They provide a visual description of the integrated findings and are commonly presented as tables, figures or graphs (Fetters et al., 2013). Furthermore, integration of the mixed methods research findings can be reported through narrative. Writing the narrative involves combining the quantitative and qualitative findings into a "theme-by-theme or concept-by-concept basis" (Fetters et al., 2013, p.2142). The themes or concepts used in this thesis are guided deductively by the HCHs model elements (Commonwealth of Australia Department of Health, 2016); and inductively by participant perspectives. In this section Phases 1 and 2 findings are thematically integrated and presented as a joint display in table form. Following each joint display, a narrative explains and summarises the meta-inferences.

### *6.3.1 Person, practitioner and practice commitment: mixed insights*

*Table 7: Person, practitioner and practice commitment: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| What is the current experience of regular GP care? | |
| Most participants with chronic conditions reported having a regular general practice (n=516, 94.3%); with one-third of these visiting their regular practice in the week prior to attending the ED (n=166, 32.3%). | **Commitment to regular GP**<br>Most have existing, positive, committed relationships with their regular GP:<br>*He knows how to manage me* (P11).<br>Participants were supportive of making a commitment to their regular GP:<br>*That's basically what I'm doing now* (P4).<br>*With my GP … I would happily hand over the reins to her* (P1). |
| 'High-quality care' was the highest ranked priority factor for alternative services to ED (n=278, 50.6%). | A majority reported that their regular GP provided 'high-quality care'. This involved having a GP that was available and accessible, listened well, communicated effectively, cared about the person's well-being, explained concepts clearly and truthfully, was effective in their scope of practice, was willing to persevere to treat the health condition and provided treatments options:<br>*High-quality care is an understanding of the problem that you are suffering and a willingness to … find a proper solution not just a Band-Aid solution* (P1). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| Few participants would have preferred to attend a local GP, rather than the ED, for the presenting problem (n=71, 12%). | **Alternative GP care**<br>When their regular GP was unavailable, some participants reported seeking care from other GPs within the practice:<br>*They're the same practice, so they know everything* (P12).<br>However, many asserted that they would not seek care with other GPs at their regular GPs practice:<br>*There are some there (other GPs in regular practice) that I would never go to* (P11).<br>For some the perceived complexity of the chronic condition and the higher cost of other GPs at their regular GP practice deterred them from sourcing their care all in one place.<br>*You go in and you have to start again, even though they have got your notes, they want to know … the whole big, long story … so I generally don't like to take appointments with other GPs in that practice … she's worth seeing [regular GP] but if I'm going to see just anyone there I'd rather it be her, than be charged to see a random* (P1). |

| | |
|---|---|
| | **Commitment to practice organisation**<br>Perspectives on nursing staff being involved in care delivery varied between individual staff members:<br>*There’s one nurse there who’s brilliant, and then the nurse who’s been there for the whole time I’ve been there … she needs to go* (P12).<br>As gatekeepers to care, reception and administrative staff were strongly valued. However, as partners in care, there was very limited support for the wider practice staff team to be involved in participant care, with the decision to attend the practice not being governed by experiences with the practice staff:<br>*I don’t go there to see the reception staff … you only see them for about two seconds anyway* (P12).<br>A high staff turnover notably impacted experiences with the practice team:<br>*They have got a really high turnover so … you are pretty faceless in there* (P1).<br>*They have … a weekly meeting and you come up, but both of the people [nursing staff] that speak on my behalf are not there …they're absent* (P3). |

## Finding 1

A person's commitment for chronic care management is to their regular GP or specialist medical practitioner

The quantitative findings established that most people living with chronic conditions in Cairns have a regular GP. The qualitative findings enhanced understanding of this relationship and explored participants connectivity with their regular practice organisation.

Those living with chronic conditions highly valued their existing relationships with a regular GP. The notion of making a formalised commitment to a regular GP, as defined in the HCHs care model, was readily supported by a majority of participants in this study. Some perceived that this was already occurring:

> *That's basically what I'm doing now* (P4).

Although unfamiliar with the HCHs model, the primary concern voiced by participants around any new care model was the impact on access to their regular GP:

> *As long as we're not into a situation where you've got to wait a month to see your GP* (P4).

The first finding from this research is that for those living with chronic conditions, the principal commitment for care management is with their regular GP.

## Finding 2

### The role of the practice organisation is to support the person-practitioner relationship

When their regular GP was unavailable for consultation, other GPs within the regular GP's practice were not automatically preferred as a source of alternative care. Decisions to seek care from other GPs within the practice were influenced by individual factors and the cost of care. While some of the other GPs were perceived to be useful for care, others were not. Additionally, there was hesitancy to pay an out-of-pocket fee for consultations with other GPs in the practice. Overall, the commitment extended by people to their regular GP did not necessarily stretch to include other GPs in the practice organisation.

Concomitantly, participants perceived the practice team to have a supportive role. Although nursing and administrative staff could be effective in their roles, this did not influence a participant's commitment to the practice for their care management. The commitment for care remained with the regular GP not with the practice organisation. The second finding from this research is that for those living with chronic conditions, the role of the practice organisation is to support the central person-practitioner relationship.

### *6.3.2 Allied health as partners in care: mixed insights*

*Table 8: Allied health as partners in care: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| What is the current experience with allied health practitioners? | |
| Nearly half (n=236, 43%) consulted a health professional (regular GP or other) about their presenting problem prior to attending the ED. | **Pharmacists**<br>Experiences with pharmacists varied widely. Transactional-style interactions with pharmacists were reported by some participants. Others described pharmacists as necessary to their care: providing medication advice and a detailed understanding of health conditions:<br>*Probably more helpful than GPs at times … They know a lot about the drugs you're taking, and they know a lot about the disease that you have* (P18).<br>There were a few reports of active collaboration between the GP practice and pharmacists. Most participants described how the pharmacist could be effective in their role without the need for active engagement with the participant's regular GP.<br>**Physiotherapists**<br>Similar findings were identified for physiotherapists, with ongoing engagement with the GP not being perceived as necessary for care management. |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
|  | **Psychologists**<br>Reports of a team-care approach and consistent communication between the regular GP and treating psychologist were perceived to be advantageous for some participants, although some preferred to limit this interaction. |

Finding 1

A person's commitment for chronic care management is to their regular GP or specialist medical practitioner

Through both the quantitative and qualitative findings participants reported that allied health practitioners made a substantive contribution to the care of their chronic condition. The qualitative findings identified that participants did not perceive a need for the regular GP to involve other health practitioners in decision-making about their care. They distinguished the role of allied health practitioners to primarily have a specialised, service provision role in care delivery. This insight supports Finding 1: A person's commitment for chronic care management is to their regular GP or specialist medical practitioner.

### *6.3.3 Access to care: mixed insights*

*Table 9: Access to care: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| What services are used outside of the regular practice for routine GP care? | |
| Most participants with chronic conditions reported having a regular general practice (n=516, 94.3%); with one-third of these visiting their regular practice in the week prior to attending the ED (n=166, 32.3%).<br>Nearly half (n=236, 43%) consulted a health professional (regular GP or other) about their presenting problem prior to attending the ED. | **Routine care**<br>Some sought routine care from unconnected GPs or the local hospital emergency department:<br>*If she's not there [the regular GP] I'll go to the hospital over seeing anybody else* (P9).<br>One participant frequently used an alternative GP at a different practice to their regular GP for the purpose of service type request, such as prescription or pathology. They reported that the alternative GP had no communication with their regular GP or medical specialist and did not review the results of tests or investigations undertaken to manage their chronic condition.<br>*I actually have two practitioners … I go and see her [regular GP] for anything that is directly related to my [chronic condition] and that will require sort of ongoing care, I also have another GP … just for any sort of really easy, simple, you know I just need a repeat of a script or something like that* (P1). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| When care is urgent, can it be accessed with the regular GP? | |
| Nearly one-third (n=144, 28.7%) reported difficulty accessing an urgent appointment at their regular GP practice. | **Urgent GP care**<br>Some participants could access same day urgent care with their regular GP, some could not.<br>Some were willing to see other GPs in their regular practice for urgent care, some were not. Prior experience influenced willingness to seek care from individual GPs:<br>*When [regular GP] is off I can either see [GP2] or [GP3] and they're both just as good* (P20).<br>*Sometimes I can't get in to see him [regular GP] so I have a few other backups … she [GP2] is quite thorough … there are a few other doctors in there that I try to avoid* (P2).<br>Being known to the practice team facilitated access to care:<br>*The receptionist, she's really good … if I'm having a, you know, upset day, to get me in with the doctor straight away* (P12).<br>Those living with cardiac and diabetes conditions described how their GP directed them to attend the ED in the event of an exacerbation of ill-health. |

<table>
<tr><th><b>QUAN</b> Finding<br><br><i>Source: Linked dataset</i></th><th><b>QUAL</b> Finding<br><br><i>Source: Semi-structured interviews</i></th></tr>
<tr><td>There was limited access to after-hours care with over half (n=308, 56.1%) arriving at the ED after-hours.</td><td><b>After-hours care</b><br><br>After-hours service provision was limited. Only one practice provided an after-hours service within the existing practice structure. Young-aged working participants were the most likely to identify their need for flexible GP access:<br><br><i>Even if it was just after work in the afternoon, because they close at 4[PM]</i> (P1).<br><br>Participants recognised that their preferred GP could not be available to them after-hours:<br><br><i>A bigger range and more after-hours services would be fantastic but again people have lives, and they want to go home and I understand that</i> (P1).</td></tr>
<tr><td colspan="2">If urgent care with the regular GP was unable to be accessed, what alternative services are used?</td></tr>
<tr><td>Those with chronic conditions did have some awareness of alternative services to the ED such as: after-hours doctor home visiting service (n=481, 87.6%); bulk-billing, after-hours GP clinics (n=376, 68.5%); and telephone health advice (n=198, 36.1%).<br><br>However, the perceived usefulness of these services for the presenting health issue was poor: after-hours</td><td><b>Alternative services</b><br><br>Participants reported accessing some alternative services for after-hours urgent care. These included the after-hours doctor home visiting service (n=10), 24-hour medical centre (n=8) and the ED (n=13).</td></tr>
</table>

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| doctor home visiting service (n=48, 10%); bulk-billing, after-hours GP clinics (n=65, 17.3%); and telephone health advice (n=15, 7.6%). | |
| | **After-hours doctor home visiting service**<br>The home visiting doctor was perceived to be useful for acute conditions, not directly related to the ongoing management of the chronic condition:<br>*I normally use them if … I had a flu or something* (P19).<br>*If I have had an ear infection, just general things that anybody can have go wrong … they have always been really good* (P1). |
| Few participants would have preferred to attend a local GP, rather than the ED, for the presenting problem (n=71, 12%). | **24-hour Medical Centre**<br>Participants identified some helpful GPs within the 24-hour medical clinic practice:<br>*They’re fairly good* (P16).<br>Appointment accessibility was an advantage of the service:<br>*I don’t love the 24-hour clinic, but, you know, I can always get an appointment there* (P1). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| | Turnover of staff and limited or inaccurate investigation of illness were perceived barriers to care in the 24-hour medical centre:<br>*You can go there 20 times and get 20 different doctors* (P11).<br>*You're in and out really quickly; they've pretty much got their alarms set on their phone, to make sure you're not overstepping* (P12).<br>*You go in and they go, 'here is a script for some antibiotics' and I am like 'that's not the problem', or 'here is a script for antidepressants' which I have been given in the past, even though I don't suffer depression* (P1).<br>Not being known by the 24-hour clinic impacted experiences of care:<br>*I've been to the 24-hour medical place a few times … When I was really sick. Well, they don't know my history … You know it's all so - what's the word?  Hopeless* (P18). |
| Participants with chronic conditions reported reasons of urgency or need as their main reason for attending the ED (n=360, 65.6%).<br>Compared with other ED attendees, those with chronic conditions were more likely to arrive by ambulance (49.4% vs 37.8%, *P*<0.001) and be triaged | **Emergency Department**<br>There were positive reports of ED care:<br>*Generally speaking, I'm very pleased with it* [the ED] (P16).<br>Several participants described how they avoided attending the ED for care unless it was a medical emergency: |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| at a higher urgency of care category (Triage Category 1,2,3: 63.6% vs 58.1%, *P*<0.001). They were less likely to be discharged home (45.5% vs 55.2%, *P*<0.001). Age stratified analysis demonstrated that these results might be attributable to older age not chronic condition status.<br>Participants with chronic conditions were more frequent ED attendees compared with others (10 or more visits in 1 year) (9.7% vs 6.1%, *P*<0.001); and were less likely to experience episodes of ED care that were potentially avoidable, as measured by the AIHW indicator of PAGP-type presentations to the ED (adjusted for age: *P*=0.001).<br>For participants with chronic conditions, there was a difference between doctor referral to the ED recorded in the administrative dataset (n=38, 6.9%) versus self-report of doctor referral to the ED (n=159, 29.0%). | *There is nothing worse than hospital … if I know there's nothing bleeding or anything like that … I'll just stay at home and put up with it* (P20).<br>Many considered themselves to be doctor-referred to the ED, reporting a standing direction from their regular GP to attend the ED when they had an acute exacerbation of their complex chronic condition:<br>*If I have any troubles (Dr name) has just told me, present yourself to the ED, just go straight to the ED because you don't muck around* (P5).<br>One participant reported that they had been advised by their regular GP to attend the ED, irrespective of urgency, when they had an acute exacerbation of their complex chronic condition [liver condition]:<br>*It's embarrassing going into the hospital all the time, you go in wasting their time and all the rest of it, they've got more urgent cases going on* (P15). |

## Finding 3

## Alternative care services are not well connected to regular GP services

Quantitative findings identified that people living with chronic conditions had an unmet need for access to care. Qualitative findings expanded understanding of routine, urgent and after-hours care. Access to urgent GP care, particularly after-hours care, was limited for participants in both study phases. For the twenty-one interview participants who accessed GP care in the local Cairns community, it was noted that only one general practice organisation was identified as providing an after-hours service within the existing practice structure.

For chronic care management, there was a limited willingness by participants to use alternative services to their regular GP. For conditions not related to their chronic condition, such as viral infections, some participants perceived a use for alternative care services. Some routinely used the ED as their alternative care provider. For others, although there was a reasonable awareness of alternative care services such as the 24-hour medical clinic, there was hesitancy to use these services. Participants expressed concern about not being known by alternative care providers and conveyed apprehension about the quality of some services.

Those that accessed care outside their regular GP's practice reported that this care provision was disconnected from their regular GP. Although some wanted to maintain a distance between their regular GP and alternative care providers, most reported dissatisfaction with disconnected care. Not being known by the alternative care provider was a common concern. This led to reports of misdiagnosis and inadequate treatment plans. The third finding from this research is that the disconnect between alternative care and regular GP services impacts chronic condition care delivery.

Finding 1 → A person's commitment for chronic care management is to their regular GP or specialist medical practitioner

Finding 4 → Methods of capturing data for input into administrative health records do not comprehensively reflect person-practitioner communications

In the quantitative phase self-reports of doctor-referral to the ED exceeded the number of referrals recorded in the hospital administrative dataset. Understanding of doctor-referral to the ED was explored with participants in the qualitative phase. Some described how they had received an ongoing direction from their regular GP to attend the ED should the need for urgent care of their chronic condition arise. In addition, there was a report whereby the regular GP directed the participant to attend the ED for routine care management of their complex condition. This participant did not perceive a need for urgent ED care and would have preferred to have their care needs met in the primary health care setting. These informal person-practitioner communications influenced participants' decisions around which service to access for care of their chronic condition. Participants reported followed their practitioner's direction, even if they were unhappy with the rationale. This insight further supports Finding 1: A person's commitment for chronic care management is to their regular GP or specialist medical practitioner. In addition, another finding for this research is that the current system of capturing data for hospital administrative records may not reflect the informal person-practitioner communications that are guiding people's decision-making when accessing care.

### *6.3.4 Care management, coordination, planning, data collection and sharing: mixed insights*

*Table 10: Care management, coordination, planning, data collection and sharing: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| What is the current experience of care management, coordination and planning in primary health care? | |
| Most participants with chronic conditions reported having a regular general practice (n=516, 94.3%); with one-third of these visiting their regular practice in the week prior to attending the ED (n=166, 32.3%). | **Care management**<br>Many participants reported that they were responsible for managing their own care.<br>*Give me the information and I'll do it; I'll sort it out myself* (P19).<br>When participants experienced poorer health, they identified a reduced ability to be active in their own care management and an increased reliance on health practitioners to guide their care.<br>*You go looking for another doctor … But there may come a time when we can't. So, while you are able, you've got to do it and then hope that your doctor sticks around* (P4).<br>**Care coordination – care activities**<br>Inconsistency in the method of delivery for medical tests results was reported. The in-person delivery of normal test results caused frustration for participants. They identified how this wasted their time and effort: |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
|  | *I've come all this way for that?* (P2).<br>Similarly, frustration was reported for the need to visit the GP to obtain a repeat prescription:<br>*We've got to actually make an appointment to go in and just get her 5 minutes to write out a script for us and I feel that's wrong, not on her [the GP's] behalf, but on the system's behalf* (P9).<br>The use of email was perceived to be advantageous for routine care activities such as repeat prescriptions and as a follow-up for complex information:<br>*If you could cut and paste your notes and just put it in an email, it would be so helpful for me, because my memory is quite unreliable … it would be so much more considerate* (P3).<br>The use of technology to improve access to GP care was perceived to be advantageous:<br>*I walk away from the GP … and it has taken me two and half hours to get that referral all up: travel time, waiting time … when I could have done it over the phone or Skype* (P1). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| | **Care coordination – information sharing**<br>Participants described maintaining their own personal health records system which they routinely shared with their health practitioners:<br>*I've got a box with all my paperwork and tablets in it, which I take in whenever I go, he also goes through all the paperwork that I present for him … which he marks on his computer* (P11).<br>Requesting of copies of reports and documents to share with practitioners was common:<br>*Each time I've gone there and said, "can you please get a copy of your report to my GP", quite often I'll wait for it and they'll give to me and I deliver it* (P11).<br>In particular, post-hospital discharge communication with the GP was identified as an area of concern, with multiple reports of absent or delayed information sharing:<br>*He's always angry [the GP] when I go to the ED and no letter gets sent to him.  And I keep on telling them to do that, but they don't do it for some reason.  There must be a communication gap there* (P19). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
|  | **Care planning**<br>Only a few participants (n=4) indicated they actively developed and used a care plan with their GP. Of these, there were some reports of positive usage:<br>*Whenever … I've got to see a strange doctor … or if I get taken into hospital for admission, I take it with me, and the doctor has a look at it … it saves me trying to stutter my way through stuff and I've got no idea what I'm saying* (P11).<br>Some (n=4) reported they had developed a care plan; however they did not review it collaboratively with their GP and perceived that it had limited use:<br>*He's got some sort of thing worked out for me … I think it's a care plan … It doesn't seem to mean anything … It's basically about the codeine* (P19). |
| What is the current experience of data collection and data sharing in primary health care? |  |
| Inaccuracy in administrative datasets for Indigenous status. Assessed EDIS dataset, with survey responses as the comparator:<br>• sensitivity 85.7% (95% CI, 78.1–91.5%);<br>• specificity 98.6% (95% CI, 97.6–99.3%); and,<br>• accuracy 97.0% (95% CI, 95.8–98.0%). | **Data collection**<br>Inaccuracy in the collection of data for medical records was observed:<br>*People don't fill in the computers properly* (P20).<br>Concerns were highlighted over the importance of listening to the person's recount of their context, not just relying on a blanket review of the medical record: |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| For participants with chronic conditions, there was a difference between self-report and the hospital administrative data record of doctor referral to the ED (Survey 29% vs EDIS 6.9%). | *Get my records from my other doctor … but listen to me and what I have to say, and not [just] what they've written down (P18).* |
| | **Data sharing**<br>Sharing of data within the practice was perceived to be advantageous:<br>*All your information's there on the computer … if you did have to see someone your information's there* (P17).<br>Willingness of participants to share their data outside of the practice was mixed, with data security being a concern to participants. Participants perceived that GPs, hospital medical staff and medical specialists could be trusted with health data; pharmacists needed access to some health records; and other allied health professionals had limited or no need to access health data:<br>*They're not prescribing me any medications so, no, they had no need to know* (P10).<br>Some participants strongly disagreed with having their medical records shared amongst their health care team: |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| | *I don’t want her [the GP] knowing … but I’m a bit worried that he [the psychologist] is going to tell her ... There’s lots of problems with interaction with your medical people* (P18).<br>**My Health Record**<br>A small number (n=3) supported using the My Health Record system and provided examples of successful usage:<br>*It was perfect in that situation, because I’d totally forgotten about this new drug I was on* (P12).<br>Even though most participants felt there was value in a shared data management system, they reported that their GP did not plan to use the My Health Record system.<br>*She said [GP] ‘it’s not going to work. I’m not doing that’* (P10).<br>*I wanted to go on it but … the medical clinic told me they were not, in no uncertain terms, interested in getting on a system like that* (P11). |

**Finding 4** → Methods of capturing data for input into administrative health records do not comprehensively reflect person-practitioner communications

**Finding 5** → There is a limited use of existing tools designed to improve care management and coordination

With the quantitative findings establishing that most people living with chronic conditions accessed a regular GP for care, the qualitative investigation explored the coordination and planning of this care. Many participants were actively involved in the management and coordination of their care. This included taking action to address the gaps in existing care coordination by compiling their own medical records system and facilitating communications between their care providers. There was limited existing use of structured care plans, although participants perceived there to be value in having a plan for care. Concern was expressed about how episodes of poorer health might impact an individual's ability to coordinate their own care.

Flexible approaches to the delivery of care were mostly welcomed by participants. This included the GP's use of email to directly communicate key, personal health information. Video or telephone consultations were perceived to be of value to some participants.

Inaccuracies in health records were identified in the quantitative findings. Concerns over errors that can occur in inputting health data were reported by interview participants. To mitigate potential health information inaccuracy or misinterpretation, participants expressed the need for health practitioners to listen to their description of their health state and history, not just rely on health data records. This insight further supports Finding 4: Methods of capturing data for input into administrative health records do not comprehensively reflect person-practitioner communications.

Potential benefits of using an online data sharing tool to support care coordination were perceived by most participants. In the majority, participants supported restricting access to their health records to involve only those providing direct medical care. There was limited knowledge, understanding or uptake of existing tools designed to improve data sharing such as My Health Record. Reports of a lack of willingness by health practitioners to use the system influenced the ability of participants to engage with My Health Record.

Overall, the finding from this research was that participants reported limited use of existing tools designed to improve care management and coordination. Many participants coordinated the management of their own health records, without using existing tools designed for this purpose, such as My Health Record. A lack of practitioner commitment to using My Health Record was reported by participants. Care plan usage was also limited, although participants perceived there to be value in establishing and actively using a shared care plan.

### *6.3.5 Uncertainty around cost of care: mixed insights*

*Table 11: Uncertainty around cost of care: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| What is the current experience of payment models in primary health care? | |
| Many adults with chronic condition reported that their regular general practice offered bulk-billing services (n=414, 80.4%).<br>Middle-aged adults (45-64 years) with chronic conditions reported the least access to bulk-billing services at their regular general practice (n = 148, 73.6%). This group was the least likely to have visited their regular general practice in the week prior to ED attendance (n = 51, 25.5%). | More than half of participants (n=14) described how their regular GP bulk-billed their consultations irrespective of whether or not the practice advertised as a bulk-billing practice. However, participants reported uncertainty around out-of-pocket expenses incurred for GP consultations.<br>*I pay a fee. But sometimes he'll take pity on me and bulk-bill me* (P8).<br>*I don't think it's fair … every now and then she'll bulk-bill it but I'd say the majority of times I'm paying out* (P18).<br>Uncertainty around bulk-billing reduced participant control over managing their own health:<br>*Because I'm lucky enough to be bulk-billed, I sit there and keep my mouth shut because I don't feel I've got the right to say something* (P12).<br>When dissatisfied with their current GP care, cost deterred participants from seeking a second opinion: |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
|  | *When I rang [GP name] to make an appointment … it could be over $100 ... for your first appointment … it is preventing me* (P18).<br>There was recognition by participants that general practice organisations were business-led models of care:<br>*It's damned expensive to run a practice today. And I'd imagine the insurance costs alone would break you* (P4).<br>*Why should a doctor when he's getting $700,000 a year in Brisbane come up here and work for $200,000, it's a business first, let's be honest* (P11). |

## Finding 6

**Uncertainty around the cost of GP care impacts access to care and reduces people's control over their own health**

Findings from the quantitative phase determined that there was a proportion of survey participants without access to bulk-billing services. Qualitative exploration found that the current practice of GPs alternating between bulk-billed and fee-paying consultations created uncertainty and deterred some participants from seeking care. Participants reported that this uncertainty around the cost of care decreased their ability to be in control of managing their own health. Alongside this, there was recognition by some participants of the necessity for practice organisations to generate a profit by charging fees, in order to be an ongoing business concern.

