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Exploring the health consumers' perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management

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Research & Development

FULL FINAL REPORT

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Acronyms

ADE	Adverse Drug Event
C	Consumer participant (identification of participant role used in the study)
CA	Carer participant (identification of participant role used in the study)
CC	Consumer and Carer participant (identification of participant role used in the study)
CALD	Culturally and Linguistically Diverse
CATI	Computer-Assisted Telephone Interview
CHO	Consumer Health Organisation
CPA	Community Pharmacy Agreement
CTG	Closing the Gap
DCE	Discrete Choice Experiment
GP	General Practitioner
HACC	Home and Community Care program
HMR	Home Medication Review
NGT	Nominal Group Technique
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PCC	Patient Centred Care
PhARIA	Pharmacy Accessibility and Remoteness Index of Australia
PSA	Pharmaceutical Society of Australia
QCPP	Quality Care in Pharmacy Program
QLD	Queensland
WA	Western Australia

Definitions

Health hub	A location (e.g. a community pharmacy) that provides a spectrum of services based on the needs of the individual consumer. This ranges from simple signposting and connections to relevant health organisations or programs, to more complex care facilitation, such as medication management, monitoring and health advocacy.
Pharmacy support staff	Non-professional pharmacy workforce including dispensary assistants, technicians and other staff involved in retail aspects of the pharmacy business.
One-stop shop	A community clinic or centre where a range of health professionals and healthcare services are co-located, to enhance convenience and coordination of services.
Over-the-counter medication	Medication that is available to purchase in a pharmacy without a prescription to access it.

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Publications and presentations

The work in this report has been presented in the following manner:

Peer-reviewed publications

- 1) McMillan SS, Sav A, Kelly F, King MA, Whitty JA, Wheeler AJ. Is the pharmacy profession innovative enough?: meeting the needs of Australian residents with chronic conditions and their carers using the nominal group technique. *BMC Health Services Research* 2014;14:476. DOI:10.1186/1472-6963-14-476.
- 2) McMillan SS, Kelly F, Sav A, Kendall E, King MA, Whitty JA, Wheeler AJ. Using the nominal group technique: how to analyse across multiple groups. *Health Services and Outcomes Research Methodology* DOI:10.1007/s10742-014-0121-1 (published online 25.07.14).
- 3) Whitty JA, Kendall E, Sav A, Kelly F, McMillan SS, King MA, Wheeler AJ. Preferences for the delivery of community pharmacy services to help manage chronic conditions. *Research in Social and Administrative Pharmacy* DOI:org/10.1016/j.sapharm.2014.06.007 (published online 15.07.14).
- 4) Whitty JA, Sav A, McMillan SS, Kendall E, Kelly F, King MA, Wheeler AJ. Chronic conditions, financial burden, and pharmaceutical pricing: insights from Australian consumers. *Australian Health Review* DOI:org/10.1071/AH13190 (published online 07.08.14).
- 5) Sav A, Whitty JA, McMillan SS, Kelly F, King MA, Wheeler AJ. Consumer health organisations for chronic conditions: why do some people access them and others don't. *Primary Health Care Research and Development* DOI:10.1017/S1463423614000036 (published online 05.02.14).
- 6) Kelly F, Sav A, McMillan SS, King M, Whitty JA, Wheeler AJ. Patient-centered care: what consumer health organisations say and do. *European Journal for Person Centred Healthcare* (in press, accepted 16.12.2013).
- 7) McMillan SS, Kelly F, Sav A, King MA, Whitty JA, Wheeler AJ. Consumer and carer views of Australian community pharmacy practice: awareness, experience and expectations. *Journal of Pharmaceutical Health Services Research* 2014; 5(1):29-36. DOI:10.111/jphs.12043.
- 8) Sav A, King M.A, Kelly F, Kendall E, McMillan SS, Whitty JA, Wheeler AJ. Self-management of chronic conditions in a rural and remote context. *Australian Journal of Primary Health* DOI:org/10.1071/PY13084 (published online 18.10.13).
- 9) McMillan SS, Sav A, Kelly F, King M, Whitty JA, Wheeler AJ. How to attract them and keep them: the pharmacy attributes that matter to Australian residents with chronic conditions. *International Journal of Pharmacy Practice* 2014;22(4):238-245. DOI: 10.1111/ijpp.12075.
- 10) McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ. Patient-centred approaches to health care: a systematic review of randomised controlled trials. *Medical Care Research and Review* 2013; 70(6):567-596. DOI: 10.1177/1077558713496318.
- 11) Sav A, Kendall E, McMillan SS, Kelly F, Whitty J, King MA, Wheeler AJ. "You say treatment, I say hard work": treatment burden among people with chronic illness and their carers in Australia. *Health & Social Care in the Community* 2013; 21(6):665-674. DOI:10.1111/hsc.12052.
- 12) Sav A, King M, Whitty J, Kendall E, McMillan S, Kelly F, Wheeler AJ. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations* DOI:10.1111/hex.12046 (published online 21.01.13).
- 13) McMillan S, Wheeler AJ, Sav A, King M, Whitty J, Kendall E, Kelly F. Community pharmacy in Australia: a health hub destination of the future. *Research in Social and Administrative Pharmacy* 2013; 9(6):863-875. DOI:org/10.1016/j.sapharm.2012.11.003.
- 14) Sav A, McMillan S, Kelly F, Kendall E, Whitty JA, King MA, Wheeler AJ. Treatment burden among people with chronic illness: what are consumer health organizations saying? *Chronic Illness* 2013; 9(3):220-232. DOI:10.1177/1742395312463411.

Conference and invited meeting presentations

- 1) Oral presentation "Chronic conditions, financial burden and pharmaceutical pricing: insights from Australian consumers" National Medicines Symposium – Brisbane, Australia, 22nd May 2014.
Whitty JA, Sav A, Kelly F, King M, McMillan S, Kendall E, Wheeler A. Chronic conditions, financial burden and pharmaceutical pricing: insights from Australian consumers. *Program and Abstract Book National Medicines Symposium* May 2014: pg 61.
- 2) Oral presentation "Identifying consumer healthcare priorities: what we didn't know, what we now know, and how we used the nominal group technique" 8th Health Services & Policy Research Conference - Wellington, New Zealand, 2nd December 2013.
McMillan SS, Sav A, Kelly F, Kendall E, Whitty JA, King MA, Wheeler A. *Health Services & Policy Research Conference Handbook* 2-4 December 2013: pg. 37.
- 3) Oral presentation "Consumer health organisations for chronic conditions" Gold Coast Health and Medical Research Conference - Gold Coast, Australia, 28th November 2012.
Sav A, McMillan S, Kelly F, Kendall E, Whitty J, King MA, Wheeler AJ. *Proceedings of the Gold Coast Health and Medical Research Conference* 28-29 November 2013: pg. 59.
- 4) Oral presentation "Chronic conditions, financial burden and pharmaceutical pricing: insights from Australian consumers" Gold Coast Health and Medical Research Conference - Gold Coast, Australia, 28th November 2012.
Whitty JA, Sav A, Kelly F, King M, McMillan S, Kendall E, Wheeler AJ. *Proceedings of the Gold Coast Health and Medical Research Conference* 28-29 November 2013: pg. 68.
- 5) Table presentation "How can community pharmacy help? Comparing the perspectives of consumers/carers and healthcare professionals." National Primary Health Care Conference – Gold Coast, Australia, 14th November 2013. Sav A, McMillan S, Kelly F, Whitty JA, King MA, Kendall E, Wheeler AJ.
- 6) Oral presentation "Meeting the needs of people with chronic conditions and carers: are you innovative enough" Pharmacy Australia Congress, Brisbane, Australia, 12th October 2013.
McMillan SS, Kelly F, Sav A, King MA, Wheeler A.
- 7) Poster presentation "Australian community pharmacy: determinants influencing choice" Royal Pharmaceutical Society Conference, Birmingham, England, 8-9th September 2013.
McMillan S, Sav A, Kelly F, King M, Whitty J, Wheeler A. Australian community pharmacy: determinants influencing choice. *International Journal of Pharmacy Practice* 2013: 21 (Suppl 2):34-35. Poster award "Practice Research Poster Winner 2013" Sara McMillan
- 8) Oral presentation "Who cares? Experiences of carer burden and how pharmacy can help" Royal Pharmaceutical Society Conference, Birmingham, England, 9 September 2013.
King M, Kelly F, McMillan S, Sav A, Whitty J, Wheeler A. *International Journal of Pharmacy Practice* 2013: 21 (Suppl 2):28.
- 9) Poster presentation "Complex consumers and carers: an insight into their experiences, expectations and awareness of Australian community pharmacy practice." 4th International Pharmaceutical Federation Pharmaceutical Sciences World Congress – Dublin, Ireland, 4 September 2013.
McMillan SS, Kelly F, Sav A, King MA, Wheeler AJ.
<http://fip.org/abstracts?page=abstracts&action=item&item=9012>.
- 10) Oral presentation "Community pharmacy as a health hub: meeting the needs of people with chronic illness" Australasian Pharmaceutical Science Association (APSA) Scientific Conference, Sydney, Australia, December 2012.
McMillan SS, Wheeler AJ, Sav A, King M, Whitty J, Kendall E Kelly F. *APSA 2012 Conference Program and Abstract Book*: pg 42.
Presentation award "Outstanding oral presentation in pharmacy practice" Sara McMillan.

- 11) Oral presentation "What are the experiences and expectations of people with a chronic illness (s) regarding community pharmacy?" Gold Coast Health and Medical Research Conference - Gold Coast, Australia, December 2012.
Sav A, McMillan S, Whitty J, Kendall E, Kelly F, King M, Wheeler AJ. *Proceedings of the Gold Coast Health and Medical Research Conference December 2012*: pg. 48.
- 12) Oral presentation "Nothing about me without me: a review of patient-centred care and treatment burden" Australian Pharmacy Professional Conference – Gold Coast, Australia, 11th March 2012.
Sav A, Wheeler A, Kendall E, McMillan S, King M, Whitty J, Kelly F.

Abstract

Background: Living with a chronic condition in the community requires self-management and health-promoting behaviours. Little is known about the treatment burden experienced by people with chronic conditions, nor how they view the role of pharmacy in their care and what services can support them.

Objective: To explore consumer and carer perceptions of treatment burden, patient centred care and choices or preferences for pharmacy services in the management of chronic conditions, amongst people who are high users of health or pharmacy services.

Methods: Stage One included a concept analysis, systematic review and 21 key stakeholder interviews. Stage Two included (i) interviews with 97 consumers and carers; (ii) discussion groups using the Nominal Group Technique (i.e. nominal group) with consumers and carers (n=103) and health professionals (n=61) to identify priorities for pharmacy services. Stage Three used a quantitative survey and discrete choice experiment to explore preferences about the nature of services (n=602 consumers and carers; n=297 health professionals).

Results: Patient centred care was highly valued by consumers and carers, influenced pharmacy loyalty and viewed as reducing treatment burden. Consumers and carers wanted streamlined, convenient, and reliable continuous access to medication, both in existing services (e.g. home delivery, prescription reminders) and innovative services (e.g. continued medication supply by the pharmacist). Pharmacy was considered a convenient, trusted destination for medication, services and referral to community support services. Overall, access to information was the most valued service reported by consumers and carers. Younger consumers were more likely to take up new pharmacy services, representing an important market for pharmacy. Financial burden strongly influenced non-adherence of medication and could be alleviated through responsive pharmacy practices (e.g. patient centred relationships) and systemic reforms (e.g. access to repayment schemes). Affordability was a priority for most participants.

Conclusion: There are clear opportunities for community pharmacy to support people with chronic conditions and carers and reduce treatment burden by streamlining access to information and medication, delivered in a patient centred manner. Advocacy for continued medication supply by pharmacists and strengthening collaborative practices between other health professionals and community organisations is a priority. Pharmacy provides a unique opportunity for targeted proactive intervention with particular groups of consumers and carers through extension of existing and innovative pharmacy services that deliver greater coordination of care and convenience for consumers and carers.

Key findings

A mixed methods approach was used to explore consumer and carer perceptions of their chronic condition(s), and choices or preferences about how to engage pharmacy in their management. In total, 661 consumers and carers and 322 health professionals participated in one or more of the research stages from four regions of Australia.

1. **Whole-of-pharmacy patient centred services are of prime importance to consumers and carers and influence pharmacy choice and loyalty, satisfaction, perceived quality of service and treatment burden.** Consumers value and benefit from patient centred services that are holistic, individualised, respectful and empowering. All stages of the research confirmed the central importance of patient centred services, revealing that it can influence choice and loyalty of pharmacy. Pharmacy is a critical intervention point to reduce medication-related treatment burden through informative, respectful relationships, clear communication and consumer engagement. Education and training about the continuum of patient centred care and the nature of treatment burden will be required to ensure a whole-of-pharmacy approach to service delivery.

2. **A continuous and reliable supply of medication and high quality advice achieved through creative, personalised, responsive, flexible and proactive services is highly valued by consumers and carers.** A primary need for consumers and carers was access to a continuous, safe and quality supply of medications. This was described from two perspectives: continued supply of prescription medications from the pharmacist (without visiting the doctor); and convenient medication supply from the pharmacy. There was a strong preference for pharmacists to continue supply of regular medications for a predefined period and for medications previously used to relieve symptom flare-ups. Other suggestions for convenient supply included expanding home deliveries and extending opening hours.

3. **Pharmacy is a convenient, accessible and trusted location that can act as a health hub or central point for appropriate referral, access to other health professionals and timely multidisciplinary information.** Consumers and carers were frequent pharmacy users, which was associated with treatment burden and highlighted the important role of pharmacy. Access to pharmacy services was a key priority, particularly in relation to pharmacy as a safe health space where consumers and carers could be connected to relevant information and services based on their needs. Pharmacy services acting as a central hub were seen as a strategy for directing people to the multitude of available community organisation resources and support programs that could assist them.

4. **Pharmacy is well placed to prevent or limit burden for specific populations, particularly for younger people who are more willing to adopt new initiatives, for carers, frequent pharmacy users and individuals experiencing financial distress or high levels of burden.** Several subgroups emerged as areas of opportunity where proactive pharmacy services could prevent or reduce treatment burden. These included younger people who were more likely to take up new services, middle-aged, low-income earners experiencing significant treatment burden, consumers with diabetes or an endocrine disorder and also carers, as recognition of their role and responsibilities was limited. Pharmacy is in a unique position to identify these groups and provide supportive and timely interventions if such initiatives are tailored to the specific needs of these populations.

5. **Financial burden is inherently linked to medication use/non-use and in the absence of broader systemic changes can be identified and addressed by pharmacy.** Affordability emerged as a key priority highlighting the need to decrease medication cost through low prices and prescription subsidies, maintain price consistency across pharmacies and develop responsive payment methods that alleviate financial stress. Financial burden was a key component of overall treatment burden with one-quarter of participants reporting that they delayed or neglected to purchase prescribed medication due to cost. Affordability influenced loyalty to a pharmacy, and cost was also a barrier to consumers and carers accessing new pharmacy services.

6. **Pharmacy services need to be tailored to economic, personal, cultural and geographical circumstances of their customer base, as prevailing needs and values differ depending on the environment in which the pharmacy is accessed.** No single model of pharmacy service will address the diverse needs of consumers and carers across Australia. Ideal pharmacy service did not reflect a particular model, but focused on timely and reliable coordination of relevant services within a patient centred and responsive relationship that was associated with pharmacy loyalty.

Overall, this research revealed opportunities for pharmacies to support chronic condition management if pharmacy staff prioritise patient centred care and tailor services to the individual needs of consumers and carers.

Executive summary

Globally, chronic conditions are the leading cause of mortality, and increasing numbers of Australians have more than one chronic condition. Although medication assists people to manage chronic conditions, treatment can create associated burden for people. How treatment burden is experienced by people with more complex conditions and multi-morbidities, and their carers, is poorly understood. Community pharmacy is ideally placed to support these consumers and carers, mainly due to accessibility and pharmacists expertise on the quality use of medication. The Pharmacy Guild of Australia engaged Griffith University to investigate consumers', carers' and health professionals' perspectives on treatment burden, their views of patient centred care, and the role of community pharmacy in assisting people to manage their condition(s) or caring role(s).

Research design

Three stages of research were conducted from November 2011 to July 2014 across four regions. Participants included healthcare stakeholders, health professionals (pharmacists, health workers, medical and allied health practitioners), consumers with chronic conditions, unpaid carers, or people who are both. Findings from each stage informed the next stage of the research.

Stage One: Literature review and key stakeholder consultations

1. A *systematic literature review* was undertaken to identify current evidence about the burden of treatment, the nature and impact of patient centred care, and role of community pharmacy.
2. *Stakeholder consultations* explored the views of health advocates, representatives from consumer health and health professional organisations on: treatment burden, patient centred care, and the role of pharmacy.

Stage Two: Semi-structured interviews and discussion groups using the nominal group technique

3. *In-depth, semi-structured interviews* explored consumer and carer experiences of managing chronic condition(s), associated burden, and what they considered as 'patient centred' care. Participants expectations, use and choice of community pharmacy services were explored.
4. Consumer, carer and health professional *nominal groups* were used to elicit creative ideas for future pharmacy services to support chronic condition management, and insight into which of these services they prioritised. Health professionals considered this from the viewpoint of their consumers to explore disparities in views.

Stage Three: Survey and discrete choice experiment (DCE)

5. Stage Three investigated consumer and carer preferences for related pharmacy services and measured:
 - a) Level of *treatment burden* experienced by consumers with chronic condition(s);
 - b) *Quality of life* reported by consumers and carers; and
 - c) Priorities and preferences for the availability and delivery of *community pharmacy services*.Health professionals completed an abridged survey for comparison with consumer and carer data.

Key results and recommendations

In total, 661 consumers and carers and 322 health professionals participated in one or more of the research stages from four regions (Logan-Baundesert and Mt Isa/North West in Queensland, Northern Rivers in New South Wales, Greater Perth in Western Australia). Interviews were conducted with 21 key stakeholders (Stage One) and 97 consumers and carers (Stage Two), nominal groups involved 103 consumers and carers and 61 health professionals (Stage Two), and 602 consumers and carers and 297 health professional/health workers completed the survey (Stage Three). The key findings and recommendations of the research are summarised below.

a. Treatment burden

Treatment burden is a dynamic multidimensional concept, consisting of medication, lifestyle, financial, healthcare access, and social components. Consumers and carers who experienced treatment burden were likely to be younger, have co-morbidities, have an unpaid carer, or to report experiencing diabetes or another endocrine condition. Burden emerged as a key issue for carers. The financial component was the most burdensome for many

consumers and carers, reducing ability to access medication or pharmacy services (e.g. dose administration aids). Approximately 25% of Stage 3 consumer or carer participants had delayed or not purchased a medication in the previous 12 months because of cost; and they had to weigh up the benefits of the medication with respect to their financial situation. Alternatively, affordability was a lesser concern for those with access to Government subsidies, e.g. Closing the Gap (CTG) but was still important. There was limited awareness of the availability, eligibility, or both, of lower co-payments amongst some participants, with 8.3% of Stage Three participants unaware if they had reached Safety Net entitlement.

Opportunities for community pharmacy: There is untapped potential for community pharmacy to further support unpaid carers and reduce *carer burden*. Key areas include recognition and support of carer responsibilities through seamless medication supply and targeted assistance.

Pharmacy-specific recommendations: Education is vital for consumers and carers to ensure that they understand financial entitlements and pharmacy services related to their medication use. Moreover, pharmacy services need to consider a range of payment methods to facilitate access to medication and services, such as pharmacy accounts or advocating for direct payments via Centrelink. Greater accommodation of carer's needs is required through recognition of their role, seamless supply of medications and targeted pharmacy services to alleviate carer burden. A carer card' or template signed by carers and the consumers they care for could offer clarity on the carer role, grant power of attorney or permission to obtain specific information, and identify the carer for targeted support services.

System-based recommendations: Co-payment and other financial benefit systems for consumers with chronic conditions require review to better reduce financial burden and improve adherence, whilst maintaining health system sustainability. Introduction of greater subsidies for specific pharmacy services that encourage medication adherence such as home deliveries and dose administration aids is recommended.

b. Patient centred care

Consumer and carer views on patient centred care reflected a spectrum from personalised service through to care that incorporated one or more attributes of patient centred care, such as empowering, respectful, individualised and holistic care. In practical terms, consumers appreciated a caring health professional who took the time to determine their individual needs, provided tailored medication advice, considered their social context beyond their chronic condition(s), and respected and valued their knowledge and expertise. Patient centred care encouraged loyalty to one pharmacy, as participants were less inclined to choose new services if they believed their current pharmacy service offered care that was responsive to their needs.

Opportunities for community pharmacy: Simple changes that can be easily implemented in pharmacies and do not require longer consultations, are just as likely as complex interventions to bring about desired outcomes. Importantly, changes need to be applied consistently by the whole pharmacy team rather than as brief short-term interventions by one or two individuals. Community pharmacies are more likely to have a loyal customer base if they adopt a patient centred approach.

Pharmacy-specific recommendations: Review of tertiary and industry training is needed to integrate patient centred care into routine practice. Pharmacies would benefit from a patient centred toolkit to support the requisite changes. These range from simple changes, such as open dialogue and respecting consumer and carer treatment and brand choices, to more complex interventions, including multicultural training for pharmacy staff, and developing skills to assess and address barriers to understanding, such as limited English skills or health literacy.

c. Community pharmacy services

Consumers and carers expressed a desire for new and extended pharmacy services that promote streamlined, convenient and on-going access to medication, such as home deliveries, text message prescription reminders, and prescription renewal. There was a strong preference amongst consumers and carers to access their pharmacist to

continue the supply of their regular medication(s) to treat chronic condition(s) for a predefined period, as well as medications previously used for symptom flare-ups. Consumers and carers wanted to see their general practitioner (GP) for any new health problems and for an annual check-up. Health professionals/workers also expected consumers to prefer access to a continued medication supply service from a community pharmacy, suggesting a degree of awareness of this issue in the health system.

The concept of community pharmacy becoming a healthcare destination, or health hub, emerged through different stages of the study with a range of meanings, from simply advertising available pharmacy services, to more complex signposting or active referral to other health services or programs. Consumers and carers also discussed, and had a strong preference for, the co-location of services (e.g. a one-stop shop). Pharmacy support staff and GP groups discussed the use of an information portal or service directory for consumers. Younger consumers and carers, as well as those with a higher treatment burden, were more likely to choose to access the new pharmacy services proposed.

Opportunities for community pharmacy: There is an emerging opportunity for pharmacy to act as a healthcare destination that both connects people to relevant information and services, and provides more streamlined medication support through expansion of the current continued medication supply service. As younger participants were more likely to have a higher level of treatment burden, providing youth-friendly services is another important avenue for community pharmacies to explore.

Pharmacy-specific recommendations: Advocating for community pharmacies to become a health hub and implement various strategies that can improve access to services is important. This can range from training pharmacy support staff in healthcare navigation, to facilitating links with other health workers and consumer health organisations in the community, co-location or active referral and care coordination. Development of services tailored to specific populations such as carers and young people is needed.

System-based recommendations: Extending the pharmacist's role to provide continued medication supply for a designated time period such as six months should be explored. Methods used to achieve this need to optimise patient safety and collaboration with other health professionals involved in the treatment of chronic conditions. Expanding the 5th CPA *Continued Dispensing* service would provide a mechanism for this innovative service.

Strengths and limitations of the study

The size and diversity of the sample and the combined qualitative and quantitative approach are the greatest strengths of this research. The sample reflected a diverse group of extensive health service users with a range of chronic conditions from affluent and disadvantaged communities. A wide spectrum of health professionals/workers and organisations participated in the study. Despite the study sample being large and diverse, there was high participant representation from less-studied populations, including older, culturally diverse and indigenous consumers and carers. Limitations of the study include the use of qualitative cross-sectional data collection conducted at four specific points in time, more than one mode of survey data collection and reliance on self-reported data, which can be influenced by researcher and participant bias. A consumer researcher was involved throughout the project to improve validity of interpretation. On-going discussions were held with a Reference Group to ensure the validity and reliability of the findings.

Conclusion

This research reveals many opportunities for community pharmacies to assist consumers with chronic conditions and their carers. The creative solutions proposed by consumers and carers have real potential to positively impact on treatment burden. Advocacy for continued medication supply by pharmacists and strengthening collaborative practices between primary care practitioners and community services is a priority. Pharmacy provides a unique opportunity for preventative proactive intervention through tailored patient centred pharmacy services with particular groups such as younger consumers and those experiencing financial burden.

1 Introduction

The Pharmacy Guild of Australia engaged Griffith University to undertake research to explore the perspectives of consumers, carers and health professionals about the burden of chronic health conditions and its treatment, patient centred services, and the role of community pharmacy in assisting consumers to better manage their health conditions. This project was funded by the Australian Department of Health as part of the Fifth Community Pharmacy Agreement Research and Development Program, managed by The Pharmacy Guild of Australia. This is the final report for the project entitled: *Exploring the health consumers' perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management*.

Chronic health conditions

Chronic health conditions are generally characterised as having a complex causality, with long periods of illness and functional impairment or disability [1]. They typically affect many aspects of a person's life [2]. However, there appears to be no consistent definition for chronic conditions in the literature [3], with a range of terminology used to describe them, including chronic illnesses, chronic diseases and long term conditions. The World Health Organization has defined chronic health conditions as including:

- non-communicable conditions, e.g. diabetes and asthma;
- persistent communicable conditions, e.g. HIV/AIDS;
- long-term mental health disorders, e.g. depression and schizophrenia; and
- on-going physical or structural impairment, e.g. blindness [4].

For consistency purposes, the term *chronic conditions* will be used throughout this report. The changing nature of what is classified as a chronic condition aligns with the rising rates, or increased predominance of chronic conditions in today's society [5, 6]. The 2011-2012 Australian Health Survey documented:

- 3.3 million (14.8%) people with arthritis;
- 3.0 million (13.6%) people with mental and behavioural conditions;
- 2.3 million (10.2%) people with asthma; and
- 1.0 million (4.7%) people with heart disease [7].

The number of people with more than one chronic health condition, otherwise referred to as multi-morbidity, is also rising [8]. Survey estimates indicate that this is a larger problem in the older population, with 8.0% of Australian residents over 65 years reporting more than four conditions [6]. Globally, chronic conditions alone are the leading cause of mortality [9], equating to more than 36 million deaths in 2008 [5].

Chronic conditions can also place a significant burden on a country's economy. For example, if a person with a chronic condition can no longer work, this affects the labour work-force, which in turn impacts negatively on economic productivity and national income [10]. Governments must subsequently allocate further funding to the healthcare system, which can affect investments in other settings [11]. In 2004-2005, the Australian Government spent \$25.5 billion on healthcare for cardiovascular and respiratory disease, diabetes, cancer, mental health conditions, injuries and musculoskeletal disorders [12]. This included spending on the hospital and community/public health sector, medical research and prescription medication [12].

Treatment burden

Although there have been significant advancements in healthcare over the past two decades, people with chronic conditions still experience burden. One component of this burden is related to the treatment or management of chronic conditions, generally known as *treatment burden*. This is defined as:

The consequences a person with a chronic condition or unpaid carer experiences as a result of undertaking or engaging in treatment, such as medications, therapies, medical interventions etc [13].

A team of researchers investigated the experience of treatment burden in patients with chronic heart failure, with the intention of developing a theoretical framework [14]. Four main tasks that led to treatment burden were identified:

- learning about treatments and their consequences;
- engaging with others and mobilising support;
- adhering to treatment and lifestyle changes; and
- monitoring treatments

Other research indicates that the healthcare system within which people receive treatment can also contribute to treatment burden [15]. For example, ineffective communication between health professionals and health consumers about treatment options, as well as disjointed care, can lead to confusion and even unnecessary treatment [15, 16]. This burden can be exacerbated by medication use [14]. Of a total of 262 million medications prescribed in Australia in 2010, most were used to treat chronic conditions [17]. Furthermore, a 2009 Australian Department of Health and Ageing report indicated that elderly Australians (65-75 years), were using, on average, four prescription medications; this figure is set to rise to six prescribed medications by 2019 [18]. Side effects and adverse events resulting from medication use, polypharmacy (i.e. taking multiple medications), inconvenience of organising medications, and the stigma associated with taking medications can also contribute to treatment burden.

Although treatment burden is recognised as a significant source of concern for people with chronic conditions, it has received relatively little attention by researchers, health professionals and health policy makers. This limits the ability of health professionals to identify whether patients are feeling overburdened by their treatment and to tailor appropriate treatment strategies to meet their individual needs. For example, most research has focused on the experiences of treatment burden among people with specific chronic conditions, such as diabetes, cancer, asthma and cystic fibrosis [19, 14]. Experiences of people with more complex conditions and multi-morbidities have largely been neglected. Chronic conditions rarely occur in isolation and most who experience one condition also report experiencing another [20]. In their struggle to live with and manage two or more chronic conditions, this group of people may have unique experiences of treatment burden, calling for research into their experiences. Also missing are the experiences of culturally and linguistically diverse (CALD) populations, Aboriginal and Torres Strait Islander peoples or those from economically and socially disadvantaged backgrounds. This is problematic because of the unique issues these groups experience, including language barriers, discrimination, and poverty.