### *6.3.6 The condition matters, one size does not fit all: mixed insights*

*Table 12: The condition matters, one size does not fit all: Integrated findings*

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| How does the type of chronic condition influence people's experiences of primary health care? | |
| Young-aged adults (18-44 years) with chronic conditions were the most frequent ED users (n=22, 15.8%).<br>Half (n=69, 49.6%) of young-aged adults consulted another health professional prior to attending ED.<br>Middle-aged adults (45-64 years) with chronic conditions were the least likely to have visited their regular general practice in the week prior to ED attendance (n = 51, 25.5%). | The youngest participants (n=3, 25-39 years) self-reported complex, uncommon chronic conditions, specifically idiopathic intracranial hypertension, fibromyalgia and ulcerative colitis. Middle- (n=11, 45-64 years) and older-aged (n=6, over 65 years) adults reported a range of uncommon and/or complex conditions including several long-term conditions of unknown origin.<br>Overall, of the 21 interview participants, 14 (67%) self-reported that they had at least one uncommon or complex chronic condition. These types of conditions were described by participants as being challenging to manage and were often perceived to be poorly understood by medical practitioners.<br>The type of chronic condition impacted care management. Participants with common conditions such as cardiac and endocrine conditions, including diabetes, identified that their care was best managed by a medical specialist or diabetes care team. They reported that their GP was useful for routine prescriptions and |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| | conditions not related to their chronic condition; however, it was the specialist, not the GP, who was in charge of care management.<br>*The GP is … a general practitioner, but doesn't have any in-depth experience in the heart, whereas my condition is directly related to the heart … prescriptions, medications, GPs fine, but your heart specialist is really the one that knows what's going on* (P2S).<br>The participant group who reported the most negative experiences of primary health care were those with complex, difficult to manage, chronic conditions such as chronic pain, fibromyalgia and conditions of unusual aetiology. Anxiety and depression were additional diagnoses consistently self-reported by this group. |
| | There were many reports of an unmet need for care by those with uncommon or complex chronic conditions:<br>*About six months before I was diagnosed, I was in tears … it was just so frustrating …*<br>*I felt that I wouldn't be like this if I had doctors years ago that listened to me …*<br>*I've built anxiety because of people just not listening to me (P14).* |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
|  | The challenge of finding a GP who was willing to manage complex care needs was described:<br>*I hate going around to different doctors …*<br>*But I've had to go to different ones … it's kind of like you're just a number* (P14).<br>*She was like the new girl there and I got fobbed off to her … that's how it felt … Because I was in the too-hard-basket … no-one knew what to do with me* (P18).<br>*You've got to explain it all again … when you're swapping GPs there's a lot to say* (P18).<br>Not being understood by GPs was a recurring concern:<br>*She listens but she doesn't understand … she tries to help; of course, she's a doctor … she hands out all these prescriptions that I don't get filled because I don't want to be on drugs ... And you feel like you're not being heard* (P18).<br>Finding a GP willing to manage their complex care needs was highly valued by participants:<br>*I just cried because I was like 'I found a doctor that's listened to me'. My whole life I haven't found anyone that's listened to me* (P14). |

| **QUAN** Finding<br>*Source: Linked dataset* | **QUAL** Finding<br>*Source: Semi-structured interviews* |
|---|---|
| | Even if the GP was not an expert in the condition, their willingness understand the person’s experience as an expert in their own care and their efforts to learn about the condition, supported the person’s experience of care.<br>*Whenever I come up with something new… he’ll go ‘yes, I don’t know either – we’d better see what we can find out about that’ and he’ll go and read up on it* (P20). |

Finding 1 → A person's commitment for chronic care management is to their regular GP or specialist medical practitioner

Finding 7 → People with complex and/or uncommon chronic conditions have unmet care needs

In the quantitative phase young- and middle-aged adults were identified as potentially having an increased need for care. Qualitative exploration enabled participants to enhance understanding of their chronic conditions. Expanding on the diagnoses recorded in the hospital administrative datasets and used for the quantitative investigation, many Phase 2 participants reported having complex and/or uncommon chronic conditions. All of the youngest participants (n=3, 100%, <39 years) and approximately two-thirds of middle-aged participants (n=7, 64%, 45-64 years) identified that they had complex and/or uncommon chronic conditions.

Alongside these complex and/or uncommon chronic conditions, interview participants reported a range of mental health conditions. Two of the three young-aged participants described additional diagnoses of depression and anxiety. Nearly three-quarters (n=8, 73%) of middle-aged participants reported a mental health condition involving depression, anxiety or stress. Importantly, only one of these participants self-reported their mental health condition as their primary diagnosis at the commencement of their interview conversation, when they were asked to identify their current chronic condition(s). All of the others disclosed their mental health condition once the interview was well underway.

For those who live with complex and/or uncommon chronic conditions, the qualitative investigation expanded understanding of their health service experiences. Participants described a range of factors that influenced their experiences of care. Reports of difficulties in finding a GP to support their complex care needs were common. Many asserted that they had to search for a GP willing to commit to managing their care; and had experienced poor care experiences as part of this process. This led to concern being expressed about any changes to the existing care model that might influence their existing relationship with a regular GP. Important needs for GP care reported by those with complex and/or uncommon chronic conditions were a need to be believed; a need to be understood; the importance of having their health practitioner listen to them; and a desire to have a regular GP that worked together with them to manage their complex care needs.

For those with common chronic conditions, such as diabetes and cardiac conditions, the qualitative findings identified that participants relied on their special medical practitioner or care team to manage their chronic condition. Having a regular GP was perceived to be useful for some of their routine chronic care management, however care decision-making was invested with the medical specialists. This insight further supports Finding 1: A person's commitment for chronic care management is to their regular GP or specialist medical practitioner. It expands understanding of this finding to include the awareness that general practice may not be the preferred medical home base for all people with chronic conditions.

### *6.3.7 Summary of integrated findings*

In summary, the key integrated findings from this research were:

| | |
|---|---|
| Finding 1 | A person's commitment for chronic care management is to their regular GP ***OR*** specialist medical practitioner |
| Finding 2 | The role of the practice organisation is to support the person-practitioner relationship |
| Finding 3 | Alternative care services are not well connected to regular GP services |
| Finding 4 | Methods of capturing data for input into administrative health records do not comprehensively reflect person-practitioner communications |
| Finding 5 | There is a limited use of existing tools designed to improve care management and coordination |
| Finding 6 | Uncertainty around the cost of GP care impacts access to care and reduces people's control over their own health |
| Finding 7 | People with complex and/or uncommon chronic conditions have unmet care needs |

In the next section these findings will be discussed to address the primary research question.

## 6.4 Discussion: How the Health Care Homes model can improve the delivery of health service to people living with chronic conditions in Cairns

The HCH trial program finished on 30 June 2021. At the time of writing this discussion, interim evaluation of the trial's progress had been undertaken by the government-appointed program evaluation team, with the final program evaluation due in late 2021. As of April 2022, the final program evaluation has not been released.

This discussion is focussed on the integrated findings generated by the mixed methods research undertaken. The available trial program evaluation and other relevant literature have been reviewed and considered in the context of these findings. The discussion is guided by the third research question:

> Can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns? What factors will influence the implementation of this model of care *(RQ3)*?

Further, this discussion addresses the primary research question:

> How can the Health Care Homes model of care improve the delivery of health service to people living with chronic conditions in Cairns?

### *6.4.1 Committing to a general practice organisation*

The HCH involves a model of care whereby people commit to the practice organisation for their chronic care management. This commitment has been formalised through the HCH model in a process of voluntary patient registration (VPR). VPR involves people agreeing to attend their preferred practice organisation for ongoing care of their health condition(s). As a key model element, this person-practice commitment aims to build a partnership approach to care management in Australia (Commonwealth of Australia Department of Health, 2016). Internationally, patient registration systems in the primary health care setting have been established in a range of countries including the United Kingdom, New Zealand, Italy and Norway. Some systems are voluntary, while others are not. Perceived benefits of enrolment include promoting provider responsibility for care outcomes; enhancing care continuity; and supporting proactive care approaches. However, challenges have been identified for people living with complex conditions as some payment models may not sufficiently compensate providers for the costs of their care management (Irurzun-Lopez, Jeffreys, & Cumming, 2021).

Following on from the HCH trial, policymakers and stakeholders have affirmed that VPR has an ongoing role in the Australian primary health care system. VPR is a foundational concept for Australia's Primary Health Care 10 Year Plan and has the support of the Australian Medical Association (Australian Medical Association, 2015; Australian Government Department of Health, 2021). However, findings 1 and 2 from this study ascertained that people are loyal to an individual GP, not the practice organisation.

For the HCH trial, people were identified by the practice as potentially suitable for HCH enrolment. Potential trial enrolees were approached by the practice team and invited to voluntarily enrol with the practice to participate in the program. A preferred clinician from the practice team was then nominated by the person, with most people nominating their regular GP. This process of enrolment resulted in HCH trial participants being previously known and connected to their existing GP practice organisation and regular GP. Additionally, the HCH evaluation team reported that most enrolees highly rated their primary care practice prior to trial enrolment (Health Policy Analysis, 2019). The result of being already known and well-connected to the practice prior to VPR has meant that for some trial participants, enrolment in the HCH program has made no discernible difference to their experience of care (Health Policy Analysis, 2020a). Findings from this study suggest that this would be the experience of many people who already feel well-serviced by their current practice organisation and the existing model of care. This lack of observable difference following model implementation is consistent with previous studies that examined the patient experience in the PCMH model of care (Maeng, Davis, Tomcavage, Graf, & Procopio, 2013).

This study identified that people with chronic conditions viewed the role of the wider practice team to be as a support to their regular GP. Although trusting relationships with practice nurses were reported, people were less willing to make a practice-specific commitment, as their approach to care management was founded on a person-practitioner not person-practice relationship. Recognising the importance of the person-practitioner relationship is vital for a person-centred model of care. More work needs to be done to support understanding of team-based care approaches. This has been the experience in the HCH trials, where barriers to implementation have included the need to support GPs to confidently share the workload with practice nurses; and a need to develop people's understanding of the expanded role of practice nurses in care management (Health Policy Analysis, 2020b).

### *6.4.2 Specialist care, integrated care and the HCH model*

People living with conditions that require ongoing specialist medical care may not consider general practice to be the preferred medical home-base for their care management. People with diabetes and cardiac conditions involved in this study identified that the care of their chronic condition was best managed by a specialist medical provider or care team. A consistent finding was found by Cheong, Armour, and Bosnic-Anticevich (2013) for those living with severe asthma. In that study people with complex or severe asthma identified that their care was best managed by a respiratory specialist, not a GP; whilst those with milder illness perceived the GP to meet their care needs.

Careful consideration of the care management needs for different types of chronic conditions is indicated. Even for those with the same overarching diagnosis, the complexity and severity of illness may determine that the HCH, situated in general practice, is not the optimal model for the delivery of care. Flexibility in the model is needed. The forerunner to the HCH model was the PCMH that was situated in specialist paediatric care (American Academy of Family Physicians, 2008). Funding streams that establish medical-home bases in specialist care for some chronic conditions may better meet the needs of those living with these illnesses.

Alternatively, strengthening ties between specialist providers, hospitals and general practice using an integrated care approach has shown promise in the Australian context (Trankle et al., 2019). Strategies to promote integrated care have included employing care facilitators to connect people from local area health services with general practices and other health services; specialist action plans provided at hospital discharge to inform GPs of the planned approach to ongoing care; a dedicated telephone support line to enhance GP access to hospital specialists and clinics; and a hospital rapid access clinic, which includes a consumer telephone service, to reduce unnecessary hospitalisations and re-admissions. These strategies have benefitted both consumers and GPs by supporting connectivity between primary and secondary care services (Trankle et al., 2019). A consideration of these types of strategies may be helpful to address the concerns identified by participants in this study about a lack of information sharing between primary and secondary care, although as hospital-initiated strategies, they would be outside the scope of the HCHs model. However, these measures to improve integrated care would support practitioners and consumers working within the HCHs model.

### *6.4.3 Embedding the person-practitioner relationship in the model of care*

People in this study consulted with a range of practitioners prior to making a commitment to their preferred GP. They described how their commitment decision was influenced by individual, personal GP characteristics such as being a good listener, communicator and competent professional. The need to be known and understood by a medical practitioner has been well-documented, with an identified need for people to have “a personal physician who knows the patient’s situation and biography and who is committed to the wellbeing of each patient, accepting responsibility for appropriate care” (Baird et al., 2014, p.184).

Contrastingly, study participants did not perceive a strong need for allied health practitioners, including pharmacists, to be guiding their chronic care decision-making. Reports indicated that allied health practitioners were valued for their discipline-specific contribution to care, however they were not perceived to be key determinators of care planning and management. This perception was supported in an Australian study on team-based primary care, in which people with chronic disease described their relationship with their GP as non-negotiable, however the role of allied health service providers in care was viewed as less of a priority (Foster, Foster, & Mitchell, 2013).

Some practices involved in the HCH trial were involved in an additional initiative that linked to community pharmacy. This initiative was not part of the original trial plan, commencing in August 2018. As part of this initiative, HCH enrolees were referred by their GP practice for a medication review with a community pharmacist, with the aim of improving the individual's medication management (Health Policy Analysis, 2019). This linkage was enabled by the GP and is an example of the person-practitioner relationship utilising the expertise of allied health professionals to potentially improve chronic care. Interim evaluation results for the community pharmacy trial have demonstrated limited uptake and impact, with some reports of hesitancy from consumers to involve pharmacists in their care management (Health Policy Analysis, 2020a). Findings from Phase 2 of this study indicated that consumers valued effective communication pathways between their regular GP and pharmacist; however, having a pharmacist integrated into their care management team was not perceived to be necessary.

From both the person- and practice-perspective, health care planners face challenges with established relationships. The HCH community pharmacy trial was impacted by existing relationships between pharmacy services and the referring GP practice Specifically, some practices had pre-existing relationships with pharmacists and were not connected to the community pharmacist involved in the HCH trial. This led to a lack of engagement by GPs with the community pharmacist (Health Policy Analysis, 2020a). From the person-perspective their preferred pharmacy service may not be the service identified by their GP. Reports from participants in this study indicated that people were prepared to travel for GP care but sourced their medications from pharmacists that were conveniently located, often near their homes. These individual preferences for care delivery make it difficult for practices to link people to other health services, including pharmacists, and provide an ongoing challenge to the implementation of connected primary care models.

Derived from the findings of this research, a model has been developed that illustrates the key features of a person-led model of care for people living with chronic conditions (see *Figure 8*). The model involves three key elements:

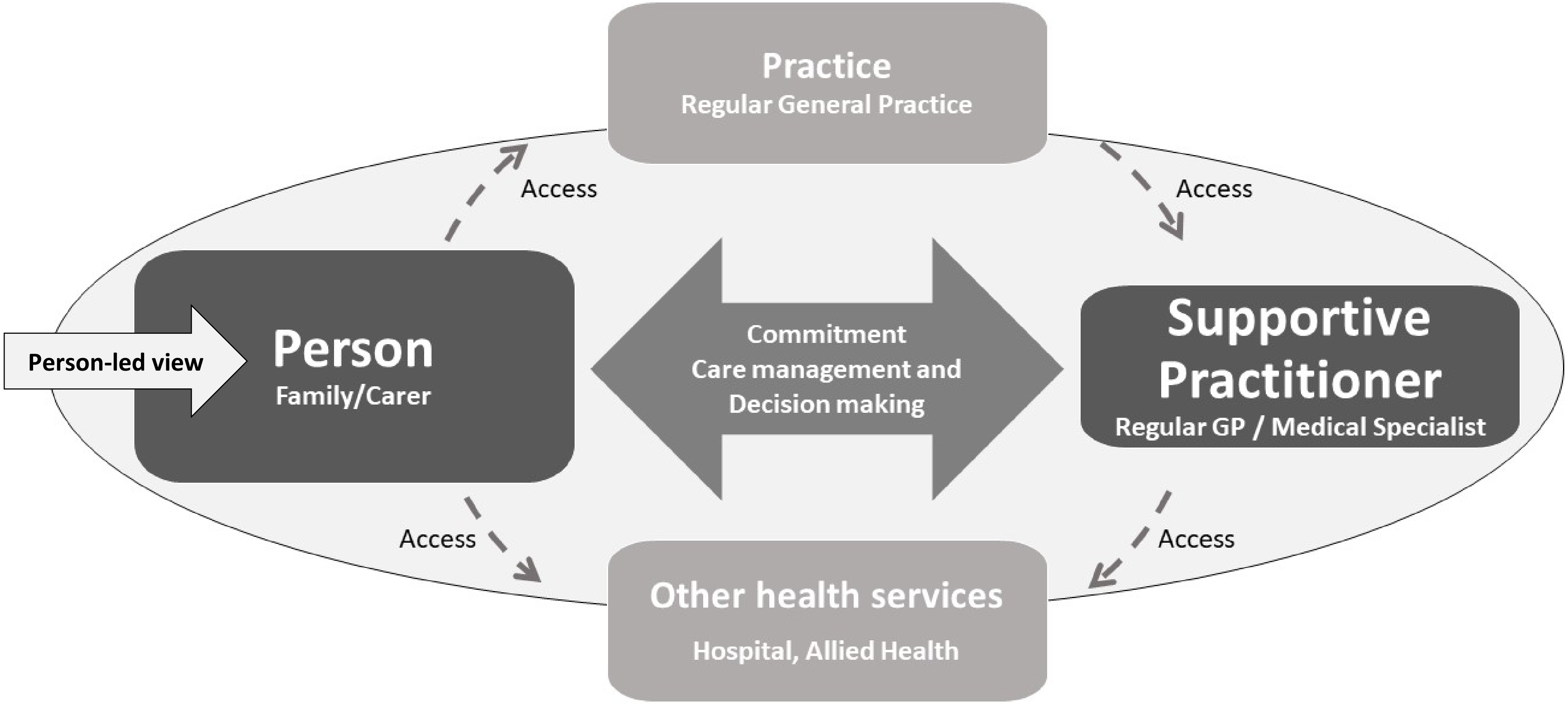
i. the primary commitment for care is between the person and their supportive medical practitioner. For most people living with chronic conditions the practitioner is likely to be their regular GP. For some specialist medical areas, including cardiology and diabetes, the practitioner may be a medical specialist or medical specialist team. A person’s chronic care management and decision-making predominantly involves direct communications between themselves and their supportive practitioner;

ii. the role of the practice organisation is to facilitate access to the supportive medical practitioner; and to assist the practitioner in their work; and,

iii. other health services, such as hospital and allied health, may be utilised to support chronic care needs. This may involve the person directly accessing these services. Alternatively access to other health services may be facilitated by the supportive medical practitioner. Irrespective of the method of accessing care, systems and processes should support connectivity between providers that is informed and led by consumer preferences for care.

The model is intended to be viewed left-to-right using a person-led perspective. People in this study perceived their care management to involve a supportive practitioner and ‘others’; with the GP or medical specialist being the practitioner with whom they make care decisions, and ‘others’ being other health services. From a health services perspective, hospitals and allied health are distinctly different services. However, from the person-perspective they are categorised as ‘other’ services that are not their supportive practitioner. The arrows describe how the person views their approach to accessing care: they use practice staff to access their supportive practitioner; and access the hospital and other services either directly or via the supportive practitioner.

*Figure 8: Person-Led Model of Chronic Care*



For Australia to have a truly person-led model of care the importance of the person-practitioner relationship needs to be foundational to the design of any care model. Working from this lens creates a model that is reflective of the needs and values of consumers. Having an effective person-practitioner relationship has been identified in this study and others as the driving force behind people's preferences for primary health care service delivery (Cheong et al., 2013; Foster et al., 2013). Implementing models of care that do not embed the person-practitioner relationship as a core element are unlikely to meet the needs of consumers.

Partnership models of primary care are not new (Holman & Lorig, 2000). Shutzberg (2021) describes three iterations of the doctor-patient relationship. The first is the paternalistic, doctor knows best style, in which power resides with the doctor over the person; the second is the consumer-driven model, in which the person dominates; and the third is the partnership model, where power is shared between person and practitioner. *The Person-Led Model of Chronic Care* is a partnership model in terms of the proposed sharing of power between person and practitioner. It could also be a consumer-driven model, depending on the activation and preferences of each individual person. Participants in this study indicated that it was not a one-size fits all approach; while some were keen to be the director and manager of their own care, others confidently shared the decision-making alongside their regular GP. This is why the model is described as person-led; it is led by the individual person's needs, preferences and values.

HCH implementation can be strengthened through his person-led model. This proposed model aligns with elements of the Chronic Care Model in which people's preferences, supported by scientific evidence, are used to guide health decision-making (Grover & Joshi, 2015). Further, the proposed model is supportive of the Stanford Model involving the Chronic Disease Self-Management Program to promote self-efficacy in health care (Grover & Joshi, 2015). Specifically, *The Person-Led Model of Chronic Care* emphasises that people are supported to self-determine who is involved in their care and to what capacity. Empowering people to lead their own care journey requires commitment from practitioners and funders. This has to be more than just person-centred rhetoric.

### 6.4.4 Whose interests are being served by the HCH model?

Findings from this study indicated that people with existing, positive relationships with a regular GP may not notice a difference in care delivery should they move from the existing model to the HCH. In either model they would expect to receive ongoing, appropriate care from their preferred provider. If people seeking better care perceive only a limited benefit to HCH enrolment, then a question to be asked is: *who is likely to benefit from implementation of a HCH model?*

Worldwide, the medical profession has successfully sought to influence the allocation of health funding through the active advocacy of peak, representative professional bodies (Mooney & Navarro, 2012). In Australia these organisations include the Australian Medical Association and the Royal Australian College of General Practitioners. People rely on health care professionals to have their best interests in mind when they make care decisions, with altruism being historically considered as a requisite for medical professionalism. In recent decades the ever-expanding demand and cost of providing health care service has placed an immense pressure on medical practitioners to perform in cost-effective, ongoing business models (Harris, 2018). Australia's Medicare funding model has increased this pressure, especially when business costs have continued to increase while the payment rates to practitioners in primary care have not, leading to an increase in out-of-pocket costs to consumers (Duckett, 2015). There is an inherent conflict between delivering person-centred health care and the profit-making nature of a business-led, general practice model. Indeed, some have argued that it is not possible for doctors to remain altruistic in their motivation when commercial transactions are the basis for the doctor-patient relationship (Harris, 2018). A consideration of this conflict is necessary in determining whose interests are being served by implementing the HCH model.

Developed in the United States and adopted in Australia, the initial Triple Aim of high performing primary care was to improve health service delivery by i) improving population health and ii) patient experience, while iii) reducing costs. A fourth element was added to make this a quadruple aim, with the additional goal being to improve the work-life of health care providers (Bodenheimer & Sinsky, 2014). Aligning with these aims, key reasons cited by policymakers for implementation of the HCH model were to better manage the costs of care while supporting the well-being of practitioners and patients (Commonwealth of Australia Department of Health, 2016).

General practice organisations in Australia face a dichotomous challenge: balancing their role in providing health care with a business-led need to generate profit (Duckett, 2015; Harris, 2018). Consumers are not naive to this imbalance. Reports from participants in this study established that they recognised the business-led model of health care, acknowledging the need to generate a profit to maintain service delivery.

Given the rising costs of delivering health services and the limitations of existing government funding models, it is unsurprising that new approaches to care delivery have been considered. Internationally, blended funding models for primary care involving both fee-for-service and capitation payments have shown promise as an alternative to the current approach (Rosser, Colwill, Jan, & Wilson, 2011; Takach, 2016). In Australia, in addition to the HCHs trial, other models have been explored in general practice including PCMH and integrated care programs.

Benefits have been reported for providers, practice staff and patients, although the current fee-for-service funding model has been identified as a constraint on practice transformation (Metusela et al., 2020). Models that focus on health outcomes and performance rather than episodes of care and length of consultation time may better serve the needs of people living with chronic conditions, by being more adaptable to an individual's health care needs (Duckett, 2015).

Strongly supported by Australia's peak medical bodies including the Australian Medical Association, the HCH bundled payment model creates an alternative type of income stream for general practice organisations (Australian Medical Association, 2015; Commonwealth of Australia Department of Health, 2016). Medical practitioners may benefit from this capitation model though sharing the workload with practice team staff. This has the potential to reduce the costs of service delivery by transferring the time spent by GPs with consumers to other members of the practice team. In addition, sharing the workload has the potential to reduce the burnout experienced by GPs in response to high levels of service demand, leading to improvements in work-life satisfaction (Commonwealth of Australia Department of Health, 2016).

At the time of writing there has been an absence of data from the HCH model trials in regard to the impact of the funding model on the practice organisation or the consumer. The interim program evaluation reports have identified difficulties for practices in managing the bundled payment scheme, with mixed reports of funding impacts, ranging from little or no improvement, to those that reported losing out under the scheme, particularly in the management of people with complex chronic conditions (Health Policy Analysis, 2020b). From the consumer perspective, if their cost of care is fully funded through Medicare, a fee-for-service or bundled payments approach may make no discernible difference. This is important for understanding of the HCH model, as it reinforces the model's strong practitioner-centric focus.

Although the cost of care for many may not change, consumers may benefit from HCH implementation alongside GPs if the practice organisation is run more efficiently, with healthier and happier GPs. Supporting the health and well-being of practitioners is integral to strengthening the GP health workforce (Commonwealth of Australia Department of Health, 2016). For regional and remote working GPs there are additional workforce challenges. These include difficulties in attracting permanent practitioners to live and work outside of Australia's major cities (Australian Government Department of Health, 2021). In a person-led model of primary health care supporting the well-being of practitioners is vital, so that they may in turn support an individual's care needs. Having a transient or insufficient GP workforce is a barrier to the provision of primary health care that is person-centred. A high GP and practice staff turnover has been identified as an impediment to effective care delivery in this study and others (Cosgriff, Reath, & Abbott, 2020).

In addition to the three doctor-patient relationship models previously described, Shutzberg (2021) proposes a fourth typology titled *The Equal Disempowerment of Physicians and Patients: Comradeship*. In this model both the person and their practitioner are disempowered by stakeholders that exert influence over health care encounters, specifically the business-led model of health care dominated by bureaucracy and funding challenges. In the spirit of comradeship, physicians and patients work together in an attempt to overcome barriers encountered with the existing health care system. Several examples of people working with their GPs to address health system challenges were identified in this study. These included the use of care plans to satisfy prescribing requirements; and the reports of GPs requesting people to maintain their own personal health records because the current system is not delivering health information to the GP in a timely and comprehensive manner. While the HCH model seeks to improve care for people living with chronic conditions, administrative requirements and funding challenges will continue to exert influence over any model of primary health care implemented in Australia.

### *6.4.5 Removing uncertainty around care costs*

For Australians ineligible to access fully government-funded primary care services, the financial cost of accessing care is governed by their GP at the time of consultation. Under the Medicare scheme, GPs may set their own fee levels and decide if, and who, they charge above the government-published scheduled fee (Duckett, 2015). This research identified uncertainty related to the provision of bulk-billed GP appointments in primary health care. Timely care is an essential component of effective chronic care management. Delayed care may increase the occurrence of complications related to the chronic condition resulting in episodes of acute care that are potentially preventable (AIHW, 2020c). This study found that although people appreciated when their GP chose to bulk-bill their appointment, not knowing if they might be charged an out-of-pocket fee deterred some from accessing care. Discretionary bulk-billing has been examined by other authors, with further research warranted to establish clearer criteria around the GP's decision to bulk-bill individual consultations (AIHW, 2020a; Song et al., 2019).

As part of the HCH model implementation, there is an opportunity to increase certainty around the cost of care. Through the process of VPR, billing can be discussed and clarified to enable certainty for people in their cost of care. The advantage to the consumer of a clearly defined funding model would be in removing any uncertainty around the cost of care. Further, having a clear understanding of the planned cost of care supports the development of the person-practitioner shared understanding of care delivery. For the wider health care system, there is the potential for a reduced demand on acute care services if people living with chronic conditions know if, and when, they will be bulk-billed for primary health care services.

A range of benefits of having a medical home-base for care have been well-recognised for both consumers and practitioners (Commonwealth of Australia Department of Health, 2016; Rosland et al., 2018; Rosser et al., 2011). Findings from this study ascertained that consumers might be willing to pay an out-of-pocket fee for care from their preferred provider, but this did not automatically extend to other GPs in the same practice. Reflecting on this issue is important for the practice organisation to encourage consumers to seek their care all in one place. Providing certainty around the cost of care from all of the providers in a practice, not just the preferred GP, has the potential to improve the person-practice relationship.

### *6.4.6 Connecting to alternative care*

As previously described, a key finding from this research was that many people living with chronic conditions reported receiving positive, helpful care from their preferred GP. Challenges to care delivery were experienced, however, when the regular GP and/or practice organisation could not be accessed for urgent care, particularly after-hours care. This need for urgent and/or after-hours care has been well documented and is of particular concern for regional communities like Cairns, where there is a limited supply of alternative care services, often leading to ED attendance (Harriss et al., 2016; Northern Queensland Primary Health Network, 2016; Ward, Humphreys, McGrail, Wakerman, & Chisholm, 2015). Improving the delivery of health services through the HCH model requires an approach that reflects the centrality of the person-practitioner relationship, while recognising the workload limitations that prevent individual GPs from providing extended after-hours care.

In this study most participants did not expect their preferred GP to be available to them after-hours. They recognised that their GPs need to balance work-life commitments and were respectful of this need. Some participants identified that adjusted hours of care might be helpful. As an example, extending care delivery until 5PM or early evening may assist consumers who work regular weekday hours. Practice organisations independently determine the hours of care delivery that are reasonable for their workforce and extended hours care may not be practical or reasonable for practitioners. To improve health service delivery, further consideration of ways to better support care needs when the regular GP is unavailable, are indicated.

Practices enrolled in the HCH trial were required to provide access to after-hours care by providing a contact number of a local area, extended hours clinic (Australian Government Department of Health, 2019b). While most practices met this requirement, it is in through this mechanism that opportunities exist to strengthen the model. Providing a contact number is a minimalist approach to the ongoing issue of limited after-hours access to primary care services. A key finding from this study is that improving the connectivity between the regular GP practice and the alternative after-hours care provider may better support the needs of people living with chronic conditions. Strategies to promote this connection can be built into the HCH model using existing tools. Tools such as My Health Record and Shared Care Plans have the potential to improve care connectivity and will be discussed further in this section.

Reports of the routine use of alternative GP care providers, unconnected to the regular GP practice, were found in this study. The use of GP providers unconnected to the regular primary care physician increases reliance on the person living with a chronic condition to communicate and connect their care. If a person is unable or unwilling to share details about their care experiences, there is the opportunity for unknown influences to impact care plans devised by the regular GP. For those that are willing to share their health history, the development and usage of a care plan may provide a repository of information for sharing. Reports from this study indicated that current care planning is limited in the primary health care setting. A recent study of MBS CDM items described an increasing number of care plans being established by GP practices for people living with chronic conditions, however there were comparatively far less being reviewed (Welberry et al., 2019). Findings from this study support this understanding. The requirement to establish and review care plans is a strength of the HCH model, with practices involved in the HCH trials reporting benefits from more regularly reviewing care plans (Health Policy Analysis, 2020b). Mechanisms to support the regular review of care plans are important to improve health service connectivity and promote continuity of care.

Further development of the HCH model is indicated to support connectivity with alternative care providers. Specifically, enabling the practice-nominated, after-hours care provider to access the shared care plans of HCH enrolees might better support their continuity of care. Efforts to improve data sharing platforms should be encouraged. Technological issues around establishing care plans were reported in the HCH interim evaluation. Challenges were experienced in connecting care plans to existing in-practice technologies; and linkages to external provider information technology systems designed to share data were difficult (Health Policy Analysis, 2019). Further work is indicated to facilitate improved data sharing within and across primary health care service providers.

Any sharing of an individual’s health information requires their explicit consent (Australian Digital Health Agency, 2017). Informed consent to share information with the after-hours care provider could be gathered from consumers as part of their HCH enrolment process. With agreements established between HCH and the alternative care provider, consumers could be asked to consent to the sharing of their care plan if, and when, they access the nominated alternative care provider for after-hours care. The impact of this approach could be viewed as a widening of the existing HCH team-based approach to include the after-hours care provider as part of a person's health care team. Potential benefits for consumers include having an increased awareness of the after-hours care provider preferred by their HCH; being better known to the alternative care practice; and improvements in communication of care decisions between providers.

An existing vehicle that could be used to improve communication and care co-ordination between the HCH and alternative care provider is the My Health Record. Enrolment in this Australian government health record management system was initially a requirement for participating in the HCH trial (Health Policy Analysis, 2019). However, following the first interim trial evaluation in 2019, due to ongoing consumer concerns regarding data privacy, the use of My Health Record became optional in the trial (Health Policy Analysis, 2020a). The uptake and usage of the My Health Record tool across the Australian health care system has been contentious (Lupton, 2019). Reports from this study indicated that GPs were reluctant to use the tool; and study participants had limited awareness of My Health Record usage. This lack of consumer awareness of My Health Record has been reported by others (Consumer Health Forum of Australia, 2019).

Poor uptake does not automatically mean that a tool is unfit for purpose, or an alternative tool cannot be found. Various state and territory governments in Australia have developed their own data linkage tools to enhance the flow of health information between primary health care providers. These have included the NT Health Chronic Conditions Management Model in the Northern Territory and Lumos in New South Wales (Productivity Commission, 2021). Developing tools that practitioners perceive to be both useful to improving care and easy to use will encourage uptake; and provide the mechanism for the necessary communication between the regular GP and alternative, after-hours care provider.

There are ongoing barriers to implementation when tools such as My Health Record are not being taken up by practitioners. It is worth considering whose interests are being served by people being dependent on a practice organisation to access and maintain their health records. An independent, person-controlled repository aligns more with a person-centred approach to care, than the current practice-dependent model. Some participants in this study reported hesitancy to disconnect from a practice that was not meeting their health care needs because they did not have easy access to their own health records. If consumers were confident that they had reliable access to a comprehensive repository of their health records, this may mean a reduced dependency on the individual practice organisation.

Strengthening strategies to promote digital inclusion across the population are necessary to enable consumers to be empowered and activated to manage their own health. More work needs to be done to support consumers to understand the potential strengths and limitations of a shared record system; to actively manage their own health records; and to develop and maintain their shared care plans. Promoting health literacy is an essential part of this process (Nichols et al., 2020). It has been well-established that those who the most economically and socially disadvantaged in society are the least likely to be digitally literate. This includes Australia’s regional and remote populations; Aboriginal and Torres Strait Islander peoples; and those living with disability and chronic conditions (Backholer, Browne, Wright, Grenfell, & Peeters, 2021b). As the point of entry to the health care system, practitioners in primary care are well-positioned to promote health literacy and be actively engaged with consumers in the co-creation and management of health records.

Establishing trust in the gathering and distribution of health data is essential to generate consumer support for data sharing tools (Productivity Commission, 2021). Sharing responsibility for data input between consumers and practitioners can build trust and provide the necessary oversight to promote accuracy in health records. Phase 1 findings from this study described issues with input into the hospital administrative dataset for Indigenous status and self-referral to the ED. In the Phase 2 interviews, participants described communications with practitioners that explained the difference between self- and doctor-referral to the ED; and expressed the need for health practitioners to listen to their direct recount rather than entirely rely on the recorded data. Supporting consumers to be actively engaged with their own health records, both initially and on an ongoing basis, can be an important mechanism to promote data accuracy. Avoiding inaccuracies in health records is of particular importance when people interact with health services to which they are not well-known, such as after-hours care providers. By building ongoing, trusting relationships with consumers, HCH practitioners are in a strong position to support consumers to understand, develop and manage their own health records using appropriate data sharing tools.

### *6.4.7 Improving care for people with complex, uncommon chronic conditions*

Conditions that are poorly understood and have unclear treatment pathways challenge health service delivery. People living with uncommon or complex chronic conditions in this study reported difficulty in accessing existing primary health care services to manage and meet their health care needs. This contrasted with those with common chronic conditions involving clear treatment plans, such as diabetes, who reported mostly positive experiences with existing service provision. For consumers with well-understood and serviced conditions, a change in the model of service delivery may not directly improve their experience of care. Opportunities exist to utilise the HCH model to establish more reliable, trusted and connected care for those living with uncommon and/or complex chronic conditions.

Formalising the person-practitioner commitment as part of the HCH model, could be advantageous for those living with complex, uncommon chronic conditions. This was the group who felt least understood by practitioners and had the most difficulty finding a GP to commit to their regular care management. Both interpersonal and longitudinal continuity of care were valued by participants in this study and others as a vital component for care delivery (Cosgriff et al., 2020; Saultz, 2003). For those that are not already connected to a preferred GP the HCH model may provide the opportunity to build a much-needed collaborative person-practitioner relationship. Meanwhile, those with existing helpful person-practitioner relationships may benefit by affirming their relationship with their existing GP.

The formalised VPR commitment, central to the HCH model, provides the much-needed opportunity for consumers with complex, uncommon chronic conditions to connect with practitioners. Through VPR consumers are recognised by their GP and practice organisation as being committed to them for the management of care. For consumers recognition by the GP and practice can support their need to be known and promote a trusting therapeutic relationship. Reinforcing these mutual commitments has the potential to enhance shared care planning and improve the supportive care management of those with complex, uncommon chronic conditions, which is of particular importance to those with unclear treatment pathways whose care plans requires an ongoing, reflective collaborative approach.

Intentionally identifying and recruiting consumers who were not already well-serviced by the existing model did not form part of the HCH program trials (Health Policy Analysis, 2020a). The trial evaluators have identified that future recruitment to the program should consider purposefully recruiting those that are “less motivated, activated and/or willing to try new things” (Health Policy Analysis, 2020a, p.26). The language of this statement places the burden of being willing to act on the consumer. Using a person-centred approach, perhaps it might be worth considering how practitioners can actively recruit those that are complex and difficult to treat, not because of their individual personal characteristics but due to the lack of clarity and understanding around the disease aetiology.

## 6.5 Chapter summary

In chapter 6 the mixed methods integration process was detailed. Integrated findings were identified and described to explore if the HCHs model might improve the delivery of health service to people living with chronic conditions in Cairns; and to consider factors that might influence the model implementation *(RQ3)*. Discussion of the integrated findings focussed on the primary research question: to determine how the HCH model of care can improve the delivery of health service to people living with chronic conditions in Cairns.

Key insights from the integrated findings were:

i. The HCH model has a strong practitioner-centric focus. More work needs to be done to support the model to be a person-led model of care.
ii. For a person-led model of primary health care, the irrefutable importance of the person-practitioner relationship needs to be recognised. Strengthening the model around this relationship will promote acceptability of the model to consumers.
iii. People who are already well-serviced by the existing primary care model may not perceive an immediate advantage from HCH enrolment.
iv. For some consumers the best place for their medical home base may be in specialist care. Those who perceive medical specialists to be the best providers of their chronic care management may not benefit from HCH enrolment with a GP organisation.
v. The benefits of HCH model implementation for providers, including sharing the workload and better funding models, may strengthen the primary health care workforce and improve service delivery. This in turn may lead to better service provision for consumers.
vi. Uncertainties around discretionary billing in primary care disempowers consumers. Enrolment in the HCH model may promote discussion and certainty about the cost of care for consumers.
vii. Improved measures to connect alternative, after-hours GP care with the regular GP are required. The HCH model can be used to facilitate this connection by increasing consumer understanding of care options; and effectively using data sharing tools to collect and share health information. A person-led approach is required to ensure consumers have control and confidence in sharing their health information. The HCH model can be a useful vehicle for improving consumer health literacy as it promotes the development of trusting person-practitioner and -practice relationships.
viii. Those living with complex, uncommon chronic conditions have an unmet need for care in the existing primary health care model. Targeting those least serviced by the existing

model for inclusion in the HCH model may better serve the needs of people living with chronic conditions in Cairns and beyond.

The next and final chapter presents the recommendations arising from this project. A reflection on the thesis process is included, as well as a consideration of the study's strengths and weaknesses.

# Chapter 7: Recommendations, Reflection and Conclusion

## 7.1 Introduction

In the concluding chapter, recommendations are identified to support the implementation of a Health Care Homes model of care. These recommendations may be applicable to people with chronic conditions in Cairns, as well as those living in other communities across Australia. Study strengths and limitations are discussed in this chapter. This discourse includes the recognition of potential threats to validity that may occur when connected data is used in a mixed methods research design; and the identification of strategies to minimise threats. The final section contemplates the process of undertaking the research. This personal reflection involves a consideration of my scholarship throughout the research process and recognises ways to improve my own practice when undertaking future research activity.

## 7.2 Recommendations

Following the conclusion of the Australian Government's HCH trials on 30 June 2021, policymakers have been examining which elements of the model might be used to strengthen primary health care service delivery into the future. At the time of finalising this thesis (early- to mid-2022) the final evaluation of the HCH trials had not been released and the consultation phase of the Australian Government's Primary Health Care 10 Year Plan has been concluded. Although there is uncertainty around the exact initiatives that will be supported by the government into the future, the Consultation Draft of the Primary Health Care 10 Year Plan has provided some insight into the potential approaches (Australian Government Department of Health, 2021). Directly relevant to the HCH model, the foundations for primary health care reform identified in the Consultation Draft include:

i. supporting people to commit to a practice and practitioner through VPR, involving an expansion of the current funding model to increase the use of blended payments in primary care;
ii. continuation and strengthening of the Telehealth method of care delivery to promote continuity of care;
iii. increased investments in after-hours care;
iv. an increasing role for allied health as part of the primary health care team; and,
v. improvements in digital health infrastructure, including efforts to enhance the effectiveness of shared health records systems (Australian Government Department of Health, 2021).

Findings from this thesis have concluded that an authentically person-centred and -led approach is needed to improve health service delivery to people living with chronic conditions in Cairns. Arising from this study, recommendations for practice and future research have been identified. These are:

1. Implementation of the HCH model could be improved if policymakers adapted the model to centralise the person-practitioner relationship. That is, if the process of VPR was with a specified practitioner and that the wider practice team was recognised for their supportive and essential role. Adjusting the focus to a person-practitioner not person-practice model would better reflect the values and needs of those who live with chronic conditions.
2. Priority for enrolment in an HCH-type model should be given to those least served by existing care models, specifically those living with uncommon or complex chronic conditions; and Aboriginal and Torres Strait Islander people living with chronic conditions who attend the ED for care and are not connected to a primary health care

organisation. A person-centred focus involves addressing the unmet needs of people living with chronic conditions. It is recommended that those who are already well-serviced by the existing model of care should not be prioritised for VPR enrolment. Recruiting those who are well-known to the practice organisation and are already well-serviced by the existing model is not an optimum approach to improving health service delivery. Identifying and supporting those whose needs are not being met by the current model has the potential to enhance care delivery for people living with chronic conditions. With GP workforce shortages increasingly challenging the delivery of health services in Cairns (Northern Queensland Primary Health Network, 2019), residents living with complex chronic conditions would benefit from this priority approach to VPR.

3. A person-led model of care recognises that for people living with some chronic conditions the GP is not their preferred care manager. Ongoing adaptations of the HCH model could benefit from further investigation of a medical home-base situated in secondary care, or the increased integration of primary and secondary care providers. This may be of benefit for specific chronic conditions that require specialist medical management, such as some endocrine, cardiac and respiratory conditions.
4. Alternative, after-hours service providers are necessary for the effective functioning of the primary health care sector. The HCH model can be strengthened by employing methods to bolster the connectivity between the HCH and alternative care providers. A person-centred approach recognises the essential role of alternative service providers and considers ways to make this connection better for consumers. Measures to improve the sharing of essential care planning information between regular and alternative providers are required. Consumer needs can be better supported through a range of person-centred approaches that include:
    i. Increased efforts can be made by providers to establish communication pathways that support person-centred care. A person-led approach may involve consumers identifying a preferred alternative provider and advising their regular GP of this preference. The role of the regular HCH practice organisation would be to support and facilitate the sharing of health information between the person-nominated care providers. With the consent of the consumer, this may involve the HCH practice initiating and liaising with the alternative care provider to facilitate a communication pathway that enables the timely and comprehensive sharing of care management decisions.

        Having a clearly established communication pathway is of particular importance for people living in regional communities such as Cairns. Living in a regional community may limit the opportunity to maintain anonymity when seeking care. Consumers in regional communities need to be confident that communication pathways between providers maintain their privacy. In this person-led approach, consumers may be more confident that their health information is private, as they have chosen the alternative care provider. Using this approach consumers may avoid potential breaches of privacy that may arise from being known by practice staff.

ii. Another approach involves the HCH organisation identifying an alternative care provider for people enrolled at their practice. This method may be utilised when an individual does not have a preferred alternative provider and is willing to use the alternative provider nominated by their HCH. Under this approach, the HCH would be responsible for identifying and advising consumers of a preferred practice organisation for them to access if/when alternative care is required. This could increase consumer certainty around sourcing alternative care. Additionally, consumers may benefit by being known to an alternative care practice; consumer confidence may be boosted with the knowledge that the alternative care provider is working in partnership with their regular GP; and care coordination may be better supported through the exchange of health information between the HCH and alternative care practice. Importantly, health information sharing can be limited to a clearly defined group of practitioners, known to the consumer. This addresses the consumer preference to limit data sharing to the health care practitioners that are directly involved in the delivery of their care; and supports efforts to protect the privacy of people living in regional communities as they access health care services.

iii. Strengthening existing data sharing tools may promote more effective communications between regular and alternative primary health care providers. Further research efforts to better understand practitioner and consumer hesitancy around the use of existing data sharing tools are indicated. Practitioner and consumer concerns need to be addressed in the ongoing development of tools to support the effective implementation and comprehensive uptake of data sharing in primary health care.

iv. In addition to the further development of practitioner- and consumer-informed data sharing tools, more work is needed to promote consumer health literacy around the collection, management and sharing of health information. This involves building tools that are straightforward to navigate; and enable consumers to easily input, review and share health information with their nominated health care practitioners. The existing My Health Record tool has many of these features but has not been well-understood or used by practitioners or consumers. Efforts to improve understanding of tools and their usage are needed to empower people to take control of their own health records and strengthen health data sharing systems.

5. The process of VPR can be used as a vehicle to reduce or remove consumer uncertainty around the cost of their care. As part of the initial patient registration process, clarity can be provided to people living with chronic conditions regarding service provision and care costs. The practice organisation can identify if, and when, any out-of-pocket fees might be incurred. This description should include consultations with the regular GP; appointments with alternative GPs within the regular GP's practice; care provided by other health care practitioners associated with the HCH; and the costs that might be incurred when using the nominated alternative care provider.
6. The HCH bundled payment model may be a useful mechanism to encourage consumers to seek their care all in one place. To promote a person-led model of care delivery, consideration should be given by the practice organisation in regard to the fee structure for care delivery that is not included in the bundled payment model. In the HCH, additional fees that might be levied by practices are for care delivery that is not related to the chronic condition; and a supplementary out-of-pocket fee paid by consumers in addition to the bundled payment. To support the person-led model, additional out-of-pocket fees should be reviewed, to remove any cost-barriers that may prevent people living with chronic conditions from seeking care all in one place. As an example, if a person has voluntarily enrolled with a practice and is funded for the care of their chronic condition through the bundled payment model, it would be disadvantageous for an out-of-pocket fee to be charged for any fee-for-service care that is not related to their chronic condition. Further, when consulting with an alternative GP in the regular GPs practice, removal of any supplementary out-of-pocket fees would support consumers to exclusively access care within the HCH. Consistent with the previous recommendation, fee schedules should be clearly communicated to consumers to remove any uncertainty around the potential costs of care.
7. The current practice of discretionary bulk-billing of primary health care services requires additional research investigation. A further understanding of the GPs rationale for bulk-billing consumers would be useful for policymakers and consumers. Additionally, an improved understanding of how discretionary bulk-billing impacts consumers would better inform practitioners and policymakers. This recommendation has informed discussion by the author of this thesis with Australia's Consumer Health Forum (CHF) as part of their membership of the research

and data special interest group. These discussions have been used to develop a planned CHF survey project around price transparency for consumers (February 2022).

8. Efforts to improve the accuracy of health data records to accurately reflect the person-perspective may strengthen health systems though the provision of more reliable health information to decision-makers. Recording the person's self-report of doctor referral to the ED in the administrative health record could enhance understanding of the primary care interface with acute care services.
9. Further research into people's reporting of Indigenous status to health services may be helpful to explain differences in health administrative records for an individual's Indigenous status. This could provide insight to better understand the experience of reporting Indigenous status. A more accurate collection of Indigenous status data by health administrators has the potential to improve the quality of the datasets used by service providers and governments for health service decision-making.

## 7.3 Strengths and limitations of the research

### *7.3.1 Study strengths*

This study explored the experiences of adults living with chronic conditions in Cairns to inform on the implementation of a new model of primary health care, the Health Care Home. A notable strength of this research was the use of a person-perspective approach. In the P3ED Survey participants were asked to self-nominate if they had a chronic condition, with those living with chronic conditions being described as having a "self-identified chronic condition". Self-identification of having a health condition esteems the person-perspective of their own health state. Placing the person at the centre of the care model requires policymakers and practitioners to value an individual's understanding and knowledge of their own health history and context. This does not reduce the value of a verified medical diagnosis for clinical decision making, however it is crucial that self-reports of health conditions are included when decisions are being made about care delivery. This is of particular importance for those with complex, long-term chronic conditions whose health may be difficult to understand and manage.

Further strengths of the study design used in this research included the use of existing datasets to maximise their value; and the linkage of these datasets to enhance understanding. Using existing datasets enhances their utility; avoiding the need to expend limited resources on gathering new data is an efficient approach to research which expands the work of earlier data collectors, consumers and researchers. This study made use of multiple, existing datasets to generate new understanding.

Strengths of the P3ED Survey that was used for the data linkage in this study included: the large sample size; participants being recruited 24/7 from within the ED; the use of trained interviewers for the face-to-face survey deployment; that the survey tool was piloted prior to deployment; and that the data linkage undertaken in this study indicated that the sample was broadly representative of all ED attendees for the relevant period.

Strengths of the qualitative inquiry included that the participants were recruited from the contact details provided during their presentation to the ED. Notably, this method of recruitment was commented on by several of the interview participants who observed that they had not previously been involved in health service research. Conducting the interviews in participant homes and workplaces enabled their participation and supported diversity in the interview participant group. The recruitment approach used in this study was a strength, capturing the perspectives of people who were not regularly or easily engaged in research.

Five articles were published from this research. Each of these was subject to a detailed peer-review process in quality, Australian journals. The process of peer-review strengthened each of the individual manuscripts, as well as the overall approach to research in this study. Findings from this research have been presented and discussed at national conferences and with local area health service organisations. In addition, the findings from this research have been shared with consumer representatives and used to inform policy development through contributions to the Consumer Health Forum's Research and Data Special Interest Group.

### *7.3.2 Study limitations*

Limitations of this research have been identified. A limitation to the generalisability of the findings was that the research was undertaken in a single community setting. The existing datasets used in the Phase 1 quantitative investigation involved only the Cairns Hospital ED and shaped the study design to a single community. Further investigation of the key findings from this research in other settings is indicated to verify the study results across a range of Australian communities.

The use of an existing survey dataset influenced this research in several ways:

i. Firstly, the P3ED Survey was not designed for the purpose of the research questions in this thesis. This meant that although many of the variables were useful, some were not, and some were not well-defined to answer this thesis' research questions. As an example, the data gathered in the P3ED Survey only included a broad grouping for the person's chronic condition. For the purpose of this study, it would have been helpful to have expanded this question to include a detailed explanation of the range and quantity of chronic conditions reported by the survey participants.
ii. The P3ED Survey tool was derived from existing tools and piloted. However, it was not a validated survey tool in itself. For future research the use of a validated tool would be preferred.
iii. The author of this thesis was not involved in the original P3ED Survey project. This meant that additional time and effort was required to understand the survey data collection process and to explore inconsistencies found in the P3ED Survey dataset. As an example, inconsistencies were identified for children's birthdates in the P3ED Survey dataset when compared with the hospital administrative datasets. Investigation revealed that some parents had provided their own birthdates when discussing their child's experiences in the P3ED Survey. Additional effort was required to ensure that the linked P3ED Survey response and hospital administrative data record accurately reflected the person as a child. As children were not included in the inclusion criteria for this research, the data for these individuals was removed to ensure that no children were included in the final linked dataset used for analysis.

iv. The P3ED Survey was conducted in the Cairns Hospital ED with participants being broadly representative of ED attendees. However, findings from this research may not be generalisable to those that do not use ED services, including those who access private hospital care and those who are well-serviced by primary care.

Although using hospital administrative datasets for research promotes utility, the use of these datasets is also a study limitation. Specifically, there are acknowledged limitations with using routinely collected data. These limitations include errors and biases in data collection which can lead to inaccuracies in classification (Hemkens, Contopoulos-Ioannidis, & Ioannidis, 2016). Inaccuracies identified in the datasets used in this research may have influenced study results.

Limitations were identified in the process of recruitment to interview:

i. Practical recruitment limitations influenced participation in the Phase 2 qualitative interviews (see *section 3.4.6 Phase 2: Recruitment to interview)*, with final recruitment involving all of those who agreed to participate. This may have limited the depth and breadth of data collection, although data saturation was achieved with the participant group.
ii. People who identified as Indigenous were underrepresented in the qualitative interview participant group (see *Table 5*). Although people who identified as Indigenous were not purposefully sampled, the recruitment approach of contacting all those who had previously provided contact details in the P3ED Survey included people who had identified as Indigenous (n=12). Of those who identified as Indigenous and were approached for interview, nearly half (n=5) were unable to be contacted as their details were not current (see *Table 4*). This meant that only a small number of people who identified as Indigenous (n=7) were available for recruitment to interview, with only one person who identified as Indigenous being interviewed in Phase 2 of this study. Reflecting on this process, further consideration of the cultural appropriateness and methods of recruitment to interview employed in this research were needed. A lack of Indigenous representation in the qualitative interviews is reported as a limitation to the study findings.