Finally, there is an absence of research on burden from an unpaid carer's perspective, those who provide assistance with a number of daily activities to people with chronic conditions [21]. They would be expected to have a different experience to those who are employed carers. In Australia, it is estimated that there are over 2.6 million carers [22], 29.0% of whom are primary carers [22].

Unpaid carers often fulfil a number of responsibilities on behalf of their care-receiver, including, but not limited to:

- household duties (e.g. washing and cleaning);
- providing personal sanitation;
- providing transport;
- obtaining healthcare information; and
- providing support, both emotionally and physically.

Unpaid carers are also likely to be involved in managing the medications for the person they care for [23]. This can include purchasing medication and supplies, assisting with and monitoring medication use, and speaking with the pharmacist about a person’s medications. Hence, unpaid carers are an important group of people that must be included in understanding how people experience treatment burden.

Patient centred care

Patient centred care has become a key feature of much debate within the healthcare sector. Providing health consumers with the opportunity to become involved in their own care, i.e. patient centred care, is considered to be a core element of healthcare quality [24, 25]. In 2010, shared-decision making in healthcare was formalised as an ‘ethical imperative’ at a global seminar in Salzburg [26].

Although health professionals are now expected to provide quality healthcare applying a patient centred approach, the concept of patient centred care has been around since the 1950’s [27]. There has been little consensus on its definition, although there is general agreement on the key attributes of patient centred care. A 2012 concept analysis identified a higher-order model of patient centred care (Table 1.1), consisting of four key domains [28]:

Table 1.1: Key domains of patient centred care

Holistic care	Responds to the true needs of consumers by valuing the entire person, considering the social context in which they live and recognising the interdependence of their parts (e.g. simultaneous assessment of physical, cognitive, and psychosocial functioning, addressing situational, family, cultural or religious needs, or both).
Individualised care	Considers the unique history, specific needs, preferences and health concerns of an individual and customises health care to meet their needs (e.g. development of an individual care plan).
Respectful care	Recognises and acknowledges consumer competence in their own care, respecting their right to choose and supporting their strengths and abilities (e.g. listening to and supporting people’s wishes, goals, or both).
Empowering care	Assists people to learn and obtain information about their healthcare and promotes self-confidence, self-determination and consumer autonomy to facilitate active participation in decision-making for their healthcare (e.g. development of an action plan, assisting people to monitor their condition(s) and make changes to their treatment plan).

Source: Adapted from Morgan and Yoder [28] and McMillan et al. [29].

While there is much information on what patient centred care can or should involve, this does not yet extend to concrete evidence about the benefits of patient centred care. A recent systematic review by Rathert *et al.* [30] attempted to identify satisfaction, clinical and organisational outcomes from a patient centred care approach. The review identified mixed results as to whether the eight dimensions of patient centred care, as developed by Gerteis, Delbanco and Daley (cited by Shaller D, 2007 [31]), lead to outcomes. Nevertheless, there was greatest evidence for satisfaction and self-management [30].

The review by Rathert *et al.* was not specific to chronic conditions and it concluded that further research was required to examine the specific dimensions of patient centred care and how they relate to outcomes [30]. The Australian Commission on Safety and Quality in Health Care encouraged further research on patient centred care in Australia, including the approaches practiced and their effectiveness [24]. Given that chronic conditions are highly prevalent in Australia [6], and there is an on-going fight to contend with this increasing burden, the delivery of patient centred healthcare must be appropriate and effective. Therefore, it is imperative to re-assess the benefits of this approach to care within the context of chronic conditions.

Role of community pharmacy

The burden associated with living with, managing, and treating chronic conditions (i.e. treatment burden), combined with the encouragement of a patient centred approach to care, have led to calls for health professionals to implement this approach. As a profession, community pharmacists have not been excluded from this directive.

Primary healthcare professionals, including pharmacists, have an important role and responsibility in relation to improving healthcare for people with chronic conditions [32]. Pharmacists have a directive to ensure the safe, effective use of medications [33], also known as the Quality Use of Medicines [34, 35]. Given the costly impact of medication burden on Australia's health system [17], pharmacists may be considered well placed to contribute to health reform in Australia. Furthermore, community pharmacies are readily accessible to most people [36, 37], with an estimated 5,200 pharmacies [38] and 24,781 registered practicing pharmacists in Australia in 2013 [39]. Given that medication is frequently used in the management or treatment of chronic conditions, pharmacists and pharmacy support staff are likely to have frequent contact with these health consumers. Pharmacists in particular, are in an ideal position to better assist health consumers to manage their chronic conditions.

Increasingly, pharmacists are being expected to provide optimal, individualised care, i.e. patient centred care. A change from a "product centred focus towards a patient centred focus" has occurred within community pharmacy practice [40]. Initially, this change involved an extension of pharmacy's dispensing function, i.e. moving from a medication supply focus into delivering more comprehensive medication care aiming to improve a health consumer's quality of life. Although there is still a key focus on dispensing medications in community pharmacy, the funding model is evolving and Australian pharmacists are now being remunerated to provide professional services, such as medication use reviews and health promotion. A medication use review, such as MedsCheck, involves a community pharmacist discussing a person's medication in a private consultation in the pharmacy [41]. The MedsCheck program has a number of aims, including educating people about their medications and identifying any potential medication-related problems, i.e. side effects or drug interactions [41]. Other remunerated services include the provision of disease management or screening and risk assessments for two of the following health priority areas: diabetes, mental health, cardiovascular or respiratory disease [42]. It is important that these services operate within a patient centred framework.

These remunerated services are currently managed under the Fifth Community Pharmacy Agreement (5CPA). Increasingly, these agreements incorporate professional pharmacy programs and services [43]. These services, whilst still focusing on the Quality Use of Medicines, require pharmacists to work collaboratively with other health professionals and health consumers. The need to work with consumers is strengthened with the adoption of the Community Pharmacy Service Charter, which is a Quality Care in Pharmacy Program (QCPP) accreditation [44], and Professional Pharmacy Program eligibility requirement [45]. The Charter outlines seven consumer rights and ways in which community pharmacy staff should respect and uphold those rights [46]. Pharmacies must comply with the Charter if they wish to provide extended services [45] such as disease management or screening, and risk assessments for chronic conditions.

In addition, the Pharmaceutical Society of Australia's (PSA) Code of Ethics specifically states that pharmacists must encourage health consumers to actively participate in their health care, with informed consent [47]. These guidelines place an obligation on pharmacists to provide information and advice that is relevant to consumers' needs [47]. As this type of individualised care has become a characteristic component of effective chronic care [48], it is not surprising that the pharmacy profession is now shifting its professional standards towards the delivery of care that is more patient centred [33]. There are ample examples within the profession of expansion of the pharmacist's professional roles, including medication reviews or consultations within medical clinics [49, 50], medication prescribing [51, 52], and more recently, vaccination administration [53].

Despite the drive towards a more patient centred practice within community pharmacy, there is limited research relating to the provision of this type of care from pharmacists and pharmacy support staff. Research is also lacking on the types of services people with chronic conditions or carers expect and/or want from community pharmacists. Similarly, the perspectives and needs of unpaid carers is needed. Carers can provide further insight into how community pharmacy can support them in their important role and better assist the person they care for. Furthermore, whilst the new pharmacy professional services aim to improve consumer healthcare, there appears to be limited input from consumers as to their design. A large proportion of pharmacy research focuses on evaluating programs implemented and designed by researchers [54-56]. Given the increasing rates of chronic conditions and comorbidities [5, 17], this raises the overall question and aim of this study: How can community pharmacy assist people with chronic health conditions to manage their health in a patient centred way?

1.1 Project purpose and outline

The purpose of this research was to explore the perspectives of health consumers on the burden of chronic health conditions and multiple treatment regimens (treatment burden), and their desire in terms of patient centred care and the related role of community pharmacy. Health consumers, carers and health professionals (pharmacists, medical practitioners, nurses, allied health practitioners and other health workers) from four areas of Australia were involved (Logan-Beaudesert region and North-West region of Queensland, Northern Rivers region of New South Wales, Mt Isa and and Greater Perth region of Western Australia).

The overall project objectives were to:

- 1) Undertake a literature review of Australian, international, and grey literature regarding the burden of chronic health conditions, the burden of treatment regimens and the benefits of using a patient centred approach to care;
- 2) Collect data that explores and measures: health consumer perspectives on the burden of chronic health conditions and of multiple treatment regimens; health consumers' expectations of community pharmacy services and how these can assist with health management;
- 3) Make recommendations on: the role that community pharmacy can play in assisting consumers with their chronic health conditions; strategies and/or models of care for community pharmacists to use when assisting consumers with chronic conditions and complex treatment regimens.

In order to meet these objectives, the **specific aims** of the current project were to:

- undertake a systematic literature review to identify current research on the burden of chronic health conditions, related treatment, the benefits of patient centred care and tools to assess this;
- conduct stakeholder interviews to explore organisational perspectives (community and professional organisations) on the burden of chronic health conditions, perceptions of patient centred care, and the role of community pharmacy;

- conduct interviews and nominal groups¹ with health consumers and carers to fully explore the diversity of perspectives of the burden of chronic health conditions, consumer health care priorities and their perceptions of what patient centred care should be in the community pharmacy;
- develop a survey, including a discrete choice experiment (DCE) based on data collected during interviews and nominal groups, and use this to examine treatment burden, quality of life, and the potential value of selected services that pharmacy may deliver;
- explore the views of pharmacists and GPs on patient centred care, treatment burden and consumer healthcare priorities to reveal any disparities between consumer and health professional views and inform future training; and
- use the qualitative and quantitative research data to describe the significance of treatment burden and contextualise this with consumer views and experiences.

The project design involved three stages undertaken over two-and-a-half-years, commencing in November 2011. An overview of the project is shown in Figure 1.1. Ethical approval for the research was obtained from the Griffith University Human Research Ethics Committee (PHM/12/11/HREC). Additional approval for Stage Three was obtained through Queensland Health (HREC/13/QPAH/605).

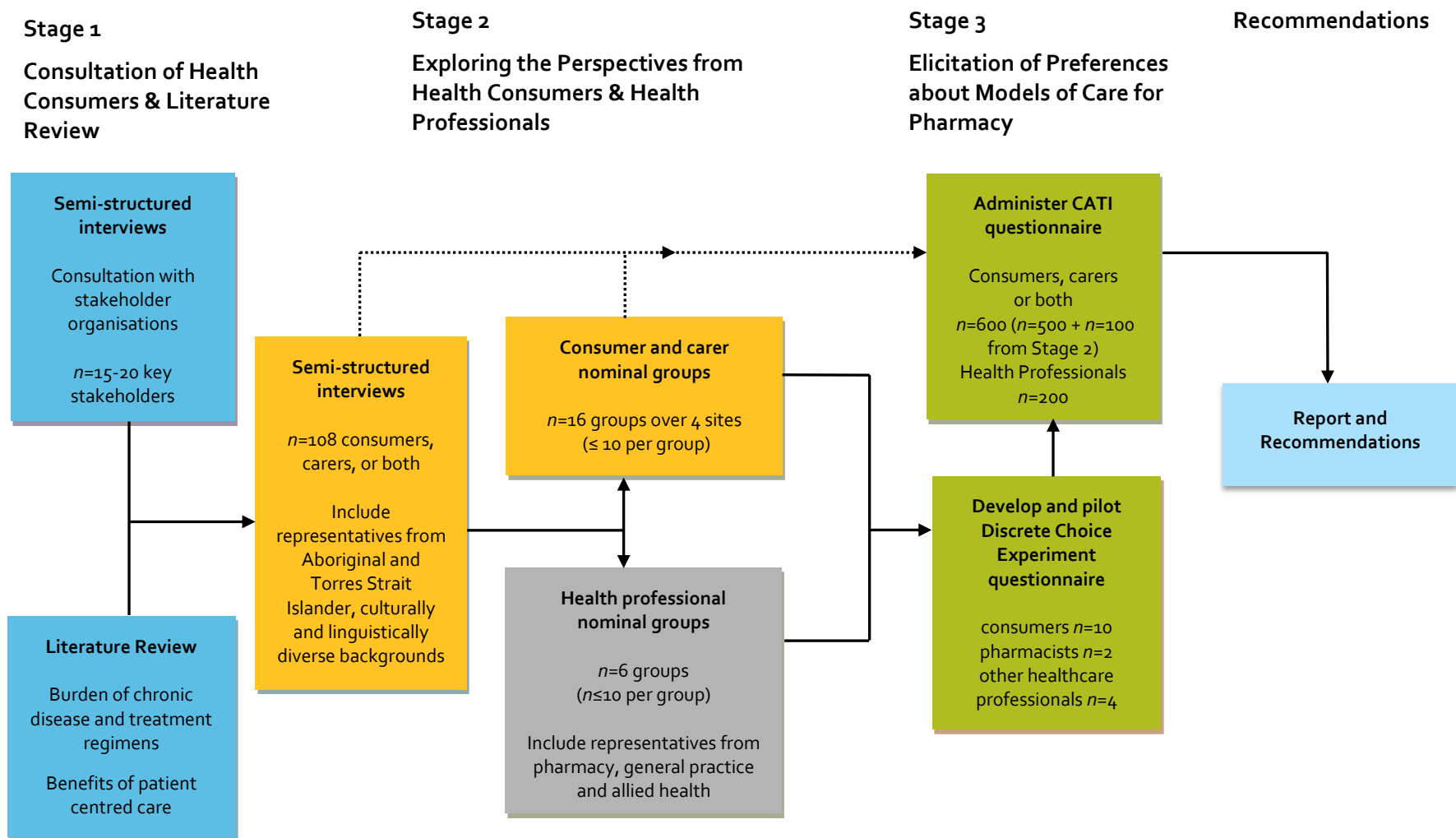
In **Stage One** we conducted a literature review and stakeholder consultation with representatives of consumer health and health professional organisations to explore the burden of chronic health conditions, benefits and perceptions of person centred care and the role of community pharmacy (for the consumers they represent or work with). The key stakeholder interviews also explored strategies to enhance consumer and carer engagement/participation in later stages of the project. This stage involved 21 participants: 14 represented consumer and carer organisations/advocates and 7 contributed health professional perspectives.

In **Stage Two** we built on the findings from the first stage to explore the perspectives and experiences of a diverse range of Australian health consumers and carers. Using qualitative methods including semi-structured interviews and nominal groups, we explored a person's experience of the burden of chronic conditions and his/her perspective on patient centred care. The Nominal Group Technique (NGT) facilitated qualitative exploration of consumer and carer priorities for their health care including ideal pharmacy services. Similar nominal groups were conducted with health professionals to explore their views on consumer and carer priorities for health care and pharmacy services. This allowed a comparison between ideas that consumers consider a priority and the perceptions that health professionals have of consumer priorities. In total, this stage involved 200 consumer and carer participants and 61 health professional/health worker participants.

In **Stage Three** we developed a survey that quantitatively explored treatment burden, quality of life and preferences for ideal pharmacy services. The themes identified from the nominal groups in the previous stage, in particular the priorities identified by consumers as relating to treatment burden, patient centred care and community pharmacy expectations, informed the design of a discrete choice experiment (DCE). The DCE measured consumer preferences about the delivery of pharmacy services to assist consumers to manage their chronic condition(s). Measuring consumer and carer preferences in this way allowed an assessment of the relative importance that they place on different characteristics of pharmacy services. Similarly, a survey including the DCE was administered to health professionals, to enable a comparison with consumer and carer preferences around what they expect would be important for consumers and carers in service delivery. This stage involved 602 consumer and carer participants and 297 health professional/health worker participants.

¹ A discussion group using the Nominal Group Technique (a structured process that promotes the generation of ideas to a specific question(s). Participants discuss, clarify and prioritise (rank) the ideas raised).

Figure 1.1: Original proposed project outline (2011)



1.2 Recruitment of participants

This project was conducted across four regions of Australia to reflect diversity in geography, accessibility, socioeconomic status, culture and language. A key factor taken into consideration when selecting project sites was the need to explore consumer needs in urban, rural and remote areas, and these sites were selected to reflect the range of PhARIA² categories [57].

- 1) Logan-Beaudesert in Queensland: an urban and semi-rural region, with a culturally and linguistically diverse population including a significant Aboriginal or Torres Strait Islander population and strong representation of Pacific Island cultures and immigrants with refugee status. The area is recognised as a socioeconomically disadvantaged region with significant rates of chronic health conditions;
- 2) Mount Isa and the surrounding North West region of Queensland is more geographically remote (PhARIA 5) and comprises a specific population that may have particular health needs including a significant Aboriginal or Torres Strait Islander population. The area is also recognised as a socioeconomically disadvantaged region with significant rates of chronic health conditions;
- 3) Northern Rivers area of New South Wales; and
- 4) Greater Perth area in Western Australia. These two sites were chosen because they are a mix of urban and rural regions and encompass PhARIA areas 1 to 3. Community pharmacists in some of these areas will be dealing with health consumers with complex needs and diverse social and cultural backgrounds.

Promotional information material about the project was produced and distributed throughout the project lifetime to support general information dissemination and recruitment activities (Appendix 2.1 and 2.2).

In Stage One, we undertook comprehensive consultation with 21 stakeholders who represented a range of health consumer organisations (nine consumer and carer support organisations, such as Diabetes Australia), professional organisations (four pharmacy/medical organisations such as the Pharmaceutical Society of Australia, the Royal Australia College of General Practitioners etc.) and four individuals with expertise relevant to this area (consumer advocacy, innovative nursing and pharmacy practice). The project team identified key stakeholders with assistance from the Reference Group, and by directly approaching key members of organisations both nationally and within the project regions by email and telephone. The information sheet is available in Appendix 2.3.

In Stages Two and Three, we invited participation from more than 800 consumers and/or carers with 'extensive' experience of services within the health system and/or with community pharmacy. The following eligibility criteria were used to guide participation (participants had to satisfy at least one of these criteria):

- Health consumers with one or more chronic illnesses for at least six months;
- Health consumers recently diagnosed with a chronic illness in the previous six months;
- Health consumers who have been self-managing their chronic condition(s) and have recently started to use pharmacy services;
- Health consumers who are eligible for a Home Medicines Review [HMR] (includes any of the following risk factors - taking five or more medications regularly, more than 12 doses of medications each day or medications that require monitoring (e.g. warfarin); recent discharge from hospital or significant changes to

² The PhARIA project provided a standardised measurement of the physical and professional remoteness of pharmacies across Australia (ARIA = Accessibility and Remoteness Index for Australia) Categories from 1-6; 1=highly accessible, 6=very remote.

- medications within three months; difficulty managing medications; experiencing an adverse drug reaction or attending multiple general practitioners or specialists);
- Health consumers who are high users of pharmacy or medical services;
- Health consumers who have reached or are expected to reach the Pharmaceutical Benefits Scheme Safety (PBS) Net threshold at their pharmacy;
- Aboriginal and Torres Strait Islander peoples who qualify for the 'Closing the Gap' (CTG) PBS co-payment³ and have had at least one chronic condition diagnosed in the past six months (this will ensure that consumers who may not be taking multiple medications but have complex needs and require assistance with their medications are eligible);
- Carers of health consumers with chronic condition(s).

These criteria were selected to ensure that a diverse range of consumers with chronic conditions and complex needs were recruited into the study and to avoid sole reliance on a one-dimensional measure of health consumer experience with health services, such as the number of medications taken. It was anticipated that using these criteria would result in the identification of health consumers with extensive experience of pharmacy services, as well as those who may have extensive experience of health services but not pharmacy services and would benefit through greater pharmacy involvement in their healthcare.

Stakeholders interviewed in Stage One provided valuable insights into approaching health consumers and carers for participation in Stages Two and Three and related recruitment processes. A key message that emerged was the need to recruit a diverse cross section of health consumers. Diversity was described from a number of different perspectives including ethnicity, disease progression, contrasting 'lived' experiences (e.g. episode of depression compared with bipolar disorder), urban versus rural consumers and level of engagement with service providers. People less likely to access health services were identified as important participants for this study and examples provided by stakeholders included culturally and linguistically diverse consumers and the 'hidden' carer. The 'hidden' carer was described as someone who may access carer subsidies yet not engage with service providers for many reasons, including competing commitments or through fear of 'appearing a failure'.

Recruitment strategies encompassed targeted promotion of the study via condition-focused consumer organisations (e.g. The Heart Foundation) and broader community-based promotion. All consumer organisations we approached were happy to advertise the study using their normal communication channels (e.g. newsletter, website) and via support groups. Strategies for wider community-based advertising included use of local newspapers and promotion of the study by culturally and linguistically diverse community health workers. Stakeholders recommended a number of other organisations who could assist with engaging consumers, often describing examples of successful collaboration with these organisations such as the Home and Community Care program (HACC), the funding body that provides services such as domestic care, transport and day respite. This information was used to establish a database of organisations and related contacts that was used throughout the lifetime of the project. Other strategies included recruitment via places that health consumers regularly visit (e.g. hospital clinics, cardiac rehabilitation units), and the use of Medicare Locals or medical practices involved with the Primary Care Collaborative to access consumers who may not visit these clinics yet are at high risk of chronic disease progression.

³ The Closing the Gap PBS co-payment measure was introduced in 2008 to address disparities in health outcomes for Indigenous Australians and improve access to the PBS medicines for Aboriginal and Torres Strait Islander peoples who already have, or are at risk of, chronic health conditions.

Stakeholders felt that consumers and carers would generally be open to telling their story and highlighted the importance of researcher awareness of participants' background, socioeconomic status and cultural sensitivities to provide a safe environment and encourage this. The need to consider cultural sensitivity as well as potential language barriers was emphasised, as was the importance of on-going consultation with multicultural services and specific communities to achieve this and promote recruitment. The research team engaged with community leaders and elders so that they could better meet specific cultural beliefs for Aboriginal, Torres Strait Islander peoples and culturally and linguistically diverse populations. Culturally and linguistically diverse organisations provided advice on the development of simple, unambiguous project materials and practical assistance with accessing interpreters. We acknowledged that chronic conditions may be associated with stigma for some Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse participants and provided the opportunity for participants to participate with a support person.

Other recruitment strategies included team members attending chronic disease or consumer support events (such as a Carer Retreat run by the Royal Flying Doctors Service in Mt Isa, July 2012), working with existing community champions (such as community pharmacists actively involved in medication management) and snowballing (referrals from participating consumers).

Health consumers interested in participating were asked to complete an expression of interest by phoning the toll free 1800 number, registering at the project website (www.chronicillnessproject.com) or faxing a completed form that was distributed via networks described above or downloaded from the website (Appendix 2.4). Consumer and carer participants could participate in all parts of Stages Two and Three or in single stages, as they wished. They were offered reimbursement for their time in the form of a supermarket gift voucher; \$150 for participation in all three parts (Stage Two interview and nominal group and Stage Three survey); \$30 for Stage Two interview participation only; \$50 for Stage Two nominal group participation only; and \$50 for the Stage Three survey participation only. Reimbursement was based on the time involved for each research activity.

In total, 200 health consumers and/or carers participated in Stage Two; 97 in interviews and 103 in the 15 nominal groups. The 200 participants represented 161 individuals with an additional 39 people who participated in both an interview and nominal group. A further 15 people expressed interest in Stage Two but did not participate, primarily due to problems with scheduling times and availability for attending the nominal groups in each of the four study regions. Interviews were conducted at times selected by the participants. The participant information sheet for Stage Two is available in Appendix 2.5.

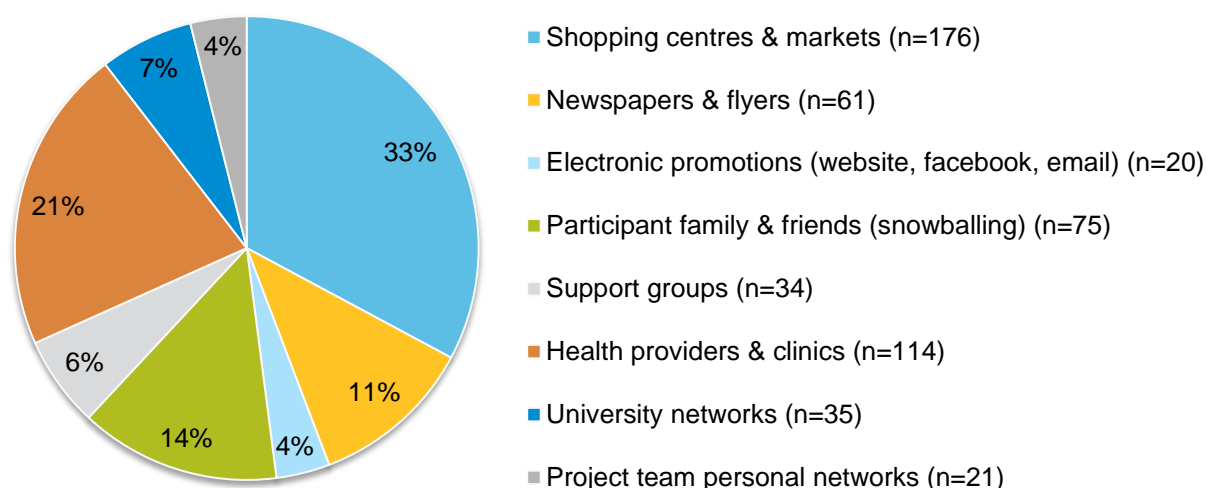
Recruitment strategies for Stage Three were built on the rapport established with key organisations and networks in Stage Two, in combination with several other strategies in order to achieve the target of 600 consumer and carer participants. These included:

- Communication emails to our database of organisations and contacts who in turn distributed the information to consumers and carers (such as the Health Consumers Council Western Australia, University of the Third Age networks in Logan-Beaudesert and Northern Rivers, Mount Isa Community Advice and Information Facebook page);
- Building on established networks and developing new relationships with promotion of the project by attending events and distributing information, presenting at events or emails disseminated by key champions (such as promotion by a multicultural champion at World Wellness Group, Brisbane Multicultural Centre);
- Promotional activities that included:

- Advertisements placed in 22 suburban and regional newspapers with a circulation of over 808,000 across the four regions between 9th August and 12th September 2013 (example Appendix 2.6);
- Email distribution to Griffith University staff and students, flyers posted on noticeboards and walls of community centres in Northern Rivers, Griffith University Logan campus, GP reception areas in Logan-Baundesert, Mt Isa, and the Mt Isa library (example Appendix 2.7);
- Distribution of promotional flyers and completion of expressions of interest by the research team in shopping centres and markets (5 conducted on weekdays and 1 on a Sunday) in each of the four project regions in October-November 2013; one in Northern Rivers, one in Perth, one in Mt Isa and four in Logan-Baundesert;
- Distribution of flyers in community health centre waiting areas or conducting face-to-face surveys with participants in Aboriginal and Torres Strait Islander Health Clinics in Perth (two services) and Mt Isa (one service);
- Human interest media stories in local newspapers and a local radio interview in Mt Isa (Appendix 2.8).

In total, 849 health consumers, carers, or both, expressed interest in Stage Three and of this group, 602 completed a survey (102/602 people had participated in a previous part of the research, i.e. either an interview or nominal group; of whom 30/102 had participated in both parts of Stage Two). The primary reason for non-participation was either being uncontactable by the Computer Assisted Telephone Interview (CATI) company or problems scheduling a suitable time to conduct the survey by phone. Data about the source of recruitment was available for 536/602 people who completed the survey (89.0%). Figure 1.2 outlines the sources of recruitment, with the largest number obtained from the direct promotional activities by research team members in shopping centres and markets (33%), followed by flyer distribution by health providers and at health clinics and centres (21%). The participant information sheet for Stage Three is available in Appendix 2.9.

Figure 1.2: Sources of recruitment for consumer and carer participants in Stage Three



In Stages Two and Three we also invited more than 350 health professionals to participate in a nominal group and the survey. These health professionals were people who worked with consumers with chronic conditions predominantly in the community setting (i.e. not acute in-patient settings) and included community

pharmacists, GPs, nurse practitioners, allied health professionals (such as psychologists, occupational therapists, dieticians) and other health workers (such as pharmacy support staff and Aboriginal and Torres Strait Islander health workers). Recruitment strategies were aligned with those used to engage health consumers and included targeted promotion of the study to the healthcare workforce via professional organisations (e.g. the Pharmaceutical Society of Australia, Australian Association of Consultant Pharmacists) and health services including Medicare Locals, General Practices, local health coalitions, Aboriginal Health Services etc.

Similarly, health professionals and health workers interested in participating were asked to complete an expression of interest by ringing the toll free 1800 number, registering at the project website (www.chronicillnessproject.com), or faxing a completed form that was distributed via networks described above or downloaded from the website (Appendix 2.10). Health professional participants could participate in both the Stage Two nominal group and the Stage Three survey or in a single stage, as they wished. They were offered reimbursement for their time in the form of a supermarket gift voucher; \$50 for the Stage Two nominal group participation and \$30 for the Stage Three survey participation (a lower reimbursement than that for health consumers reflected the shorter survey time for health professionals).

In total, 77 health professionals expressed interest in Stage Two and 61 subsequently participated in a nominal group. The information sheet for Stage Two is available in Appendix 2.11.