Time was a limitation that impacted the conduct of this research. When the initial research questions were devised, the Health Care Homes trials had not begun. As the model was trialled in the real-world setting it was adapted in response to the interim evaluation feedback. The research undertaken in this study was required to adapt to the changes in this emerging model of care. An example of this was the My Health Record, which was initially a requisite for trial inclusion but became optional in later stages of the HCH trial. The findings from this thesis required additional consideration on the impact of removing the My Health Record as an essential element of the HCH model of care.

Changes in the wider primary health care setting across time also influenced this research. The impact of the COVID-19 pandemic not only impacted the author’s ability to complete the research in a timely way but changed some of the long-wanted features of primary health care service delivery in Australia. This was particularly notable for telehealth services which had been promoted as a key model feature in the early stages of the HCH trials. The HCH model was perceived to be a useful mechanism to fund telehealth services in primary care, through the bundled payment approach. When the COVID-19 pandemic resulted in the necessity for the population to isolate, the Australian Government introduced funding for telehealth GP consultations. Data collection for the qualitative interviews occurred in 2017 and 2018, prior to the pandemic. This included a discussion of the value of a proposed telehealth service to participants. By 2022, when this thesis was being finalised, telehealth was a reality in the Australian primary health care setting. This meant that the data collected for this research on a proposed model of telehealth in primary care was outdated and no longer useful to inform practice. For this reason, the analysis and discussion on a proposed HCH model of care that includes telehealth has been removed from the thesis.

## 7.4 Validity of the mixed methods design

This study was an explanatory sequential mixed methods design. This was a study strength. The study exemplified how quantitative data collection and analysis can be used to identify patterns and potential explanations about people's experiences of health care services. The sequential design demonstrated how these quantitative findings can be built on, using a connected qualitative inquiry, to generate a contextual understanding of people's engagement with health care services for treatment of their chronic condition.

Using a mixed methods approach requires a consideration of validity that is specific to the study design. Validity in mixed methods research considers the "strategies that address potential issues in data collection, data analysis, and the interpretations that might compromise the merging or connecting of the quantitative and qualitative strands of the study and the conclusions drawn from the combination" (Creswell & Plano Clark, 2011, p.239). These authors identify a series of potential threats to validity when data is connected and suggest strategies to minimise these threats. Potential threats to validity, suggested strategies for threat minimisation and approaches used in this research to minimise threats, are presented in *Table 13*.

*Table 13: Connecting data in an explanatory sequential mixed methods design: Potential threats to validity and strategies for minimisation**

| Potential threat to validity | Suggested strategy to minimise | Approach used in this research |
|---|---|---|
| Selecting inappropriate study participants for data collection in the quantitative and qualitative phases | Use same individuals from the earlier phase in the connected phase | Phase 2 interview participants were recruited from their participation in the Phase 1 P3ED Survey |
| Using inappropriate sample sizes for each phase | Use larger sample size for quantitative phase, smaller sample for qualitative | Phase 1 involved n=549 adults living with chronic conditions<br>Phase 2 involved n=21 adults living with chronic conditions |
| Choosing Phase 2 qualitative participants who cannot | Use individuals from the earlier phase in the connected phase | Phase 2 interview participants were recruited |

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| explain Phase 1 quantitative results |  | from their participation in the Phase 1 P3ED Survey |
| Choosing weak quantitative results for follow-up in qualitative phase | Be selective in the choice of results for follow-up | Key Phase 1 quantitative results were followed up. |
| Comparing the findings from each phase, when the intention in an explanatory design is to build understanding | Be guided by the mixed methods research question to interpret the combined quantitative and qualitative findings. | Integration of Phases 1 and 2 findings are guided by the mixed methods research question (*RQ3*). |

*Table adapted from Creswell and Plano Clark (2011, p.242).

## 7.5 Reflections on the process

Reflection is a necessary component of the research process. Employing a pragmatic perspective, reflectivity involves a consideration of how the research findings were constructed and considers if, and how, the approach to research may be improved (Mortari, 2015). *Table 14* describes my personal reflection on the research process and was informed by Hesse-Biber (2010), who has provided guidance for reflecting on the process of undertaking a mixed methods research approach.

*Table 14: Reflection on the research process*

| Reflective approach | Approach used in this research |
|---|---|
| Consideration of personal skills for undertaking quantitative, qualitative and mixed methods research | At the beginning of this research my experience had been in quantitative analysis, with a very limited experience of qualitative analysis and no mixed methods experience. This research enabled me to expand my skillset in all three approaches.<br>**Quantitative Research Skills**<br>Through this research my quantitative analytical skill set was expanded in the areas of data linkage; descriptive statistics; logistic regression; and sensitivity and specificity analysis. At times I struggled with the messiness of the data linkage. The hospital administrative datasets involved a huge amount of information. As I was worked through the large amounts of data, issues of errors and missing data required an extended time commitment to clean the data and ensure that it was accurately reflecting the person's care episodes. Additionally, I found the data in the linked dataset to be limited in explaining the patient's experience of care. As an example, the length of medical consultation time could be calculated numerically, but this did not consider other factors that could have impacted the length of care experience, such as ED and hospital staffing levels, and access to and availability of diagnostic services. Overall, I felt that the quantitative work in this thesis improved my technical skills but strengthened my resolve to use mixed methods approaches when exploring person perspectives and experiences. |

**Qualitative Data Collection Skills**

In the data gathering stage of the qualitative phase of the project I felt that I built on my existing skillset. The qualitative characteristic of rapport enables an environment of trust and open communication (Braun & Clarke, 2013). With my background working as a Registered Nurse, I felt comfortable with people and could readily adapt my own language and approach to build a trusting communication. This was demonstrated in several ways:

i. I had been given a brief insight into participants' history of chronic conditions from their hospital records, self-report in the P3ED Survey and as part of the recruitment to interview process. Undertaking the interviews revealed a more detailed insight into their experiences of chronic conditions. In particularly only one person from the interview participant group had nominated having a mental health condition in the P3ED Survey. Contrastingly, eleven participants disclosed having a mental health condition part-way through their interview (n=11, self-reported depression, anxiety, stress). Building trust in the person-practitioner relationship is necessary to enhance people's self-disclosure of health conditions (Ritholz, Beverly, Brooks, Abrahamson, & Weinger, 2014), with people being less likely to disclose their mental health condition to health professionals not directly involved in their care (Reavley, Morgan, & Jorm, 2018). As rapport between myself and a participant developed through the interview process, there was an observable increase in the self-disclosure of mental health conditions.

ii. Several participants directly stated that they felt comfortable discussing their experiences about health care services directly with me. Some observed that they felt that measuring their experiences of health care service through a survey tool was a waste of time. They reported that they no longer participated in the hospital's patient experience surveys as they did not believe these to be an effective tool for change – and that they were being undertaken only to satisfy administrative requirements. This disclosure by participants demonstrated that they were trusting in their interactions with myself as an interviewer.

Undertaking this research built on my qualitative data collection skills through the process of refining the interview schedule (see *Section 3.4.7 Phase 2: Semi-structured interviews*). Following each interview, the schedule was reviewed to ensure that the data being collected was addressing the research questions (see *Section 3.4.8 Phase 2: Grounded theory approaches to data generation and analysis in mixed methods research*). Through this process my understanding of how to phrase and situate questions within an interview schedule was developed.

**Qualitative Data Analysis Skills**

Following the processes of initial coding and manual coding I felt that I was lost in the data. The analytical approach prior to this point had been useful to describe people's perspectives of the existing health care services; identify aspects of health service delivery that were valued by people living with chronic conditions; and to summarise the key ideas under the Health Care Homes model elements. Critically reflecting on this process, I felt that I was summarising but not sufficiently analysing the data.

On the advice of my advisors, I stepped away from this descriptive approach and used a storyline approach to data analysis (see *Section: 3.4.8 Phase 2: Grounded theory approaches to data generation and analysis in mixed methods research*). It was through this storyline approach that a deeper level of analysis was explored. Looking at the data differently led to a realisation: people were reporting different perspectives based the type of chronic condition(s) they experience. Following this idea, I separated the data into those with common

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|  | and uncommon chronic conditions using the AIHW criteria for common chronic conditions. This led to the findings around the care experiences of people with uncommon, complex chronic conditions (see *Section: 5.2.1 Manuscript*). Through utilising a range of different techniques in this research my approach to qualitative data analysis has been strengthened.<br>**Mixed Methods Research Skills**<br>Mixed methods research has its own language and set of techniques. I did not understand this at the beginning of this thesis project. My initial ideas around mixed methods research involved a simpler approach, whereby the sum of quantitative and qualitative findings would add up to the mixed methods results. Through undertaking this project, I have learnt that mixed methods designs are much more developed than I had initially thought; that the data needs to be connected and to build; and that data integration needs to be done purposefully, not casually. |
| Consideration of approaches to future research with health consumers | **Exploratory sequential mixed methods approach**<br>Following my experience in this project, I am strongly supportive of the mixed methods approach to research, particularly for studies involving health care consumers. For future research it is recommended that researchers consider the utility of an exploratory sequential mixed methods design. The rationale for this has been developed from my own experience in this explanatory sequential study. Specifically, I would recommend using an exploratory sequential mixed methods approach for two main reasons:<br>i. To promote a person-centred focus in health research, asking the person what they think/feel/value about health services may enhance the generation of new ideas and thinking. In quantitative study designs, and in explanatory sequential mixed methods studies which lead with a quantitative first phase, the quantitative data collection relies on what is known already. Survey |

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| | questions are derived from the literature, based on what is already known about the issue under investigation. Using an exploratory design involves undertaking the qualitative inquiry first. Exploring understanding qualitatively with health care consumers enables data to be generated that is not pre-conceived but is sourced from the study participants' perspectives. This is a person-led model of research, rather than a researcher-led model.<br>ii. The second reason for planning the use of an exploratory sequential approach involves using the data collected from participants in the first phase to verify the understanding in the second quantitative phase. My rationale for this is as follows: policymakers like numbers. They want to know "what proportion of people think that or do that?" Numbers and statistics are requisite for decision-making. For this reason, an exploratory mixed methods design makes sense: start with a person-generated understanding from the qualitative inquiry and then build and strengthen the key findings through a quantitative investigation.<br>Reflecting on the mixed methods approach taken in this study, if I had my time again, I would use an exploratory design. However, it was only by learning and developing my own understanding through the conduct of this study that I have come to this conclusion.<br>**Co-Design**<br>At the beginning of this project my background as a health practitioner had developed a view of people as 'patients' in the health care system. Throughout the experience of undertaking this project my language and perspective has developed. This has been demonstrated in the series of publications included in this thesis, with the Chapters 2 and 4 manuscripts describing 'patient' perspectives and the Chapter 5 manuscript using the term 'consumer'. Shifting my personal focus from people |

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| | “patient-ly” waiting for health care to occur, to activated consumers of health care services has reframed my thinking on health service research.<br>In future research activities I plan to use a co-design approach. Co-designing with consumers enables the product of the research to have meaning to the end-user, because they have been engaged in the design, conduct and plan for the implementation of study outcomes (Slattery, Saeri, & Bragge, 2020). Co-designing recognises the person as the expert in their own care and provides a vehicle for authentic person-centred health care research. |

## 7.6 Conclusion and thesis summary

The aim of this research was to explore the experience of people living with chronic conditions in Cairns as they access local-area primary health care services; then use this knowledge to explain how the introduction of the Health Care Homes model might improve the delivery of health care services, from the perspective of the people who utilise these services.

Across the seven thesis chapters the person-perspective of the Health Care Homes model was explored. This included five published articles; one draft report which was created at the request of the local hospital’s Aboriginal and Torres Strait Islander Community Consultation Committee; and a detailed explanation of the mixed methods approach and integrated findings. In this final thesis chapter, study strengths and limitations were identified, including a personal reflection on ways to improve future research practice involving health consumers. A range of recommendations were identified for practice, policymakers and health service managers. It is hoped that these may contribute to the body of evidence that informs ongoing person-led models of primary health care service delivery.

The Health Care Homes model of care can improve the delivery of health service to people living with chronic conditions in Cairns if there is a genuine commitment to implementing authentically person-centred approaches to care delivery. This begins with an acknowledgement of the practitioner focussed lens that drives many existing models of care. Health services in Australia can move from a patient-centred rhetoric to a person-centred reality through the development and implementation of person-led models of care.

Adapting the Health Care Homes model to support people’s preferences for a direct connection with their preferred medical practitioner is essential, with the practice team and other health care professionals supporting this fundamental relationship. This includes a consideration of whether or not the GP is the best health care practitioner to manage the care of all chronic conditions, with medical specialists potentially being the preferred practitioners for some types of chronic care. Prioritising the Health Care Homes model to include people living with uncommon, complex chronic conditions who are not well serviced by the existing models of primary health care would maximise the utility of model implementation.

The findings from this research were only possible because of the efforts and insights of the study participants: both the original P3ED Survey participants and the twenty-one interview participants. My genuine thanks, appreciation and respect is extended to each individual. Your time, knowledge and input into this process has been greatly valued. I wish you well.

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# List of Appendices

## Appendix G – Dissemination of Findings

G1 Public Health Association of Australia: National Primary Health Care Conference, December 2016 (poster presentation)

G2 JCU Nursing, Midwifery and Nutrition Research School, December 2017 (oral presentation)

G3 Aboriginal & Torres Strait Islander Community Consultation Committee CHHHS, March 2018 (oral presentation)

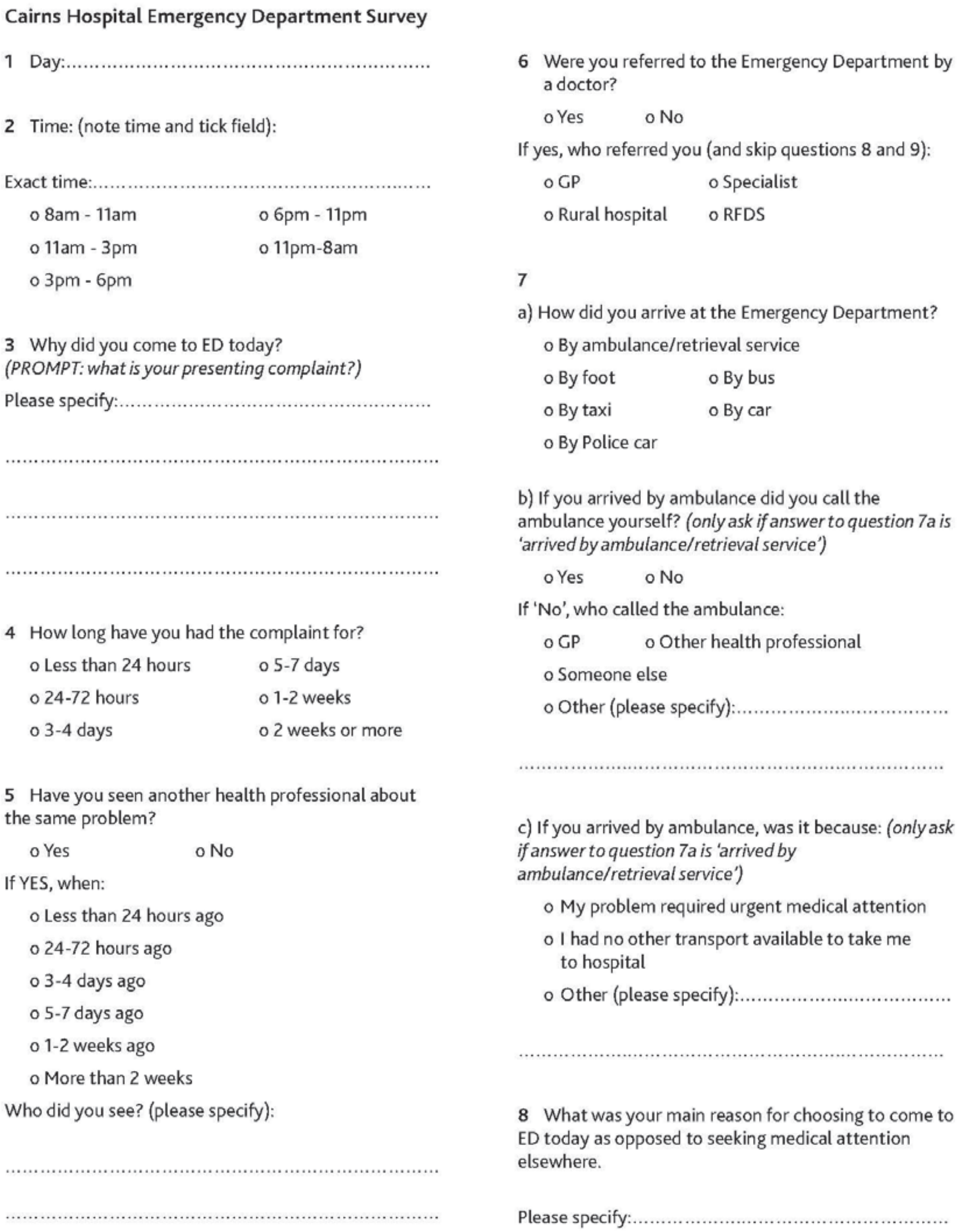
G4 Public Health Association of Australia: Australian Public Health Conference Cairns, September 2018 (oral presentation)

G5 Weekend Post, Cairns, September 2018 (media report)

G6 Apunipima Cape York Health Council journal club, November 2018 (oral presentation)

# Appendix A - Survey Questions

The Patients' Psychological and Practical Reasons for Attending the Cairns Hospital Emergency Department (P3ED) - Survey questions (Mills et al., 2014).



**Cairns Hospital Emergency Department Survey**

**1** Day:……………………………………………………

**2** Time: (note time and tick field):

Exact time:……………………………………………………

○ 8am - 11am ○ 6pm - 11pm
○ 11am - 3pm ○ 11pm-8am
○ 3pm - 6pm

**3** Why did you come to ED today?
*(PROMPT: what is your presenting complaint?)*

Please specify:……………………………………………

……………………………………………………………

……………………………………………………………

……………………………………………………………

**4** How long have you had the complaint for?

○ Less than 24 hours ○ 5-7 days
○ 24-72 hours ○ 1-2 weeks
○ 3-4 days ○ 2 weeks or more

**5** Have you seen another health professional about the same problem?

○ Yes ○ No

If YES, when:

○ Less than 24 hours ago
○ 24-72 hours ago
○ 3-4 days ago
○ 5-7 days ago
○ 1-2 weeks ago
○ More than 2 weeks

Who did you see? (please specify):

……………………………………………………………

……………………………………………………………

**6** Were you referred to the Emergency Department by a doctor?

○ Yes ○ No

If yes, who referred you (and skip questions 8 and 9):

○ GP ○ Specialist
○ Rural hospital ○ RFDS

**7**

a) How did you arrive at the Emergency Department?

○ By ambulance/retrieval service
○ By foot ○ By bus
○ By taxi ○ By car
○ By Police car

b) If you arrived by ambulance did you call the ambulance yourself? *(only ask if answer to question 7a is 'arrived by ambulance/retrieval service')*

○ Yes ○ No

If 'No', who called the ambulance:

○ GP ○ Other health professional
○ Someone else
○ Other (please specify):…………………………………

……………………………………………………………

c) If you arrived by ambulance, was it because: *(only ask if answer to question 7a is 'arrived by ambulance/retrieval service')*

○ My problem required urgent medical attention
○ I had no other transport available to take me to hospital
○ Other (please specify):…………………………………

……………………………………………………………

**8** What was your main reason for choosing to come to ED today as opposed to seeking medical attention elsewhere.

Please specify:……………………………………………

Only ask if answer to question 6 is 'No'. Interviewer to note answer verbatim and tick box most appropriate.

- Asked to return by Cairns Hospital Doctor or Nurse
- Sent by another health professional (i.e. dentist, optometrist, pharmacist)
- Sent by Queensland Health's 13HEALTH help line
- Sent here by someone else
- Convenient location
- Open 24 hours
- The hospital has the services that I need in one location (x-ray, bloods tests etc.)
- Quicker than getting a GP appointment
- Would be a shorter wait
- Best place for my particular problem
- I don't have a GP
- I wanted a second opinion
- I didn't want to bother my GP
- There are no bulk-billing clinics nearby
- I always come to the hospital for my care
- ED is cheaper than a GP visit
- I came so I could be seen by someone who does not know me
- I feel reassured after I have been assessed by ED staff
- I knew I needed to be admitted to the hospital
- I have been very happy with the care I have received in the past
- NGO sent me (please specify):......................

.....................................................................

- Other (please specify):...................................

.....................................................................

**9** Please choose any other reasons that may have influenced your decision to come to ED today (please tick up to three boxes in order of importance). (Note: choices to be ranked)

Please specify:

1 .................................................................

2. ................................................................

3..................................................................

Only ask if answer to question 6 is 'No'. Interviewer to note answers verbatim and tick boxes most appropriate.

- Asked to return by Cairns Hospital Doctor or Nurse
- Sent by another health professional (i.e. dentist, optometrist, pharmacist)
- Sent by Queensland Health's 13HEALTH help line
- Sent here by someone else
- I wanted a second opinion
- I didn't want to bother my GP
- There are no bulk-billing clinics nearby
- I always come to the hospital for my care
- ED is cheaper than a GP visit
- I came so I could be seen by someone who does not know me
- Convenient location
- Open 24 hours
- The hospital has the services that I need in one location (x-ray, bloods tests etc.)
- Quicker than getting a GP appointment
- Would be a shorter wait
- Best place for my particular problem
- I don't have a GP
- I feel reassured after I have been assessed by ED staff
- I knew I needed to be admitted to the hospital
- I have been very happy with the care I have received in the past
- NGO sent me (please specify):......................

.....................................................................

- Other (please specify):...................................

.....................................................................

**10** Where do you usually seek healthcare when you are unwell?

- Go to a GP
- Go to the Emergency Department
- Go to local Aboriginal Medical Service
- Go to the pharmacist
- Call the Queensland Health's 13HEALTH help line
- Other (please specify):...................................

.....................................................................

11

a) Do you have a regular general practice that you attend?

o Yes o No

If YES, when was your last visit?

o <1 week ago o 1-4 weeks ago
o 1-3 months ago o 3-6 months
o 6-12 months o >12 months ago

b) Does your regular general practice offer you bulk-billing?

o Yes o No

c) Have you ever experienced difficulty obtaining an urgent appointment (i.e. an appointment for the same day)?

o Yes o No

If 'Yes', did you tell your GP that you needed a same-day appointment as your problem was urgent?

o Yes o No

d) In the last 12 months have you visited the ED after not being able to get an urgent appointment with your general practice?

o Yes o No

e) If you do not have a regular general practice that you attend, why is that? (tick one)

- o I am visiting or working for a short time in this region
- o I have recently moved here
- o Cannot find one accepting new patients or visitors
- o I cannot afford to visit the GP
- o Have not looked for one
- o I do not need a regular general practitioner
- o Other (please specify):……………………………

……………………………………………………………

***Narrative: The next questions relate to your awareness of other alternatives to the Emergency Department, that is whether you are aware of other healthcare alternatives for decisions in the future.***

12 Are you aware of the 13-Health phone line for health advice over the phone?

o Yes o No

13 Are you aware of bulk-billing, walk-in GP services that operate after hours in your local area?

o Yes o No

If yes, have you used these services before?

o Yes o No

Did you consider using these services today?

o Yes o No

If no, please give a reason:

- o Too long to wait
- o Health issue too complicated
- o Needed multiple health services
- o Too far away
- o Other (please specify):……………………………

……………………………………………………………

14 Are you aware of the Dial-a-Doctor service?

o Yes o No

If yes, have you used this service before?

o Yes o No

Did you consider using this service today?

o Yes o No

If no, please give a reason:

- o Too long to wait
- o Health issue too complicated
- o Needed multiple health services
- o Too far away
- o Other (please specify):……………………………

……………………………………………………………

15 (Do not ask this question if clearly inappropriate for the health condition, but note 'NO CHOICE' for survey purposes)

o No choice

If you had a choice, where would you have preferred to go for the problem that you have come to hospital about today?

o ED o Local GP
o No preference o Other GP
o After-Hours service
o Other (please specify):……………………………

……………………………………………………………

**16** If an alternative service to ED were available, what would be the most important factors for you? *(pick top three choices in order of importance): (Note: choices to be ranked)*

○ Extended or 24 hours opening
○ Bulk-billing
○ Access to x-rays and blood tests in one location
○ Other specialist services
○ Easy to get an appointment
○ Convenient location
○ Reliable appointment time
○ High quality care
○ Longer standard consultation length
○ Other (please specify):..................................

.......................................................................

**17** What other alternative services could be offered in Cairns to help meet your health needs? (please specify):

.......................................................................

.......................................................................

**18** Do you have any of the following long-standing or chronic conditions?

○ Complete or serious hearing impairment
○ Complete or partial vision impairment
○ A long-standing physical condition (example, arthritis, chronic pain)
○ A mental health condition
○ A long–standing illness (example, cancer, HIV, diabetes, chronic heart disease, COPD, liver disease, illness requiring dialysis, epilepsy)
○ No, I do not have a long-standing condition

**19** Are you a permanent resident of Australia?

○ Yes ○ No

**20** Are you a resident of Cairns?

○ Yes ○ No

If YES, which suburb do you live in:

.......................................................................

If NO, where do you normally live (if overseas please provide country, if within Australia please provide town/community and state):

.......................................................................

What is the postcode of your usual place of residence? (ask for all participants)

.......................................................................

**21** Which suburb/town/community did you travel from to come to ED today?

.......................................................................

**22** What is your gender?

○ Male ○ Female ○ Other

**23** What is your age?

○ 0-4 yrs ○ 5-9 yrs ○ 10-14 yrs
○ 15-19 yrs ○ 20-24 yrs ○ 25-29 yrs
○ 30-34 yrs ○ 35-39 yrs ○ 40-44 yrs
○ 45-49 yrs ○ 50-54 yrs ○ 55-59 yrs
○ 60-64 yrs ○ 65-69 yrs ○ 70-74 yrs
○ 75-79 yrs ○ 80-84 yrs ○ 85+ yrs

**24** Is English your main language?

○ Yes ○ No

**25** What is the highest education level that you have completed?

○ None ○ Primary
○ Year 10 or equivalent
○ Year 12 or equivalent
○ TAFE certificate/diploma
○ Trade certificate/diploma
○ University degree (undergraduate/postgraduate)

**26** In the past month how would you describe your occupational status?

○ Full-time work ○ Unemployment benefits
○ Part-time work ○ Disability benefits
○ Casual work ○ Aged pension
○ Full-time student ○ Self-funded retiree
○ Part-time student ○ Home duties
○ Other (please specify):

.......................................................................