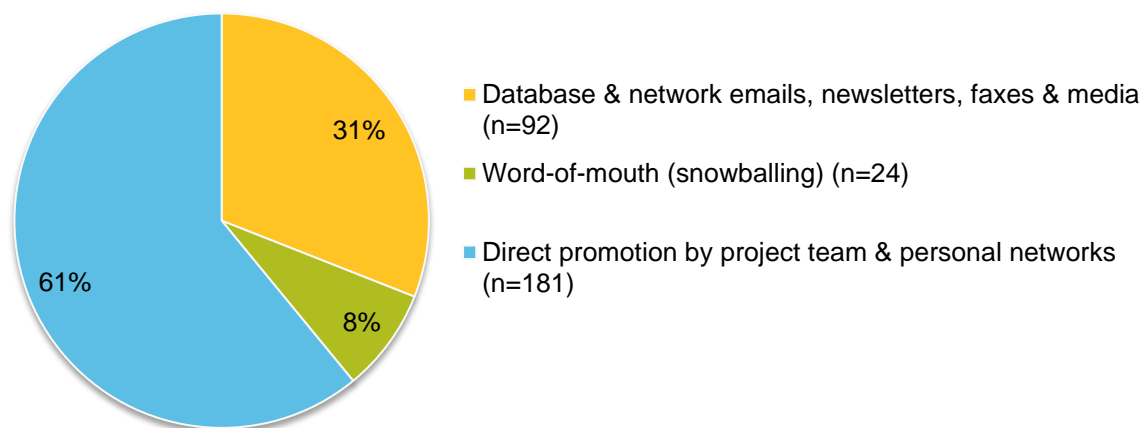
Recruitment strategies for Stage Three built on the rapport established with key organisations and networks in Stage Two, in combination with several other strategies, in order to achieve the target of 250 participants. These included:

- Communication emails to our database of organisations and contacts who in turn distributed the communication to their health professional members or staff (such as The Pharmacy Guild of Australia fax to all members via state branches, Allied Health Professionals Australia Western Australia email, e-newsletter via Medicare Local weekly updates) (example in Appendices 2.12 and 2.13);
- Building on established networks and developing new relationships with promotion of the project by attending events and distributing information, presenting at events, or emails disseminated by key champions (such as promotion at the National Primary Health Care Conference at the Gold Coast in November 2013, and the Pharmaceutical Society of Australia's Early Career Pharmacists Facebook page);
- Promotional activities that included:
 - Attending lunch time meetings with health professionals at their workplace and conducting face-to-face surveys with participants in General Practices (one in Perth, one in Mt Isa, four in Logan-Beaudesert), Community Health Clinics (three in Logan-Beaudesert, one in Mt Isa), Aboriginal and Torres Strait Islander Health Clinics (one in Mt Isa and two in Perth) during October-January 2014;
 - Distribution of promotional flyers and completion of expressions of interest by the research team at community pharmacies and medical practices located in shopping centres in each of the four project regions in October-November 2013; one in Northern Rivers, six in Perth, five in Mt Isa and four in Logan-Beaudesert (example in Appendix 2.14);
 - Project flyer promoted for one week as a computer screen saver for staff at Queensland Health in Logan-Beaudesert area.

In total, 412 health professionals and health workers expressed interest in Stage Three and of this group, 297 completed a survey (36 people also participated in a nominal group in Stage Two). Data about recruitment sources were available for all 297 survey participants. Figure 1.3 outlines the sources of recruitment, with the

majority (61%) derived from the direct promotional activities conducted by the research team at lunch time meetings, visits to health services, clinics and pharmacies located in shopping centres ,and email invitations sent to professional networks. The participant information sheet for Stage Three is available in Appendix 2.15.

Figure 1.3: Sources of recruitment for health professional/worker participants in Stage Three



2 Stage One:

Literature review and stakeholder consultation

This stage set out to explore the international experience with the three key project elements and also gain Australian insights that would inform subsequent project stages. The specific objectives of this stage included:

- a) a systematic literature review to synthesise research that describes how different elements of patient centred care have been operationalised (i.e. intervention type) and subsequent outcomes and benefits;
- b) a concept analysis to identify research on treatment burden for chronic conditions, conceptualise treatment burden and also describe related attributes, antecedents and consequences; and
- c) stakeholder consultation with representatives from consumer health and professional organisations to explore:
 - treatment burden encountered by the consumers and carers who access their services;
 - organisational perspectives on patient centred policy and related service delivery; and
 - the potential for community pharmacy to further support consumers with chronic health conditions.

2.1 Systematic literature review

The following information summarises the key findings of this section. More detailed information on the methods, findings and discussion is available in Appendices 3.1 and 3.2. This work has been published in the following peer-reviewed journals:

- Sav A, King MA, Whitty JA, Kendall E, McMillan SS, Kelly F, Hunter B, Wheeler AJ. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations* DOI: 10.1111/hex.12046 (published online 13.01.13).
- McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F, Wheeler AJ. A systematic review of the outcomes from patient-centred approaches to health care. *Medical Care Research and Review* 2013;70(6):567-96. DOI: 10.1177/1077558713496318.

Results

a. Treatment burden

Treatment burden is a significant and costly problem for people with chronic conditions and for the health system in general. Medications have a particularly marked impact on treatment burden. The number and cost of medications, time taken to obtain them, administer and manage treatment and the side effects experienced all contribute to treatment burden. However, treatment burden is a poorly understood problem that may not be easily alleviated. Indeed, our concept analysis of the treatment burden literature revealed important elements of this concept that can be better understood by pharmacists (Box 2.1).

Our concept analysis revealed that health professionals can impact both positively and negatively on treatment burden. Poor health professional and health consumer relationships, poor communication and lack of information can all negatively impact upon burden. In contrast, positive outcomes are associated with sensitivity to a person's treatment preferences, explanations of options and possible side effects (Figure 2.1).

Opportunities exist for pharmacists to better communicate with health consumers and improve medication management in ways that will reduce treatment burden, such as assisting with self-management of medication (e.g. organising and monitoring medications).

Box 2.1: Summary of treatment burden concept analysis

- Treatment burden is multidimensional, dynamic and cyclic in nature;
- Although medication use and treatments contribute to the burden experienced by many people with chronic conditions, there are also subjective elements of treatment burden. Many of these are psychosocial in nature (e.g. fear relating to treatment, embarrassment about public use of medications);
- The antecedents of treatment burden include personal characteristics (e.g. age, gender), disease-related factors (e.g. number of chronic conditions), level of social support and the nature of the healthcare system within which people experience disease and its treatment;
- Treatment burden can result in adverse health outcomes and poorer quality of life, which subsequently affects a person's ability to manage their treatment and may result in requiring additional or increased intensity of treatment.

b. Patient centred care

If treatment itself can generate burden, then it is not surprising that the solution is thought to lie in changing the way in which services are delivered (i.e. patient centred care). Patient centred care has been applied to many areas of healthcare, but less often in pharmacy. Indeed, there is little knowledge about how to implement patient centred care or how it improves outcomes. Our systematic review revealed some important conclusions that can be applied to pharmacy services in the future (Box 2.2).

Box 2.2: Summary of systematic review on patient centred care

- Simple changes are just as likely as complex interventions to bring about positive outcomes - these small changes can be easily implemented in pharmacies and do not require longer consultations.
- Most successful changes focused on consumer empowerment through awareness skills training for professionals, or training and prompting consumers to ask questions about their healthcare.
- To bring about positive outcomes, however, changes need to be applied consistently rather than as brief short-term interventions.
- These simple empowerment interventions were associated with increased consumer satisfaction with their care, providers and progress, and perceived quality of care, particularly in provider commitment, communication, co-ordination of services and decision-making.
- For providers, training was associated with perceptions of competence, capability and knowledge, but also increased their critical assessment of practice.
- Confident providers and actively engaged consumers developed stronger and productive relationships, based on higher trust and greater agreement about care decisions.
- In the longer term, empowerment interventions were associated with greater emotional wellbeing, independence in daily life and greater overall health status.
- Patient centred care is not likely to directly influence symptoms, but it does produce more actively engaged consumers who have a sense of control over their own health, are more knowledgeable and desire involvement in their healthcare.
- More actively involved consumers are more likely to manage their symptoms well, adhere to recommendations and engage in self-care. This is likely to translate into improved health outcomes, although the evidence was mixed.

2.2 Stakeholder consultation

Insight into the views of non-traditional service providers and mainstream health service providers is critical to the development of truly patient centred services. Consumer Health Organisations (CHOs) are one example of non-traditional service providers that have been linked to improved quality of life, psychosocial wellbeing, knowledge, health literacy, and coping strategies [58-61], yet are often overlooked by health professionals. In-depth consultation was conducted with expert health advocates and representatives from CHOs and health professional organisations. Stakeholder consultation explored organisational perspectives on three key areas, particularly as it related to the people represented by these organisations (i.e. members):

- Treatment burden for chronic conditions;
- Organisational philosophy on patient centred care and related initiatives or programs;
- Expectations of community pharmacy support for people with chronic health conditions.

The following information is a summary of this section. For further detail please see Appendix 3.3, 3.4 and 3.5. This work has been published in the following peer-reviewed journals:

- Sav A, McMillan SS, Kelly F, Kendall E, Whitty JA, King MA, Wheeler AJ. Treatment burden among people with chronic illness: what are consumer health organizations saying? *Chronic Illness* 2013; 9(3):220-32. DOI: 10.1177/1742395312463411;
- McMillan SS, Wheeler AJ, Sav A, King MA, Whitty JA, Kendall E, Kelly F. Community pharmacy in Australia: a health hub destination of the future. *Research in Social & Administrative Pharmacy* 2013; 9(6):863-75. DOI: 10.1016/j.sapharm.2012.11.003;
- Kelly F, Sav A, McMillan SS., King MA, Whitty JA, Wheeler AJ. Patient centred care: what consumer health organisations say and do. *European Journal for Person Centered Healthcare* (in press, accepted 23 December 2013).

A resource for all community pharmacy staff was developed outlining the key support services provided by specific consumer health organisations for consumers and carers (Appendix 3.6)

Method

Twenty-one semi-structured interviews were conducted from January to March 2012, either via telephone (n=11) or face-to-face (n=10). The interview guide is available in Appendix 3.7. Stakeholders were purposively sampled to reflect diversity across the CHO⁴, pharmacy and health sectors and described according to their particular roles (Table 2.1). Two people were interviewed from selected CHOs to explore both policy and implementation perspectives on patient centred care. Interviews were recorded and transcribed verbatim, with an average duration of 64 minutes (range 42-84 minutes). Three researchers used the qualitative data software QSR NVIVO 9[®] to code transcripts into 'units' of data, and to categorise ('cluster') units until themes emerged. Each researcher described data for one of the three areas outlined above. Interviews ended once no more new ideas were heard (i.e. data saturation).

⁴ Consumer organisations were selected to represent the chronic conditions identified as high priority areas by the Australian Government (National Health Priority Areas Initiative; 1996).

Table 2.1: Categories of key stakeholder interviews

Interview categories	Interviews	Organisational /individual foci/expertise
Consumer organisations	9 organisations (12 individuals)	Consumer organisations with expertise/operating in the areas of healthcare, advocacy, engagement, education, support, diverse communities, capacity building and linkages across sectors.
Pharmacy organisations/ individuals	5	Key pharmacy organisations and individuals with expertise in contemporary practice and diverse communities.
Health care organisation/ individual	2	A key healthcare organisation and individual practitioner.
Health advocates (individuals)	2	Individuals with significant expertise/experience in health system advocacy, practice and issues pertaining to cultural change.
Total	21	

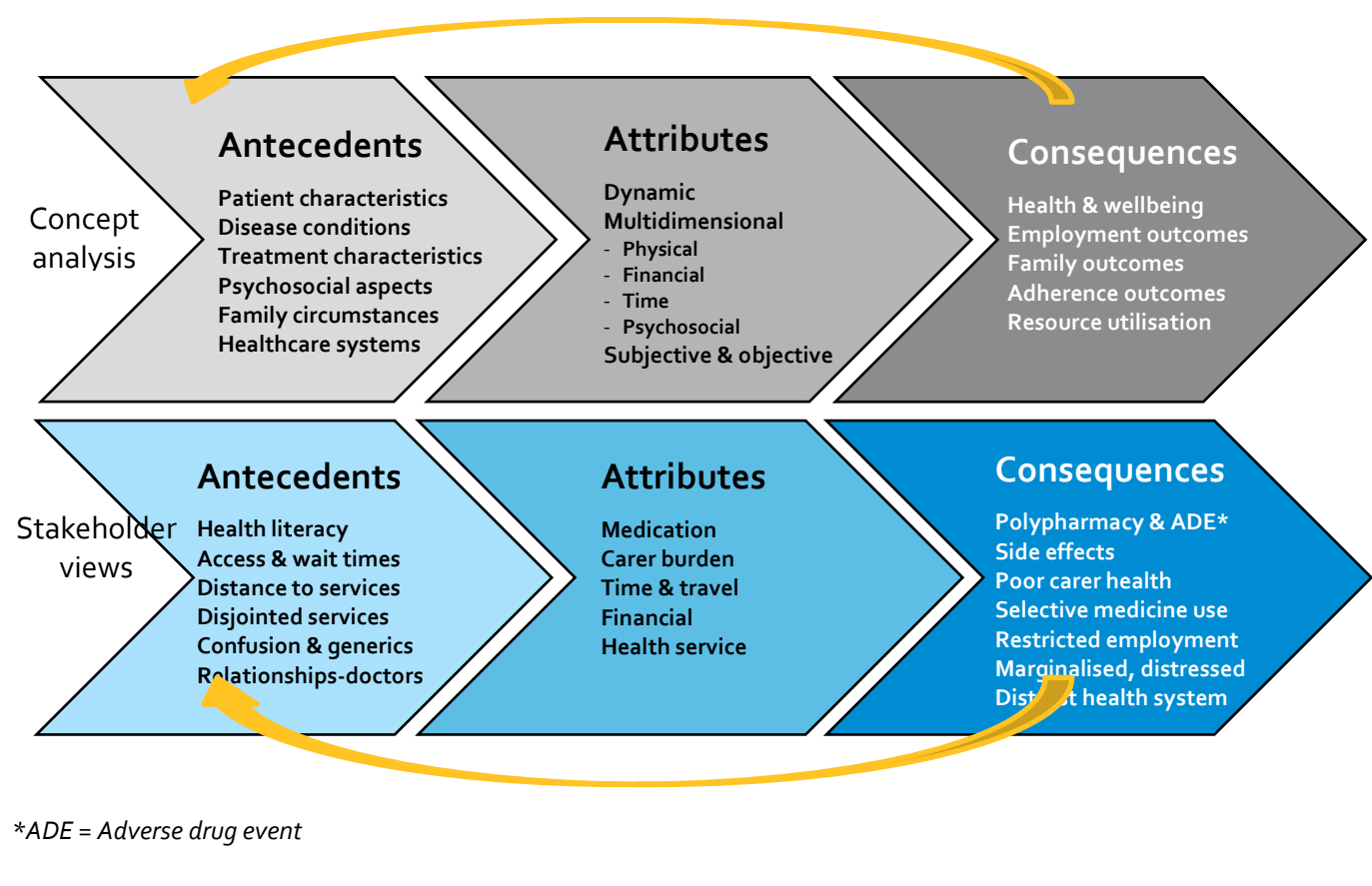
Results

a. Treatment burden

Participants discussed treatment burden in the context of five broad themes or attributes: *medication burden*, *carer burden*, *time and travel burden*, *financial* and *health service use burden*. Medication burden emerged as a substantial and prevalent theme with multiple consequences considered burdensome for consumers, such as associated stigma with using medication and side effects (e.g. weight gain, nausea). Financial burden was widely cited as an issue, particularly for low-income earners and from the perspective of consumers' or carers' ability to sustain employment. Time taken to learn about administering and monitoring treatment, or travel to access health services emerged as other attributes of treatment burden. Difficulty accessing treatment was also considered onerous, particularly for consumers without reliable transport or residing in regional areas.

Organisational representatives described numerous consequences of treatment burden such as negative carer health outcomes or selective use of prescribed medications due to financial burden (Figure 2.1). Disjointed healthcare services were reported to create a sense of confusion, frustration and distress among consumers, and marginalised carers, particularly when health professionals provided mixed messages. Factors thought to contribute to burden (antecedents) included low health literacy, confusion over generic medications, poor relationships with doctors, waiting, and limited consultation times. The complexity of treatment burden was acknowledged when strategies introduced to address one aspect of burden (e.g. dose administration aids to simplify medication regimens) created another burden (e.g. financial).

Figure 2.1: Treatment burden – findings from the literature and stakeholder views



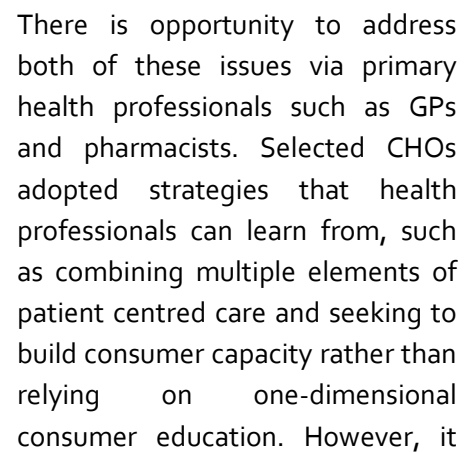
b. Patient centred care

In-depth stakeholder interviews provided valuable insight into important considerations for delivering patient centred care. There was general consensus that this care approach depended upon two significant paradigm shifts;

- a shift in power balance from health professionals to more active health consumer control of their health; and
- a need to move beyond the one-dimensional approach that is inherent in the biomedical model of care.

Organisational perspectives on patient centred care varied from a broad conceptual approach to description of specific domains such as holistic, respectful, individualised and empowering care [28]. The stakeholder organisations that applied specific domains of patient centred care to service structure often delivered innovative services aiming to build consumer capacity to self-manage and take active control. The necessity of respect for 'patient choice' to take or not take greater control, or disagree with health professional recommendations, also emerged as a significant theme.

Participants described a wealth of innovative and often patient centred services, and ascribed under-utilisation of these resources, limited consumer awareness and underdeveloped referral pathways from health professionals. Varied experiences of patient centred care were described by representatives of CHOs.



c. Community pharmacy

There was a strong perception that a patient centred health hub would minimise treatment burden. Stakeholders envisaged pharmacy becoming part of the *cycle* of care, through provision of medication support and referral to CHO support. It was discussed as a model that pharmacy should move towards, with three primary features (Appendix 3.4)

- *Healthcare system navigation* – that assesses consumer needs and signposts relevant CHO services for psychosocial support, or direct referrals to health professionals.
- *Medication management* – that builds on the value of current programs (e.g. MedsCheck) and extends to chronic conditions services, particularly for people with complex needs.
- *Health advocacy* - as an extension of medication management services.

Box 2.3: Opportunity for community pharmacy to act as a health hub

- Connector to CHOs and support (i.e. sign-posting);
- Reduce treatment burden through referral to CHOs and health professionals;
- Potential role for pharmacy support staff to assist with healthcare system navigation;
- Previously unexplored opportunity for collaboration.

Other interconnected themes that emerged from the data included the pharmacist's current role, and barriers to expanding this role. Participants acknowledged structural and societal barriers facing the pharmacy profession in terms of implementing a new model of care. The dominant pharmacy remuneration model, which stakeholders perceived to be focused on product supply, appeared to be the over-arching barrier, with other identified barriers seen as emerging directly from this model. particularly the current remuneration model, which emphasises product supply. They raised concerns that this emphasis on the supply role of pharmacy, combined with the lack of consumer awareness of the breadth of expertise and skills within pharmacy, could impede role expansion. Other barriers described included the retail oriented image of pharmacy, restricted or minimal relationships between consumers, carers, and pharmacists, and a perception of pharmacists as reactive, or problem solvers who do not typically adopt a holistic approach to a person's health. These interviews added further support for pharmacists to collaborate more with CHOs and other health providers and extend their role in chronic condition management. However, significant changes are needed in attitudes, behaviour, and the pharmacy environment, alongside a major culture change, to dispel the image of pharmacists as 'shopkeepers.'

Summary

Key findings

- Important antecedents of treatment burden identified by stakeholders included low health literacy, confusion over generic medications, poor relationships with doctors, waiting and limited consultation times;
- Service providers implemented patient centred care in a variety of ways, but they recognised the need to shift power from services to consumers (respect 'patient choice') and adopt a multidimensional approach to meeting people's needs;
- Barriers to patient centred care were health professional education, attitudes, current infrastructure, and remuneration;
- Consumer health organisations were underutilised resources, with little in the way of referral from health professionals;
- Stakeholders acknowledged the potential to facilitate consumer access to patient centred services through collaboration between pharmacy and other health professionals, organisations or programs;
- Stakeholders agreed that there was potential value in pharmacy becoming a health hub that offers more than medication. This included connecting people to relevant support services available from consumer health organisations, health professionals, medication management services and health advocacy;
- Barriers to the health hub concept included the perception that community pharmacies were a retailer and medication supply destination, and consumers may lack awareness of the pharmacist's breadth of expertise and skills.

Insights for community pharmacy: New or extended services

- Develop pharmacy services that assess and reduce treatment burden. This entails services that:
 - consider the multidimensional, dynamic and cyclical nature of treatment burden;
 - accommodate the antecedents of treatment burden (e.g. health literacy);
 - implement individualised strategies;
 - promote effective communication between health professionals and consumers;
- Community pharmacy becomes a health hub or healthcare destination through:
 - collaboration with CHOs or other health professionals to improve consumer access to relevant patient centred services;
 - medication management support that builds on current programs;
 - potential health advocacy role.

Insights for community pharmacy: Improvements to existing services

- Patient centred care should be an underlying component of all pharmacy services:
 - it contains distinctive elements - holistic, respectful, individualised and empowering care;
 - simple, easily implementable strategies can be as effective as complex interventions;
 - positive outcomes rely on consistent application of new practices;
 - all pharmacy staff should proactively encourage more active consumer control of their health;
 - empowering actively involved consumers increases satisfaction with care, adherence to recommendations, emotional wellbeing and overall health status;
 - pharmacy can assist in building consumer capacity to engage in their healthcare.

Insights for community pharmacy: Training and education

- Implementation of patient centred pharmacy services that reduce treatment burden relies on training that:
 - increases awareness of the multidimensional, dynamic and cyclic nature of treatment burden;
 - improves understanding of how to respond to antecedents of treatment burden (e.g. health literacy);
 - improves knowledge of how pharmacists and pharmacy support staff can positively and negatively impact on burden;
 - uses the wealth of patient centred resources available to health professionals;
 - provides staff with practical patient centred strategies that do not create additional burden;
 - improves all pharmacy staff confidence and competence in providing patient centred care;
 - promotes reflection by all pharmacy staff on how patient centred their practice is;
 - builds staff capacity to promote pharmacy as a health hub;
 - promotes effective referral pathways to additional support (e.g. CHO).

3 Stage Two: Exploring the perspectives of health consumers and unpaid carers

This stage utilised qualitative research methods to examine the views and experiences of consumers with chronic condition(s) and their carers, elicit preferences for related health and pharmacy services and inform the development of the survey for Stage Three. The specific objectives of this stage included:

- a) in-depth, semi-structured interviews to explore the experiences and views of a diverse sample of consumers with chronic health conditions, unpaid carers, or both (i.e. carers who also have a chronic condition) on treatment burden, patient centred care and pharmacy services;
- b) consumer, carer and health professional discussion groups using the Nominal Group Technique (i.e nominal groups) to elicit priorities for ideal pharmacy services.

3.1 Interviews with health consumers and carers

Interviews explored participants' **lived experiences of managing**, or caring for someone with a chronic condition(s). Questions **explored the impact** (i.e. burden) of **having a chronic health condition** on their personal and professional life, how they manage the condition(s), and **what they consider to be patient centred care** and the actions that represent this care. Participants were also asked how pharmacists or pharmacy support staff currently assist them and how staff could further improve that support (Appendix 4.1).

The following information is a summary of this section. For further detail please see Appendices 4.2 to 4.7. This work has been published in the following peer-reviewed journals:

- Sav A, King M.A, Kelly F, Kendall E, McMillan SS, Whitty JA, Wheeler AJ. Self-management of chronic conditions in a rural and remote context. *Australian Journal of Primary Health* DOI: [org/10.1071/PY13084](https://doi.org/10.1071/PY13084) (published online 18.10.13).
- McMillan SS, Sav A, Kelly F, King M, Whitty JA, Wheeler AJ. How to attract them and keep them: the pharmacy attributes that matter to Australian residents with chronic conditions. *International Journal of Pharmacy Practice* 2014;22(4):238-245. DOI: [10.1111/ijpp.12075](https://doi.org/10.1111/ijpp.12075).
- Sav A, Kendall E, McMillan SS, Kelly F, Whitty JA, King MA, Wheeler AJ. "You say treatment, I say hard work": treatment burden among people with chronic illness and their carers in Australia. *Health & Social Care in the Community* 2013; 21(6):665-674. DOI:[10.1111/hsc.12052](https://doi.org/10.1111/hsc.12052).
- Sav A, Whitty JA, McMillan SS, Kelly F, King MA, Wheeler AJ. Consumer health organisations for chronic conditions: why do some people access them and others don't. *Primary Health Care Research and Development* 2014 DOI:[org/10.1017/S1463423614000036](https://doi.org/10.1017/S1463423614000036) (published online 05.02.14).
- McMillan SS, Kelly F, Sav A, King MA, Whitty JA, Wheeler AJ. Consumer and carer views of Australian community pharmacy practice: awareness, experience and expectations. *Journal of Pharmaceutical Health Services Research* 2014; 5(1):29-36. DOI:[10.1111/jphs.12043](https://doi.org/10.1111/jphs.12043).
- Whitty JA, Sav A, Kelly F, King MA, McMillan SS, Kendall E, Wheeler AJ. Chronic conditions, financial burden and pharmaceutical pricing: insights from Australian consumers. *Australian Health Review* DOI:[org/10.1071/AH13190](https://doi.org/10.1071/AH13190) (published online 07.08.14).

Method

Semi-structured interviews were undertaken between May and October 2013, with 97 consumers and carers (32 men and 65 women). Participants (Table 3.1) represented a broad range of ages, ethnicity, type of health condition, duration and complexity. Interviews occurred across all four project areas, either face-to-face (n=49) or via telephone (n=48), averaging 50 minutes in duration (range 15-91 minutes). The constant comparison method was employed for data analysis purposes. This method involved three researchers reading the transcripts and using QSR NVIVO 9[®] to identify initial codes, further development of subthemes from consequent interviews, and constant discussion and clarification of themes to develop and refine categories (i.e. higher order themes). Interviews ended once no more new ideas were heard (i.e. data saturation).

Table 3.1: Participant characteristics for semi-structured interviews

Participant characteristics (n=97)	n	%
Consumer	70	72.2
Carer	8	8.2
Consumer and carer	19	19.6
Cultural background		
Caucasian	55	56.7
Culturally and linguistically diverse people	19	19.6
Aboriginal and Torres Strait Islander people	23	23.7
Study location		
Logan-Beaudesert	41	42.3
Mount Isa and North West	15	15.5
Northern Rivers	21	21.6
Greater Perth	20	20.6
Chronic condition(s)^a		
One	10	11.8
Two	19	22.3
Three or more	56	65.9

^aConsumer and consumer/carers only. Source: adapted from McMillan et al. (64)

Results

a. Burden of illness and treatment

The impact of a chronic condition on a person was multifaceted and four inter-related components of treatment burden emerged (Table 3.2).

These four components of treatment burden operated in a cyclical manner. For example, contradictory advice about treatment from different health professionals (healthcare access burden) could lead to multiple medications (medication burden), which could then result in both a requirement for extra time to organise medications (time burden) and financial pressure (financial burden). Although treatment burden was objective in some ways (e.g. number of medications, and time to access treatment), it was also a subjective experience. For

example, although medication burden emerged as a significant issue among most participants, some participants praised their medications as being a source of relief and recovery.

Table 3.2: Components of treatment burden

Four components of treatment burden	
Financial burden	Time and travel burden
Created by the cost of treatment, including medication and healthcare consultations. <i>"Every time you go to a specialist it is about \$150 to \$160 always upfront unfortunately" [C_1005]</i>	Time and travel required to access, administer and monitor treatment. <i>"You look at the calendar and say ohhh there is no medical appointments this week" [C_1008]</i>
Medication burden	Healthcare access burden
Burden resulting from medication side effects and adverse events, taking multiple medications, the inconvenience of organising medications and medication-related stigma. <i>"...the side effects are often more prohibitive than the benefits of being pain free" [C_1080]</i>	Difficulties associated with accessing and managing healthcare and providers. <i>"...it takes up to three weeks to get to see a doctor" [in a rural/remote area] [C_1004]</i>

C = consumer

Financial burden

When participants discussed how treatment burden impacted on their lives, financial burden was described as highly problematic, particularly for those taking several long-term medications, or when multiple family members had chronic condition(s). Frustration was exacerbated when medications were not subsidised on the PBS or costs varied between pharmacies. Financial burden reduced peoples' ability to purchase medical and non-medical items for themselves or family members, and exacerbated healthcare access burden. Although consumers and carers viewed some pharmacy services as positively impacting upon time burden (e.g. dose administration aids), this was offset by associated financial cost.

Government subsidies were valued as a strategy to limit financial burden, such as the CTG or the PBS Safety Net scheme. There was limited awareness of the availability, eligibility, or both, of lower co-payments amongst some participants. This highlights the need for all pharmacy staff to facilitate consumer access to relevant subsidies, particularly when personal circumstances change. In New Zealand, 180,000 people continued to pay for prescribed medication after becoming eligible for fully-subsidised medication, even after extensive public awareness campaigns [63]. Individual strategies used to alleviate financial burden by consumers and carers in this study included: stockpiling medications when the Safety Net threshold was reached, obtaining free samples from their GP and selective adherence. Some participants reported that they could not always afford all of their medication and, on occasion, selectively purchased the medication considered 'best' for their health. It is unclear how informed these decisions were and whilst financial burden may be reduced in the short-term, non-adherence could lead to more serious long-term clinical and financial consequences. These findings align with reports that financial burden reduces medication adherence [64, 65], particularly when co-payments are higher [65], with adverse effects on health outcomes [64].

Treatment burden and restriction

Restriction emerged as another particularly challenging issue for many, with subsequent impact on their psychological wellbeing and capacity to manage. Many areas of participants' lives were affected, such as their employment, and family life (Table 3.3). This was attributed directly to the chronic condition(s), or to how other people responded to them having a condition. Symptoms such as pain or physical deterioration limited mobility and capacity to complete tasks. Restriction in employment or education was attributed to variation in employer and educator capacity to recognise, respond and cater to specific needs.

Anxiety related to the impending threat of worsening health potentially contributed to restriction for some, with reports of isolation from the workplace, family or the community. Participants also described examples of restriction imposed on family members due to the extra financial burden or domestic workload. Certain aspects of restriction are unavoidable such as Occupational Health and Safety regulations in workplaces. However, others can be improved or perhaps prevented through support from health professionals such as pharmacists or community organisations.

Table 3.3: Key elements of restriction

Key elements of restriction	
Employment limitations	Challenges in education
<ul style="list-style-type: none">• Employers do not always understand• Degree of acceptance from workmates• Physical restrictions limit capacity• Limited flexibility of work tasks• Occupational Health & Safety restrictions	<ul style="list-style-type: none">• Teachers do not always understand• Learning limited through:<ul style="list-style-type: none">– Absenteeism– Lack of flexible approaches– Limited facilities
Restriction in daily life	Impact on family and community
<ul style="list-style-type: none">• Less mobility at home and in the community• Difficulty with domestic activities	<ul style="list-style-type: none">• Family life affected• Social and leisure activities limited

Managing treatment burden

Ultimately, chronic conditions can create treatment burden and pose challenges for health consumers, their families and carers. Effective management of these challenges is paramount to minimising treatment burden and although self-management has been hailed as an important strategy, there is growing recognition that this can also contribute to treatment burden [66]. In this study, management of treatment burden was influenced by factors such as how people viewed their chronic condition(s), their support-seeking behaviour, where they lived and cultural background.

How people viewed their condition(s) appeared to set the scene for their experiences and coping mechanisms. Themes of 'acceptance' and 'denial' of diagnosis or living with a chronic condition(s) were influential, with denial associated with feelings of isolation, and for many, depression. A strategy adopted to manage negative emotions was to find alternative meaningful activities that were still achievable. Other participants associated acceptance of their condition(s) and treatments with a more positive outlook, healthier lifestyles for themselves and their families or better relationships with family members.

Managing treatment burden was influenced by available support, which came from health professionals, family members and CHOs. Although Aboriginal and Torres Strait Islander participants relied on family support over CHOs, they emphasised the importance of culturally appropriate health services (e.g. community health workers and Aboriginal Health Services). Those participants that accessed CHO support described a range of benefits related to knowledge, connection and learning from others [67]. Participants described gaining knowledge about their condition(s), practical coping strategies and improved awareness of treatment options. Connection to people with similar experiences provided practical and emotional support, particularly for people with less developed personal networks. However, barriers to CHO access emerged through limited referrals by health professionals and individual consumer beliefs about the benefits of such a group. There have been calls to address underdeveloped referral pathways to CHOs, particularly when constraints within primary healthcare limit consumer exposure to important psychosocial aspects of care [68]. Pharmacists and pharmacy support staff are ideally placed to identify and match individual consumer and carer needs to relevant CHO services, thereby addressing issues of limited referral.

In rural areas, geographic isolation and limited healthcare access created additional burden. For example, higher levels of organisation and planning were required to arrange transport and accommodation for metropolitan-based treatment. If carers were relied on for transport, there was potential disruption to work commitments and finances. Scarcity of resources necessitated strategies to effectively utilise existing support and creativity to address unmet needs. For example, some participants accessed alternative health providers when medical appointments were unavailable, and there was increased reliance on immediate family or local support networks.

There was a promotion of greater self-reliance and a greater sense of community in the rural setting. Some rural participants considered self-management their only option, and tailored self-management strategies to their individual needs, as reported in other rural contexts [69-71]. However, this may introduce some clinical risk if health professional supervision is limited and critical aspects of care are overlooked. Researchers have questioned the utility of standard self-management programs in the rural setting [72, 73], proposing a more collaborative approach where locally directed and innovative forms of self-management are devised between rural residents and health professionals [74-76]. Rurally-based pharmacists understand the challenges experienced by people in these areas and are ideally placed to help tailor self-management strategies in this context [77]. Implementation of these strategies should adopt a collaborative approach at the local level and build on existing infrastructure and support already provided to rural pharmacies [78].

These findings underscore the importance of alleviating treatment burden through individualised healthcare that considers each person's characteristics and preferences, and offers consumer-focused holistic care that is responsive to their needs. However, since treatment burden is a relatively new concept [66], health professionals may need additional skills to enable them to identify, explore and address treatment burden with consumers [19]. Furthermore, development and implementation of patient centred pharmacy services should consider both the attributes of patient centred care that consumers and carers value, in addition to how these could address treatment burden in different contexts.

b. Experiences of carer burden

Carer descriptions of burden were either unique to them or paralleled consumers' experiences (Table 3.4). Participants acknowledged that caring requires sacrifices such as time, and that this was borne out of love, duty, obligation, or desperation due to a lack of alternatives. Carers' personal identity, relationships and mental and physical health were significantly impacted upon, and inadequate support for carers presented challenges that were compounded by bureaucracy or limited insight into the carer's situation.

Carers can have varied responsibilities, such as medication management, which includes monitoring prescription supplies and assisting with medication use [79]. Although carers in this study associated medication-related issues with burden, many were overwhelmed by the sheer enormity and intensity of the caring role. Attention on specific carer needs has been limited [80] and study participants believed that even small respite periods would help.

When asked how community pharmacy could support them, the majority of carers focused on medication supply issues and medication-related information. Medication supply issues included the burden of frequent visits to the doctor for prescriptions, PBS subsidy restrictions limiting supply of some medications to hospital and others to community pharmacy, which was further complicated when pharmacies did not carry sufficient stock. Carers were often hungry for information about the medications they were collecting, or organisations that could assist them in their caring role. Few carers were aware of additional pharmacy services that could assist them, such as dose administration aids, and increasing this awareness could ease their burden if these services are affordable. These findings align with research exploring carer experiences and needs [81, 82].

Carers contribute to national health savings, yet the evident lack of support for carers has implications for carer health, wellbeing and long-term capacity to support others. Recognition of carers, especially those who do not self-identify, i.e. hidden carers, is not straightforward, nor is it easy to ascertain their role and responsibilities. A 'carer card' [83] could offer clarity by providing information that identifies the person(s) they care for, whether the carer has been granted power of attorney, or has permission to obtain specific types of information on behalf of the consumer.

Table 3.4: Carer burden, needs and how community pharmacy can help

Key elements of carer burden	
Medication-related burden <ul style="list-style-type: none"> • Supply-related issues (PBS quantities, availability) • Logistics of coordinating prescriptions • Confusion about generic medications 	<i>...most of the time they don't have all the medications available...So that is a bit of difficult...Especially when we get a prescription, when she really needs it for that afternoon...[CC_1124]</i>
What carers wanted <ul style="list-style-type: none"> • Personal support as well as support for the consumer • Information on medication and where to access help • Respite from carer burden 	<i>...listen to me and my troubles or worry what I got, and if they can help me in that way...[CA_1169]</i>
How pharmacy can help <ul style="list-style-type: none"> • Acknowledge the carer role • Listen and check in on the health of the carer • Optimise stock control to meet individual needs • Providing information on medication and health services • Informing carers about available pharmacy services 	<i>.... they [pharmacy staff] were just amazing...they gave me like tissues and sat down...I just wanted to get out of there, but you know they were just really nice. [CA_1013]</i>
Impact of carer burden <ul style="list-style-type: none"> • Feelings of guilt and stress • Self-neglect and isolation 	<i>I was just not feeling well in myself and so, that's a sad situation when the carer feels like they need a carer. [CA_1071]</i>

CA=carer; CC=Consumer and carer

c. Patient centred care

When consumers and carers were asked to define patient centred care, they visualised themselves at the centre of care, participating in treatment decisions. There was consensus that patient centred care relied on the presence of caring health professionals who took the time to determine individual needs, considered the social context in which consumers lived by looking beyond their chronic conditions, and respected and valued their experiences and expertise. Consumers and carers had clear opinions about care that was considered to be patient centred and care that was not (Table 3.5).

Patient centred care recognises the integral role of the patient/person, and promotes partnership between them and health professionals. This is necessary to ensure that people can make informed choices that optimise their quality of life (Table 1.1).

Table 3.5: Consumer and carer views of patient centred care

Healthcare that is not patient centred	Healthcare that is patient centred
A number not a person	Personalised care and relationships - remember, recognise and relate
Health care in a hurry – no time	Time taken to get to know them, their situation and needs
The silo approach – treating by condition	Complexity of conditions considered and addressed
Tunnel vision – treating by numbers	Wellbeing valued alongside clinical targets
Incomplete care – delay to diagnosis	Thorough investigation, consumer concerns heard and believed
Incomplete care – disease progression	Proactive monitoring that involves consumers and carers
No respect for consumer or carer expertise	Working with consumer and carer strengths to manage health care
Treatment in the dark – not enough information	On-going information exchange to inform and reassure
No consideration of individual health goals	Healthcare that is tailored to accommodate health and life goals

Participants' views on patient centred care aligned most strongly with respectful and individualised care. However, they also provided examples of holistic and empowering care. Participants' descriptions of patient centred care provided important insights for community pharmacy.

- **Individualised care** *"They've got great rapport with him [patient], you know like they really pick out who he is and his strengths. He's not just treated like another patient...I'm just really, really happy with, she's [doctor] really getting to know him as not only as a patient, but you know for who he is, a person."* [CA_1013]
- **Respectful care** *"I guess for some, probably more at a specialist level, by actually listening to their patients, that would really help. Because the higher up the food chain they get the less personable they are."* [C_1080]

- **Holistic care** *"I'm a very complex person I would say, because not only I've got a physical disability, now I've got an emotional disability. So if you treated me you will have to treat both, you know."* [C_1069]
- **Empowering care** *"My relationship with my GP whom I've had now for thirteen years is extremely good. Now he will see me if I request to see him even though he doesn't take on new clients anymore and he's always extremely busy. But he's very good and he talks to me like I know what I'm doing about my health and he trusts me to do what I have to do. And I would have to say the same for my endocrinologist even though it's taken a long time for us to develop a relationship."* [C_1022]

d. Community pharmacy

Consumers' and carers' experiences of pharmacy and their knowledge of what it can offer them influenced their choice of pharmacy, and their views on the potential value of expanded pharmacy services for chronic conditions.

Consumer and carer experiences of community pharmacy

Participants could be categorised into three patron groups, those who always patronised one pharmacy (regular), people who patronised one pharmacy most of the time and only used another pharmacy to meet specific needs, and those who visited multiple pharmacies (i.e. casual user). Five key factors were identified as being important when choosing a pharmacy [84]:

- a) patient centred care;
- b) convenience;
- c) prices;
- d) personal traits and preferences/habit; and
- e) match with service or medication needs.

An ideal pharmacy would offer and deliver service that was patient centred, convenient, reasonably priced and aligned with personal preferences and individual service or medication needs. Figure 3.1 highlights the factors that particularly influenced consumer choice, and the various factors important to different types of consumers. For example, availability of specialised services, such as compounding, was important to both regular consumers and those who had a regular pharmacy but used the compounding pharmacy for the specialised service only.

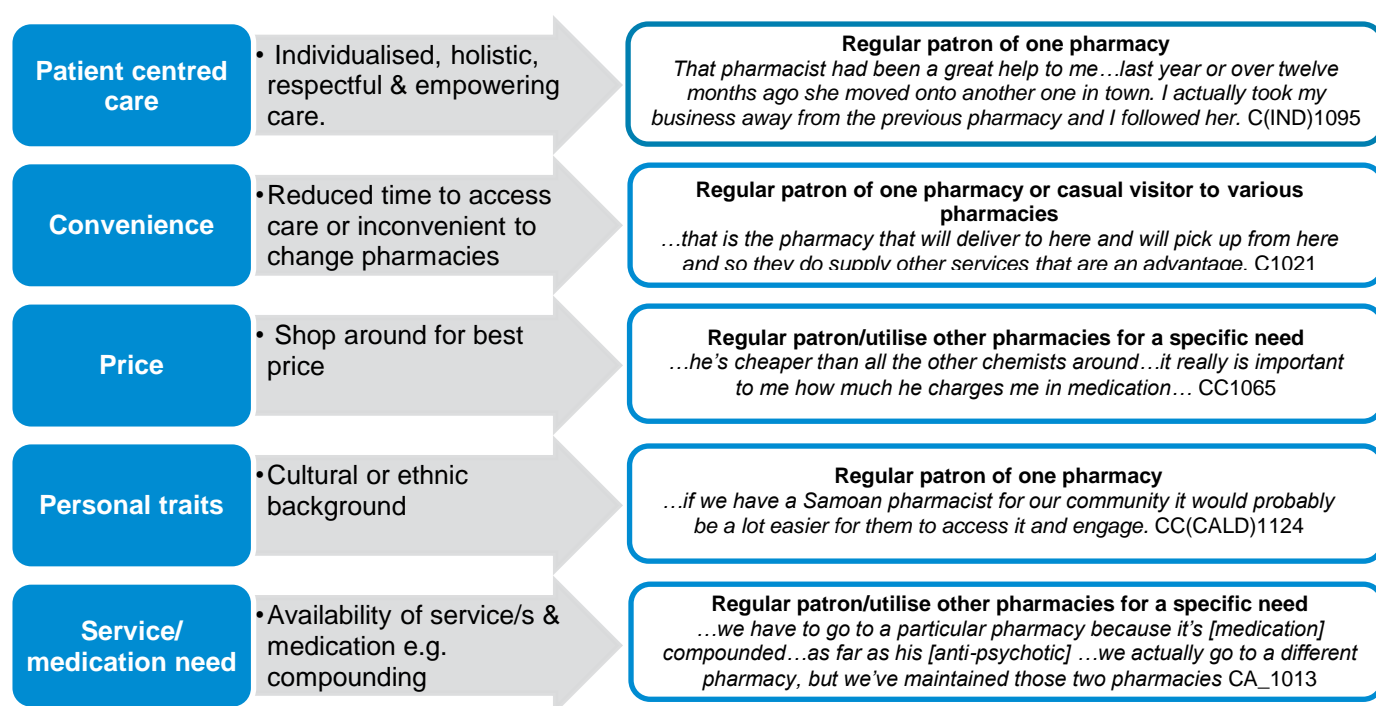
The importance of patient centred care featured prominently for regular pharmacy patrons, and was described along a spectrum from patient focused or supportive staff through to the establishment of caring and trusting relationships with staff delivering services responsive to individual needs (patient centred). Some participants reported using one pharmacy to promote medication safety, believing a more complete medication history would facilitate individualised counselling and minimise medication interactions. A similar 'protector' role emerged for pharmacists with mental health consumers [85]. The value placed on their relationship with pharmacists and support staff also meant that a negative experience, e.g. a medication error, did not change their pharmacy choice, if errors were not a regular occurrence. Furthermore, some consumers and carers reported feeling disloyal to their regular pharmacy when they used a different pharmacy to obtain a cheaper medication/product.

Convenience was a consistent factor for some consumers when choosing a pharmacy [86-88, 62], for those who regularly used one pharmacy (i.e. their choice was often associated with convenience even though the relationship maintained their connection to that pharmacy), as well as to casual visitors (i.e. those who used the

pharmacy that was most convenient at the time). This factor also meant that some people did not change pharmacies, even when they experienced poor service, if this was physically or practically inconvenient.

Most participants did not expect or envisage a higher level of service elsewhere, and hence did not perceive any reason for moving pharmacies. Limited expectations were particularly apparent in relation to pharmacy medication management services; these were not drivers of pharmacy choice, reinforcing a need to explore consumer awareness of, and provide targeted education on, the value of these services. To maintain a competitive edge, all pharmacy staff need to promote a patient centred approach to care and emphasise how the services that they provide can reduce treatment burden, such as storing prescriptions, providing prescription reminders and home deliveries.

Figure 3.1: Factors influencing pharmacy choice



Consumer and carer knowledge and use of community pharmacy services

Low expectations of pharmacy service could be attributed to both limited awareness of these services and the fact that pharmacists were viewed as medication suppliers with a primarily technical (dispensing) role. These findings are consistent with the 5th CPA *Consumer Needs Project* [62]. Some participants could not actually conceive a pharmacy role beyond timely supply of medication. Through the interviews it became apparent that consumers and carers *do not know what they do not know* about how pharmacists and pharmacy services can support them and reduce treatment burden.

Although participants were generally unaware of the breadth of the pharmacist's skill set, there was considerable discussion about seeking or obtaining the pharmacist's advice regarding new medication and drug interactions. Some participants using regular medication also explained that they would seek the pharmacist's advice if they had any further questions about their use. However, there was limited discussion about obtaining general health advice for their condition(s).

When asked who should provide medication-related advice, participants were less likely to seek advice from pharmacy support staff, a finding which aligns with those from the 5CPA *Consumer Needs Project* [62]. They did acknowledge the broader role of support staff, including the initial assessment of problems and triage to the pharmacist, the provision of dispensed medication, and relaying advice from the pharmacist. Participants had limited understanding of the training and roles of support staff, and minimal awareness of the forward pharmacy concept, which utilises the dispensary technician skills to allow pharmacists to focus on interacting with consumers and carers.

Barriers to seeking advice from the pharmacist did emerge during interview. These included a lack of awareness of the pharmacist's role, cultural barriers, lack of privacy and the retail focus of some pharmacy. Some interviewees reflected that pharmacists were not proactive in offering information, and that it was 'standard' [C_006] for people to have to ask for advice; others, particularly those of an older generation, asked their GP questions instead.

There was limited use of professional pharmacy services beyond dose administration aids, home deliveries and blood pressure testing. While it would be expected that this study population with chronic conditions would be higher users of professional pharmacy services (i.e. extended services beyond medication supply), compared to general pharmacy consumers [62], this was not the case. It is possible that the pharmacies these participants used did not offer or promote additional services, they were too costly for consumers to access, services were viewed as providing no benefit above what the GP offered or could do, were not believed to be needed by consumers, consumers were unaware [89], or did not expect additional services [90]. For example, stories of medication mismanagement were heard in a rural setting where a community member advised her mother not to take her medication if its use was unknown, meaning information may not have been provided. However, some participants from outreach areas did not think they needed a pharmacist. These concerns were also highlighted by Tan *et al.* whose study investigated the issues and challenges surrounding medication management in rural Queensland [91]. The authors highlighted how pharmacy could become more involved, such as through funding of out-reach or tele-pharmacy services [91].

New and expanded roles for community pharmacy in managing chronic conditions

During the interviews, few participants were able to provide specific recommendations about future roles for pharmacy. This finding is consistent with other studies whereby Australian consumers are 'satisfied' with the services provided and therefore have difficulty in identifying what else pharmacy staff can do for them [62]. However, interviews revealed unmet health needs that community pharmacy could potentially address (Table 3.6). This would ideally change public perception of the pharmacist's role from medication suppliers to medication managers or facilitators of care. A medication management role would incorporate a more holistic approach to care, where the pharmacist is focused on the person's broader health needs as well as their medication support needs. This would include medication and health information, disease monitoring, referrals to support organisations and relevant services. This would promote a broader view of pharmacy as a healthcare destination or health hub that promotes community health.

Table 3.6: Identified gaps in healthcare that community pharmacy could address

Theme	Subtheme	Example
Access	<i>Move beyond bricks and mortar</i>	Outreach services to rural areas with limited/no pharmacy access (e.g. medication reviews).
	<i>Convenience</i>	Longer opening hours, direct provision of repeat prescriptions (i.e. continuous medication supply).
Inform	<i>Health literacy</i>	Recognise individual needs, check understanding of medical directions. Provide information and discussion about novel and current treatment options, encourage people to ask questions.
Monitor	<i>Disease management</i>	Pharmacist driven disease monitoring/screening programs and collaboration with GPs to make treatment changes (e.g. blood pressure, lung function tests).
Connect	<i>Health system navigation (signposting)</i>	Referrals to CHOs and other health professionals and practitioners.

There are clear opportunities for community pharmacy to become more involved in supporting consumers to manage their chronic condition(s), and to further assist carers. This was also highlighted in the Grattan Institute 'Access all Areas' report which recommended that pharmacists expand their current scope of practice to include collaborative chronic care management, immunisation and repeat prescribing services [77].

However, any strategies for change need to address three fundamental factors:

- a) limited consumer expectations;
- b) innovation in pharmacy services and delivery methods; and
- c) capacity of pharmacists and pharmacy support staff.

Summary

Key findings

- Consumers and carers were extremely clear about the actions that demonstrated patient centred care, all of which were relevant and applicable to all community pharmacy staff;
- Treatment burden impacted on numerous aspects of a person's life: employment, education, family and daily life. Furthermore, the process of self-managing, despite being necessary and valued, can contribute to treatment burden;
- Financial burden was the most significant experience and this impacted negatively on medication use for some participants;
- Carer burden was not recognised adequately and could be identified, acknowledged and alleviated by pharmacists via optimising medication information and supply services;
- A major barrier to receiving adequate support services was the lack of referral by health professionals to consumer health organisations. Consumers recommended greater links between pharmacy and consumer health organisations to reduce access barriers and help manage treatment burden;
- Five factors influenced consumers' choice of pharmacy choice; patient centredness, convenience, prices, personal traits and preferences and service/medication need;
- There was limited discussion as to how community pharmacies could better support consumers with chronic conditions and carers beyond medication information and supply; a lack of awareness of professional pharmacy services was evident;
- Future roles for pharmacy include increased access through outreach and innovative services, information, monitoring and connecting people with services relevant to their needs. However, greater staff capacity and a shift in public awareness is needed to do this.

Insights for community pharmacy: New or extended services

- Introduce pharmacy services that address unmet health needs both generally and locally:
 - Signposting to CHOs or health providers (as part of a health hub);
 - Collaborative chronic condition management – screen, monitor, promote adherence;
 - Outreach services for selected communities;
 - Innovate in rural/regional areas;
 - Local innovations such as walking groups, self-management programs;
- Pharmacy services for carers that alleviate burden by:
 - Recognising and understanding the carer's role, responsibilities and limitations (carer card);
 - Addressing the carer's information needs and establishing supportive relationships.

Insights for community pharmacy: Improvements to existing services

- Broader implementation of patient centred pharmacy services is integral to reducing treatment burden. This entails:
 - *Holistic care* that relies on knowing the consumer, their condition and related social context through open engagement and dialogue;
 - *Individualised care* – moving beyond personal service (i.e. greeting by name);
 - *Respectful care* – engaging with individuals and community leaders;
 - *Empowering care* – increased awareness and use of referral pathways to additional support (i.e. pharmacy as health destination);
- Promote adherence to medication by reducing complexity and increasing convenience:
 - reduce complexity via community pharmacy access to hospital medications;
 - reduce complexity via medication management services (e.g. HMR);
 - provide subsidised home delivery of medication for people with limited mobility;
 - provide subsidised dose administration aids for eligible consumers with chronic conditions;
- Transform consumer awareness and use of pharmacy services from supply to support:
 - promote pharmacist expertise and availability of medication support services;
 - increase expectations and build consumer and carer capacity to use pharmacy in broader ways
 - promote pharmacy as a health hub for integrated health and medication information and referral pathways.

Insights for community pharmacy: Training and education

- Effective implementation of patient centred pharmacy services relies on training that:
 - Increases awareness and understanding of treatment burden amongst all pharmacy staff;
 - Improves knowledge about patient centred care (e.g. holistic care);
 - Engenders cultural awareness and promotes culturally appropriate care;
 - Equips staff with communication skills that promote appropriate questioning;
 - Facilitates skills development in relation to providing individualised service/advice;
 - Builds staff capacity to deliver patient centred care.

Insights for community pharmacy: Workforce development

- Workforce strategies for implementation of patient centred pharmacy services include:
 - Formal and informal career pathways that capitalise on individual skills sets (e.g. develop pharmacy assistants who naturally engage well with consumers);
 - Identify pharmacy role models and use them as industry champions;
- Creatively use existing resources – i.e. non-dispensing pharmacists across pharmacies
- Support from pharmacy organisations and government to transition to new professional services that address unmet needs:
 - Staff capacity to promote pharmacy as a health hub that provides a range of services;
 - Effective referral pathways to additional support (e.g. CHOs, health professionals).

3.2 Nominal groups with health consumers, carers and health professionals

This section illustrates the findings of discussion groups conducted with consumers, carers and health professionals/health workers using the NGT (i.e. nominal groups), to explore what people prioritised when they envisaged ideal future pharmacy services. For further detail please see Appendices 5.1 to 5.3. This work has been published in or is under review in the following peer-reviewed journals:

- McMillan SS, Kelly F, Sav A, Kendall E, King MA, Whitty JA, Wheeler AJ. Using the nominal group technique: how to analyse across multiple groups. *Health Services and Outcomes Research Methodology* DOI:10.1007/s10742-014-0121-1 (published online 25.07.14).
- McMillan SS, Sav A Kelly F, King MA Whitty JA, Wheeler AJ. Is the pharmacy profession innovative enough? Meeting the needs of Australian residents with chronic conditions and their carers using the nominal group technique. *BMC Health Services Research* (submitted 12th March 2014);
- McMillan SS, Kelly F, Sav A, Kendall E, King M, Whitty J, Wheeler AJ. Consumers and carers versus pharmacy staff nominal groups: do their priorities for community pharmacy services align? *The Patient* (submitted 22nd July 2014).

Method

Consumers and carers participated in nominal groups across the four project areas, and when possible, homogenous groups were conducted with Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people and people of Caucasian descent. Health professional/health worker groups were conducted with pharmacists, GPs, allied health staff and pharmacy support staff.

Consumers and carers were asked to propose and prioritise their ideas for ideal pharmacy services (Box 3.1). Health professionals/workers were asked to reflect on what their clients would prioritise as ideal pharmacy services.

Box 3.1: Questions asked in nominal groups

Consumer and carer groups: Imagine your local pharmacy several years into the future, what services could they offer to help you to meet your individual health goals?

Health professional/worker groups: Imagine the local pharmacy several years into the future, what services do you think consumers and carers would like to help them meet their individual health goals?

The NGT was chosen as a method that facilitates identification of what is important to, or valued by, health consumers [92] and to aid comparison between different groups [93, 94]. It is a highly structured process that promotes the generation of ideas to a specific question(s). Participants discuss, clarify and prioritise (rank) the ideas raised (Table 3.7). In this study, the NGT was combined with an appreciative enquiry approach [95] to encourage consumers to be creative and solution-focused (see Appendices 5.4 and 5.5). Prior to the nominal group, participants were sent an outline of the group process to prepare them and an overview of the pharmacy services currently available (Appendix 5.6). The overview was provided to address the issue of consumers not knowing what they do not know about pharmacy services, thereby promoting greater discussion of potential future services.

To ground data within the broader health system, participants were asked to propose and prioritise their ideas on what constitutes ideal healthcare services (i.e. beyond pharmacy) as a separate nominal process for selected groups (Appendix 5.7).

Table 3.7: Nominal group process

Group stages	Process
<i>Brainstorming*</i>	Describe your most positive experience with a healthcare service or professional.
<i>Silent generation</i>	Participants silently list their ideas in response to the nominal group question.
<i>Round robin</i>	Participants present a single idea in turn until there are no more new ideas.
<i>Clarification</i>	Ideas are clarified, similar ideas grouped and duplicates removed if appropriate.
<i>Ranking</i>	Participants select and score their top FIVE preferences (top priority=5).
<i>Discussion</i>	Total scores for nominal group are presented and discussed with group.