**27** Do you identify as:

- ○ Aboriginal
- ○ Both Aboriginal and Torres Strait Islander
- ○ Torres Strait Islander
- ○ Not specified

**28** Do you have any other comments about your visit to the hospital today?

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

## References

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Steele, S, Anstett, D, & Milne, W. (2008). Rural emergency department use by CTAS IV and V patients. CJEM, 10(3), 209.

# Appendix B - Interview Schedules

### *B1 Initial interview schedule - 13 September 2017*

*Phase 1: Setup*

- Check recording quality.
- 2 Recording devices on.
- Purpose: to explore the experience of health service by people living with chronic conditions in Cairns and use this information to inform on a new model of health care that the government is going to be trialling over the next few years, called the Health Care Home, which involves a different way for GPs/AMS to manage the health care needs of people living with chronic conditions.
- Participant information sheet.
- Consent form.

*Phase 2: Begin interview*

- Demographics: confirm age range, gender, local Cairns resident, working/retired
- Could you identify what type of chronic condition/conditions you have and how long you have had the condition?

*Phase 3: Body of interview*

| |
|---|
| Thinking about managing your health, do you have a regular GP practice? A regular GP?<br>If NO: Why not?<br>If YES: How long have you been going to the practice/GP? Is it easy to get to the practice from your home? Why do you choose to go to this practice/practitioner? What is your experience of care at this practice/GP? What do you like/dislike about your practice/GP? |
| Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. hospitals, clinics, specialists, allied health (physio, pharmacist)) |
| Thinking about getting access to health services such as GPs, what has been your experience of accessing health services in-hours? Out-of-hours? For routine health needs? Urgent health needs?<br>Can you think of any approaches that might improve your access to care? (length of hours, in-person consultations, telephone, email, videoconference) |

| |
|---|
| Thinking about your GP practice, what is your experience with the practice staff? Do they work together to support your care with the GP? |
| Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? eg follow up of test results, co-ordination with specialists, allied health (physio, pharmacist), hospital.<br>What types of approaches could you suggest to improve the co-ordination of your care?<br>…. *Has a health professional worked with you to develop a plan for your health care needs? Has this been shared with other health services? (hospital, allied health: eg physio, pharmacist) If not, do you think a health care plan would be useful?* |
| Who do you think is responsible for managing your care? Who should be responsible?<br>What do you think about having one health professional, such as a GP, being responsible for the co-ordination of your care?<br>How would you feel about enrolling with one health provider (GP Practice or AMS) to co-ordinate care for your chronic condition/s? |
| What has been your experience of health professionals collecting and sharing data or information about your health?<br>How do feel about the sharing of your health information within the GP/AMS practice? With other health services? (eg hospital, allied health) |
| Do you feel that health professionals involve you in making decisions about your own care? Is this what you want? More or less involved?<br>Do you want your family/partner/carer to be involved in understanding and making decisions about your care? If yes, more or less involved? |
| In our earlier research a majority of people said that if there was an alternative health service to the Hospital Emergency Department then it would need to offer ‘high-quality care’. Thinking about your health and your health care needs, what does ‘high-quality care’ mean to you? |
| Can you suggest any other approaches that might improve the delivery of health service for people living with chronic conditions in Cairns? |

*Phase 4: Review and finalise interview*

- Recheck checklist/interview guide.

- Recording device off.

### *B2 Interview schedule - 22 September 2017*

#### *Phase 1: Setup*

- Check recording quality.
- 2 Recording devices on.
- Purpose: to explore the experience of health service by people living with chronic conditions in Cairns and use this information to inform on a new model of health care that the government is going to be trialling over the next few years, called the Health Care Home, which involves a different way for GPs/AMS to manage the health care needs of people living with chronic conditions.
- Participant information sheet. Consent form. Voucher sign.

#### *Phase 2: Begin interview*

- Demographics: confirm age range, gender, local Cairns resident, working/retired
- Could you identify what type of chronic condition/conditions you have and how long you have had the condition?

#### *Phase 3: Body of interview*

| |
|---|
| Thinking about managing your health, do you have a regular GP practice? A regular GP?<br>If NO: Why not?<br>If YES: How long have you been going to the practice/GP? Is it easy to get to the practice from your home? Why do you choose to go to this practice/practitioner? What is your experience of care at this practice/GP? What do you like/dislike about your practice/GP? Fees? |
| Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. hospitals, clinics, specialists, allied health eg physio, pharmacist, Home visit doctor) |
| Thinking about getting access to health services such as GPs, what has been your experience of accessing health services in-hours? Out-of-hours? For routine health needs? Urgent health needs?<br>Can you think of any approaches that might improve your access to care? (length of hours, in-person consultations, telephone, email, videoconference) |

| |
|---|
| Thinking about your GP practice, what is your experience with the practice staff? Do they work together to support your care with the GP? |
| Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? eg follow up of test results, co-ordination with specialists, allied health (physio, pharmacist), hospital.<br>What types of approaches could you suggest to improve the co-ordination of your care?<br>…. *Has a health professional worked with you to develop a plan for your health care needs? Has this been shared with other health services? (hospital, allied health: eg physio, pharmacist) If not, do you think a health care plan would be useful?* |
| Who do you think is responsible for managing your care? Who should be responsible?<br>What do you think about having one health professional, such as a GP, being responsible for the co-ordination of your care?<br>How would you feel about enrolling with one health provider (GP Practice or AMS) to co-ordinate care for your chronic condition/s? |
| What has been your experience of health professionals collecting and sharing data or information about your health?<br>How do feel about the sharing of your health information within the GP/AMS practice? With other health services? (eg hospital, allied health) |
| Do you feel that health professionals involve you in making decisions about your own care? Is this what you want? More or less involved?<br>Do you want your family/partner/carer to be involved in understanding and making decisions about your care? If yes, more or less involved? |
| In our earlier research a majority of people said that if there was an alternative health service to the Hospital Emergency Department then it would need to offer 'high-quality care'. Thinking about your health and your health care needs, what does 'high-quality care' mean to you? |
| Under this new model of care patients will choose to enrol with one practice to manage their chronic care needs. Could this model work for you? What would encourage/discourage you to enrol? |

| |
|---|
| Can you suggest any other approaches that might improve the delivery of health service for people living with chronic conditions in Cairns? |

*Phase 4: Review and finalise interview*

- Recheck checklist/interview guide.
- Recording device off.

### *B3 Interview schedule - 20 October 2017*

*Phase 1: Setup*

- Check recording quality, 2 Recording devices on.
- Purpose: to explore the experience of health service by people living with chronic conditions in Cairns and use this information to inform on a new model of health care that the government is going to be trialling over the next few years, called the Health Care Home, which involves a different way for GPs/AMS to manage the health care needs of people living with chronic conditions.
- Participant information sheet. Consent form. Voucher sign.

*Phase 2: Begin interview*

- Demographics: confirm age range, length of residency in Cairns, working/retired
- Identify what type of chronic condition/conditions and how long had the condition?

*Phase 3: Body of interview*

| |
|---|
| Do you have a regular GP practice? A regular GP?<br>If NO: Why not?<br>If YES: How long have you been going to the practice/GP? Is it easy to get to the practice from your home? Why do you choose to go to this practice/practitioner? What do you like/dislike about your practice/GP? Fees? What does a consultation with your GP look like? Length? No of items? What does a “good” consultation look like? |
| Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. hospitals, clinics, specialists, allied health eg physio, pharmacist, Home visit doctor) |
| Thinking about getting access to health services such as GPs, what has been your experience of accessing health services in-hours? Out-of-hours? For routine health needs? Urgent health needs? |

| |
|---|
| Can you think of any approaches that might improve your access to care? (length of hours, in-person consultations, telephone, email, videoconference) |
| Thinking about your GP practice, what is your experience with the practice staff? Do they work together to support your care with the GP? |
| Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? eg follow up of test results, co-ordination with specialists, allied health (physio, pharmacist), hospital.<br>What types of approaches could you suggest to improve the co-ordination of your care?<br>…. *Has a health professional worked with you to develop a plan for your health care needs? Has this been shared with other health services? (hospital, allied health: eg physio, pharmacist) If not, do you think a health care plan would be useful?* |
| Who do you think is responsible for managing your care? Who should be responsible?<br>What do you think about having one health professional, such as a GP, being responsible for the co-ordination of your care?<br>How would you feel about enrolling with one health provider (GP Practice or AMS) to co-ordinate care for your chronic condition/s? |
| What has been your experience of health professionals collecting and sharing data or information about your health?<br>How do feel about the sharing of your health information within the GP/AMS practice? With other health services? (eg hospital, allied health) |
| Do you feel that health professionals involve you in making decisions about your own care? Is this what you want? More or less involved?<br>Do you want your family/partner/carer to be involved in understanding and making decisions about your care? If yes, more or less involved? |
| In our earlier research a majority of people said that if there was an alternative health service to the Hospital Emergency Department then it would need to offer ‘high-quality care’. Thinking about your health and your health care needs, what does ‘high-quality care’ mean to you? |

| |
|---|
| Under this new model of care patients will choose to enrol with one practice to manage their chronic care needs. Could this model work for you? What would encourage/discourage you to enrol? |
| Can you suggest any other approaches that might improve the delivery of health service for people living with chronic conditions in Cairns? |

*Phase 4: Review and finalise interview*

- Recheck checklist/interview guide.
- Recording device off.

## *B4 Interview schedule - 14 June 2018*

*Phase 1: Setup*

- Check recording quality, 2 Recording devices on.
- Purpose: to explore the experience of health service by people living with chronic conditions in Cairns and use this information to inform on a new model of health care that the government is going to be trialling over the next few years, called the Health Care Home, which involves a different way for GPs/AMS to manage the health care needs of people living with chronic conditions.
- Participant information sheet. Consent form. Voucher sign.

*Phase 2: Begin interview*

- Demographics: confirm age range, length of residency in Cairns, working/retired
- Identify what type of chronic condition/conditions and how long had the condition?

*Phase 3: Body of interview*

| |
|---|
| Do you have a regular GP practice? A regular GP?<br>If NO: Why not?<br>If YES: How long have you been going to the practice/GP? How did you find this GP? Is it easy to get to the practice from your home? Why do you choose to go to this practice/practitioner? What do you like/dislike about your practice/GP? Fees? What does a consultation with your GP look like? Length? No of items? What does a "good" consultation look like? |
| Thinking about getting access to GPs, what has been your experience of accessing health services in-hours? Out-of-hours? For routine health needs? Urgent health needs? |

| |
|---|
| Can you think of any approaches that might improve your access to care? (length of hours, in-person consultations, telephone, email, videoconference) |
| Thinking about your GP practice, what is your experience with the practice staff? Do they work together to support your care with the GP? |
| Thinking about managing your chronic condition, what is your experience of other health care services in Cairns? (eg. hospitals, clinics, specialists, allied health eg physio, pharmacist, Home visit doctor) |
| Thinking about how your care is co-ordinated, what has been your experience of health professionals working with each other to care for you? eg follow up of test results, co-ordination with specialists, allied health (physio, pharmacist), hospital.<br>What types of approaches could you suggest to improve the co-ordination of your care?<br>Has a health professional worked with you to develop a plan for your health care needs? Has this been shared with other health services? (hospital, allied health: eg physio, pharmacist) If not, do you think a care plan would be useful? |
| What has been your experience of health professionals collecting and sharing data or information about your health?<br>How do feel about the sharing of your health information within the GP/AMS practice? With other health services? (eg hospital, allied health) |
| Do you feel that health professionals involve you in making decisions about your own care? Is this what you want? More or less involved?<br>When making decisions about your care, how well do you think that the GP understands your personal circumstances? (ie Is the GP getting all necessary information?) |
| Is your family involved in your care (access, management, decision making)?<br>If yes, would you like them to be more or less involved? |
| In our earlier research a majority of people said that if there was an alternative health service to the Hospital Emergency Department then it would need to offer ‘high-quality care’. Thinking about your health and your health care needs, what does ‘high-quality care’ mean to you? |

| |
|---|
| Under this new model of care patients will choose to enrol with one practice to manage their chronic care needs. Would committing to one practice be suitable for you? What would encourage/discourage you to enrol? |
| Can you suggest any other approaches that might improve the delivery of health service for people living with chronic conditions in Cairns? |

*Phase 4: Review and finalise interview*

- Recheck checklist/interview guide.
- Recording device off.

# Appendix C - Ethics and Research Approvals

## *C1 Far North Queensland Human Research Ethics Committee - P3ED Study - New investigators amendment*

Addition of new investigators M O'Loughlin and L Harriss to P3ED Study.

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### *C2 Far North Queensland Human Research Ethics Committee - Study approval*

Study approval. includes waiver of consent.

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has been removed

### *C3 Far North Queensland Human Research Ethics Committee - Study grant amendment*

Amendment resulting from receipt of Far North Queensland Hospital Foundation grant funding.

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has been removed

### *C4 Far North Queensland Human Research Ethics Committee - New investigator amendment*

Addition of new investigator C. West.

This administrative form
has been removed

### *C5 James Cook University Human Research Ethics Committee - Study approval*

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has been removed

### *C6 Queensland Government Public Health Act - Approval*

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## *C7 Queensland Government Site Specific Assessment - Approval*

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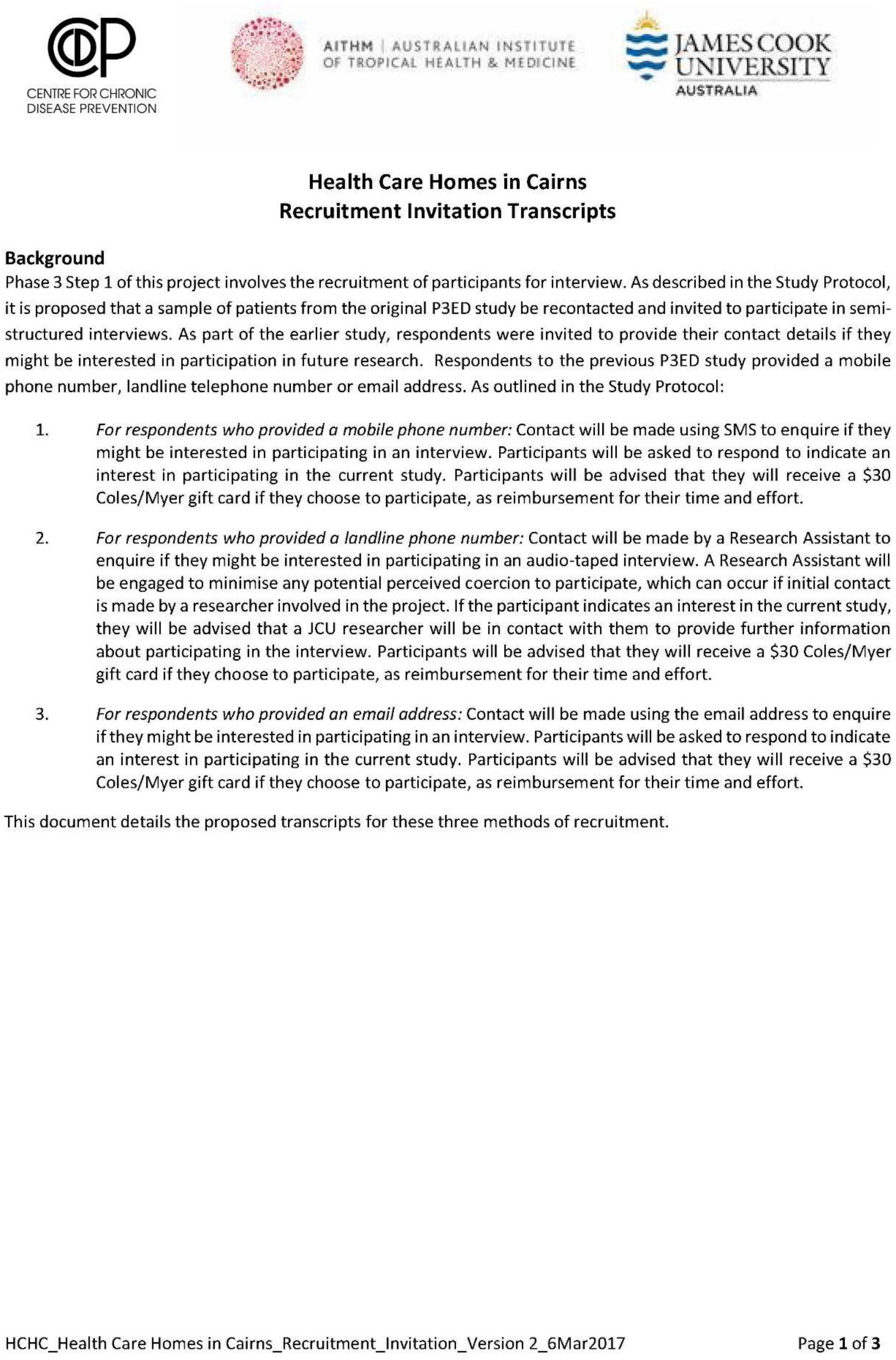
# Appendix D – Interview Documents

## D1 Recruitment Invitation



CENTRE FOR CHRONIC DISEASE PREVENTION

AITHM | AUSTRALIAN INSTITUTE OF TROPICAL HEALTH & MEDICINE

JAMES COOK UNIVERSITY AUSTRALIA

### Health Care Homes in Cairns
### Recruitment Invitation Transcripts

**Background**

Phase 3 Step 1 of this project involves the recruitment of participants for interview. As described in the Study Protocol, it is proposed that a sample of patients from the original P3ED study be recontacted and invited to participate in semi-structured interviews. As part of the earlier study, respondents were invited to provide their contact details if they might be interested in participation in future research. Respondents to the previous P3ED study provided a mobile phone number, landline telephone number or email address. As outlined in the Study Protocol:

1. *For respondents who provided a mobile phone number:* Contact will be made using SMS to enquire if they might be interested in participating in an interview. Participants will be asked to respond to indicate an interest in participating in the current study. Participants will be advised that they will receive a $30 Coles/Myer gift card if they choose to participate, as reimbursement for their time and effort.
2. *For respondents who provided a landline phone number:* Contact will be made by a Research Assistant to enquire if they might be interested in participating in an audio-taped interview. A Research Assistant will be engaged to minimise any potential perceived coercion to participate, which can occur if initial contact is made by a researcher involved in the project. If the participant indicates an interest in the current study, they will be advised that a JCU researcher will be in contact with them to provide further information about participating in the interview. Participants will be advised that they will receive a $30 Coles/Myer gift card if they choose to participate, as reimbursement for their time and effort.
3. *For respondents who provided an email address:* Contact will be made using the email address to enquire if they might be interested in participating in an interview. Participants will be asked to respond to indicate an interest in participating in the current study. Participants will be advised that they will receive a $30 Coles/Myer gift card if they choose to participate, as reimbursement for their time and effort.

This document details the proposed transcripts for these three methods of recruitment.

HCHC_Health Care Homes in Cairns_Recruitment_Invitation_Version 2_6Mar2017 Page **1** of **3**

1. ***For respondents who provided a mobile phone number***

**Recruitment by Mobile Phone SMS Text**

You are invited to take part in a James Cook University research study looking at health services for people living with chronic conditions in Cairns. If you might be interested in participating in an interview, please text YES to this number and a researcher will call you to discuss further. Participants will receive a $30 Coles/Myer gift card as reimbursement for their time and effort. Alternatively, please call Mary O'Loughlin on [redacted] for more information.

2. ***For respondents who provided a landline phone number***

**Recruitment by Landline Telephone**
*This initial telephone contact is to be undertaken by a Research Assistant.*

Hello, may I speak with (name)
My name is (name) from James Cook University. I have received this phone number from a previous study that you participated in at the Cairns Hospital Emergency Department (The 'P3ED Study') in 2014.
The reason for my call today is to find out if you might be interested in participating in a related study which is looking at health services for people living with chronic conditions in Cairns. The researchers are looking to speak to people about their experiences with the health services here in Cairns. If you choose to participate you will receive a $30 Coles/Myer gift card as reimbursement for your time and effort.
The main researcher is Mary O'Loughlin and she would like to speak with you further about meeting up and undertaking an interview.
If you might be interested I can pass your details along to Mary?
Is this the best contact number?
Thank you for your time.

3. ***For respondents who provided an email address***

**Recruitment by Email**

Dear (name)

In March-April 2014 James Cook University researchers conducted a study to investigate reasons for attendance at the Cairns Hospital Emergency Department (The 'P3ED Study'). At that time, you provided this email address to the researchers to indicate that you might be interested in participating in future research related to health service in Cairns.

**You are invited to take part in a research study examining health service delivery for people living with chronic conditions in Cairns.** We want to investigate the experience of people living with chronic conditions as they access health services and find out which aspects of health service delivery are valued by people living with chronic conditions.

The study is being conducted by Ms Mary O'Loughlin and it will contribute to her PhD project in Public Health. Mary is based at the Centre for Chronic Disease Prevention at James Cook University.

**Reimbursement for your time and effort**

If you choose to participate you will receive a $30 Coles/Myer gift card in recognition of any inconvenience.

**What will happen?**

If you agree to be involved in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the Centre for Chronic Disease Prevention at James Cook University, or a venue of your choice.

**What are the possible benefits and harms?**

Although there may not be any direct benefit to you immediately, this research may help to improve the delivery of health services for people living with chronic conditions in Cairns in the longer term.

There have been no potential harms identified for participants in this study. Taking part in this study is completely voluntary and you can stop taking part in the study at any time. The interview responses and your contact details will be kept confidential.

**What to do next?**

If you are interested in participating in this study please reply to this email: mary.oloughlin@my.jcu.edu.au by (day, month) 2017.

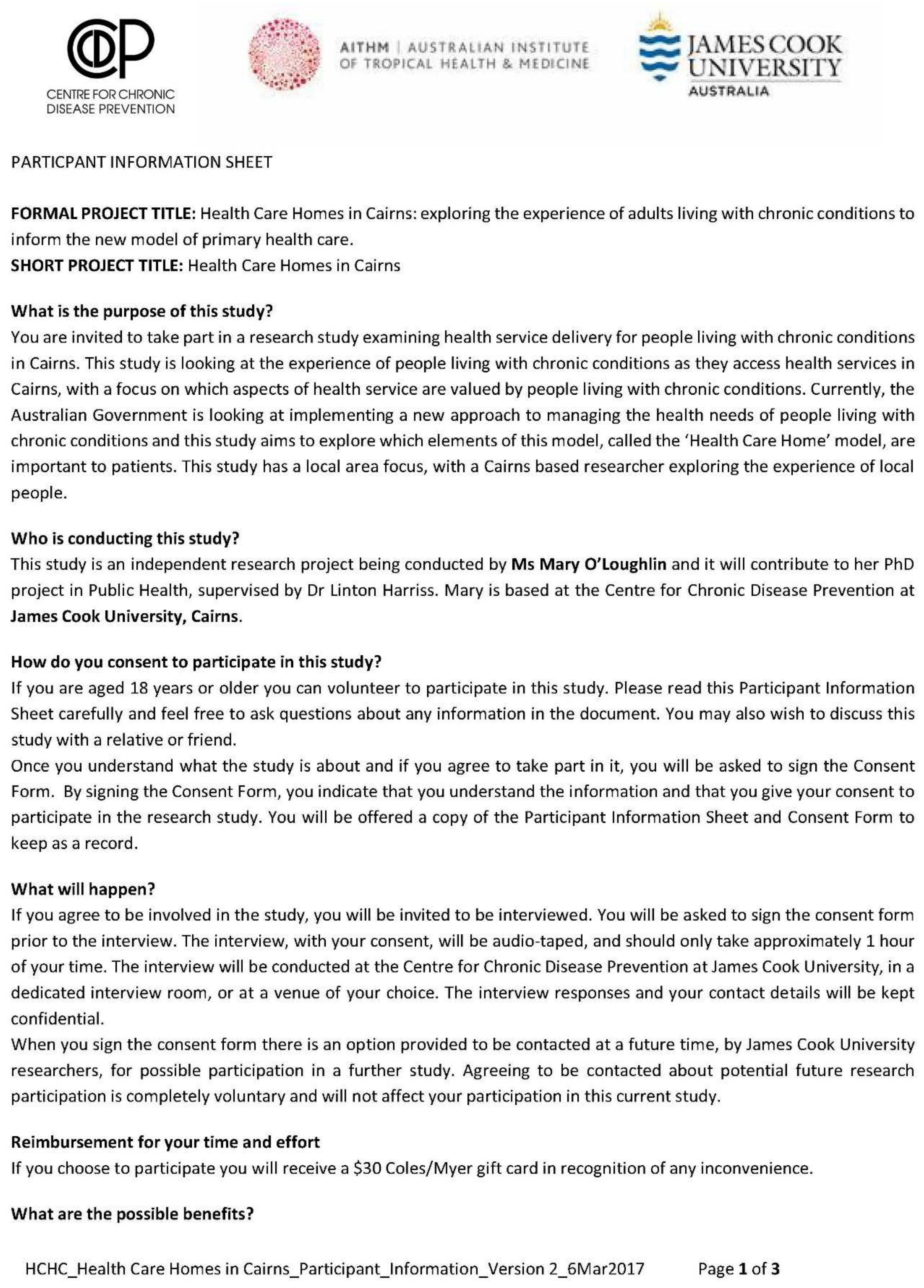
Alternatively, if you would like to ask any questions about the study you are welcome to telephone me on

Thank you for considering this request.