**Appreciative inquiry approach.*

Twenty-six nominal groups were conducted between December 2012 and May 2013 involving 164 participants in 15 consumer and carer groups and 11 health professional/health worker groups (Table 3.8). Nine groups were conducted in Logan-Beaudesert (62 participants), five in Mt Isa and the North West region (21 participants), five in the Northern Rivers, (38 participants) and greater Perth (33 participants) areas. When difficulties were experienced in recruiting GPs, two groups were conducted in the greater area of Brisbane (8 participants). The ideal healthcare question was asked in 15 groups, 11 consumer and carer and four health professional/worker groups. There were on average six participants per group, ranging from 2-14 people. It is important to note that recruitment for nominal groups aimed to recruit a diverse sample in order to elicit a broad range of ideas.

Table 3.8: Participant characteristics (nominal groups)

Consumer and carer participants (n=103)	n	%
Consumer	62	60.2
Carer	16	15.5
Consumer and Carer	25	24.3
Cultural background		
Caucasian	51	56.7
Culturally and linguistically diverse people	17	19.6
Aboriginal and Torres Strait Islander people	35	23.7
Study region		
Logan-Beaudesert	39	37.9
Mount Isa & North West	15	14.6
Northern Rivers	31	30.1
Greater Perth	18	17.5
Health professional and health worker participants (n=61)	n	%
Community pharmacists	22	36.1
Medical practitioners	9	16.4
Other health professionals/workers	17	27.9
Pharmacy support staff	13	21.3
Study region		
Logan-Beaudesert ^a	33	54.1
Mount Isa & North West	6	9.8
Northern Rivers	7	11.5
Greater Perth	15	24.6

^aEight of the medical practitioners were from practices located slightly outside the study region.

Data collected during nominal groups included a list of the ideas proposed by participants in that group, individual scores for each person's top five priorities and the total scores for each idea suggested (to identify the top five priorities for that group). Nominal groups were also audiotaped and transcribed to capture participant discussion related to their priorities. Data analysis followed the steps outlined below:

- Individual group scores and summary were emailed to the research team following each group to aid on-going analysis-based discussion;
- Thematic analysis of raw data allowed comparison of consumer and carer ideas across multiple groups [96]. Twelve themes were developed from the data and refined using a consensus approach amongst the research team (see Appendix 5.8). Researchers individually coded raw data (individual ideas) as themes;
- Overall priorities for the consumer and carer sample were calculated using a method that combined average score with how often themes appeared in the top five for groups and frequency of themes across groups. Overall priorities were calculated separately for health professionals [97];
- Between-group comparisons were conducted using a relative importance score that considered the total value placed on a theme by each group, even when individuals prioritised different aspects of that theme (e.g. extended opening hours vs. delivery both relate to access) [98];

- Qualitative data of participant discussion were coded according to the 12 themes to provide contextual insight into participant suggestions and preferences.

Results

A key focus of this project was how community pharmacy could best support consumers with chronic health conditions and their carers. Accordingly, this section predominantly presents the findings collated when consumers and carers were asked to propose and prioritise their ideas for their ideal pharmacy services. Comparative insight is provided of health professionals' views on their clients' priorities for their ideal pharmacy services. Selected findings are also presented on consumer and carer priorities for the broader health system to highlight where these converge or diverge from their pharmacy services priorities. Appendix 5.9 provides more detail about the priorities. The results are presented in the following order:

- a) Top five priorities overall for consumers' and carers' **ideal pharmacy services** compared with health professionals;
- b) Top five priorities overall for consumers' and carers' **ideal health service** compared with health professionals;
- c) Top five consumer and carer priorities explored in detail;
- d) Top health professional priorities in detail; and
- e) Consumer and carer priorities compared with health professional/worker views.

a. Top five priorities overall – ideal pharmacy services

Consumers and carers prioritised medication-related information and patient centred care in pharmacy services that they could access, afford and offered continuity and coordination of care (Table 3.9). Consumer information and education was rated as the top priority overall for consumers and carers, and the remaining top five priorities were access, affordability, patient centred care and continuity and coordination of care. Patient centred care was discussed in 11 of the 15 consumer and carer nominal groups. In nine of the 15 groups, consumers and carers expressed a preference for innovative services and roles, although this did not appear in the top five. Selected examples of innovative services included high-tech pharmacies, pharmacists visiting the community and pharmacy-led walking groups.

Medication-related services (e.g. dose administration aids) were not prioritised as highly by consumers and carers, which may signify that consumers consider these to already be integral pharmacy services. Quality of service (e.g. professional competency) was ranked at a similar priority to medication management, suggesting that quality is assumed or that people are currently satisfied, even though there have been reports of variable standards of pharmacy service [99]. Consumers and carers ranked health promotion and government/legislative change as their lowest priorities. Individual ideas suggested in nominal groups that related to health promotion were predominantly associated with clinical monitoring (e.g. blood pressure, cholesterol), which is already provided by some pharmacies. This may also reflect satisfaction with the status quo, limited confidence that clinical monitoring will accommodate privacy, a perception that it is beyond pharmacists' scope or that there is limited room for change.

Table 3.9: Comparison of top priorities for the ideal pharmacy question

Consumers and/or carers	FINAL RANK	Health professionals/workers	FINAL RANK
Consumer information or education	26.50	Continuity and coordination of care	24.50
Access	25.50	Consumer information or education	22.50
Affordability	25.00	Quality of service delivery	20.50
Patient centred care	24.50	Innovative services and roles	20.50
Continuity and coordination of care	24.00	Affordability	20.00
Innovative services and roles	21.00	Access	19.50
Medication management	13.00	Patient centred care	17.00
Quality of service delivery	12.50	Medication management	11.50
Supply-related service	9.50	Health promotion	6.00
Health promotion	9.00	Government initiative/legislative changes	3.00
Government initiative/legislative changes	7.50		

Appendix 5.9 provides a detailed description of the priorities.

When the priorities of consumer and carers and health professionals were compared, consumer information or education emerged as a similarly high priority, ranking second for health professionals. Likewise, affordability and continuity or coordination of care were common top five priorities, and carer concerns were not prioritised by either population in relation to pharmacy service. Health professionals considered medication-related services to be less of a priority and this may reflect similar views to consumers and carers. It appears that health professionals valued service-based attributes such as continuity of care, innovative services and quality of service delivery over the consumer priorities of access and patient centred care. Health professionals may perceive that they already provide access and patient centred care, but may not fully understand the importance of these concepts from consumer and carer perspectives with respect to pharmacy. Alternatively, health professionals may assume that patient centred care is integral to quality. Interestingly, health professionals did prioritise patient centred care more highly when describing an ideal health service; this may signify their views on the image of pharmacy and related importance of pharmacy delivery of patient centred care.

b. Top five priorities overall – ideal health service

Health professionals' views on what consumers and carers would identify as their top five priorities for ideal health services were more aligned to the actual priorities than was observed for the ideal pharmacy services question (Table 3.10). Access was the top priority for both groups in relation to ideal healthcare, whereas it was less prioritised for ideal pharmacy services. This may reflect the accessibility of community pharmacies to consumers and carers, or that access to pharmacy may be considered less important because of the perception that pharmacists primarily perform a medication supply rather than a health-oriented role. Both groups also highly prioritised affordability of healthcare, patient centred care and continuity and coordination of care. Consumers afforded similar priority to patient centred care for both questions, confirming their preference for this type of service irrespective of who delivers it. However, health professionals considered that patient centred care would be a greater priority for health services than pharmacy services, which may reflect a perception of pharmacy as primarily a retail destination. Medication management was not prioritised for ideal health services by either group, perhaps signifying that it is considered the domain of pharmacy or confirming it is not a well-understood concept.

Table 3.10: Comparison of top priorities for the ideal health question

Consumers and/or carers	FINAL RANK	Health professionals/workers	FINAL RANK
Access	33.00	Access	28.00
Patient centred care	30.00	Continuity and coordination of care	26.00
Continuity and coordination of care	30.00	Affordability	25.00
Affordability	30.00	Patient centred care	21.00
Quality of service delivery	20.50	Government initiative/legislative change	16.50
Consumer information or education	20.00	Consumer information or education	14.50
Government initiative/legislative change	18.00	Quality of service delivery	13.50
Carer	18.00	Health promotion	9.50
Health promotion	15.50	Innovative services and roles	6.00
Supply-related service	9.00	Carer	5.00
Innovative services and roles	6.50		
Medication management	3.50		

c. Top five consumer and carer priorities in detail

Table 3.11 shows the breakdown of the top priorities for consumers and carers in the four study regions (see Appendix 5.9 for detail). Groups consisting of Aboriginal and Torres Strait Islander participants nominated patient centred care as a priority, irrespective of region. Most often, they described solutions that focused on culturally appropriate care (e.g. awareness of CTG, absence of discrimination/racism). In contrast, groups consisting of culturally and linguistically diverse participants nominated affordable medications and services and medication advice as their most important priorities. Meanwhile, Caucasian groups nominated affordability and medication management as their most important priorities for ideal pharmacy services. A preference for innovative services and roles was restricted to the Northern Rivers and Greater Perth region. Carers prioritised continuity and coordinated care, medication management and supply.

Table 3.11: First priority for consumer and carer groups (by frequency)

Priority	Logan-Beaudesert			Mt Isa & North West **			Northern Rivers			Greater Perth		
	C	CA	Mixed	C	CA	Mixed	C	CA	Mixed	C	CA	Mixed
Affordability			*	*						*		
Innovative services & roles							*		*			*
Patient centred care	*						*			*		
Access	*					*						
Continuity & coordinated care		*	*									
Consumer education/information				*								
Medication management					*							
Supply-related services							*					

C=group with only consumers, CA=group with only carers, Mixed=groups with consumers and carers. * Top priority for one group. ** Affordability and consumer information or education were awarded equal priority in one Mt Isa group.

Consumer information or education

Consumer information or education emerged as the top priority overall for ideal pharmacy services. Conversely, the *Consumer Needs Project* identified that the majority of their consumers would choose to see their GP for prescription medication advice [62], indicating that people with chronic conditions are more likely to expect or want medication information from their pharmacist. Consumer and carer preferences were discussed in the context of: what information should be provided, who ideally should provide this information, how it could be delivered and the factors that influence this (Figure 3.2). Consumer suggestions generally focused on how consumer information provided via pharmacies could be improved. Medication-related information was deemed a high priority with respect to what they are used for, how to use them, potential side effects and drug interactions, when further therapeutic monitoring was necessary, and updates on new medications or treatment changes for their respective conditions. Further explanation was also sought with regards to generic medication, particularly with how they differ from the original brand.

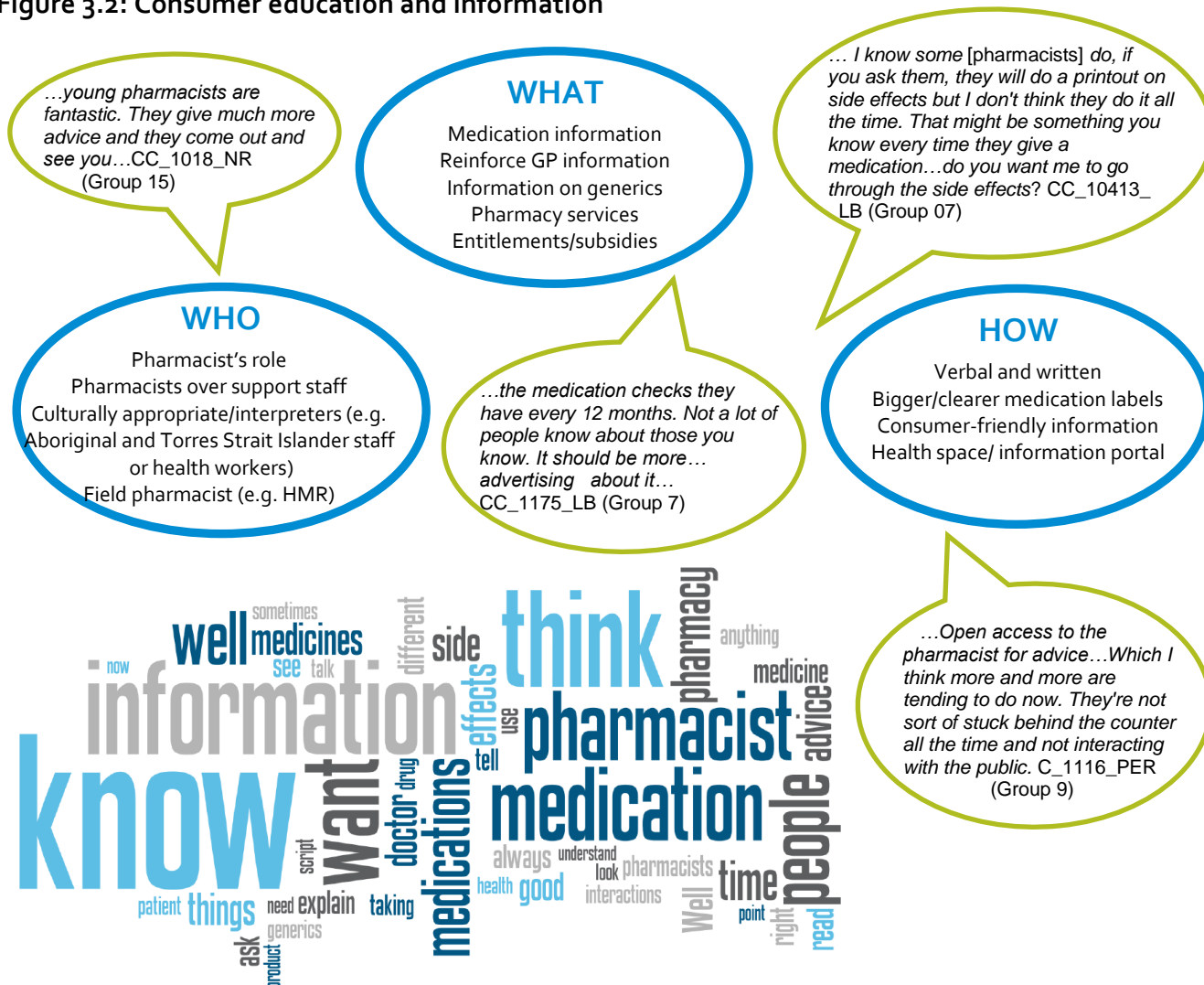
The need to better inform people of the expertise and qualifications of pharmacists, support staff, and the range of pharmacy services and entitlements available to support people was also discussed. This was also expressed by consumers in the interviews (see Section 3.1). However, when consumers were asked to prioritise, they expressed a preference for medication-related information over increased awareness of pharmacy services.

When asked who should provide this information, health professionals, consumers and carers all perceived this as the primary role of pharmacists. Some consumers also stressed the importance of the pharmacist's advice in the context of a 'triage' role in distinguishing between minor ailments and when they needed to see a doctor. There was a definite preference for pharmacists to provide information rather than support staff, who themselves preferred to take on technical tasks to free up pharmacists. Aboriginal and Torres Strait Islander participants advocated for more pharmacists and pharmacy staff of similar cultural background, and articulated a preference for Aboriginal health workers to work with pharmacists and reinforce medication information.

Consumers and carers wanted pharmacists to be more proactive and consistently offer verbal and written medication information, rather than wait to be approached, and spend time explaining this information in a meaningful, patient centred way. There was a sense that information needed to be straightforward, consumer friendly, without medical jargon. Pharmacists should tailor their advice to accommodate individual needs such as, low health literacy, limited vision or when English is a second language. The importance of proactive provision of respectful education that informs without being condescending was highlighted by Aboriginal and Torres Strait Islander participants.

Consumers and carers also proposed innovations and improvements to current formats of written and verbal information. Innovative strategies included a pharmacist telephone line, an evidence based information portal in the pharmacy, and a field pharmacist providing consumer education outside of the pharmacy environment. Suggested improvements included provision of medication labels with larger print and offering information leaflets in alternative languages.

Figure 3.2: Consumer education and information



Factors influencing medication information and education

Consumer factors

- Individual consumer and carer characteristics e.g. cultural background, low health literacy, shyness;
- Limited awareness of pharmacist expertise and available pharmacy services.

How information is provided

- Consumers needing to ask for, rather than being offered medication-related information;
- Feeling overloaded or 'bamboozled' with information from other health professionals;
- Time spent fixing prescription problems limits breadth and depth of counselling (pharmacist availability);
- Pharmacy environment – supermarket-like space limits privacy, busy pharmacy limits information provision.

What information is provided

- Confusion over generic medication e.g. the differences, who benefits, their appearance.

Who provides information

- Provision of information on health condition(s) viewed as being more the responsibility of GPs;
- Reservations over ethical integrity of pharmacists' product recommendations;
- Uncertainty in pharmacy assistant training and competency.

C=consumer; CA=carer; CC=consumer and carer.

Access

There was a clear need for continued or better access to quality medication and services from community pharmacy (Figure 3.3). This related to *what* community pharmacies supplied, i.e. stock, equipment and devices, *how* to increase access, i.e. longer opening hours, and the *factors* that influenced this supply, i.e. rural context, the PBS system, the pharmacy model and its physical environment. Suggestions related to access primarily related to improving or more broadly implementing existing pharmacy services, with some innovations also proposed.

Participants expressed frustration when the pharmacy did not have sufficient supply of their required medication in stock. Regular pharmacy users expected pharmacists and support staff to be aware of their individualised requirements and maintain sufficient stock of medication, equipment and devices, particularly in rural areas where options were more limited. Although having a consumer's medication available when needed was viewed as good customer service, there was acknowledgement of stock having limited shelf life. Others wanted more product choice, thereby catering for all socioeconomic groups. Participants who accessed their medication via their medical specialist or hospital ideally wanted to be able to obtain this from their community pharmacy instead. The need for improved pharmacy disposal services, such as acceptance of used syringes and free sharp disposal kits, was emphasised by people with diabetes.

Convenience emerged as a key underlying theme to access, and consumer and carer suggestions for improvement included longer pharmacy opening hours (including 24 hours), being able to order medications from home and drive-through pharmacies. Increased access to pharmacy medication and services was discussed in terms of being able to obtain medication outside normal pharmacy opening hours, particularly for the more rural/semi-rural areas (Mt Isa and Northern Rivers). When asked if the three pharmacies in Mt Isa were sufficient to cater for public demand, participants did not necessarily want more pharmacies but suggested longer hours, or to '*stagger their hours*' (CC_1218_ISA; Group 17). Conversely, an urban consumer and carer group (Perth) questioned the safety of staff if pharmacies were open for longer.

Factors influencing access were related to either how medication was supplied or the pharmacy environment. Greater flexibility with respect to the PBS system was sought in terms of prescribing or supplying larger medication quantities. A *pharmacy environment* conducive to healthcare and increased access, such as a clean, friendly and comfortable environment (e.g. waiting area with chairs and water, no stock on the floor), increased privacy (e.g. consultation rooms, counselling booths), more time with the pharmacist, and subsequently more pharmacists on staff, was also discussed. *Privacy* in the form of a separate consultation area was viewed as particularly important if needing to discuss a delicate health matter, or for people who had health literacy problems and wanted to further understand their condition and its management.

Figure 3.3: Themes pertaining to pharmacy access

...I know pharmacists are gearing more towards we need to offer more services, well I think if they do want to offer more services, whether it's education or you know appointments, you need to have private rooms to do that in.

[CC_1049_LB (Group 7)]

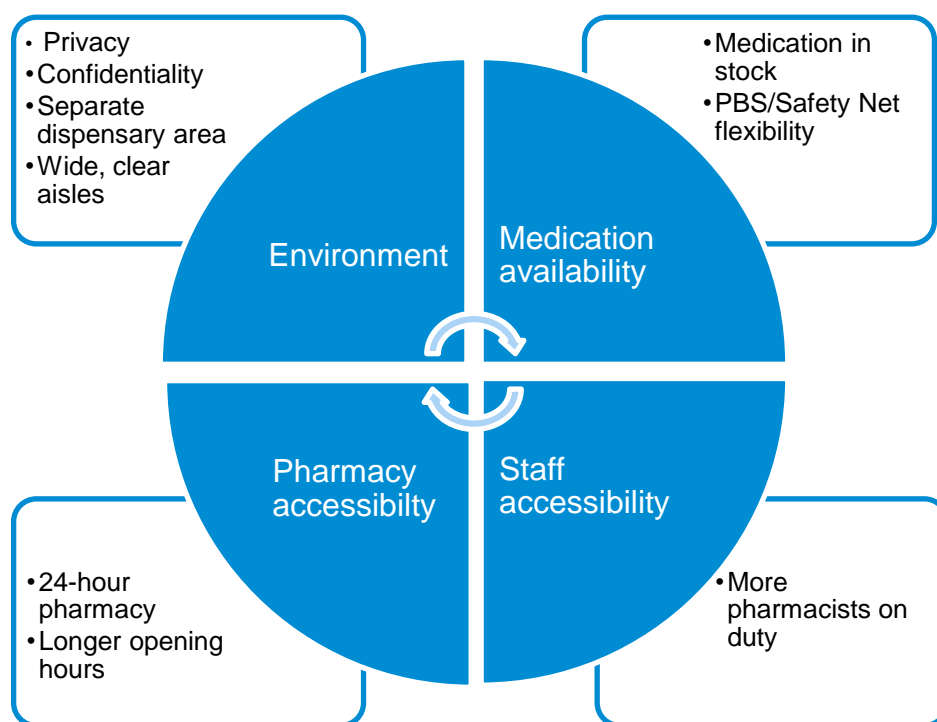
...when the young 15-year-old work experience girl is saying, you know, who's ordering this, who's got this, or whatever, everybody's looking, ooh. There isn't any confidentiality...

[CC_1118_PER (Group 13)]

...they [pharmacy staff] should know that he's on it [the medication] and how long it's going to last and have it there. [CC_1221_ISA (Group 17)]

Better supply of medications in rural areas, because you don't have the choice you have in the city... [C_1222_ISA (Group 16)]

I think once you've been classed chronic condition, which most of us have, you should have access to whatever you need... As in the higher quantity sort of thing. [CC_1206 (Group 9)]



I think they should have a 24-hour pharmacy because my boy has got asthma I remember sometimes I had to get him to the hospital when he ran out of his Ventolin... There was no pharmacy open to get it. So then you've got to sit around and wait for about an hour or two just to get it... It would be handy if you run out during the night.

[IND_CA_1224_ISA (Group 20)]

...they should have an extra chemist on the floor to explain all these things, to different people... [IND_C_1106_NR (Group 4)]

C=consumer; CA=carer; CC=consumer and carer.

Affordability

...I'm standing there waiting for the script to be filled thinking oh my God, are they going to charge me some ridiculous amount because the concession card thing hasn't gone through, and they didn't ask me if I wanted a generic, I wonder if the script has the generic brand on it, is it going to cost me more money than I think it is...[C_1183_LB (Group 2)]

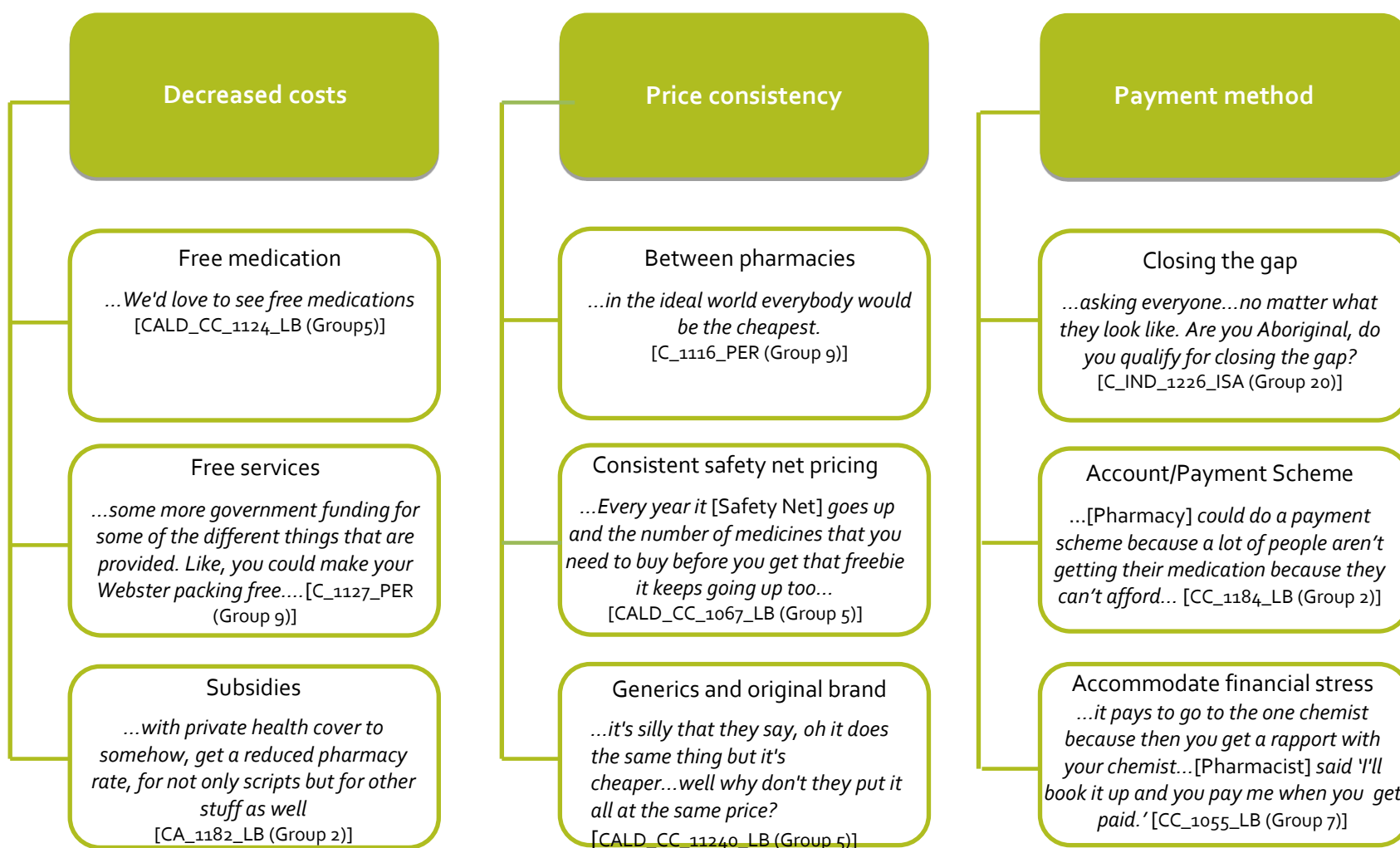
The above quote further highlights the financial burden of medication that emerged through interviews and the importance of affordable health services to consumers and carers. Affordability was raised as a concern across all four project areas, and discussed as free or decreased cost, price consistency and information on prices, and payment methods (Figure 3.4). This theme was selected by three nominal groups (Logan-Beaudesert, Perth and Mt Isa) as their top priority for ideal pharmacy services (Figure 3.4 and Appendix 5.9).

Participants were appreciative of the systems in place to reduce medication costs, such as the PBS and the CTG initiative. Nevertheless, their ideal pharmacy was described as having increased affordability in terms of additional subsidies for medication (i.e. free), devices, or services (e.g. dose administration aids). Other ideas included: people with chronic conditions being eligible for government subsidies, regardless of their employment status, and private health insurers increasing their list of subsidised medications to include over-the-counter medication.

A consistent discussion point for consumer and carer groups was price discrepancies between pharmacies, particularly when pharmacies charged more for their products but did not provide a higher level of service. While participants acknowledged the pharmacy within the context of a business, more competitive pricing was sought in rural areas, and more consistent prices between pharmacies in urban areas. Therefore, participants may be more inclined towards 'price fixing' pharmacy products, which is an illegal practice in Australia. A need for consistency in the Safety Net scheme was also discussed; ideally, that there be no increase in co-payments or changes to Safety Net thresholds. The question was also raised as to why the provision of the generic, or most cost efficient medication, was not the 'standard' when filling prescriptions (i.e. an 'opt out' system for generics).

Medication affordability was less of a priority or concern for Aboriginal and Torres Strait Islander participants, who attributed this to the CTG initiative. However, participants emphasised the need to improve knowledge of all pharmacy staff about, and promote proactive assessment of consumer eligibility for this initiative to increase availability of this scheme in pharmacies. Participants also suggested a range of payment methods for inclusion in their ideal pharmacy services, such as access to a pharmacy account and direct payments via Centrelink. Other groups discussed the possibility of bulk-billing pharmacy services and the importance of developing rapport with pharmacists and pharmacy support staff, as they would be more likely to assist consumers in times of financial hardship.

Figure 3.4: Affordability



C=consumer; CA=carer; CC=consumer and carer; LB=Logan-Beaudesert; ISA=Mt Isa; Per=Perth; CALD=Culturally and linguistically diverse; IND=Aboriginal and Torres Strait Islander peoples.

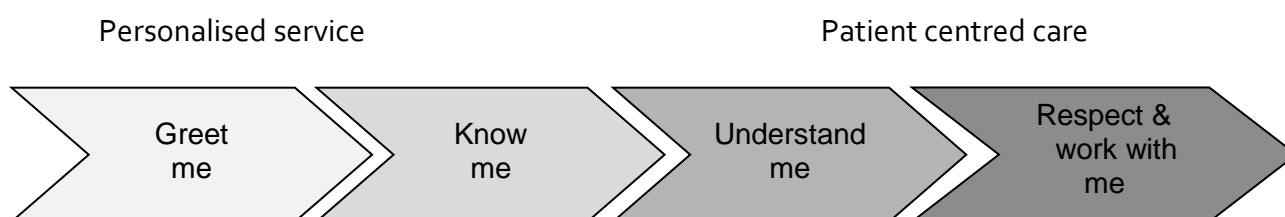
Patient centred pharmacy

Consumers and carers wanted patient centred care that encompassed friendly, approachable pharmacy staff who take time to listen to them and provide personalised service that recognises and respects their individual needs. Patient centred care was the fourth highest priority overall and prioritised highly in 11 of 15 consumer and carer nominal groups. Clearly, it is an important component of pharmacy services. Twenty-five patient centred ideas were proposed for ideal pharmacy services and these related primarily to two key aspects; the spectrum from patient focused, i.e. friendly and supportive, through to the establishment of patient centred care, i.e. working with the consumer in a trusting and respectful relationship to deliver individualised service.

The spectrum of patient centred care

Consumer and carer views on patient centred care reflected a spectrum from personalised service through to fully patient centred care that incorporated one or more attributes of patient centred care (empowering, respectful, individualised and holistic care) [28]. We have conceptualised this spectrum in Figure 3.5. At a minimum, people wanted all pharmacy staff to smile, be friendly, welcoming, attentive, and know their names. Consumers and carers expressed the need for pharmacists to “*come out of their comfort zone*” and spend more time with them, thus increasing their approachability and providing an opportunity to build relationships. Personalised services was aligned with loyalty to one pharmacy and as the service became more patient centred, consumers discussed trust and relationships with pharmacists and support staff with a view towards working in partnerships. Mental health consumers and carers indicated a similar preference for such a pharmacy service, and those who had established relationships with pharmacists were more comfortable sharing health related information and perceived greater value in pharmacy medication support services [85]. Ultimately, consumers and carers wanted pharmacists to be proactive and ask how they could help them, rather than vice versa. This suggestion is not new [100], and participants provided specific insights into how pharmacy staff could align with what they envisage as ideal pharmacy services in the context of patient centred care.

Figure 3.5: Spectrum of consumer preferences for patient centred care on pharmacy



Respect was a collective need for consumers and carers when interacting with all pharmacy staff. This was discussed in various ways, including maintaining privacy and confidentiality, respecting brand or medication preferences and avoiding a patronising tone when questioning or providing advice. Consumers and carers appreciated staff who followed-up on their progress or provided services tailored to their needs. However, differences in the importance that people placed on particular aspects of patient centred care became apparent when groups were compared.

Culturally appropriate care

Culturally appropriate care emerged as a high priority for Aboriginal and Torres Strait Islander peoples, and reflected a spectrum from improved awareness of individual needs through to specific culturally-based services

(e.g. liaising with Aboriginal health workers). Other patient centred ideas included avoiding assumptions and stereotypes, a more sensitive and supportive pharmacy service and a preference for face-to-face consultations. Strategies suggested for implementation of these ideas included:

- enhanced multicultural training for all pharmacy staff;
- inviting Aboriginal and Torres Strait Islander community members to share their needs and experiences with pharmacy students;
- promote or expand existing programs that support opportunities for Aboriginal and Torres Strait Islander peoples to train and work in pharmacy or become pharmacists such as the Northern Rivers program [101].

Culturally and linguistically diverse participants also expressed a desire for culturally appropriate care; pharmacists should assess and address barriers to understanding, such as limited English skills or health literacy. More consistent use of interpreters was one strategy suggested to address misunderstanding and reduce negative health outcomes, such as reduced medication adherence.

Continuity and coordinated care

Continuity and coordinated care was rated the most important priority for only two consumer and carer groups (Logan-Beautesert), but did appear as a top five priority for nine consumer and care groups across all four areas (Appendix 5.9). Continuity of care and effective coordination between health professionals was described from three key perspectives: co-location and coordination of health services or health professionals, sharing of healthcare records and effective communication (Table 3.12).

Suggestions for co-location and coordination of health professionals related to all health professionals being located in a one-stop shop; having a coordinator, or other health care professionals, or both, located in the pharmacy; pharmacists situated within the medical centre; and pharmacists having the ability to signpost or directly refer to other services or specialists. The pharmacy was viewed as an ideal setting for this to be based, whether this was undertaken by a pharmacist or another health professional. These findings strongly align with Stage 1 stakeholder views (see section 2.2), which supported community pharmacy becoming a health care destination or health hub to facilitate consumer navigation of the health system. Participants also sought to extend the pharmacist's role in being able to refer consumers directly to another health professional or health service. This role would promote streamlined care; consumers would save time and money through not having to see both the GP and specialist. Streamlined care could also be facilitated by having other health professionals working in the pharmacy, or vice versa.

Consumers and carers expressed a desire for a complete electronic medication/health record accessible to both them and their health providers as a way of promoting continuity of care and the safe use of medications. This was discussed in the form of a chronic illness card/chip (Mt Isa, Perth), or a national online database. These records were described as having a dual purpose, acting as a portable record to enable supply of medication (e.g. whilst travelling), and individualised information on medication, related diagnosis and precautions for the card holder. Furthermore, healthcare records were viewed as a way to promote continuity of information when people patronise multiple pharmacies, reduce the administration for pharmacists, and act as a trigger to prompt pharmacists to remind consumers when they are due for a check-up or eligible for related pharmacy services.

Continuity of care was emphasised with respect to home follow-ups to see how consumers were fairing, particularly for elderly consumers. This service was also important if pharmacists or consumers were unable to finish a consultation within the pharmacy or a more in-depth consultation was needed at a later time via a phone call, email text message or home visit.

Table 3.12: Continuity and coordinated care

Theme	Subtheme	Quotes
Co-location and coordination of health services	One-stop shop	<i>The shop itself should always be attached to a one-stop shop'. [IND_C_1106_NR (Group 4)]</i>
	Pharmacist as coordinator	<i>They [pharmacists] could get paid to do care coordination through Medicare... [C_1183_LB (Group 2)]</i>
	Facilitation of care based in the pharmacy	<i>...accommodate my ideal case coordinator. Because the pharmacy isn't as intense as, say, even going to your GP or going to your specialist...house this person who would then have enough room to bring in guest speakers...have all the resources there...and information pertaining to that client... [C_1014_NR (Group 15)]</i>
	Other health professionals in the pharmacy	<i>I want a nurse practitioner at the pharmacy....they can test your BP, they can do vaccinations, they can do pathology and they can write certain scripts. So why can't we have them at the pharmacy? [C_1166_PER (Group 13)]</i>
	Direct referrals to other health professionals	<i>...the knowledge and skills to refer to professionals if needed, also able to get me into the professionals or specialists in a timely manner... [CC_1179_LB (Group 2)]</i>
Healthcare records	Pharmacists in GP clinics	<i>...wouldn't it be great if the [GP] receptionist was basically a pharmacist and pharmacy assistant. So you come out, you've got your script, hand it over to the receptionist, pay your bill, pick up your pharmacy items and leave...And then they have everything on file... [CA_1013_PER (Group 13)]</i>
	Chronic illness card	<i>A chronic conditions card....so that it says you have a chronic condition...so that the pharmacist knows...you don't have to go through that third degree every time. [CC_1206_PER (Group 9)]</i>
	Access to dispensing history or electronic record	<i>...have a computer available that we're able to access our own [prescription] histories...It gives me the autonomy to go into the chemist at any time and have a look at when I've had my scripts dispensed and what I'm having. [C_1005_LB (Group 6)]</i> <i>Chemist to provide electronic record of all my medications with a full description of that medication... [C_1166_PER (Group 13)]</i>
	National register with a person's medication/health information	<i>...a national register for people who are on prescription medication because in [town name] people come out of communities and they don't have their prescription but the medication they need to take every day... [C_1226_ISA (Group 20)]</i>
		<i>So then if you walk into another pharmacy, they just type in your name and everything comes up...So you don't have to constantly tell everyone the same story... [CA_1013_PER (Group 13)]</i>
Online medication management	Electronic scripts	<i>...electronic scripts direct to pharmacies and transferable...It would just be a lot easier to maintain. [CC_1041_LB (Group 7)]</i>
Continuity of care	Home follow-ups	<i>...that would be valuable for the elderly people [for the pharmacy] to keep a record and check [home follow up via delivery]. [CALD_C_1180_LB (Group 2)]</i>
	Therapeutic monitoring/alerts	<i>...I've got to go for scans, but don't ask me how long ago the last one occurred, but like I've gone into the chemist to get that same medication...the chemist should say to you, hey, I hope your doctor's done something about it because you've had this [medication] twice in the last three months or something... [C_1004_ISA (Group 16)]</i>

C=consumer; CA=carer; CC=consumer and carer; LB=Logan-Beaudesert; ISA=Mt Isa; Per=Perth; NR=Northern Rivers; CALD=Culturally and linguistically diverse; IND=Aboriginal or Torres Strait Islander peoples.

Innovative services and roles

The initiation of a new service or way of doing things in pharmacy has been described as innovative [102]. For this report, innovation was further defined to include *the extension of the community pharmacist's current role/s or services*. The innovations described or prioritised by nominal group participants were primarily to improve convenience, introduce more flexible services that accommodate the challenges associated with managing chronic conditions, and mitigate related treatment burden.

New roles for the community pharmacist and pharmacy services

This project is unique in that consumers with chronic conditions and their carers were able to discuss and prioritise a range of new and innovative services that would assist them.

Continued medication supply was consistently identified as a new and desirable role for pharmacists by consumers and carers. There was emphasis on continuing the supply of medications that were initially medically prescribed and that consumers were now stabilised on. This was discussed within the proviso of a limited time frame, such as up to 12 months, thus ensuring an annual medical review. The Grattan report has proposed that pharmacists continue established medications for up to 18 months in rural areas [77]. There was no discussion around prescribing new medications to treat chronic conditions in either consumer or health professional groups. However, there was dialogue around prescribing for minor ailments or flare-ups as part of a treatment plan authorised by the consumer's GP, and making changes to prescribed medication if appropriate (e.g. allergy or medication side effect) (Table 3.13).

Consumers and carers were interested in having a more specialised pharmacy service incorporating a higher level of service delivery and healthcare focus (e.g. health hub/'Rolls Royce' service). This type of pharmacy would involve coordinated care with other professionals, greater access to the pharmacist for advice (e.g. virtual pharmacy assistance) and the provision of health information. More unique suggestions included co-ordinating walking groups, cooking classes and developing a loyalty card in conjunction with local health focused retailers to promote healthy eating. Another novel suggestion was the option of a drive-through service to enable more streamlined medication access (Table 3.13).

Innovations that extend current services

Sometimes, consumers and carers suggested pharmacy services that already exist, an extension of these services to other health conditions, or broader implementation of the services. When the services suggested were not novel to all community pharmacies, this implies variable availability. An example of this was monitoring of clinical measures, such as blood glucose and international normalised ratio (INR). Others wanted more consistency with the service, such as an alert system that flagged when a person had not visited the pharmacy recently, to prompt clinical monitoring, when their medication was due or a new prescription was needed. Dispensing machines in the pharmacy were identified as a way to increase convenience as this could reduce administration tasks for pharmacists. Further ideas endorsed the Australian government's e-health initiatives, for example, the chronic illness card or national record database, ideas which have been discussed previously (Table 3.13).

Table 3.13: Innovative services and roles for pharmacists and the pharmacy

Innovation		Consumer and carer	Pharmacists and pharmacy support staff	Other health professional
New roles for the community pharmacist				
Medication continuance	Continuing supply	<i>...prescribe drugs, without having to go to your doctor... That would be one that would be helpful for me...</i> [C_CALD_1069_LB (Group 5)]	<i>...pharmacists being able to... give repeat scripts... things that reduce the need to see a GP.</i> [Pharmacist_2056_NR (Group 22)]	<i>...continue dispensing for a period beyond the script repeats.</i> [Allied Health_2044_ISA (Allied Health Group 19)]
	Minor ailments or flare-ups	<i>...you can walk in any chemist there [overseas country] and buy whatever you want, so antibiotics, anything, without going to have to see a doctor... Well, why can't we do it here?</i> [C_1040_LB (Group 6)]	<i>...basic prescribing ... [currently] you see your pharmacist if you've had a UTI three months ago, that's what you think it is, the pharmacist thinks that's probably what it is but now go [and] see a doctor.</i> [Pharmacist_2002_PER (Group 10)]	<i>...I'd say even prescribing for maybe minor stuff...</i> [Allied Health_2099_LB (GP Group 24)]
	Dose or medication adjustment	<i>...I think the pharmacist profession is... much limited by legislation... For example, if there is a side-effect for our medication... you go to the pharmacist, and he should be able to replace this medication...</i> [C_1208_PER (Group 13)]	<i>Pharmacist reviews with the ability to adjust meds [medication]...</i> [Pharmacist_2049_ISA (Group 18)]	
New community pharmacy services				
Increased access	Health hub/Rolls Royce service	<i>...the specialist pharmacy who probably is in a health hub... they are highly trained and you probably pay a bit more. They work very closely in this health hub, or wherever they're situated, with the other providers...</i> [CA_1217_NR (Group 15)]	<i>Always get to talk to your pharmacist and your scripts are always ready for you so you jump the queue essentially...</i> [Pharmacist_2000_PER (Group 10)]	
	Virtual assistance	<i>...I'd like to have a virtual one [pharmacy assistance] where you can have somebody talk to you on the line</i> [CC_1118_PER (Group 13)]	<i>...have an in-pharmacy setup... they can consult straight away online on a virtual doctor.</i> [Pharmacist_2062_LB (Group 23)]	
	Drive-through	<i>...more drive-through pharmacies... where you can ring ahead and have your prescription filled and just drive through.</i> [CC_1118_PER (Group 13)]		<i>...to be able to e-mail my scripts in beforehand so that I can just drive by and pick them up</i> [GP_2117_Bris (Group 27)]

Table 3.13 Continued...

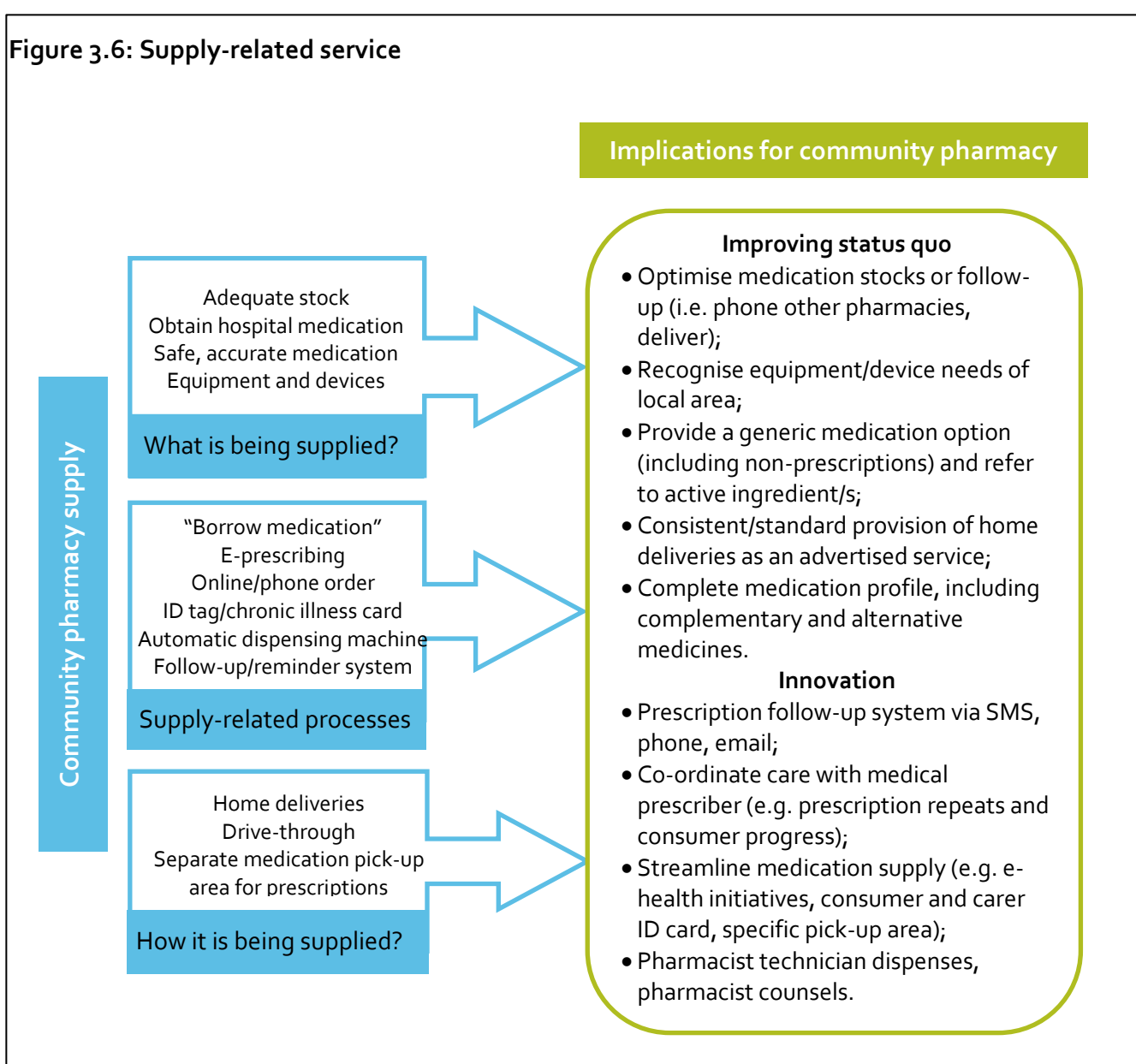
Innovation		Consumer and carer	Pharmacists and pharmacy support staff	Other health professional
Extension of current pharmacy services				
Health information	Health promotion and service directory	...one stop for local fitness and information, brochure and referrals to things like the chronic disease programs... [CA_1182_LB (Group 2)]	Information nights run by pharmacists and doctors for specific health conditions. [Pharmacist_2053_NR (Group 22)]	...an information portal...pharmacy would be a perfect spot for that where they can look up how to access disability aids...other community service providers, information like that... [GP_2111_Bris (Group 27)]
Increased access	To pharmacists	...I think we should have like a [phoneline, .. and there are pharmacists manning phones constantly, that you can ring and ask a question... [CA_1013_PER (Group 13)]	Why not have someone who relieves the pharmacist from dispensing and checking. [Pharmacy Assistant_2025_PER (Group 11)]	Better access to the pharmacist in person. [Allied Health_2047_ISA (Group 19)]
	Dispensing machines	...some sort of system like a machine at the front or something that you could access, and the script goes through to them with a private password... [CC_1041_LB (Group 7)]	...a terminal with maybe a barcode scanner and if people want to it would be like supermarkets, they could lodge their own scripts or they can be served. [Pharmacist_2054_PER (Group 10)]	
Continuity and coordinated care	Working with/using other health professionals	I think the health worker is very important in closing the gap, pharmacists can't do it, he can't close the gap. [C2_IND_LB (Group 3)]	We used to have a nurse practitioner working in the pharmacy, so people could come in, they could prescribe sort of, your general antibiotics and that sort thing... [Pharmacy Assistant_2007_PER (Group 11)]	That might not be the pharmacist that is doing that [providing other services] it might be utilising other health professionals in which to be able to provide those services. [Allied Health_2071_LB (Group 26)]
	Referrals	...refer to professionals and get me into professionals in a timely manner.... [CC_1179_LB (Group 2)]	Pharmacist referable to another health practitioner [Pharmacist_2053_NR (Group 22)]	...self-referral for home medicine review or maybe a pharmacist generated referral. [AlliedHealth_2051_ISA (Group 19)]
	Monitoring (therapeutic and compliance)	If they see people aren't coming to the chemist they haven't got regular to take the blood pressure they should make it their business to go out to their house [C_IND_1191_LB (Group 3)]	Maybe the ability for some particular trained pharmacists to be able to order pathology. [Pharmacist_2068_LB (Group 23)]	...doing blood pressures or blood sugar levels...if patients are stable... be able to get a 12-monthly script rather than a six-monthly or something like that. [GP_2098_Bris (Group 25)]
	Online medication management	...online prescriptions. So when the doctor types it out ...go straight to the chemist, and then hey you haven't got another bit of paper to carry around... [C_1037_NR (Group 8)]	Online ordering of repeat dispensings. [Pharmacist_2054_NR (Group 22)]	
	Profile card/national database	...medical history on a card...that card would be priceless if they had that... [C_IND_1158_PER (Group 12)]		...some national system where all pharmacies are linked as well...[Allied health_2108_LB (Group 26)]
	Repeat reminder system	I mean before the due date, like two days, get an alert, get it [medication] ready and send it to them. [CC_1133_LB (Group 7)]		a reminder system when the medications are due to be renewed. [GP_2114_Bris (Group 27)]

C=consumer; CA=carer; CC=consumer and carer; LB=Logan-Beautesert; ISA=Mt Isa; Per=Perth; Bris=Brisbane; NR=Northern Rivers; CALD=Culturally and linguistically diverse; IND=Aboriginal or Torres Strait Islander peoples.

Supply-related services

Nominal group participants were asked to consider their ideal pharmacy services, beyond what they currently experience. Consequently, supply-related services was not a high priority overall; only three rural/semi-rural groups included this theme in their top five priority list. This perhaps reflects limited access to healthcare services in these areas, with participants seeking continued or better access to quality medication and services from community pharmacy. Supply-related services include what was supplied, associated processes, and how products were supplied (Figure 3.6). Being able to obtain their individualised medication from the pharmacy was discussed in two-thirds of the groups. The majority of consumer and carer groups highlighted the need for the pharmacy to provide a home delivery service (n=12; 80%), to improve convenience and assist those consumers who have problems accessing or should not access the pharmacy (e.g. people who have disabilities or are immunocompromised). This aligns with findings from the 5th CPA *Consumers Needs Project*, which recommended wider adoption of home delivery services [62].

Figure 3.6: Supply-related service



Carer priorities

Advice and information about, and supply of medication, were key priorities for carers of people with chronic conditions. **Affordability** was the only consistent top five theme for all three carer groups (Appendix 5.9). Affordability was a particularly important element of an ideal community pharmacy by some carers, particularly those who had a chronic condition(s) themselves, or were struggling with medication and healthcare costs. Other than providing cheaper medication, carers sought free or bulk-billed pharmacy services such as home deliveries.

Carers did not prioritise the need to increase pharmacy staff awareness, or recognition of their key roles or responsibilities. However, some carers expressed considerable frustration in the **medication supply** process, relating experiences such as being unable to obtain the medication for the person they cared for because of legal and confidentiality requirements. Although they acknowledged the legal constraints for pharmacies, a solution to address this issue was discussed by a Logan-Beaudesert group in the form of a carer identification tag. This was viewed as a tool to facilitate the attainment of medication for the person they cared for, and reduce the risk of being refused or 'interrogated' by pharmacists or support staff.

Carer groups raised a variety of ideas associated with reducing carer burden in relation to **medication management**, including: storing prescriptions in the pharmacy and prescription renewal reminders; a pre-emptive home delivery service; prescription processing machines; flexibility with respect to the PBS Safety Net 20 day rule; and simplification of the Safety Net recording system for easier monitoring.

How **consumer information** was delivered was emphasised by Northern Rivers carers with respect to using interpreters and improved medication labelling. The Logan-Beaudesert carer group focused on a broader range of information needs, e.g. increased awareness of the availability of HMRs, the training/qualifications of pharmacy assistants and medication-specific information.

Furthermore, all groups focused on the use of, or the processes involved with, generic medication supply. This included why there were price differences between brands, how pharmacy staff 'sell' generics to consumers, differences between generic and original brands, and patient confusion. A key suggestion was for the standardisation of generic medications in terms of size, shape and colour.

Consumer and carer group comparisons

When consumer and carer groups were compared via group type (Figure 3.7) and location (Figure 3.8), all groups emphasised the need for information about medication(s), with a preference for information delivery individualised to their specific needs. Other common themes to emerge included preference for easy, on-going access to prescription medication(s) without a doctor's appointment (for up to a year), more efficient pharmacy supply of medication, consistent access to home deliveries and a follow-up service.

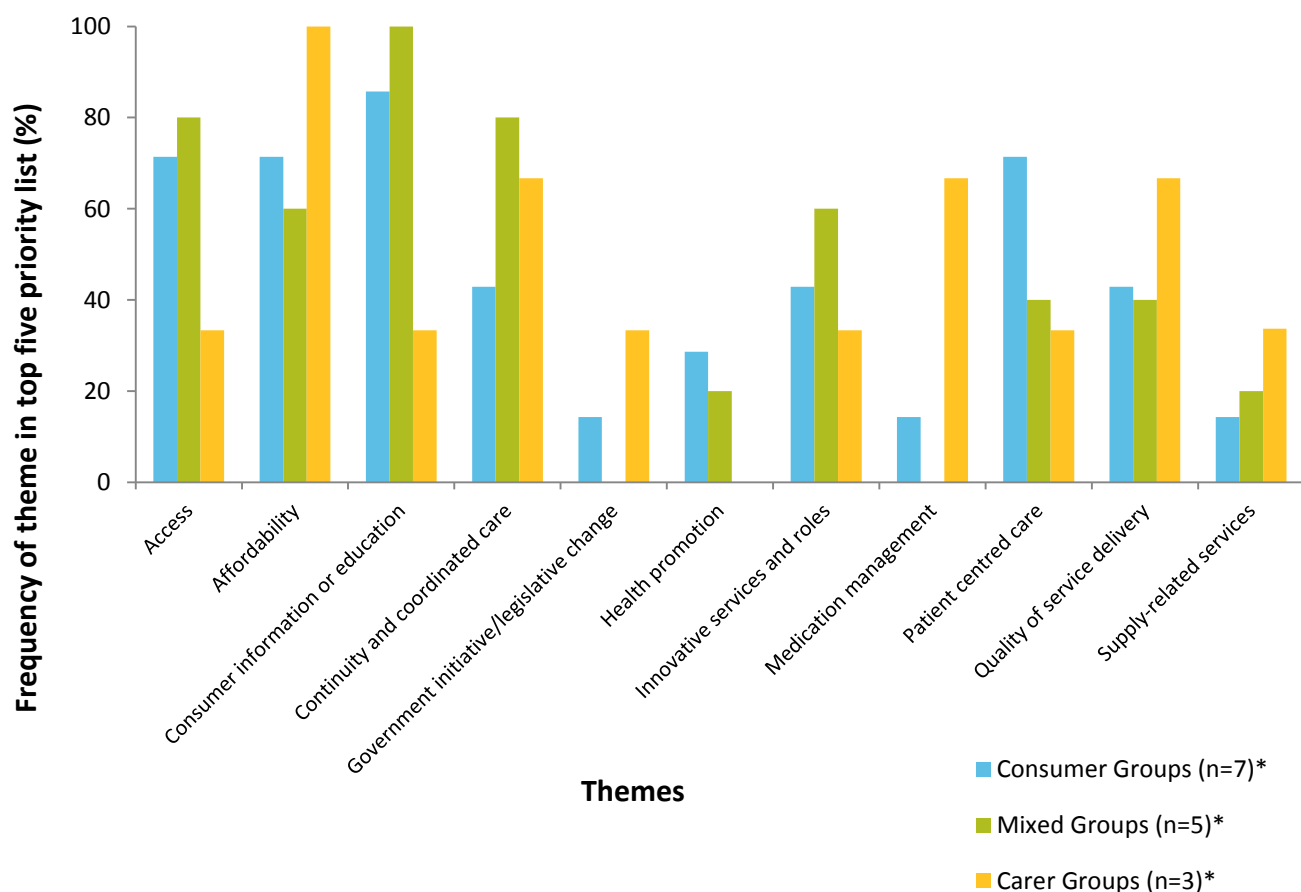
Consumer information or education was important across all project areas, particularly for consumer or mixed groups with respect to the type of information and how it was delivered (i.e. use friendly language, face-to-face or online).

Access: also arose as a top five priority in all four regions. For example, it was the top priority for an urban (Logan-Beaudesert) and rural (Mt Isa) area, where increased pharmacy opening hours was high on the agenda. The Logan-Beaudesert group also discussed the need for greater physical access to the prescription processing

area, particularly for people with disabilities. Consumer and mixed groups placed greater emphasis on access, particularly in relation to pharmacies having sufficient stock of their required medication.

Affordability: of medications was a top five priority for all three carer groups, which is likely due to being the financial support person for the care receiver. This was also the most common theme for groups based in Logan-Beaudesert and Mt Isa. Aboriginal and Torres Strait Islander groups sought greater awareness of the CTG initiative by all pharmacy staff and more flexible payment systems.