Kind regards

**Mary O'Loughlin**
**Centre for Chronic Disease Prevention**
**College of Public Health, Medical and Veterinary Sciences**
**James Cook University**
**Phone:**
**Email:** mary.oloughlin@my.jcu.edu.au

## D2 Participant Information Sheet



CENTRE FOR CHRONIC DISEASE PREVENTION
AITHM | AUSTRALIAN INSTITUTE OF TROPICAL HEALTH & MEDICINE
JAMES COOK UNIVERSITY
AUSTRALIA

PARTICPANT INFORMATION SHEET

**FORMAL PROJECT TITLE:** Health Care Homes in Cairns: exploring the experience of adults living with chronic conditions to inform the new model of primary health care.
**SHORT PROJECT TITLE:** Health Care Homes in Cairns

### What is the purpose of this study?

You are invited to take part in a research study examining health service delivery for people living with chronic conditions in Cairns. This study is looking at the experience of people living with chronic conditions as they access health services in Cairns, with a focus on which aspects of health service are valued by people living with chronic conditions. Currently, the Australian Government is looking at implementing a new approach to managing the health needs of people living with chronic conditions and this study aims to explore which elements of this model, called the 'Health Care Home' model, are important to patients. This study has a local area focus, with a Cairns based researcher exploring the experience of local people.

### Who is conducting this study?

This study is an independent research project being conducted by **Ms Mary O'Loughlin** and it will contribute to her PhD project in Public Health, supervised by Dr Linton Harriss. Mary is based at the Centre for Chronic Disease Prevention at **James Cook University, Cairns**.

### How do you consent to participate in this study?

If you are aged 18 years or older you can volunteer to participate in this study. Please read this Participant Information Sheet carefully and feel free to ask questions about any information in the document. You may also wish to discuss this study with a relative or friend.

Once you understand what the study is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research study. You will be offered a copy of the Participant Information Sheet and Consent Form to keep as a record.

### What will happen?

If you agree to be involved in the study, you will be invited to be interviewed. You will be asked to sign the consent form prior to the interview. The interview, with your consent, will be audio-taped, and should only take approximately 1 hour of your time. The interview will be conducted at the Centre for Chronic Disease Prevention at James Cook University, in a dedicated interview room, or at a venue of your choice. The interview responses and your contact details will be kept confidential.

When you sign the consent form there is an option provided to be contacted at a future time, by James Cook University researchers, for possible participation in a further study. Agreeing to be contacted about potential future research participation is completely voluntary and will not affect your participation in this current study.

### Reimbursement for your time and effort

If you choose to participate you will receive a $30 Coles/Myer gift card in recognition of any inconvenience.

### What are the possible benefits?

Although there may not be any direct benefit to you immediately, this research may help to improve the delivery of health services for people living with chronic conditions in Cairns in the longer term.

**What are the potential risks?**

Taking part in this study is completely voluntary and you can stop taking part in the study at any time, without giving a reason. In all research studies, there is potential for confidentiality to be breached, however, every effort will be made to ensure this does not occur, through a range of measures detailed below.

If you become upset at any time during the interview, the interviewer, who is a Registered Nurse, will offer contact details for a local counselling service, contactable through the After Hours GP Helpline: Phone: 1800 022 222.

**Privacy, Confidentiality and Disclosure of Information**

Any information obtained will remain strictly confidential, this includes your interview responses and contact details. Audio-taped interviews will be transcribed and de-identified in order to be analysed. All data generated during the study will be password protected and stored in a secure environment within James Cook University. Access to data will be restricted to authorised study personnel only. At the conclusion of the study all study records will be stored securely to maintain your confidentiality and kept for a minimum of 5 years as per James Cook University policy.

Data from the study may be used for research publication and presentation, however, you will not be identified in any way. Future publications from this study, for example articles published in research journals, will be made available for those who wish to view.

**Ethical Guidelines**

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by the FNQHREC.

**If you would like to join the study and you are happy that you have understood what this study is about, please sign the consent forms. If you have any questions about the study, please contact Mary O'Loughlin or Dr Linton Harriss.**

Principal Investigator:
Mary O'Loughlin
Centre for Chronic Disease Prevention
College of Public Health, Medical and Veterinary Sciences
James Cook University
Phone:
**Email:** mary.oloughlin@my.jcu.edu.au

Supervisor:
Dr Linton Harriss
Centre for Chronic Disease Prevention
College of Public Health, Medical and Veterinary Sciences
James Cook University
Phone:
**Email:** linton.harriss@jcu.edu.au

If you have any concerns regarding the ethical conduct of the study, please contact:
**Far North Queensland Human Research Ethics Committee (FNQHREC)**
**PO Box 902**
**Cairns QLD 4870**
Phone: 07 4226 5513
**Email:** cairns_ethics@health.qld.gov.au

***D3 Consent Form***

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has been removed

# Appendix E – Research Grants

### *E1 Far North Queensland Hospital Foundation Grant - 2017*

### *E2 JCU College of Public Health, Medical and Veterinary Sciences Higher Degree Research Enhancement Scheme – Round 2, 2019*

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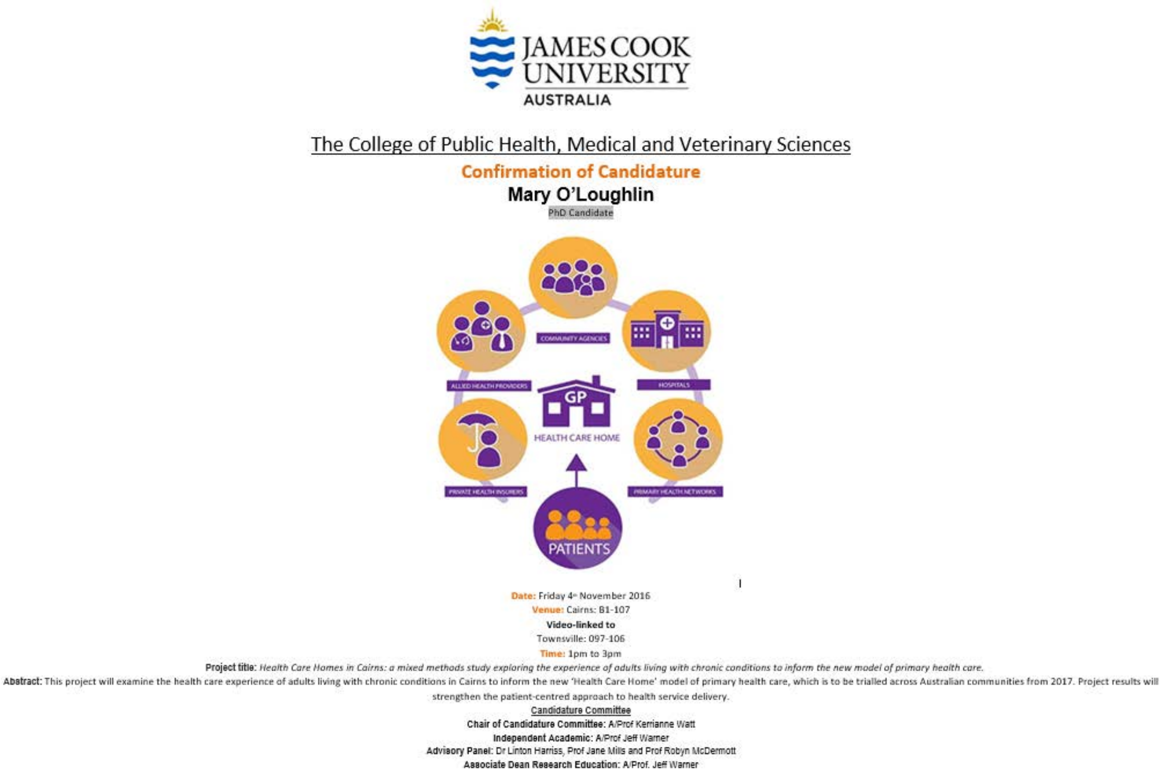
# Appendix F - Confirmation and Pre-Completion Seminars

## *F1 Confirmation of Candidature Seminar Invitation*



JAMES COOK UNIVERSITY
AUSTRALIA

The College of Public Health, Medical and Veterinary Sciences

**Confirmation of Candidature**

**Mary O'Loughlin**

PhD Candidate

**Date:** Friday 4th November 2016
**Venue:** Cairns: B1-107
**Video-linked to**
Townsville: 097-106
**Time:** 1pm to 3pm

**Project title:** *Health Care Homes in Cairns: a mixed methods study exploring the experience of adults living with chronic conditions to inform the new model of primary health care.*

**Abstract:** This project will examine the health care experience of adults living with chronic conditions in Cairns to inform the new 'Health Care Home' model of primary health care, which is to be trialled across Australian communities from 2017. Project results will strengthen the patient-centred approach to health service delivery.

**Candidature Committee**
**Chair of Candidature Committee:** A/Prof Kerrianne Watt
**Independent Academic:** A/Prof Jeff Warner
**Advisory Panel:** Dr Linton Harriss, Prof Jane Mills and Prof Robyn McDermott
**Associate Dean Research Education:** A/Prof. Jeff Warner

## *F2 Pre-Completion Seminar Invitation*

College of Public Health, Medical and Veterinary Sciences

JAMES COOK UNIVERSITY
AUSTRALIA

Invites you to attend the

Pre-completion Seminar

Mary O'Loughlin

PhD Candidate

Date: 28th May 2021
Time: 2pm
Location: This seminar will be held via zoom.

**Title:**
**Health Care Homes in Cairns: a mixed methods study exploring the experience of adults living with chronic conditions to inform the new model of primary health care.**

**Abstract:**
This research explores health service experiences and preferences of adults living with chronic conditions in Cairns. This knowledge is used to explain how the introduction of a new model of primary health care, the Health Care Homes model, might improve service delivery.

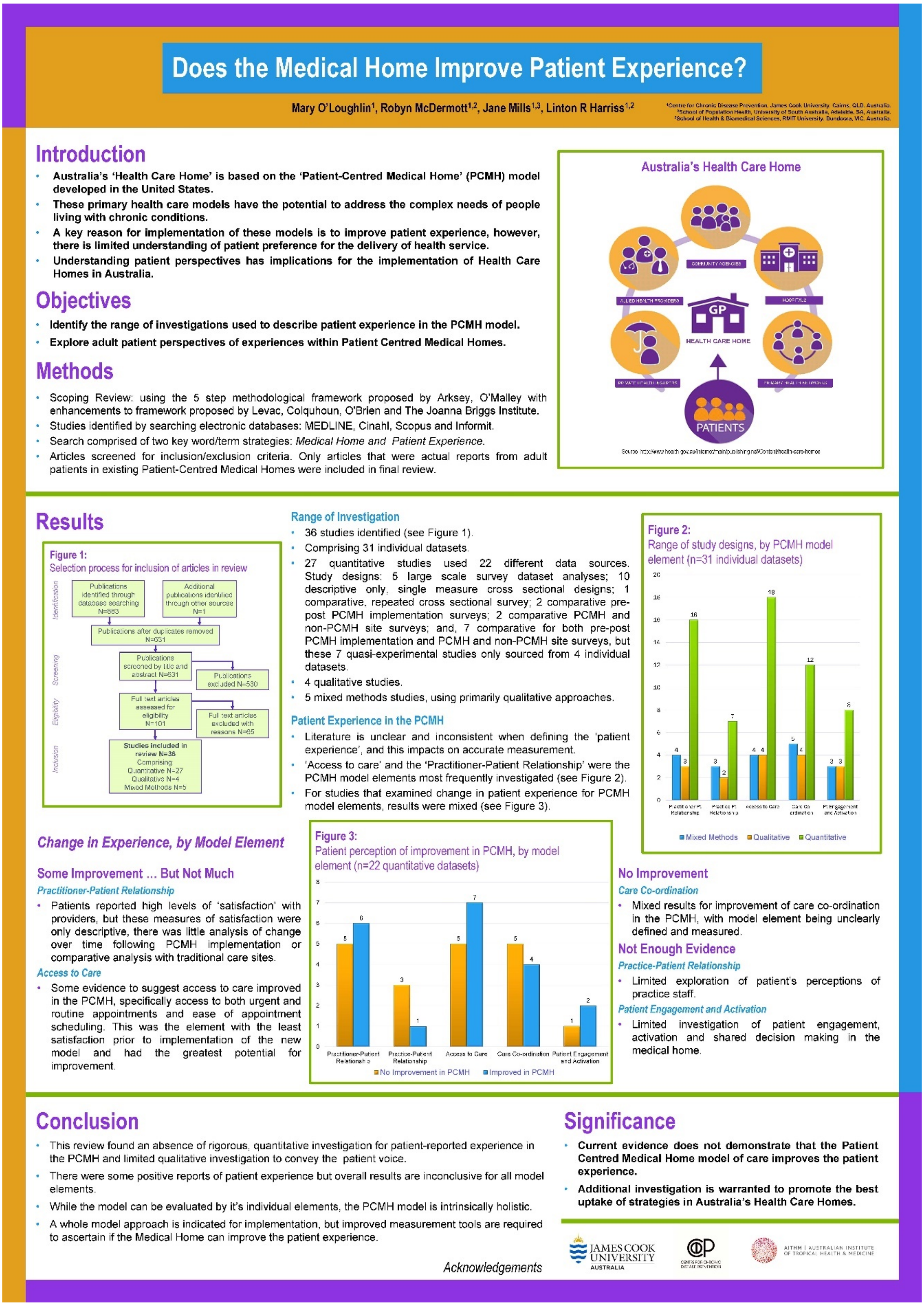
**Candidature Committee**
Chair of Candidature committee: Prof Kerrianne Watt
Independent Academic: A/Prof Steph Topp
Advisory Panel: Dr Linton Harriss, Prof Jane Mills, Prof Caryn West, Prof Robyn McDermott
Associate Dean Research Education: A/Prof Ellen Ariel
Dean of College: Prof Maxine Whittaker

College of Public Health, Medical and Veterinary Sciences
Division of Tropical Health and Medicine
Location: TSV 042-101 and 097-008
E: cphmvs.hdr@jcu.edu.au

Cairns
Singapore
Townsville

# Appendix G – Dissemination of Findings

## *G1 Public Health Association of Australia: National Primary Health Care Conference, December 2016 (poster presentation)*



# Does the Medical Home Improve Patient Experience?

Mary O'Loughlin[1], Robyn McDermott[1,2], Jane Mills[1,3], Linton R Harriss[1,2]

[1]Centre for Chronic Disease Prevention, James Cook University. Cairns. QLD. Australia.
[2]School of Population Health, University of South Australia, Adelaide, SA, Australia.
[3]School of Health & Biomedical Sciences, RMIT University. Bundoora, VIC. Australia.

## Introduction

- **Australia's 'Health Care Home' is based on the 'Patient-Centred Medical Home' (PCMH) model developed in the United States.**
- **These primary health care models have the potential to address the complex needs of people living with chronic conditions.**
- **A key reason for implementation of these models is to improve patient experience, however, there is limited understanding of patient preference for the delivery of health service.**
- **Understanding patient perspectives has implications for the implementation of Health Care Homes in Australia.**

## Objectives

- **Identify the range of investigations used to describe patient experience in the PCMH model.**
- **Explore adult patient perspectives of experiences within Patient Centred Medical Homes.**

## Methods

- Scoping Review: using the 5 step methodological framework proposed by Arksey, O'Malley with enhancements to framework proposed by Levac, Colquhoun, O'Brien and The Joanna Briggs Institute.
- Studies identified by searching electronic databases: MEDLINE, Cinahl, Scopus and Informit.
- Search comprised of two key word/term strategies: *Medical Home and Patient Experience.*
- Articles screened for inclusion/exclusion criteria. Only articles that were actual reports from adult patients in existing Patient-Centred Medical Homes were included in final review.

### Australia's Health Care Home

Source: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes

## Results

**Figure 1:**
Selection process for inclusion of articles in review

### Range of Investigation

- 36 studies identified (see Figure 1).
- Comprising 31 individual datasets.
- 27 quantitative studies used 22 different data sources. Study designs: 5 large scale survey dataset analyses; 10 descriptive only, single measure cross sectional designs; 1 comparative, repeated cross sectional survey; 2 comparative pre-post PCMH implementation surveys; 2 comparative PCMH and non-PCMH site surveys; and, 7 comparative for both pre-post PCMH implementation and PCMH and non-PCMH site surveys, but these 7 quasi-experimental studies only sourced from 4 individual datasets.
- 4 qualitative studies.
- 5 mixed methods studies, using primarily qualitative approaches.

### Patient Experience in the PCMH

- Literature is unclear and inconsistent when defining the 'patient experience', and this impacts on accurate measurement.
- 'Access to care' and the 'Practitioner-Patient Relationship' were the PCMH model elements most frequently investigated (see Figure 2).
- For studies that examined change in patient experience for PCMH model elements, results were mixed (see Figure 3).

**Figure 2:**
Range of study designs, by PCMH model element (n=31 individual datasets)

### *Change in Experience, by Model Element*

### Some Improvement … But Not Much

***Practitioner-Patient Relationship***

- Patients reported high levels of 'satisfaction' with providers, but these measures of satisfaction were only descriptive, there was little analysis of change over time following PCMH implementation or comparative analysis with traditional care sites.

***Access to Care***

- Some evidence to suggest access to care improved in the PCMH, specifically access to both urgent and routine appointments and ease of appointment scheduling. This was the element with the least satisfaction prior to implementation of the new model and had the greatest potential for improvement.

**Figure 3:**
Patient perception of improvement in PCMH, by model element (n=22 quantitative datasets)

### No Improvement

***Care Co-ordination***

- Mixed results for improvement of care co-ordination in the PCMH, with model element being unclearly defined and measured.

### Not Enough Evidence

***Practice-Patient Relationship***

- Limited exploration of patient's perceptions of practice staff.

***Patient Engagement and Activation***

- Limited investigation of patient engagement, activation and shared decision making in the medical home.

## Conclusion

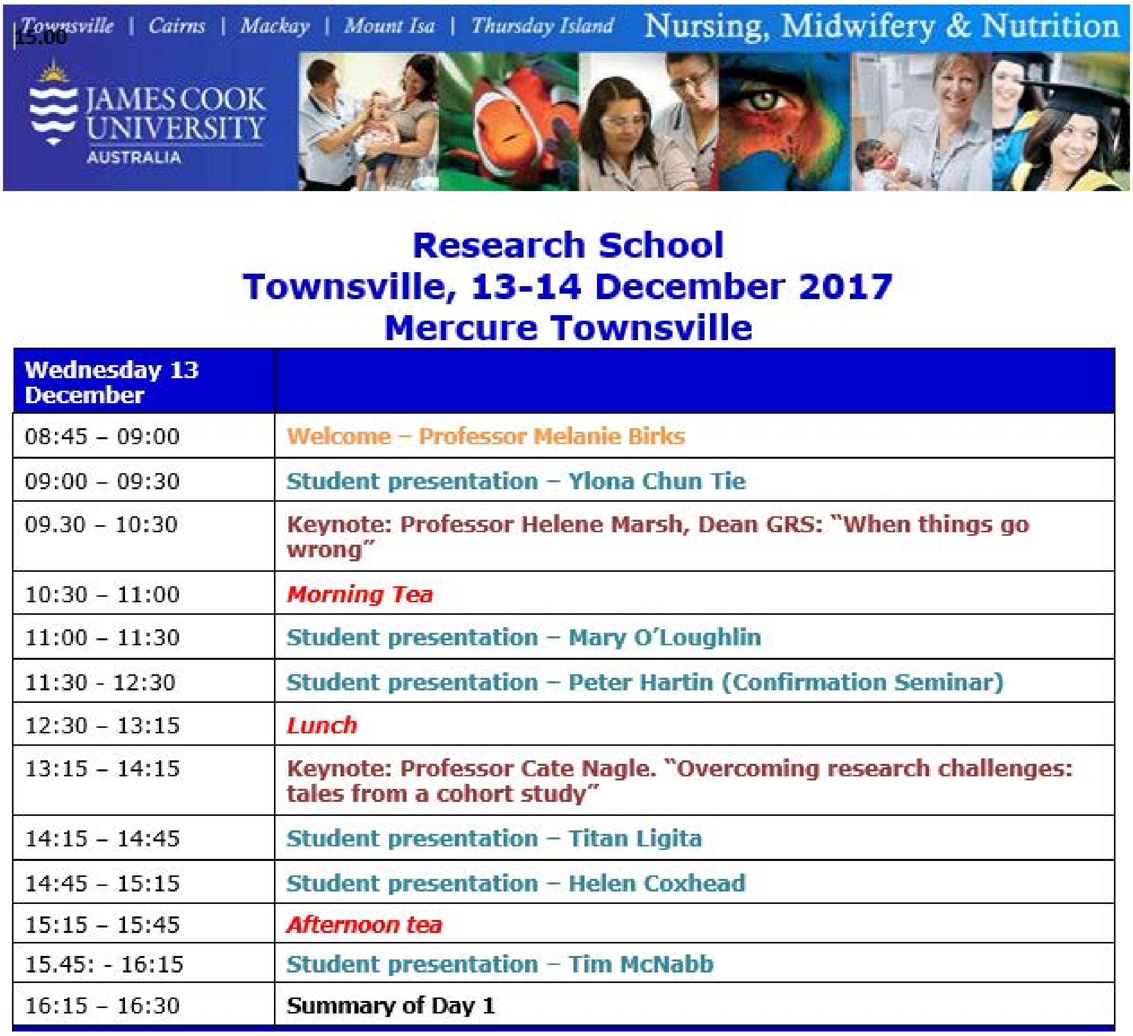
- This review found an absence of rigorous, quantitative investigation for patient-reported experience in the PCMH and limited qualitative investigation to convey the patient voice.
- There were some positive reports of patient experience but overall results are inconclusive for all model elements.
- While the model can be evaluated by it's individual elements, the PCMH model is intrinsically holistic.
- A whole model approach is indicated for implementation, but improved measurement tools are required to ascertain if the Medical Home can improve the patient experience.

*Acknowledgements*

## Significance

- **Current evidence does not demonstrate that the Patient Centred Medical Home model of care improves the patient experience.**
- **Additional investigation is warranted to promote the best uptake of strategies in Australia's Health Care Homes.**

***G2 JCU Nursing, Midwifery and Nutrition Research School, December 2017 (oral presentation)***



15.00

Townsville | Cairns | Mackay | Mount Isa | Thursday Island

Nursing, Midwifery & Nutrition

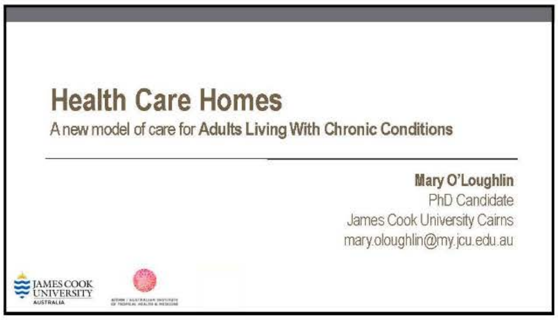
JAMES COOK UNIVERSITY
AUSTRALIA

**Research School**
**Townsville, 13-14 December 2017**
**Mercure Townsville**

| **Wednesday 13 December** | |
|---|---|
| 08:45 – 09:00 | Welcome – Professor Melanie Birks |
| 09:00 – 09:30 | **Student presentation – Ylona Chun Tie** |
| 09.30 – 10:30 | **Keynote: Professor Helene Marsh, Dean GRS: "When things go wrong"** |
| 10:30 – 11:00 | ***Morning Tea*** |
| 11:00 – 11:30 | **Student presentation – Mary O'Loughlin** |
| 11:30 - 12:30 | **Student presentation – Peter Hartin (Confirmation Seminar)** |
| 12:30 – 13:15 | ***Lunch*** |
| 13:15 – 14:15 | **Keynote: Professor Cate Nagle. "Overcoming research challenges: tales from a cohort study"** |
| 14:15 – 14:45 | **Student presentation – Titan Ligita** |
| 14:45 – 15:15 | **Student presentation – Helen Coxhead** |
| 15:15 – 15:45 | ***Afternoon tea*** |
| 15.45: - 16:15 | **Student presentation – Tim McNabb** |
| 16:15 – 16:30 | **Summary of Day 1** |

### *G3 Aboriginal & Torres Strait Islander Community Consultation Committee CHHHS, March 2018 (oral presentation)*

Following this presentation, a report was prepared at the Committee's request. This report is included in the thesis (see *section 4.5.1 Manuscript*).