Figure 3.7: Consumer and carer group comparison: top five priorities for ideal pharmacy (by role)

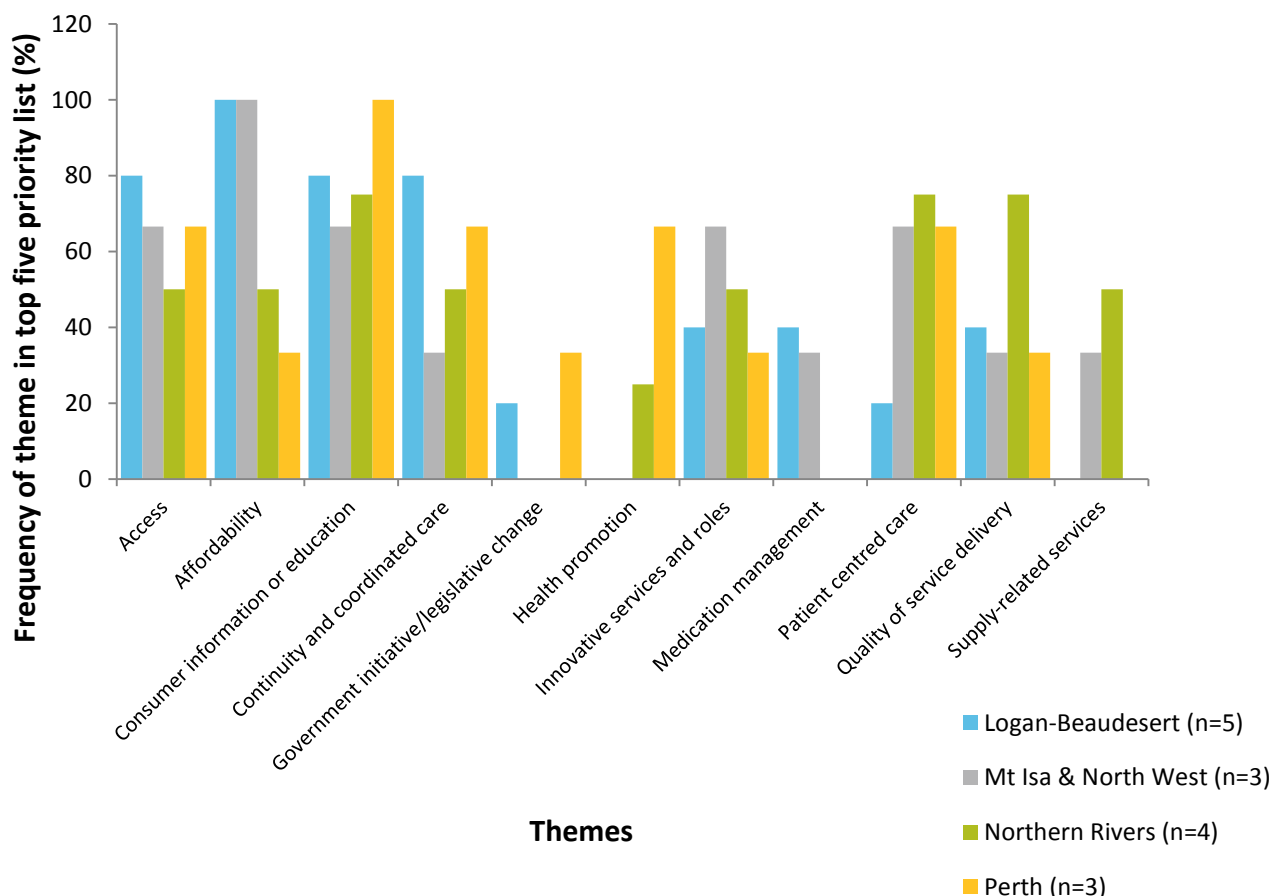


* Nominal Groups

Patient centred care was more a focus for homogenous consumer groups than mixed or carer groups; three of four Aboriginal and Torres Strait Islander groups (Logan-Beaudesert, Northern Rivers and Perth) selected this theme as their top priority in terms of their ideal pharmacy. In these groups, patient centred care was discussed in the context of cultural awareness, cultural competency, gender balance in staffing and using Aboriginal and Torres Strait Islander health workers and pharmacy employees to provide further care. Patient centred care was overshadowed by a greater need for access by the Aboriginal and Torres Strait Islander group in Mt Isa. Being 'known as a person' was highlighted by two of the above urban groups, where there is greater pharmacy choice. This raises the following questions: *if there is less pharmacy choice, will a consumer-pharmacist relationship more likely develop?* Or, *is patient centred care less important if healthcare access is an issue?* Overall, patient centred care was much less of a priority in the area of Logan-Beaudesert, yet this has a higher population of culturally and

linguistically diverse people compared to other project areas. It is possible that access to health care in this area is a more fundamental concern than the patient centredness of that care.

Figure 3.8: Consumer and carer group comparison: top five priorities for ideal pharmacy (by location)



Continuity and coordinated care was a priority for all project areas, including two Aboriginal and Torres Strait Islander groups (Perth and Mt Isa), two carer groups (Mt Isa and Logan-Beaudesert) and all mixed consumer and carer groups (Logan-Beaudesert, Northern Rivers and Perth). However, what continuity and coordinated care involved differed between them: healthcare records in the form of a chronic illness card (Aboriginal and Torres Strait Islander groups) or national database (carers), compared with referrals/triage by mixed groups. Greater emphasis was placed on continuity and coordinated care in urban areas where more pharmacies are located, and was of less importance for Caucasian consumer groups.

Innovative services and roles focused on the provision of medication without a prescription, i.e. continued medication supply, and was described with various terminology, e.g. 'make', 'renew,' or 'prescribe' medication (see Appendix 5.2). There was a greater emphasis placed on this priority in Mt Isa where it can take a number of weeks to see a GP, which further highlights the issues of healthcare access facing this community. Caucasian consumers mostly discussed this new role, whereas carers prioritised more assistance from pharmacists with respect to holding prescriptions, renewal reminders, or to contact the doctor on their behalf to organise new prescriptions.

Medication management services mostly related to initiatives that would promote adherence such as (free) dose administration aids, and verbal or SMS text reminders as to when a new prescription or medication supply was needed. This service-based role was more important for carers than consumers, which could reflect their significant role in managing the prescriptions and medication for the person they care for.

Quality of service delivery was of greater importance in the Northern Rivers region, and for carers compared with other groups. Professional competency was a particular focal point, including ethical integrity with respect to product recommendations, confidentiality and understanding the training/qualifications of pharmacy assistants.

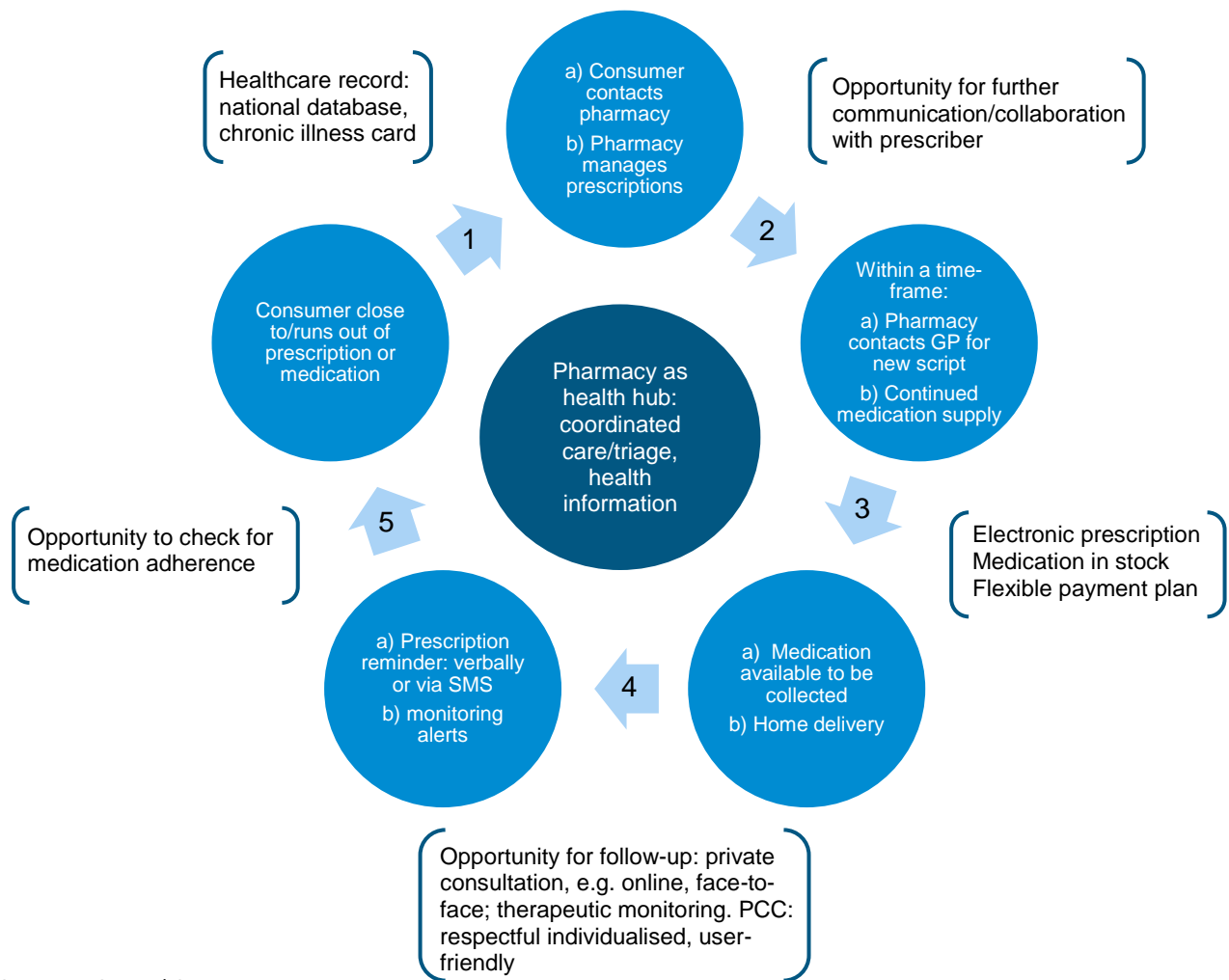
Supply-related services was a top priority for one carer group, and arose in two other mixed and consumer groups in two rural/semi-rural areas (Northern Rivers and Mt Isa). However, this theme was discussed by most groups, primarily with respect to home deliveries (n=12; 80%).

Health promotion Beyond monitoring/screening and preventative services (n=12; 80%), other novel ideas were discussed, including collaborating with other health retailers for cheaper health food, walking groups and cooking classes. Participants from Perth were particularly keen on health promotion services within pharmacy, as well as Aboriginal and Torres Strait Islander consumers.

Government initiative/structural change was more of a priority amongst urban carers, with ideas associated with assisting their caring roles. This included an improved Safety Net recording system, standardising pharmacy regulations and the appearance of generic medication to reduce consumer confusion.

Figure 3.9 is a pictorial representation of some of the key elements of ideal pharmacy services from the perspective of consumers and carers. Although it does not include all innovative ideas or themes, it provides a simple overview of streamlined access to medication and advice. Consumers and carers wanted pharmacists to manage their prescriptions (via collaboration with their prescriber), and be able to obtain their medication in a timely manner with convenient access to advice when needed.

Figure 3.9: Streamlined pharmacy access for people with chronic conditions and their carers

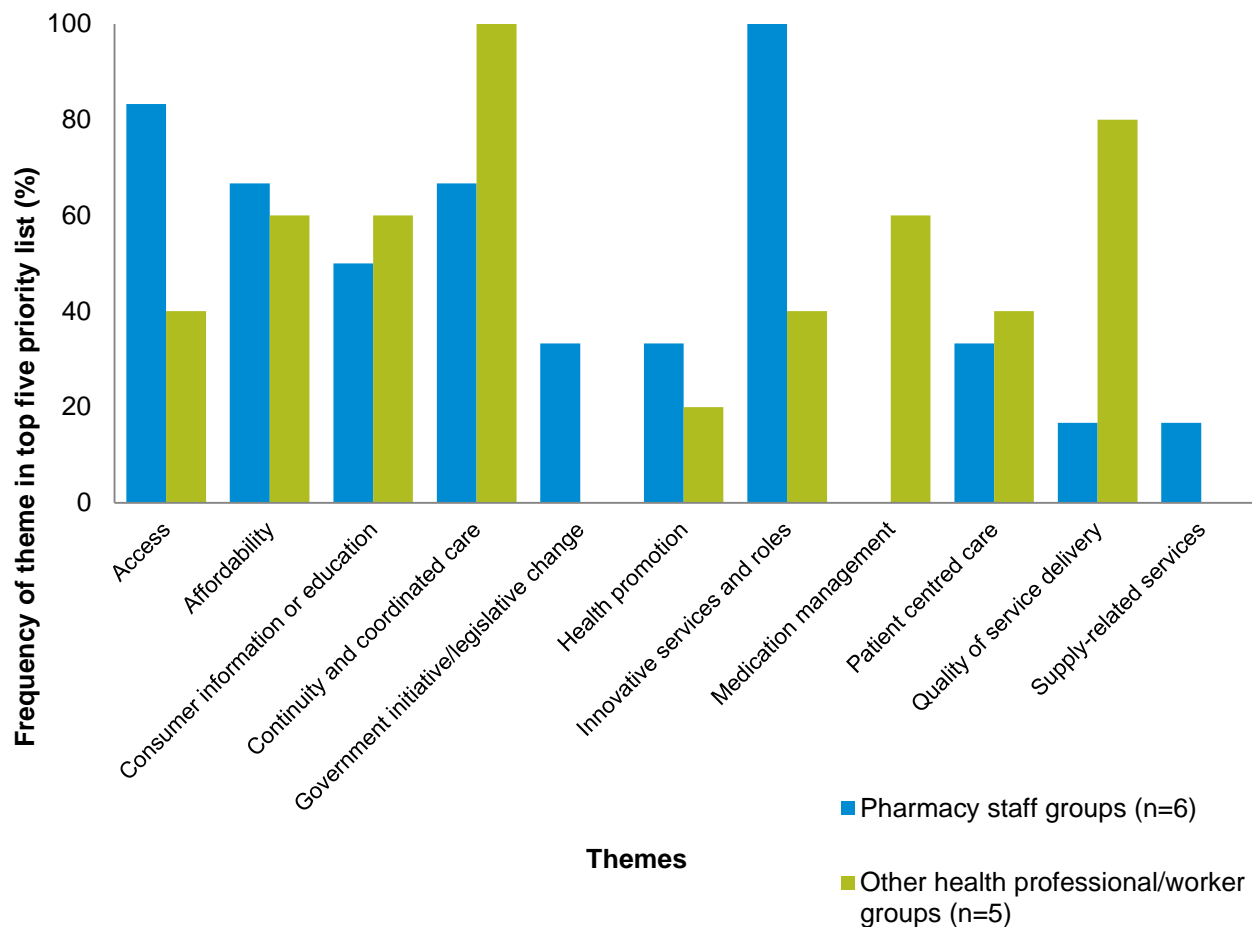


PCC=Patient Centred Care

d. Top five health professional priorities in detail

This section provides further comparisons between health professional groups for the five priorities that they considered would be most important to consumers and carers. These were continuity and coordinated care, consumer information or education, quality of service delivery, innovative services and roles and affordability. As identified in Figure 3.10, continuity and coordinated care was the most common theme for these groups (n=9; 81.8%), and consequently, the most important priority overall. There were consistent views with respect to ranking consumer information or education and affordability, yet there were also subtle differences between pharmacists and pharmacy assistants, GPs and allied health professionals. For example, other than free or cheaper medication which was common to all groups, pharmacists discussed more pharmacy (e.g. competitive pricing) or system-specific (e.g. increased Safety Net threshold) ideas in relation to affordability. Alternatively, GPs considered affordability within the context of the pharmacists ensuring quality use of medications by reviewing polypharmacy and adherence issues. There were also more prominent differences, with GPs and allied health professionals focusing on the quality of service delivery, such as the provision of unbiased and simplified advice, while pharmacists explored more innovative services and roles such as the ability to adjust medication dosages.

Figure 3.10: Comparisons between pharmacy staff and other health professionals: top five priorities for ideal pharmacy



Continuity and coordinated care Although this theme appeared to be a higher priority for GP and allied health groups (Fig 3.10), there were related ideas coded under Innovative services and roles for a pharmacist and pharmacy assistant group. There was a strong belief that consumers and carers would want more streamlined care and that this could be facilitated by the use of information portals or online healthcare databases with medication history or test results, open dialogue between pharmacists and GPs regarding a consumer's progress, or both. All pharmacist, GP and allied health professional groups discussed the importance of consistent healthcare records that could be linked with Medicare and Centrelink information. Although most groups discussed the need for better collaboration between each other, co-location of health professionals was mostly discussed by pharmacy-specific groups. This concept was also viewed as a way to improve patient convenience. The pharmacy support staff group in Perth also emphasised the importance of consistent staff members to improve patient care, i.e. having familiar faces in the pharmacy. Furthermore, the pharmacy was in an ideal position to liaise with other services that could be of greater assistance to the consumer. Providing direct referrals to other health professionals was also viewed as an important part of continuity of care by pharmacists and allied health professionals. However, pharmacy support staff and a GP group discussed this in the form of a local information directory or portal, so that consumers and carers could personally search for required services (Box 3.2).

Box 3.2: Key quotes for continuity and coordinated care

... collaboration between the pharmacist and the patient's other healthcare professionals to improve their outcomes...so really the patient would feel like they had a whole team trying to work for them to improve their health ...[Pharmacist_2068_LB (Group 23)]

..pharmacy would be a perfect spot for that [information portal] where they can look up how to access disability aid....or even just in general, access to other community service providers...[GP_2111_Bris (Group 27)]

...one would hope that patients would like to see proper monitoring and overall management that's not to their detriment by this fragmentation. [HCP_2097_Bris (Group 25)]

...if they're delivering medications which so many of them do, then they have an insight into the patient's, sort of setup and could refer onto Meals on Wheels or liaise with them, or liaise with Blue Care or home care or those sort of services. [AHP_2108_LB (Group 26)]

LB=Logan-Baundesert; Bris=Brisbane; HCP=Healthcare Professional; AHP=Allied Health Professional; GP=General Practitioner

Consumer information or education was discussed in the context of what should be provided, e.g. medication-specific information, how it should be provided e.g. simplified information, and who should provide it, e.g. pharmacists rather than pharmacy support staff. The need for pharmacists to explain generic medication and their differences to avoid consumer confusion was a common discussion point among health professional groups, as was the topic of increasing consumer access to pharmacist consultations. This included a 24-hour information hotline and using pharmacy technicians to complete administration (dispensing) tasks. However, only one pharmacist group (Northern Rivers) prioritised consumer information or education; it was not even raised as an idea by Mt Isa pharmacists. This may be because pharmacists consider that they already do this in their day-to-day job, or other needs took priority in certain areas, e.g. improving healthcare access in Mt Isa. Both pharmacy assistant groups discussed the need for consumers to have more time with the pharmacist to answer queries and provide information, which was also a top priority for a Brisbane based GP group. Providing a place where consumers can obtain medication and services information was discussed by both a group of pharmacy support staff (Group 14) and a GP group (Group 25), e.g. an information portal. There were key differences between subgroups; non-pharmacy staff groups raised the need for unbiased and more simplified advice from pharmacists, e.g. no medical jargon. Two GP groups focused on the need for pharmacists to demonstrate how to use medication devices, and emphasise the relative risk of side effects and drug interactions. There were also more specific ideas from each sub-group, including information nights on health conditions (pharmacists), increased public awareness about the skills of pharmacy assistants to facilitate information access (pharmacy support staff), larger print size for medication information (allied health participants), and information on the availability of medication overseas (GPs) (Box 3.3).

Box 3.3: Key quotes for consumer information and education

I think that generics are still an issue so less confusion, more patient counselling. [Pharmacist_2003_PER (Group 10)]

...I would often rather be up in the dispensary dispensing and having the pharmacist making more of an impact with the customers when they have the knowledge. [PSS_2024_PER (Group 11)]

...it would be good if patients could have a 24-hour contact number...Where they can say, "I'm just confused about my medications", and they've got a pharmacist to talk to. [GP_2102_LB (Group 24)]

LB=Logan-Beaudesert; PSS=Pharmacy Support Staff; GP=General Practitioner

Quality of service delivery was a key focus for one GP group (top priority). The emphasis was for pharmacists to provide high quality, evidence-based advice and service, not driven by profit. This included ceasing marketing of products with a limited evidence base, removal of non-health-related products from the pharmacy, stocking products that staff knew how to use, and counselling within an individual's scope of practice. System-based suggestions included reviewing the prescription format so that consumers can better understand how many repeats remain, enabling consumers to pick up more than one supply of medication and pharmacists conducting medication reviews in hospital outpatient clinics. Pharmacists and GPs in Logan-Beaudesert suggested labelling medication by their active ingredient(s) to reduce confusion. Quality of service was only prioritised in one pharmacy assistant group as a need for psychosocial training to support pharmacy staff in how to effectively deal with difficult situations or mental health consumers (Box 3.4).

Box 3.4: Key quotes for quality of service delivery

...it would be great if there were no brand names and all drugs were just generics - or the other way around, if there was only one name for a certain medication...it's very confusing. [GP_2102_LB (Group 24)]

...Pull back on what supermarkets can sell and at the same time, encourage the pharmacies to get rid of some of their non-health related stuff. [AHP_2047_ISA (Group 19)]

...Making money out of... [product name] and giving really poor, unsafe advice to clients. So if they are going to offer that service, it needs to be evidence-based and they should offer a service to refer on. [AHP_2108 (Group 26)]

...what do you say when one of your customers says I just found out that he's got cancer? You know, with that sort of thing, what can you say to them? [PSS_2031_LB (Group 14 14)]

LB=Logan-Beaudesert; ISA=Mt Isa; AHP=Allied Health Professional; GP=General Practitioner; PSS=Pharmacy Support Staff;

Innovative services and roles was a key priority for pharmacy groups (Fig 3.10) and there were elements of this theme coded elsewhere for an allied health and GP group (i.e. medication management and continuity and coordinated care). Ideas focused on facilitating medication adherence and optimising the provision of healthcare services. Pharmacist groups discussed a broader range of ideas such as medication dosage adjustments and administering vaccinations in the pharmacy. Eight health professional groups prioritised innovation as a continued prescribing/medication renewal role for medication for chronic conditions, basic prescribing for minor ailments, or both. Alternatively, one GP group suggested that GPs could prescribe a medication for extended periods, as long as the pharmacist was monitoring the consumer's progress (Box 3.5).

Box 3.5: Key quotes for innovative services and roles

...pharmacists able to prescribe for various conditions...rather than having to go to the GP and wait there for however long, plus not be able to access GP, you can just go to the pharmacy.

[Pharmacist_2066_LB (Group 23)]

...going to a chemist where's she's [mother] built a rapport, who can actually renew a prescription...

[AHP_2099_LB (GP Group 24)]

I would even be happy to see a patient who's well stabilised on blood pressure medication to maybe see them 12 monthly if they were going to be monitored at the.....point of...receiving their medication.

[GP_2098_Bris (GP Group 25)]

LB=Logan-Beaudesert; Bris=Brisbane; AHP=Allied Health Professional; GP=General Practitioner

Affordability was considered less of a priority by health professional groups, raising the question as to whether they were aware of the *extent* of financial burden for this consumer group. Other than the provision of cheaper dose administration aids, affordability was predominantly discussed with respect to free or cheaper medication rather than free services. However, pharmacists and GPs raised concerns that consumers and carers would not value medication if it was free: *"...if someone pays nothing for it they don't value it, so even if they're paying \$2.00 dollars for it that's still a value for them..."* (Pharmacist_2053; Group 22). Pharmacists recognised a need for pharmacy-specific changes such as fewer companion sales, competitive pricing and flexible payment systems and refund policies. Suggested system changes were similar to those proposed by consumers and carers with respect to expanding the PBS formulary and eligibility for additional subsidies. Perth pharmacy assistants thought that consumers and carers would want free monitoring and screening services and free access to other health professionals within a one-stop shop. Although affordability was not discussed by Logan-Beaudesert pharmacy assistants, the idea of pharmacists renewing prescription medication may be indirectly associated with improving affordability (e.g. consumers may avoid a consultation fee). Ideas proposed by health professional groups may also impact positively on affordability, such as medication reviews to ensure the quality use of medications and minimise polypharmacy. A GP group also identified that pharmacists were in an ideal position to monitor medication adherence, and explore whether people were choosing not to obtain a medication because of financial constraints (Box 3.6).

Box 3.6: Key quotes for affordability

... I think patients would like to have the provision of medicines and information, when it's required, no waiting and no fees...[Pharmacist_2068 (Group 23)]

...if there's an ability for the pharmacist to monitor for adherence to medications because if prescriptions are not being filled or if they're - because maybe perhaps financial reasons choosing I'll get this script but I can't afford this prescription...[GP_2098 (Group 25)]

...the patients going from different doctors and different doctors and they come to the chemist to get prescriptions, that pharmacist can ring somebody because they are now on five diabetes medications....they're paying lots of money for stuff they shouldn't have and it's no good for their health to be on so much different stuff. But the pharmacist just dispenses, dispenses. [AHP_2077 (Group 26)]

LB=Logan-Beaudesert; AHP=Allied Health Professional; GP=General Practitioner

e. Comparison of consumer and carer and health professional groups: do their priorities align for community pharmacy services?

This is the first study, to our knowledge, that has asked pharmacy staff what they think their customers would prioritise from pharmacy services. Overall, priorities between consumer and carer and health professional groups were aligned with respect to certain themes. There was general agreement that consumers and carer would want or value a service whereby pharmacists renewed their chronic disease medication for a specified length of time. This aligns with recommendations in the Grattan report that pharmacists continue chronic condition medications, for up to 18 months, in rural areas to reduce GP workload [77]. However there were key differences, with consumers placing greater emphasis on access and patient centred care than did health professionals, who placed a higher priority on quality of service delivery and innovative pharmacy services. This section explores some of these key similarities and differences.

Consumers and carers considered access to be a high priority for ideal pharmacy services, yet it received limited attention from GPs or allied health professionals. Consumers and carers discussed access in the context of increased time with the pharmacist, longer pharmacy opening hours, or obtaining medication via home deliveries; pharmacists' and pharmacy assistants' views aligned with these. Divergent views included a faster/speedier dispensing process and simplification of the home medication review process. Providing pharmacy accounts or payment schemes were ideas solely raised by consumer and carer groups, and this is something that community pharmacies should consider offering to people with chronic conditions to ensure on-going access to medication.

In direct contrast to consumer and carer views, health professionals did not consider that the clients they worked with would prioritise patient centred care as part of their ideal pharmacy services. This could reflect a propensity to view pharmacy as a retail location rather than a healthcare destination, or an assumption that pharmacy services are already patient centred. The patient centred ideas that health professionals did propose aligned with some consumer suggestions and reflected the spectrum depicted in Figure 3.5; they were primarily related to the pharmacy being 'patient-focused,' supportive, providing professional customer service, but also acknowledged

the need for deeper levels of patient centredness through the development of a consumer-pharmacist relationship. Other examples of support included follow-up inquiries as to how people were doing, improved communication with consumers and families, and one GP group suggested that pharmacists facilitate self-management support groups. Compared to consumer and carer groups, cultural awareness was not specifically discussed amongst health professionals as something they thought their clients would want from pharmacy. However, individualised care was considered a priority. These findings emphasise the importance of pharmacists providing information that is tailored to the consumer in a format that they can understand, i.e. rather than simply handing out standardised information such as a Consumer Medicine Information sheet.

Quality of service delivery was more likely to be viewed as a priority by health professionals (other than pharmacists) than consumers and carers. GPs placed emphasis on ethical integrity, trust and for pharmacists to recommend products based on consumer needs and the existing evidence base. Limited consumer emphasis on this theme may indicate that they assume or believe that pharmacies provide a quality service, particularly when pharmacists are one of the most trusted Australian health professionals [103].

Consumers and carers, other health professionals and GPs all prioritised improved information provision as part of ideal pharmacy services. However, only one pharmacist group identified this as a priority, possibly because pharmacists perceived this group of consumers to be 'experts' on their condition(s) and less likely to need information. Alternatively, pharmacists may have considered counselling to be a non-negotiable aspect of any pharmacy service. Pharmacy assistant groups did prioritise improved information, and they are more likely to be faced with consumer information requests that are either answered directly, or indirectly, by the pharmacist. Regardless, medication information was what consumers wanted, or valued the most from community pharmacies. However, this did not necessarily equate to more time with the pharmacist, as perceived by health professional groups.

Recurring themes related to medication management across the project stages include medication and service information, streamlined care, the ability for pharmacists to view their complete healthcare/medication records, direct referrals to other health professionals, and prescription and therapeutic monitoring (e.g. medical test) reminders. One suggestion on how this could be implemented included installing a care-coordinator in the pharmacy, whether this was a pharmacist or other health professional. Streamlined care was further emphasised by health professional groups; pharmacists discussed having access to consumer and carer pathology/test results, while pharmacists and allied health groups discussed direct referrals to other health care professionals. Conversely, pharmacy support staff and GP groups discussed the use of an information portal or service directory for consumers to use themselves.