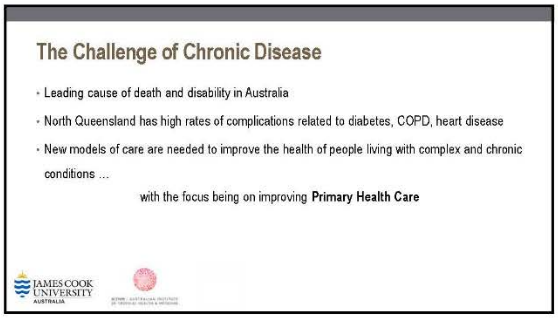
## Health Care Homes

A new model of care for **Adults Living With Chronic Conditions**

**Mary O'Loughlin**
PhD Candidate
James Cook University Cairns
mary.oloughlin@my.jcu.edu.au

## Overview

- What is a Health Care Home/Patient Centred Medical Home/Medical Home?
- Patient Experience in the Medical Home
- Ongoing research



## The Challenge of Chronic Disease

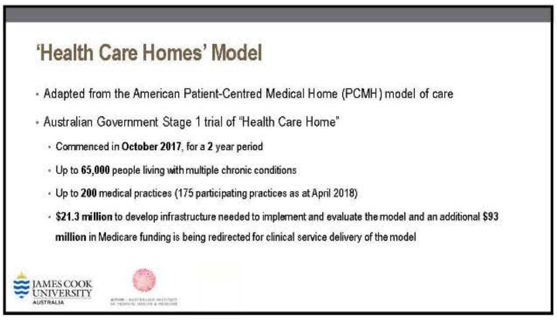
- Leading cause of death and disability in Australia
- North Queensland has high rates of complications related to diabetes, COPD, heart disease
- New models of care are needed to improve the health of people living with complex and chronic conditions …

with the focus being on improving **Primary Health Care**

## A Health Care Home is …

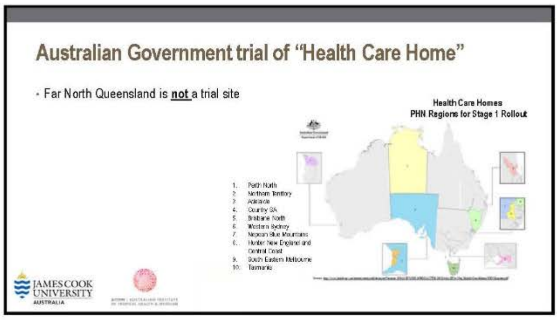
*an existing General Practice or Aboriginal*
*Community Controlled Health Service*
*that makes a commitment to systematically improve*
*the co-ordination of care for people living with*
*chronic and complex conditions*

*Source: http://www.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes*



## 'Health Care Homes' Model

- Adapted from the American Patient-Centred Medical Home (PCMH) model of care
- Australian Government Stage 1 trial of "Health Care Home"
  - Commenced in **October 2017**, for a **2** year period
  - Up to **65,000** people living with multiple chronic conditions
  - Up to **200** medical practices (175 participating practices as at April 2018)
  - **$21.3 million** to develop infrastructure needed to implement and evaluate the model and an additional **$93 million** in Medicare funding is being redirected for clinical service delivery of the model



## Australian Government trial of "Health Care Home"

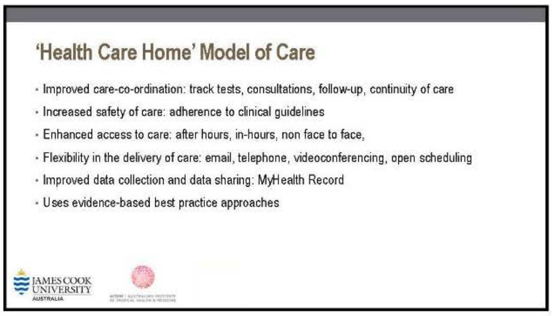
- Far North Queensland is **not** a trial site

**Health Care Homes**
**PHN Regions for Stage 1 Rollout**

1. Perth North
2. Northern Territory
3. Adelaide
4. Country SA
5. Brisbane North
6. Western Sydney
7. Nepean Blue Mountains
8. Hunter New England and Central Coast
9. South Eastern Melbourne
10. Tasmania

## 'Health Care Home' Model of Care

- 'Medical home'
  - *a 'home base' for managing health care*
  - *where the healthcare team and medical records are kept in one place*
- Based in the existing primary health care setting
- Patients voluntarily enrol at a 'Health Care Home' with their preferred clinician
- Commitment to a care partnership
- Systematic assessment - a team approach to deliver care – shared care plan
- Patient activation, empowerment and shared decision making



## 'Health Care Home' Model of Care

- Improved care-co-ordination: track tests, consultations, follow-up, continuity of care
- Increased safety of care: adherence to clinical guidelines
- Enhanced access to care: after hours, in-hours, non face to face,
- Flexibility in the delivery of care: email, telephone, videoconferencing, open scheduling
- Improved data collection and data sharing: MyHealth Record
- Uses evidence-based best practice approaches

## 'Health Care Home' Model of Care

- Question: What is the difference between a 'Health Care Home' and existing high quality General Practice / Aboriginal Community Controlled Health Service?

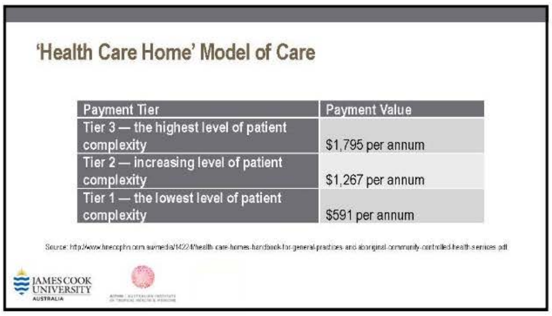
Source: https://[illegible]

## 'Health Care Home' Model of Care

- Question: What is the difference between a 'Health Care Home' and existing high quality General Practice / Aboriginal Community Controlled Health Services?
- Answer: **Bundled payments**

> *"regular periodic payments … will enable Health Care Homes to be flexible and innovative in how they deliver care"* Australian Government, 2016

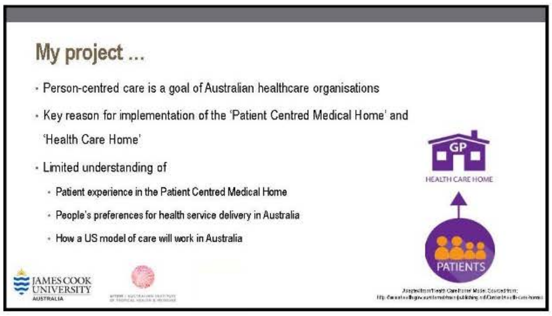
Source: https://[illegible]



## 'Health Care Home' Model of Care

| Payment Tier | Payment Value |
|---|---|
| Tier 3 — the highest level of patient complexity | $1,795 per annum |
| Tier 2 — increasing level of patient complexity | $1,267 per annum |
| Tier 1 — the lowest level of patient complexity | $591 per annum |

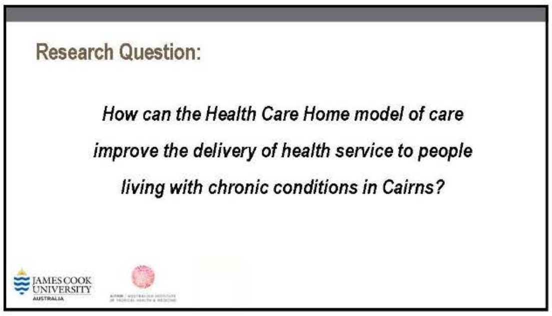
Source: http://www.hneccphn.com.au/media/14224/health-care-homes-handbook-for-general-practices-and-aboriginal-community-controlled-health-services.pdf



## My project …

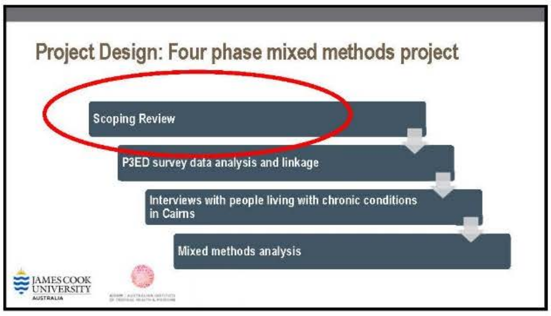
- Person-centred care is a goal of Australian healthcare organisations
- Key reason for implementation of the 'Patient Centred Medical Home' and 'Health Care Home'
- Limited understanding of
  - Patient experience in the Patient Centred Medical Home
  - People's preferences for health service delivery in Australia
  - How a US model of care will work in Australia

Adapted from 'Health Care Home' Model. Sourced from: [illegible]



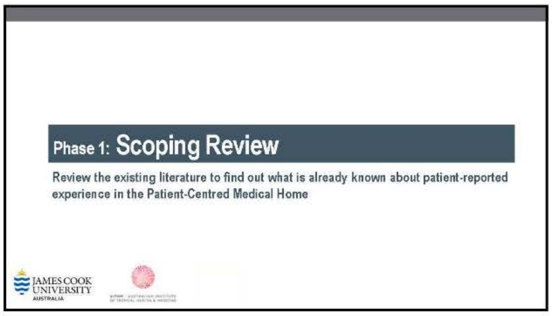
## Research Question:

*How can the Health Care Home model of care improve the delivery of health service to people living with chronic conditions in Cairns?*



## Project Design: Four phase mixed methods project

- Scoping Review
- P3ED survey data analysis and linkage
- Interviews with people living with chronic conditions in Cairns
- Mixed methods analysis



## Phase 1: Scoping Review

Review the existing literature to find out what is already known about patient-reported experience in the Patient-Centred Medical Home

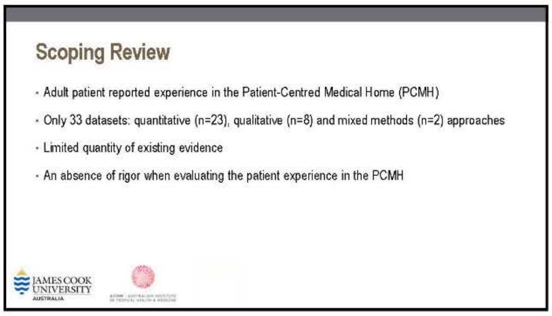
## Scoping Review

CSIRO PUBLISHING
*Australian Journal of Primary Health*, 2017, **23**, 429–439
https://doi.org/10.1071/PY17063

*Review*

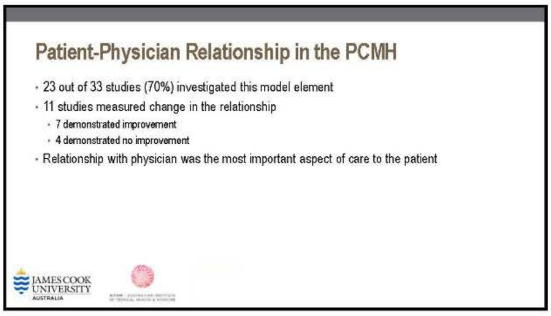
**Review of patient-reported experience within Patient-Centered Medical Homes: insights for Australian Health Care Homes**

Available from: http://www.publish.csiro.au/PY/PY17063



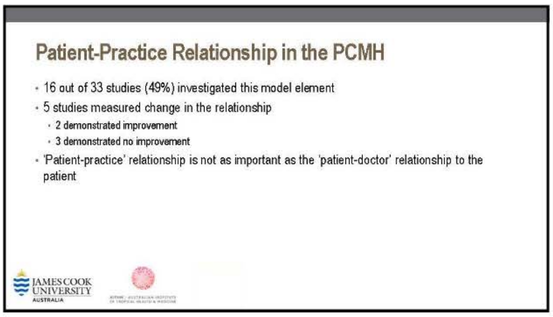
## Scoping Review

- Adult patient reported experience in the Patient-Centred Medical Home (PCMH)
- Only 33 datasets: quantitative (n=23), qualitative (n=8) and mixed methods (n=2) approaches
- Limited quantity of existing evidence
- An absence of rigor when evaluating the patient experience in the PCMH



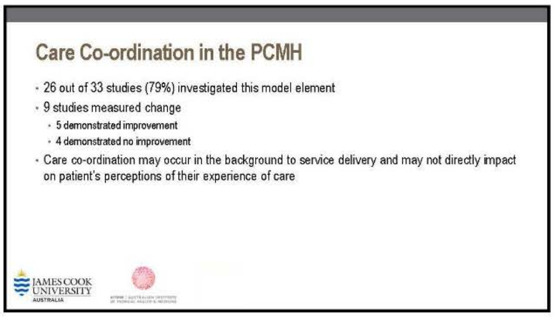
## Patient-Physician Relationship in the PCMH

- 23 out of 33 studies (70%) investigated this model element
- 11 studies measured change in the relationship
  - 7 demonstrated improvement
  - 4 demonstrated no improvement
- Relationship with physician was the most important aspect of care to the patient



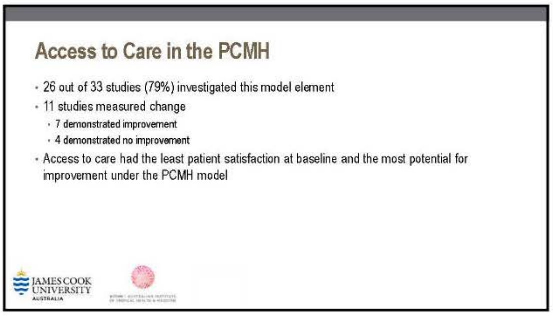
## Patient-Practice Relationship in the PCMH

- 16 out of 33 studies (49%) investigated this model element
- 5 studies measured change in the relationship
  - 2 demonstrated improvement
  - 3 demonstrated no improvement
- 'Patient-practice' relationship is not as important as the 'patient-doctor' relationship to the patient



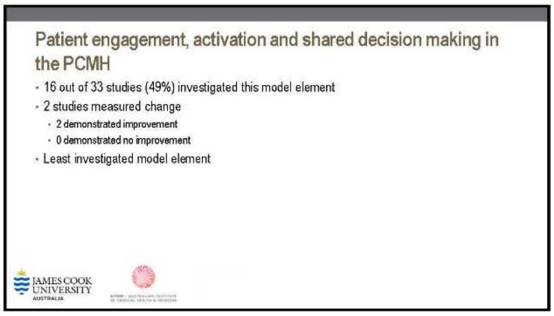
## Care Co-ordination in the PCMH

- 26 out of 33 studies (79%) investigated this model element
- 9 studies measured change
  - 5 demonstrated improvement
  - 4 demonstrated no improvement
- Care co-ordination may occur in the background to service delivery and may not directly impact on patient's perceptions of their experience of care



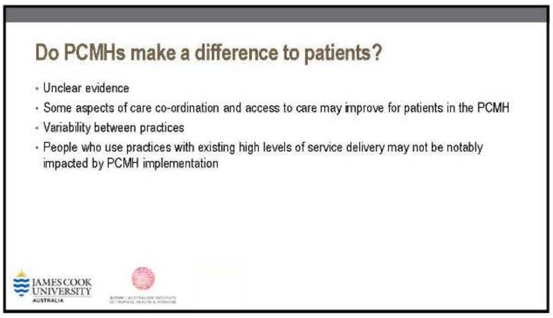
## Access to Care in the PCMH

- 26 out of 33 studies (79%) investigated this model element
- 11 studies measured change
  - 7 demonstrated improvement
  - 4 demonstrated no improvement
- Access to care had the least patient satisfaction at baseline and the most potential for improvement under the PCMH model



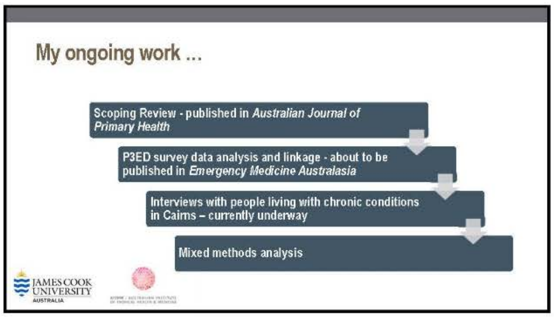
## Patient engagement, activation and shared decision making in the PCMH

- 16 out of 33 studies (49%) investigated this model element
- 2 studies measured change
  - 2 demonstrated improvement
  - 0 demonstrated no improvement
- Least investigated model element



## Do PCMHs make a difference to patients?

- Unclear evidence
- Some aspects of care co-ordination and access to care may improve for patients in the PCMH
- Variability between practices
- People who use practices with existing high levels of service delivery may not be notably impacted by PCMH implementation



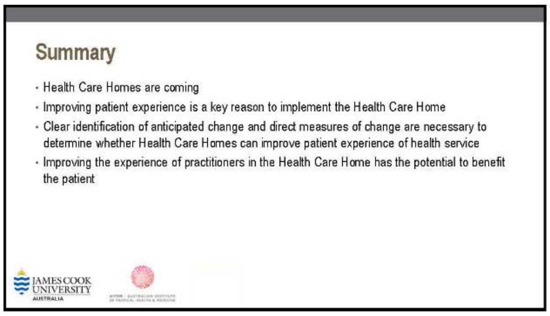
## My ongoing work ...

Scoping Review - published in *Australian Journal of Primary Health*

P3ED survey data analysis and linkage - about to be published in *Emergency Medicine Australasia*

Interviews with people living with chronic conditions in Cairns – currently underway

Mixed methods analysis



## Summary

- Health Care Homes are coming
- Improving patient experience is a key reason to implement the Health Care Home
- Clear identification of anticipated change and direct measures of change are necessary to determine whether Health Care Homes can improve patient experience of health service
- Improving the experience of practitioners in the Health Care Home has the potential to benefit the patient

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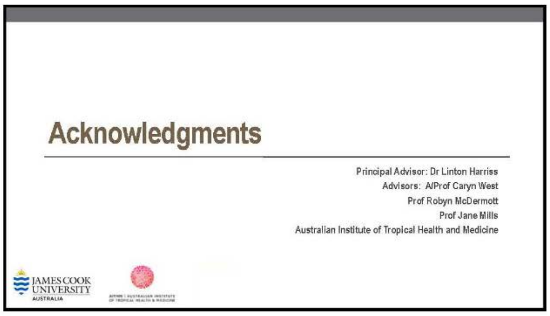

## Acknowledgments

Principal Advisor: Dr Linton Harriss
Advisors: A/Prof Caryn West
Prof Robyn McDermott
Prof Jane Mills
Australian Institute of Tropical Health and Medicine

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## *G4 Public Health Association of Australia: Australian Public Health Conference Cairns, September 2018 (oral presentation)*

Factors that influence Emergency Department attendance in Cairns

### A patient perspective study

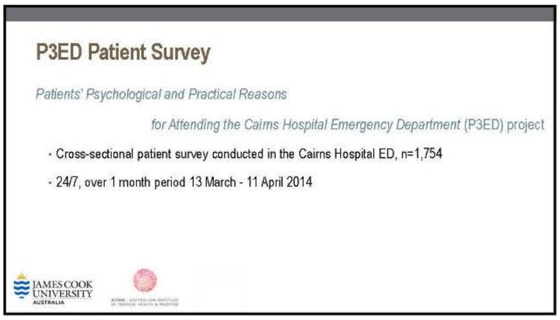
**Mary O'Loughlin**
AITHM PhD Candidate, RN, BN, MPH
James Cook University Cairns
mary.oloughlin@jcu.edu.au

Study Authors: Mary O'LOUGHLIN, Dr Linton HARRISS, Fintan THOMPSON, Prof Robyn MCDERMOTT and Prof Jane MILLS

### Background

- Person-centred care is a goal of Australian healthcare organisations
- Limited understanding of people's preferences, needs and values
- Project Aim:

*To explore the patient perspective of health services in Cairns*

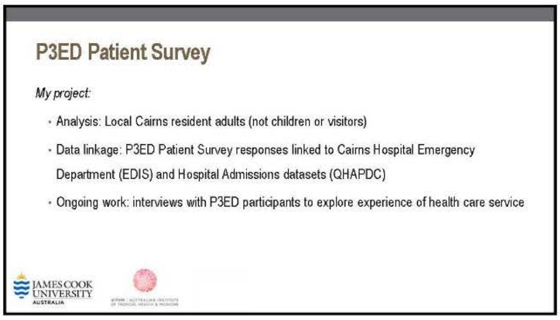


### P3ED Patient Survey

*Patients' Psychological and Practical Reasons*

*for Attending the Cairns Hospital Emergency Department (P3ED) project*

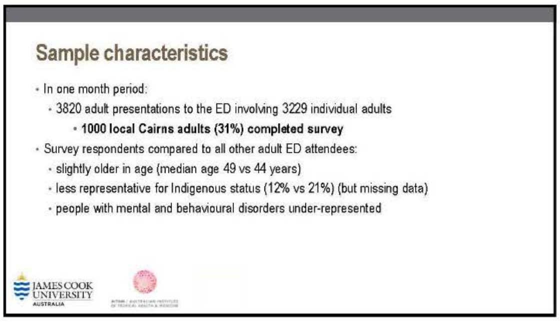
- Cross-sectional patient survey conducted in the Cairns Hospital ED, n=1,754
- 24/7, over 1 month period 13 March - 11 April 2014



### P3ED Patient Survey

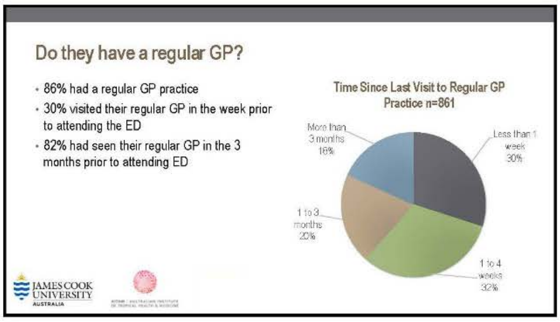
*My project:*

- Analysis: Local Cairns resident adults (not children or visitors)
- Data linkage: P3ED Patient Survey responses linked to Cairns Hospital Emergency Department (EDIS) and Hospital Admissions datasets (QHAPDC)
- Ongoing work: interviews with P3ED participants to explore experience of health care service



### Sample characteristics

- In one month period:
  - 3820 adult presentations to the ED involving 3229 individual adults
    - **1000 local Cairns adults (31%) completed survey**
- Survey respondents compared to all other adult ED attendees:
  - slightly older in age (median age 49 vs 44 years)
  - less representative for Indigenous status (12% vs 21%) (but missing data)
  - people with mental and behavioural disorders under-represented



### Do they have a regular GP?

- 86% had a regular GP practice
- 30% visited their regular GP in the week prior to attending the ED
- 82% had seen their regular GP in the 3 months prior to attending ED

## Immediately prior to arrival

- Many (57%) had their presenting complaint for less than 24 hours
- Some (42%) had consulted another health professional (eg. regular/non-regular GP, pharmacist, physiotherapist) prior to attending ED

## Self-referred or doctor-referred?

- Patient's reported 29% referred by a medical practitioner to the ED (n = 290)
- EDIS dataset indicated 7% were referred by a medical practitioner to the ED (n = 67)

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## At the ED: arrival, triage and discharge

| | Survey Participants n (%) | All other ED attendees n (%) | P diff |
|---|---|---|---|
| ED attendees | 1,000 | 2,229 | |
| Arrived outside normal working hours | 569 (57) | 1251 (56) | 0.72 |
| Arrived by ambulance | 376 (38) | 1007 (45) | **< 0.001** |
| Triage Category 1,2 or 3 | 581 (58) | 1220 (55) | 0.08 |
| Discharged home from the ED | 552 (55) | 1100 (49) | **0.002** |

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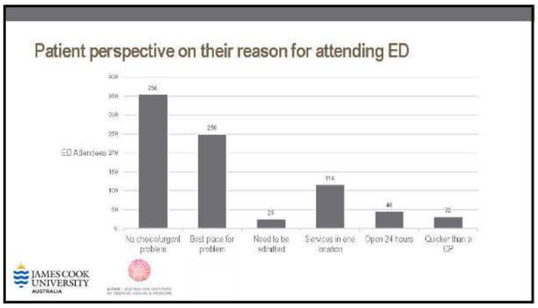
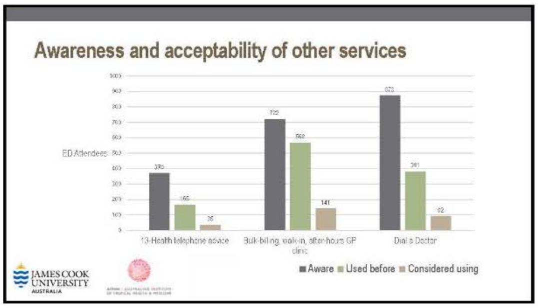
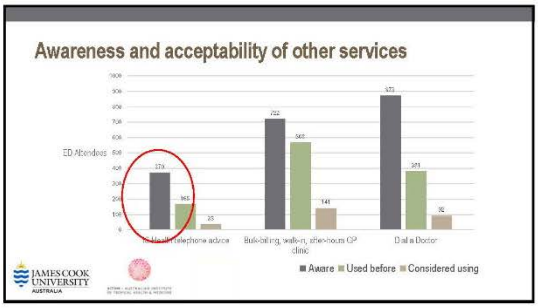
Data sourced from Emergency Department Information System (EDIS)
P-value <0.05 is presented in bold. P diff., P difference. P diff. adult survey participants versus all other adult, non-survey attendees.
Outside normal working hours: 6 pm–8 am weekdays, weekends excluding 8 am–12 noon Saturday



## Patient perspective on their reason for attending ED



## Awareness and acceptability of other services



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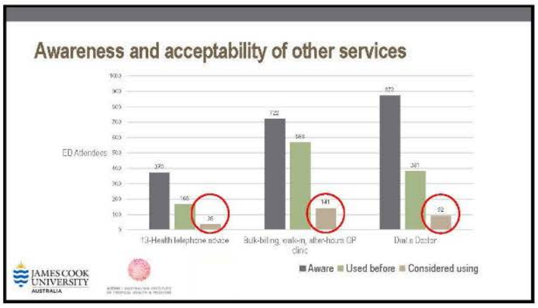


## Awareness and acceptability of other services

## Patient-informed opportunities to improve care in Cairns

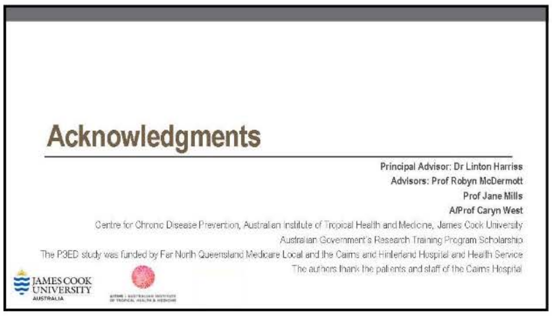
- Increase access to regular GP service for urgent care
- Extend hours of regular GP practice (some suggested late night, some till 7pm) and provide on-site pharmacy
- Increase awareness of 13 Health telephone advice service
- Increase south-side services (Edmonton, Gordonvale, White Rock), Kuranda services, mental health services and access to specialist care
- Consider young adults (18-44 years) with chronic conditions:
  - more likely to consult another health professional prior to attending the ED
  - attend the ED more frequently (10 or more visits in any 1 year period)
- Consider middle aged adults (45-64 years) with chronic conditions:
  - least access to bulk-billing at regular GP
  - least likely to visit their GP practice in week prior to attending ED

EMA Emergency Medicine Australasia

*Exploring factors that influence adult presentation to an emergency department in regional Queensland: a linked, cross-sectional, patient perspective study*

https://onlinelibrary.wiley.com/doi/10.1111/1742-6723.13094

Patient factors that influence ED presentation



## Acknowledgments

**Principal Advisor: Dr Linton Harriss**
**Advisors: Prof Robyn McDermott**
**Prof Jane Mills**
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The P3ED study was funded by Far North Queensland Medicare Local and the Cairns and Hinterland Hospital and Health Service
The authors thank the patients and staff of the Cairns Hospital

## Project Approvals

✓FNQ HREC – Approved HREC/16/QCH/81 – 1068

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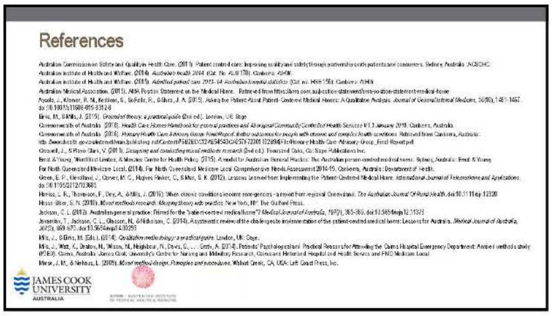

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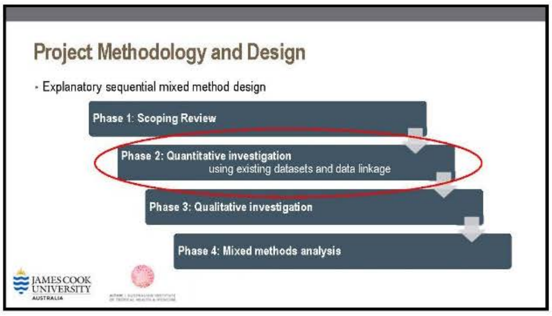


## Project Methodology and Design

- Explanatory sequential mixed method design

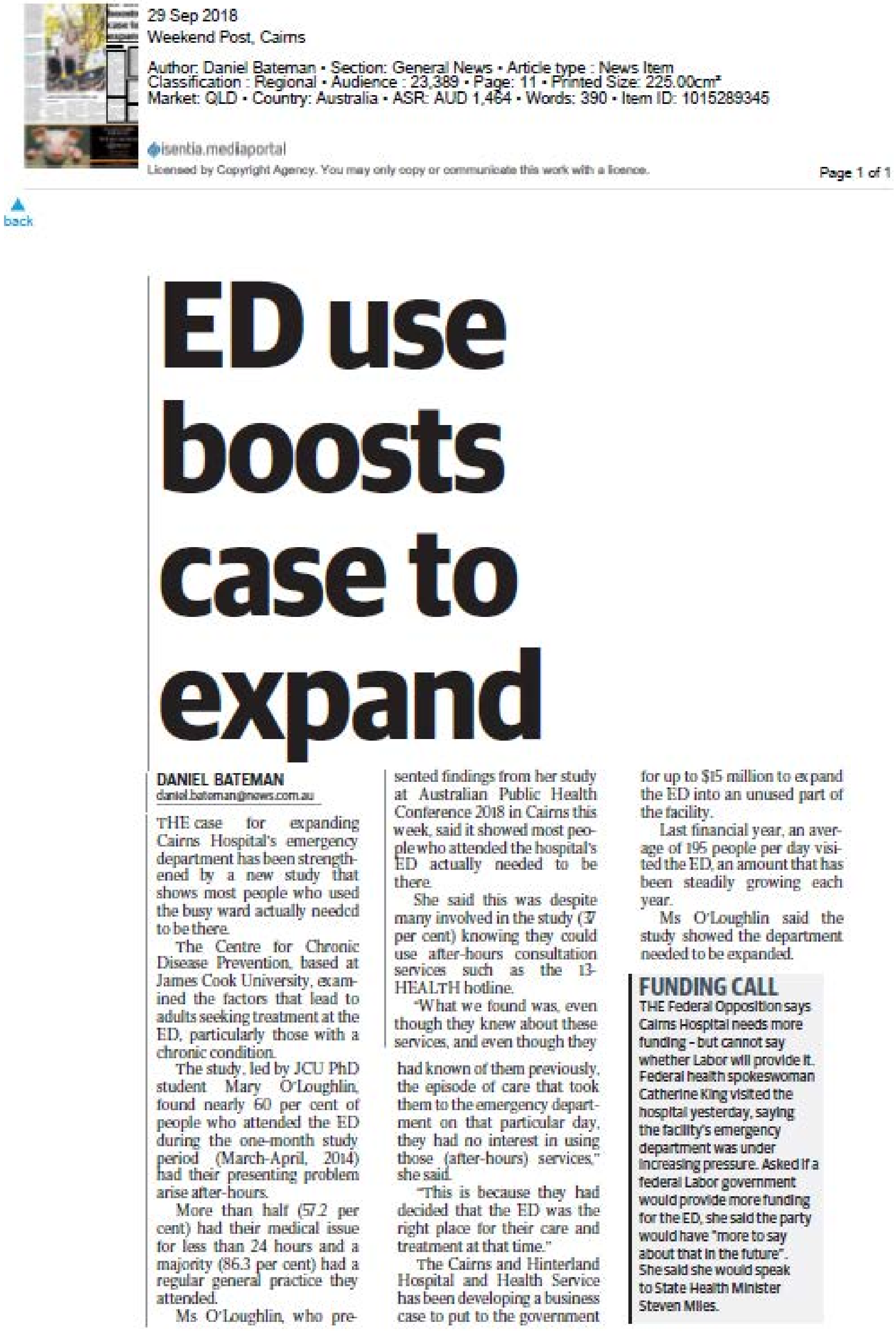
Phase 1: Scoping Review

Phase 2: Quantitative investigation
using existing datasets and data linkage

Phase 3: Qualitative investigation

Phase 4: Mixed methods analysis

***G5 Weekend Post, Cairns, September 2018 (media report)***



29 Sep 2018
Weekend Post, Cairns

Author: Daniel Bateman • Section: General News • Article type : News Item
Classification : Regional • Audience : 23,389 • Page: 11 • Printed Size: 225.00cm²
Market: QLD • Country: Australia • ASR: AUD 1,464 • Words: 390 • Item ID: 1015289345

isentia.mediaportal

Page 1 of 1

# ED use boosts case to expand

**DANIEL BATEMAN**
daniel.bateman@news.com.au

THE case for expanding Cairns Hospital's emergency department has been strengthened by a new study that shows most people who used the busy ward actually needed to be there.

The Centre for Chronic Disease Prevention, based at James Cook University, examined the factors that lead to adults seeking treatment at the ED, particularly those with a chronic condition.

The study, led by JCU PhD student Mary O'Loughlin, found nearly 60 per cent of people who attended the ED during the one-month study period (March-April, 2014) had their presenting problem arise after-hours.

More than half (57.2 per cent) had their medical issue for less than 24 hours and a majority (86.3 per cent) had a regular general practice they attended.

Ms O'Loughlin, who presented findings from her study at Australian Public Health Conference 2018 in Cairns this week, said it showed most people who attended the hospital's ED actually needed to be there.

She said this was despite many involved in the study (37 per cent) knowing they could use after-hours consultation services such as the 13-HEALTH hotline.

"What we found was, even though they knew about these services, and even though they had known of them previously, the episode of care that took them to the emergency department on that particular day, they had no interest in using those (after-hours) services," she said.

"This is because they had decided that the ED was the right place for their care and treatment at that time."

The Cairns and Hinterland Hospital and Health Service has been developing a business case to put to the government for up to $15 million to expand the ED into an unused part of the facility.

Last financial year, an average of 195 people per day visited the ED, an amount that has been steadily growing each year.

Ms O'Loughlin said the study showed the department needed to be expanded.

## FUNDING CALL

THE Federal Opposition says Cairns Hospital needs more funding – but cannot say whether Labor will provide it. Federal health spokeswoman Catherine King visited the hospital yesterday, saying the facility's emergency department was under increasing pressure. Asked if a federal Labor government would provide more funding for the ED, she said the party would have "more to say about that in the future". She said she would speak to State Health Minister Steven Miles.

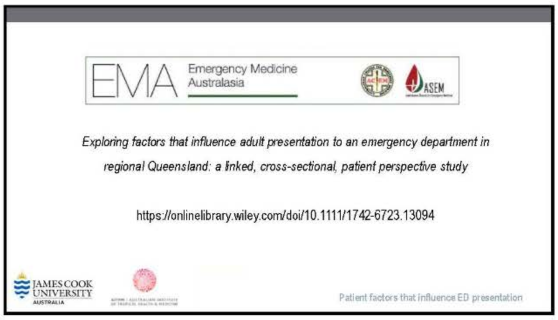
### *G6 Apunipima Cape York Health Council journal club, November 2018 (oral presentation)*

Factors that influence Emergency Department attendance in Cairns

**A patient perspective study**

**Mary O'Loughlin**
AITHM PhD Candidate, RN, BN, MPH
James Cook University Cairns
mary.oloughlin@jcu.edu.au

Study Authors: Mary O'LOUGHLIN, Dr Linton HARRISS, Fintan THOMPSON,
Prof Robyn MCDERMOTT And Prof Jane MILLS



EMA Emergency Medicine Australasia

*Exploring factors that influence adult presentation to an emergency department in regional Queensland: a linked, cross-sectional, patient perspective study*

https://onlinelibrary.wiley.com/doi/10.1111/1742-6723.13094

Patient factors that influence ED presentation

**Background**

- Person-centred care is a goal of Australian healthcare organisations
- Limited understanding of people's preferences, needs and values
- PhD Project Aim:

*To explore the health service experience of adults living with chronic conditions in Cairns*

**Project Methodology and Design**

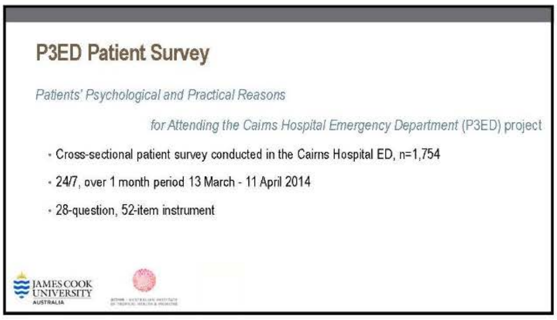
- Explanatory sequential mixed method design

Phase 1: Scoping Review

Phase 2: Quantitative investigation
using existing datasets and data linkage

Phase 3: Qualitative investigation

Phase 4: Mixed methods analysis

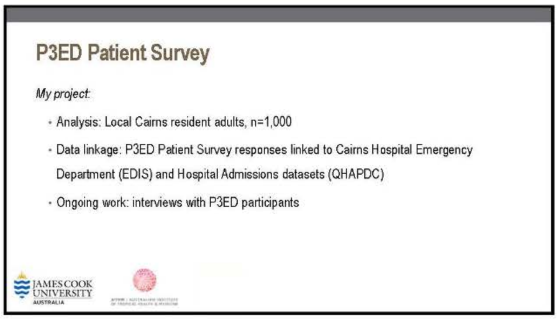


**P3ED Patient Survey**

*Patients' Psychological and Practical Reasons*

*for Attending the Cairns Hospital Emergency Department (P3ED) project*

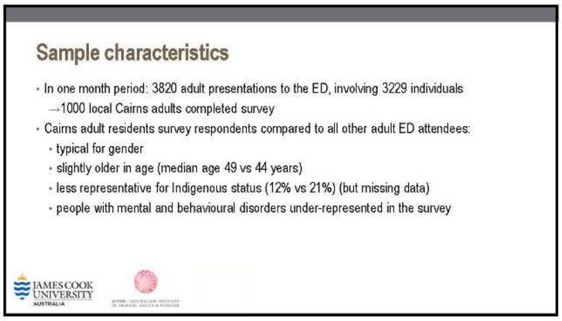
- Cross-sectional patient survey conducted in the Cairns Hospital ED, n=1,754
- 24/7, over 1 month period 13 March - 11 April 2014
- 28-question, 52-item instrument



**P3ED Patient Survey**

*My project:*

- Analysis: Local Cairns resident adults, n=1,000
- Data linkage: P3ED Patient Survey responses linked to Cairns Hospital Emergency Department (EDIS) and Hospital Admissions datasets (QHAPDC)
- Ongoing work: interviews with P3ED participants



## Sample characteristics

- In one month period: 3820 adult presentations to the ED, involving 3229 individuals →1000 local Cairns adults completed survey
- Cairns adult residents survey respondents compared to all other adult ED attendees:
  - typical for gender
  - slightly older in age (median age 49 vs 44 years)
  - less representative for Indigenous status (12% vs 21%) (but missing data)
  - people with mental and behavioural disorders under-represented in the survey

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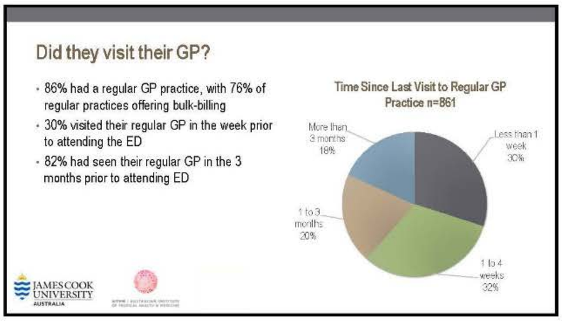
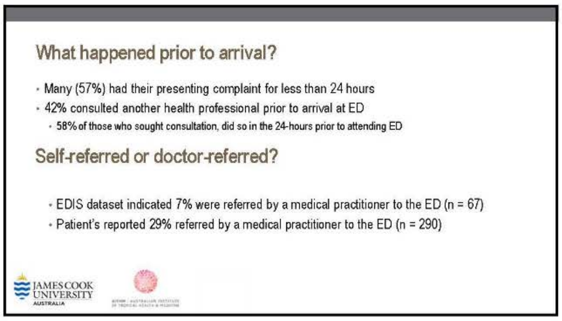


## Did they visit their GP?

- 86% had a regular GP practice, with 76% of regular practices offering bulk-billing
- 30% visited their regular GP in the week prior to attending the ED
- 82% had seen their regular GP in the 3 months prior to attending ED

Time Since Last Visit to Regular GP Practice n=861

8



## What happened prior to arrival?

- Many (57%) had their presenting complaint for less than 24 hours
- 42% consulted another health professional prior to arrival at ED
  - 58% of those who sought consultation, did so in the 24-hours prior to attending ED

## Self-referred or doctor-referred?

- EDIS dataset indicated 7% were referred by a medical practitioner to the ED (n = 67)
- Patient's reported 29% referred by a medical practitioner to the ED (n = 290)

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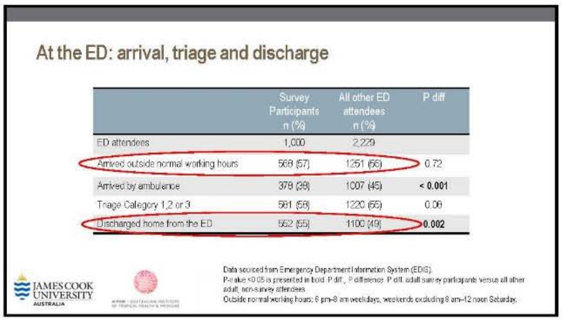

## At the ED: arrival, triage and discharge

| | Survey Participants n (%) | All other ED attendees n (%) | P diff |
|---|---|---|---|
| ED attendees | 1,000 | 2,229 | |
| Arrived outside normal working hours | 568 (57) | 1251 (56) | 0.72 |
| Arrived by ambulance | 378 (38) | 1007 (45) | **< 0.001** |
| Triage Category 1,2 or 3 | 581 (58) | 1220 (55) | 0.06 |
| Discharged home from the ED | 552 (55) | 1100 (49) | **0.002** |

Data sourced from Emergency Department Information System (EDIS).
P-value <0.05 is presented in bold. P diff., P difference. P diff. adult survey participants versus all other adult, non-survey attendees.
Outside normal working hours: 6 pm–8 am weekdays, weekends excluding 8 am–12 noon Saturday.

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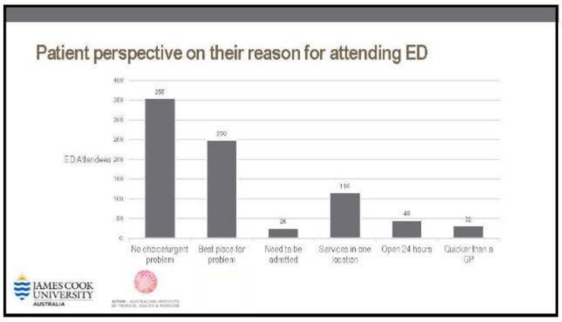

## Patient perspective on their reason for attending ED

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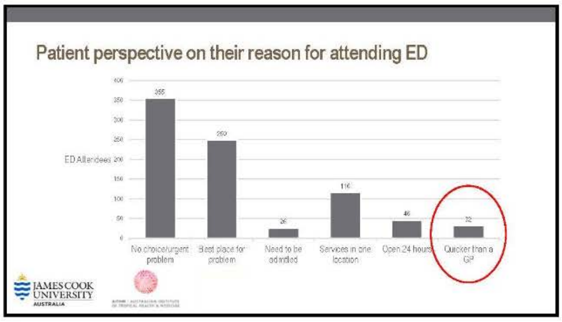

## Patient perspective on their reason for attending ED

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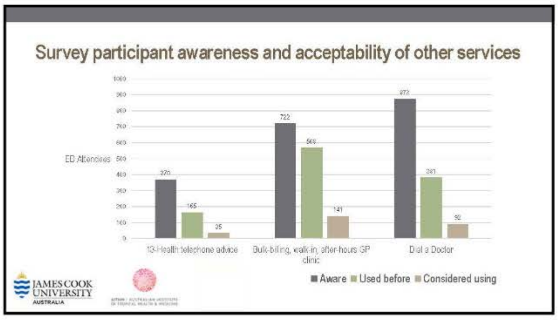
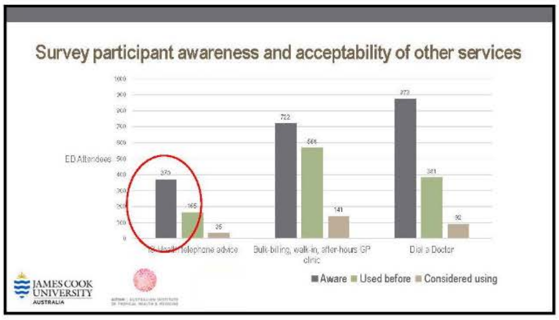


## Survey participant awareness and acceptability of other services



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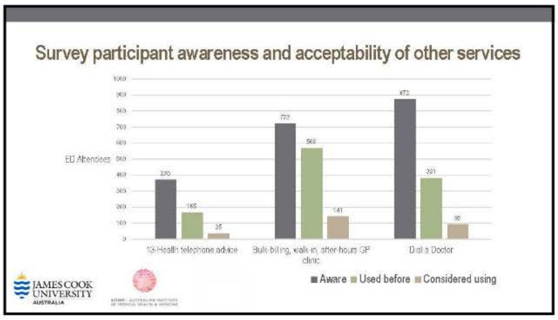

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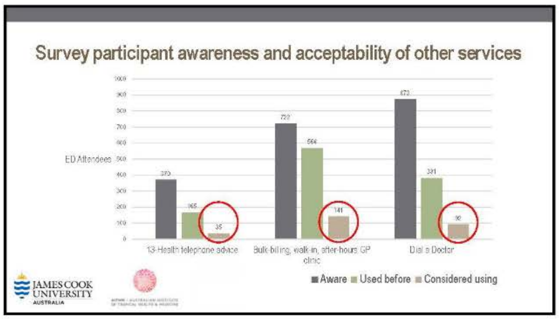

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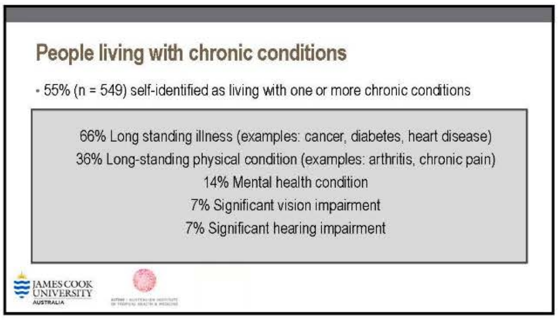
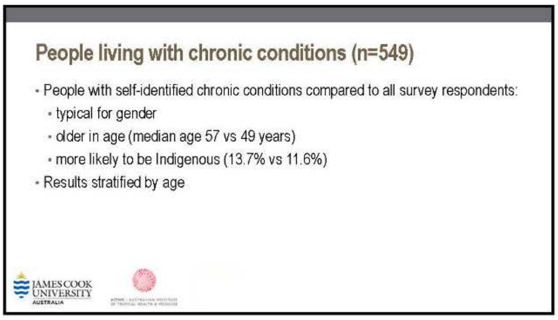


## People living with chronic conditions

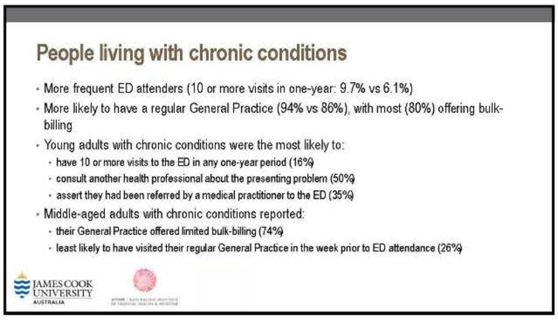
- 55% (n = 549) self-identified as living with one or more chronic conditions

66% Long standing illness (examples: cancer, diabetes, heart disease)
36% Long-standing physical condition (examples: arthritis, chronic pain)
14% Mental health condition
7% Significant vision impairment
7% Significant hearing impairment



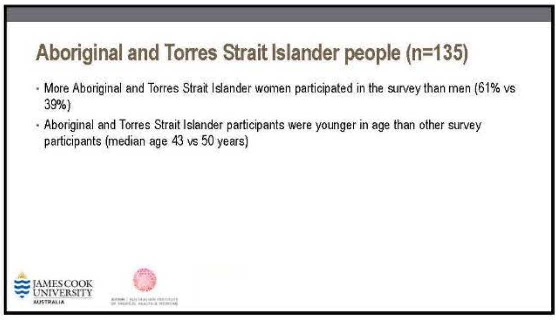
## People living with chronic conditions (n=549)

- People with self-identified chronic conditions compared to all survey respondents:
  - typical for gender
  - older in age (median age 57 vs 49 years)
  - more likely to be Indigenous (13.7% vs 11.6%)
- Results stratified by age



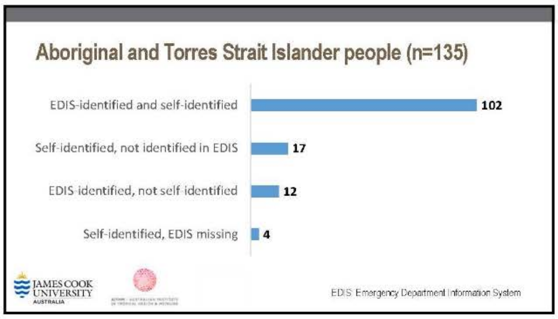
## People living with chronic conditions

- More frequent ED attenders (10 or more visits in one-year: 9.7% vs 6.1%)
- More likely to have a regular General Practice (94% vs 86%), with most (80%) offering bulk-billing
- Young adults with chronic conditions were the most likely to:
  - have 10 or more visits to the ED in any one-year period (16%)
  - consult another health professional about the presenting problem (50%)
  - assert they had been referred by a medical practitioner to the ED (35%)
- Middle-aged adults with chronic conditions reported:
  - their General Practice offered limited bulk-billing (74%)
  - least likely to have visited their regular General Practice in the week prior to ED attendance (26%)



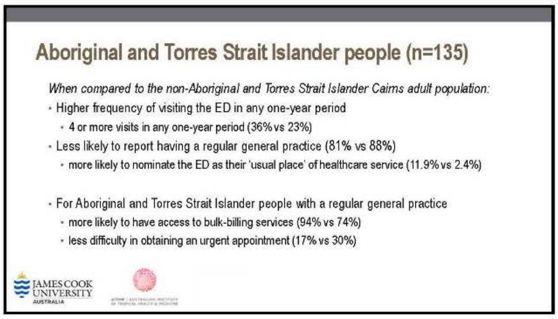
## Aboriginal and Torres Strait Islander people (n=135)

- More Aboriginal and Torres Strait Islander women participated in the survey than men (61% vs 39%)
- Aboriginal and Torres Strait Islander participants were younger in age than other survey participants (median age 43 vs 50 years)



## Aboriginal and Torres Strait Islander people (n=135)

EDIS: Emergency Department Information System



## Aboriginal and Torres Strait Islander people (n=135)

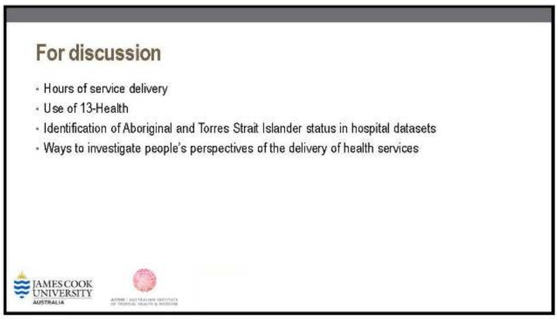
*When compared to the non-Aboriginal and Torres Strait Islander Cairns adult population:*

- Higher frequency of visiting the ED in any one-year period
  - 4 or more visits in any one-year period (36% vs 23%)
- Less likely to report having a regular general practice (81% vs 88%)
  - more likely to nominate the ED as their 'usual place' of healthcare service (11.9% vs 2.4%)

- For Aboriginal and Torres Strait Islander people with a regular general practice
  - more likely to have access to bulk-billing services (94% vs 74%)
  - less difficulty in obtaining an urgent appointment (17% vs 30%)

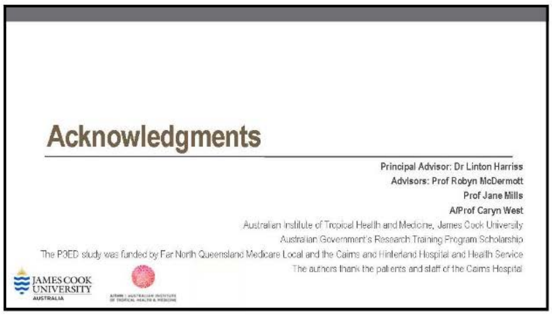
## Patient-informed opportunities to improve care in Cairns

- Increase access to GP for urgent care
- For local primary health care services, extend hours of care (some suggested late night, some till 7pm) and on-site pharmacy
- Increase awareness of 13 Health telephone advice service
- Consider young adults (18-44 years) with chronic conditions:
  - more likely to consult another health professional prior to attending the ED
  - attend the ED more frequently (10 or more visits in any 1 year period)
- Consider middle aged adults (45-64 years) with chronic conditions:
  - least access to bulk-billing at regular GP
  - least likely to visit their GP practice in week prior to attending ED
- Increase south-side services (Edmonton, Gordonvale, White Rock), Kuranda services, mental health services and access to specialist care



## For discussion

- Hours of service delivery
- Use of 13-Health
- Identification of Aboriginal and Torres Strait Islander status in hospital datasets
- Ways to investigate people's perspectives of the delivery of health services



## Acknowledgments

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