Summary

Key findings

- The top five priorities across all consumer and carer groups were: information or education, access to pharmacy or pharmacist services, affordability, patient centred care and continuity and coordinated care;
- Consumers and carers were able to identify innovations that could become future pharmacy services (e.g. continued medication supply), suggesting that consumer engagement may be beneficial;
- Advice and information about, and supply of medication, were key priorities for carers of people with chronic conditions. Overall, consumers and carers wanted pharmacists to manage their prescriptions (via collaboration with their prescriber), and be able to obtain their medication in a timely manner with convenient access to advice when needed;
- Health professionals assumed that consumers and carers would prioritise continuity and coordinated care (e.g. consistent healthcare records), information or education (e.g. to reduce generic confusion), quality of service delivery (e.g. high quality, evidence based advice not driven by profit), innovative services (e.g. continued medication supply) and affordability (e.g. free or cheaper medication);
- Priorities between consumer and carer and health professional groups were aligned with respect to affordability and information, yet health professionals did not consider that their clients would prioritise patient centred care as a core component of pharmacy services;
- Consumer and carer priorities differed slightly between regions and populations (e.g. limited healthcare access, lower socioeconomic status, cultural needs). Health professional views also differed depending on the profession involved.

Insights for community pharmacy: New or extended services

Address disjointed healthcare with flexibility, innovation and targeted services

- Advocate to expand continued medication supply across chronic health conditions to:
 - reduce consumer burden of multiple GP appointments;
 - promote flexible medication supply to address PBS restrictions;
- Develop the concept of pharmacy as a health hub that:
 - engages in continuous chronic condition management with health monitoring alerts for medical check-ups;
 - integrates into referral pathways to facilitate access to health services;
 - empowers self-management through improved utilisation of CHOs and health professionals;
 - fosters innovations such as walking groups and 'healthy' loyalty cards;
- Pharmacists can become chronic health care facilitators (i.e. sign-post to support services);
- Utilise technology to promote more coordinated and continuous care:
 - a chronic illness card that optimises use and portability of health records;
 - promote uptake of tools that streamline processes (e.g. e-prescribing);
 - text reminders for repeat prescriptions to promote adherence;
 - use IT platforms for consumer consultation (e.g. Skype, online chat).

Insights for community pharmacy: Improving existing services

Improve consumer information or education (top priority)

- More consistently provide relevant information to consumers and carers as:
 - medicines information that complements prescriber advice;
 - updates on changes to medicines, PBS, and the healthcare system;
- Improve existing information to meet specific needs (e.g. health literacy);
- Deliver information more effectively:
 - proactively ask people if they need help;
 - use language specific resources;
 - improve written information (e.g. larger label font size);
- Increase consumer access to information (e.g. online, telephone help lines);
- Increase public awareness of pharmacist expertise and services.

Optimise access to medicines and services

- Convenience is a key component of access with respect to:
 - the pharmacy – extend opening hours (especially in rural areas);
 - the pharmacist – improve availability of the pharmacist;
 - the medicines – optimise medication and medical device availability;
 - in-pharmacy services – streamline dispensing and prescription pick-up;
 - external pharmacy services – promote home delivery and utilise as method for consumer follow-up.
- Optimise pharmacy environment for access:
 - effectively use private spaces to maintain confidentiality;
 - ensure physical environment caters for consumer needs (e.g. chairs).

Address challenges of affordability of medicines and services

- Effectively use existing entitlements such as Closing The Gap;
- Advocate for increased medication subsidies;
- Advocate for expanded payment options (e.g. direct Centrelink payments, payment plans);
- Price discrepancies between pharmacies emerged as a significant issue;
- support carers with medicine management and affordability of care.

Insights for community pharmacy: Training and education

Educate and train on how to deliver patient centred care

- Train and educate all pharmacy staff on:
 - consumer experiences of and preferences for pharmacy service;
 - the need for proactively interacting with people with chronic conditions;
 - how to apply attributes of patient centred care, such as respect;
- Use a practical framework to guide implementation of patient centred care (Figure 3.5);
- Implement strategies that facilitate and reinforce change;
- Integrate patient centred training across educational curricula.

Promote culturally appropriate and non-discriminatory care

- Improve staff knowledge and utilisation of:
 - the CTG initiative;
 - interpretative services;
- Enhance staff members' ability to recognise barriers to understanding, and subsequently individualise information;
- Provide training opportunities to interact with consumers and carers across cultural groups and for different chronic conditions.

Insights for community pharmacy: Workforce development

Actively recruit a workforce that addresses patient centred priorities

- Promote or review existing programs that promote a culturally diverse workforce:
 - increase Aboriginal and Torres Strait Islander pharmacy workforce;
 - collaborate with Aboriginal and Torres Strait Islander health workers.

4 Stage Three:

Elicitation of preferences from consumers, carers and health professionals about the delivery of pharmacy services

The overarching objectives of this final stage were to:

- investigate health consumer and carer **preferences for pharmacy services** to assist with the management of chronic conditions and multiple treatment regimens;
- quantitatively describe the extent to which treatment burden was reported by people with chronic condition(s); and
- compare perceptions of consumers and carers with health professionals about pharmacy services.

Specifically, this stage addressed the following project objectives:

- use findings from Stages One and Two to develop a health consumer survey, including a Discrete Choice Experiment (DCE) to examine treatment burden, quality of life, and the potential value of selected services that pharmacy could deliver; and
- survey the views of pharmacists, GPs and other health professionals/workers on patient centred care, treatment burden and consumer healthcare priorities to reveal any disparities between consumer and health professional views and inform future training.

The following information is a summary of this section. For further details of the DCE, see Appendix 6.1. This work has been published in the following peer-reviewed journal:

- Whitty JA, Kendall E, Sav, A, Kelly F, McMillan SS, King M, Wheeler AJ. Preferences for the delivery of community pharmacy services to help manage chronic conditions: *Research in Social and Administrative Pharmacy* DOI:org/10.1016/j.sapharm.2014.06.007 (published online 15.07.14).

Method

A rigorous process was employed to develop the survey to be used by both consumer and carer and health professional participants. Development of the survey built on the findings of Stages One and Two. The development process involved iterative rounds of pilot testing, feedback from the project Reference Group and Advisory Panel, and a plain English review. Indicative copies of the two surveys are included in Appendix 6.2.

The survey consisted of the following parts:

- Characteristics of current pharmacy service/s (consumers and carers only):** This part asked four questions about current pharmacy use; how often consumers and carers used community pharmacy, the characteristics of the pharmacy, important factors in choosing a pharmacy, and the type of services used at the pharmacy.
- Importance of ideal pharmacy services (all participants):** This part assessed the importance of a range of characteristics of ideal pharmacy services. The characteristics were developed from the themes arising from the nominal groups, including those themes that were not incorporated into the DCE. In total 22 potential pharmacy services were measured. An example item included: *the pharmacy/pharmacists should be available on the phone, internet or email for consultations*. Consumers and carers were asked whether these pharmacy services would make any difference in helping them to manage their chronic condition(s), and/or the chronic condition(s) of the person they cared for, by rating the expected impact of each service using a scale of 0 to

100 (i.e. 100=the pharmacy service has a very high importance for me, and 0=this pharmacy service is not important to me). In contrast, health professionals were asked to rate each service according to the importance they thought the service would have for consumers, not what they would want as a health professional.

- **Preferences for characteristics of pharmacy services (all participants):** This part used a discrete choice experiment (DCE) to assess the preferred characteristics and relative priorities for pharmacy services. Participants were provided with four choice tasks that required them to choose between two hypothetical pharmacy services (i.e. a trade-off between different pharmacy service characteristics). For each choice task, consumers and carers were asked a two-step question. They were initially asked to make a “forced choice” between two alternatives (Service A and Service B) that differed on the attributes developed during previous stages of the research. They were then asked to indicate whether or not they would access their preferred service (i.e. A or B) or retain their existing service with their current pharmacy. Health professionals were asked the first step only, that is to indicate which service (A or B) they thought consumers would prefer. The services were described by six attributes, one with four levels, four with three levels, and one with two levels. The development and design of the DCE is described in Appendix 6.1. In total, the DCE consisted of 72 choice tasks, which were divided into 18 survey versions each containing four different choice tasks. One version of the survey for each participant group is presented in Appendix 6.2. However, these are indicative of all survey versions, which differed only by which four of the 72 choice tasks were included. Consumers and carers and health professionals were randomised to one of the 18 versions and completed four choice tasks each.
- **Health conditions and treatment burden (for consumers and carers who experienced a chronic condition themselves only):** This part measured the extent and duration of chronic disease, their experiences of their chronic condition(s), their use of medications, pharmacy and GP services. Participants were asked about their treatment burden using an adapted version of a measure developed by Tran *et al.* [104]. For each of the 15 items in the treatment burden measure, participants were asked to select the one response that came closest to the way they felt about their treatment. Each item was measured using a scale of 0 to 10, (0=no burden, 5=some burden, 10=considerable burden).
- **Health conditions (for carers only):** This component adapted the above measure to suit those participants who were in a caring role. The questions elicited information relating to the primary person for whom they provided care. This part did not assess the level of treatment burden which was specific to those with chronic conditions.
- **Quality of life (for consumers and carers only):** The Australian version of the EQ-5D-3L (a commonly used generic health related quality of life instrument) was included to evaluate consumer and carer quality of life [105]. Participants were requested to respond to statements across the domains of mobility, personal care, usual activities, pain/discomfort and anxiety/depression, selecting one of three responses to best describe their own level of health and quality of life.
- **Participant demographic characteristics (all participants):** Demographic questions were asked for consumers and carers (14 questions) and health professionals (9 questions) to collect necessary background information such as age, gender etc.

Data collection

Surveys were conducted between October 2013 and January 2014. Data collection was predominantly carried out via a CATI provider, who mailed surveys to participants for pre-reading approximately 1-2 weeks prior to conducting the survey (Appendix 6.2, 6.3 and 6.4). A CATI representative contacted each participant via telephone to undertake the survey.

A completed sample size of 600 consumers and carers and 250 health professionals was targeted based on representation of the adult population with chronic conditions in Australia, and the anticipated precision of estimates from the DCE analysis. For a population of approximately 17 million adults, with an estimated 77% reporting one or more chronic condition(s) [106], a completed sample of 600 has a margin of error of 4% [107]. There is no consensus on appropriate sample sizes for DCE tasks to give precise estimates, and sample sizes are based on rules of thumb [108, 109]. One commonly applied rule of thumb suggests that for the proposed DCE design, a minimum sample size of 250 is required [109]. The targeted consumer and carer sample size of 600 substantially exceeds that used for the majority of DCEs in healthcare [110], and would be expected to support the greater number of analyses to explore associations between preference and participant characteristics of interest [111].

Some interviews were conducted face-to-face with participants, by the research team (n=54 consumer and carers, and 117 health professionals). This dual approach to data collection was undertaken to maximise the diversity of the sample and to ensure that everyone who wanted to participate was able to do so. Face-to-face delivery was used particularly for groups that might be considered difficult to reach via the telephone or who preferred face-to-face discussion, including Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse participants and younger employed men. In the later stages of the project, some interviews were also undertaken face-to-face at the time of recruitment (for example, in health professional educational meetings at their place of work). Although the approach was flexible and accommodating for participants, surveys were always completed individually.

Data analysis

Data was initially analysed descriptively. Treatment burden and quality of life were summarised and described across the consumer and carer sample. For each participant, the individual treatment burden item scores were summed to give a score out of 150 indicating total treatment burden (with higher scores representing a higher level of burden). A utility weight was assigned to each participant's self-reported EQ-5D-3L health state, based on the Australian EQ-5D-3L utility index [105]. This index describes quality of life on a preference-based scale from 0 (representing the state of being dead) to 1 (representing full health), with negative values representing states considered worse than death. Associations between participant characteristics, including the EQ-5D-3L and health service and medication utilisation were evaluated using routine statistical tests, such as chi-square tests for categorical data and non-parametric tests (e.g. Mann-Whitney U) for continuous data. Associations between participant characteristics and treatment burden were evaluated using multiple linear regression.

The choice data from the DCE were analysed as two separate datasets, consumers and carers, and health professionals/workers. For consumers and carers, the propensity to choose their current pharmacy service in the choice sets, rather than take up a new service, was analysed descriptively. The reasons given by consumer and carer participants for choosing their current pharmacy service were analysed thematically. Correlations between participant characteristics and choice of current service were analysed using Pearson's correlation coefficients.

To estimate the preferred characteristics of pharmacy services, the choice observations were analysed using a mixed logit regression model [112, 110]. This model assesses the relative impact that each attribute level (service characteristic) has on the choice. This method allows individuals in the sample to have different relative strengths of preference for the different attributes. For each attribute level, the model estimates a mean (i.e. average) preference weight for the sample, indicating its relative importance. Covariates representing participant characteristics (such as sociodemographics) were entered into the model to explain the variation in preference around the sample mean. The analytic approach is detailed in Appendix 6.1.

Results

Overall, 849 consumer and carer and 412 health professional/worker participants expressed interest in participating in Stage Three. However, 602 consumers and carers (70.1% response) and 297 health and professionals (72.1% response) actually participated. The average completion time for consumers and carers was 23 minutes and 10 seconds, versus 18 minutes and 37 seconds for the health professionals.

Figures 4.1, 4.2 and Appendix 6.5 show the distribution of consumers, carers and health professional/health workers from the four study regions.

Figure 4.1: Geographical distribution of consumer and carer participants

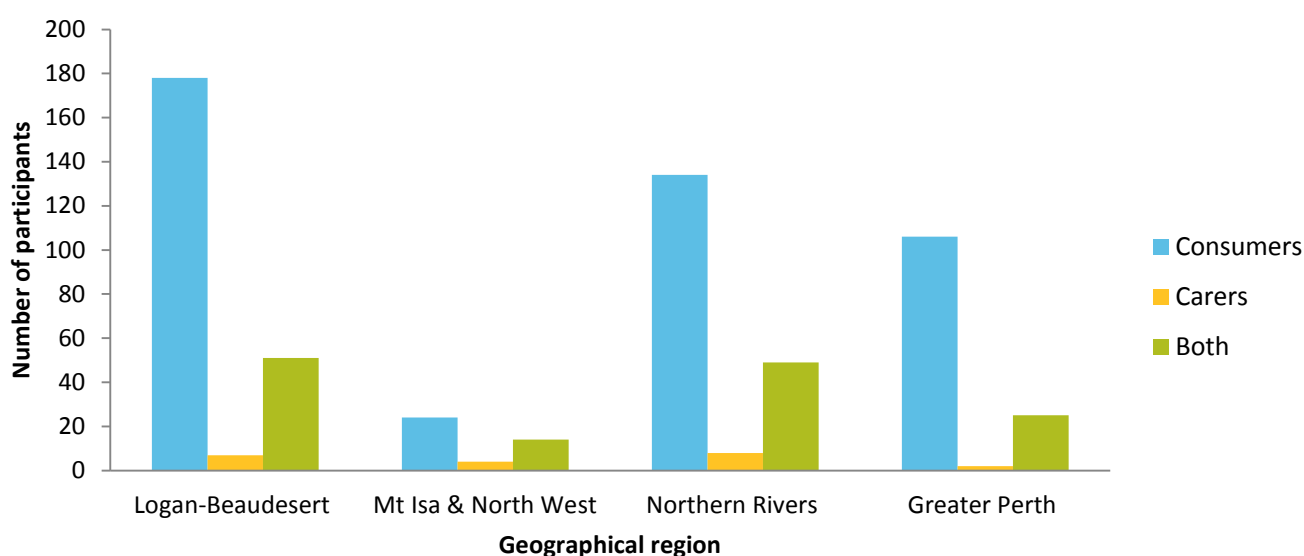
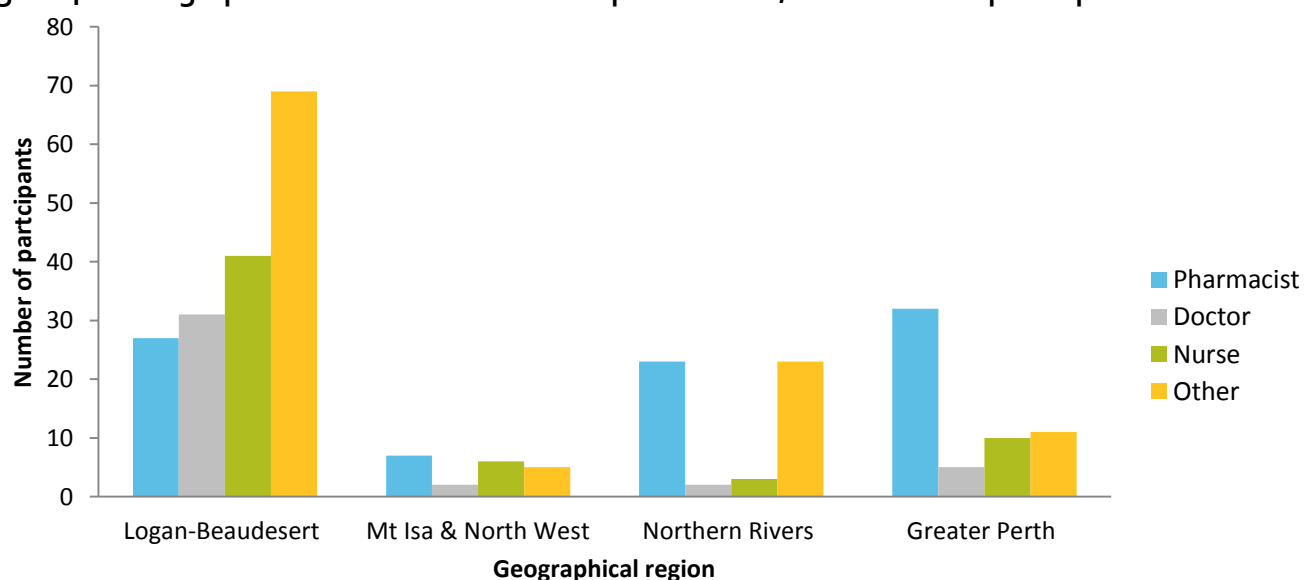


Figure 4.2: Geographical distribution of health professional/health worker participants



'Doctor' = general and specialist medical practitioner. 'Other' = medical receptionist, dietician, Aboriginal health worker, etc.

Table 4.1 outlines the demographic characteristics of consumers and carers; 70% were female, with a mean age of 57.0 years (SD=15.72 years). Although 61.2% of participants reported being from an Australian (non-

indigenous) background, participants came from diverse cultural backgrounds, including Chinese, Filipino, Pacific Islander people, German, Italian, and New Zealanders. Furthermore, 9.0% of participants identified as being from an Aboriginal or Torres Strait Islander background. Participants were generally educated beyond secondary school (56.5%) but not employed at the time of the survey (72.9%). There was a high representation of participants over 65 years of age (33.6%), who were retired or receiving an age pension. Sixty percent of participants reported a total household income of less than \$50,000 per annum, which is comparable with the median Australian household income of \$918.00 per week (\$47,736 per annum in 2011/12) [113].

Fewer than half of participants (43.2%) had private health insurance and three-quarters qualified for a government concession. The most common concession was an age pension card (29.8%), followed by a disability pension (22.8%). Despite the survey being mostly undertaken in the final quarter of the year, half of all participants indicated that they had not reached the PBS Safety Net threshold. Reaching this threshold would have allowed participants to purchase prescription medications at a subsidised cost for the remainder of the calendar year. A further 8.3% did not know whether they had reached the PBS Safety Net threshold limit.

There is little relevant and published data available in Australia on individuals with chronic condition(s) with which to meaningfully compare the sample characteristics. Although limited by the different aims and selection processes for the studies, comparison to the Australian National Health Survey (NHS) 2007-8 sample [114] is feasible for selected characteristics of consumers in the survey sample (Appendix 6.6). Overall, the survey and NHS subsample with selected chronic conditions were similar on some key characteristics (age, proportion identifying as being from an Australian background, proportion with two or more conditions, and proportion reporting a cardiovascular condition). However, females, those with a higher educational qualification, lower income or government concession, were over-represented and the employed, those with private health insurance, were under-represented in the survey sample as compared to the NHS 2007-8 subsample. The apparent differences between the current survey and the NHS 2007-8 survey subsample likely reflects the focussed aim of the current study on chronic conditions to access the opinions of individuals who were extensive users of pharmacy and healthcare service (as opposed to the NHS which also focussed on lifestyle, risk factors and disability).

Table 4.1: Characteristics of consumer and carer participants

Characteristic	Consumers (n=442)		Carers (n=21)		Both (n=139)		TOTAL ^d (n= 602)	
	n	%	n	%	n	%	n	%
Gender								
Male	139	31.5	6	28.6	35	25.1	180	29.9
Female	303	68.5	15	71.4	104	74.8	422	70.1
Age								
≤25	18	4.1	2	9.5	2	1.4	22	3.7
26-40	61	13.9	4	19.1	16	11.5	81	13.5
41-65	195	44.3	12	57.1	88	63.3	295	49.2
>65	166	37.7	3	14.3	33	23.7	202	33.6
Cultural background								
Australian (non-indigenous)	271	61.5	9	42.6	88	63.3	368	61.2
Aboriginal or Torres Strait Islander	48	10.9	2	9.5	4	2.9	54	9.0
Other (including CALD)	122	27.7	10	47.6	47	33.8	179	29.8
Educational qualification								
Primary/secondary school	193	43.7	7	33.3	51	36.7	251	41.7
Certificate/diploma	132	29.9	7	33.3	60	43.2	199	33.1
Bachelor/postgraduate qualification	108	24.4	6	28.6	27	19.4	141	23.4
Other	9	2.0	1	4.8	1	0.7	11	1.8
Employment status								
Not employed	332	75.1	13	61.9	94	67.6	439	72.9
Employed ^c	110	24.9	8	38.1	45	32.4	163	27.1
Total household income								
<\$50,000	273	62.1	12	57.1	78	56.1	363	60.5
≥\$50,001	123	27.9	8	38.1	49	35.3	180	30.0
Prefer not to say	44	10.0	1	4.8	12	8.6	57	9.5
Private Health Insurance								
Yes	180	40.7	10	47.6	70	50.4	260	43.2
Government concession^b								
Yes	341	77.6	13	61.9	97	69.8	451	74.9
Reached PBS Safety Net^a								
Yes	190	43.0	3	14.3	58	41.7	251	41.7
Worked in healthcare								
Yes	84	19.1	5	23.8	30	21.7	119	19.8

^aPBS refers to the Pharmaceutical Benefits Scheme; ^bTypes of government concession included pension card, healthcare card, carers card, disability card etc; ^cIncludes part-time, casual or full-time employment; ^dAge, cultural background, educational qualification and total household income had missing/incomplete data. Percentages are based on actual number of individual responses; CALD=Culturally and linguistically diverse people.

Table 4.2 shows the demographic characteristics of the 297 health professionals/health workers who participated in Stage Three, including 89 pharmacists, 60 nurses, 40 doctors, (including GPs and specialist medical practitioners), and 108 other health workers. There were more females than males, and the mean age of participants was 41.6 years (SD=12.04). Most health professionals/workers (86.5%) reported receiving their training in Australia, although a considerable number of medical practitioners (40.0%) indicated receiving their

training elsewhere. The majority of health professionals/workers (70.9%) had been employed in their current professional role for more than five years.

Table 4.2: Characteristics of health professional participants

Characteristic	Pharmacist (n=89)		Doctor* (n=40)		Nurse (n=60)		Other ** (n=108)		TOTAL ^b (n=297)	
	n	%	n	%	n	%	n	%	n	%
Gender										
Male	27	30.3	19	47.5	6	10.0	15	93	67	22.6
Female	62	69.7	21	52.5	54	90.0	93	86.1	230	77.4
Age										
≤25 years	16	18.0	Nil	Nil	1	1.7	11	10.2	28	9.5
26-40 years	44	49.4	17	43.6	13	22.0	42	38.9	116	39.3
41-65 years	28	31.5	21	53.8	44	74.6	54	50.0	147	49.8
≥66 years	1	1.1	1	2.6	1	1.7	1	0.9	4	1.4
Country of training										
Australia	86	96.6	24	60.0	47	78.3	100	92.6	257	86.5
Other	3	3.4	16	40.0	13	21.7	8	7.4	40	13.5
Cultural background										
Australian (non-indigenous)	56	62.9	16	40.0	34	57.7	66	61.1	172	57.9
Aboriginal or Torres Strait Islander	Nil	Nil	Nil	Nil	2	3.3	8	7.4	10	3.4
Other (including CALD people)	33	37.1	24	60.0	24	40.0	34	31.5	115	38.7
Sector of employment										
Private	66	75.0	31	81.6	6	10.0	18	17.3	121	41.7
Public	18	20.5	5	13.2	47	78.3	79	76.0	149	51.4
Not for profit	2	2.3	Nil	Nil	6	10.0	5	4.8	13	4.5
Other	2	2.3	2	5.3	1	1.7	2	1.9	7	2.4
Industry of employment										
Hospital	7	8.0	4	10.5	6	10.2	15	14.3	32	11.0
General practice	2	2.3	33	86.8	5	8.5	8	7.6	48	16.6
Primary care	24	27.3	1	2.6	7	11.9	13	12.4	45	15.5
Community/home-based care	47	53.4	Nil	Nil	33	55.9	49	46.7	129	44.5
Other ^a	8	9.1	Nil	Nil	8	13.6	20	19.0	36	12.4
Time in profession										
≤5 years	34	38.6	8	21.1	12	20.0	29	28.7	83	28.9
>5 years	54	61.4	30	78.9	48	80.0	72	71.3	204	71.1

*Includes general and specialist medical practitioner; **Includes diabetes educators, case workers, pharmacy assistants and other allied health professionals; ^aOther includes research, mental health, education and training etc; ^bAge, language spoken at home, sector of employment and time in profession, had incomplete and/or missing data; CALD=Culturally and linguistically diverse people.

a. Health status reported by consumer and carer participants

Chronic conditions

Participants reported a wide range of conditions (Table 4.3). In accordance with the rising rates of comorbidity in Australia [17], 83.2% of participants (n=501) reported experiencing two or more chronic conditions. The most common chronic conditions, each reported by between 25% and 45% of participants, were high blood pressure,

arthritis, chronic neck/back pain, depression, anxiety and asthma. Chronic conditions that impacted most commonly on their lives were chronic neck/back pain (13.3%), diabetes (11.4%), and arthritis (10.2%).

About a quarter of consumers (23.9%) reported having an unpaid carer to help them. The carer typically helped with household duties, such as cooking, cleaning and personal care (e.g. bathing), transport (e.g. travel to and from the health clinic) and medication management (e.g. purchasing medications, arranging dose administration aids, helping with taking medications). Most unpaid carers were spouses/de-facto partners (40.3%), children/step-children (27.9%) or parents/step-parents (20.1%) of the person for whom they provided care. Although it is difficult to compare the number of participants in our study who reported being an unpaid carer and/or having an unpaid carer with the general trend in Australia, the Australian Bureau of Statistics data (2012) indicates that there are approximately 2.7 million carers in Australia in 2012 [115]. Knowledge about the needs and preferences of this substantial population is critical.

Table 4.3: Chronic health conditions reported by consumer and carer participants

Chronic condition	Consumers (n=442)		Both (n=139)		TOTAL ^a (n=581)	
	n	%	n	%	n	%
Diabetes	115	26.4	23	16.7	138	24.0
Other endocrine conditions	31	7.1	12	8.7	43	7.5
Heart disease	102	23.4	17	12.3	119	20.7
High blood pressure	198	45.4	56	40.6	254	44.3
Other cardiovascular conditions	45	10.3	11	8.0	56	9.8
Asthma	116	26.6	37	26.8	153	26.7
Chronic obstructive pulmonary disease	56	12.8	10	7.3	66	11.5
Other respiratory condition	69	15.8	19	13.8	88	15.3
Kidney conditions	45	10.3	5	3.6	50	8.7
Cancer	43	9.9	19	13.8	62	10.8
Depression	150	34.4	51	36.9	201	35.0
Anxiety	141	32.3	40	29.0	181	31.5
Other mental health conditions	38	8.7	8	5.8	46	8.0
Chronic neck/back pain	189	43.4	47	34.1	236	41.1
Arthritis	199	45.6	47	34.1	246	42.9
Musculoskeletal and joint diseases	56	12.8	16	11.6	72	12.5
Skin conditions	77	17.7	29	21.0	106	18.5
Other central nervous system conditions ^b	64	14.9	26	18.8	90	15.7
Eye conditions	11	2.5	7	5.1	18	3.1
Gastrointestinal system conditions	46	10.6	9	6.5	55	9.6
Autoimmune conditions	10	2.3	5	3.6	15	2.6
Infection	10	2.3	4	2.9	14	2.4
Other conditions ^c	54	12.4	8	5.8	62	10.8

^aTotal exceeds 100% as respondents were asked to indicate all that applied. Percentages are based on actual number of individual responses; ^bOther central nervous system conditions include epilepsy, migraine, Huntington's disease etc. ^cIncludes hearing loss, cirrhosis, ovarian cyst, etc.

We compared the rates of chronic conditions reported by study participants with the estimates for a selected subsample including six long-term condition groups made from the Australian National Health Survey 2007-8 [114] (Appendix 6.6). Although the percentages of chronic disease in our study were higher than the NHS 2007-8 subsample estimates, this was to be expected given the focus of our study. It was not the purpose of our research

to examine population trends. Rather, the purpose of our study was to examine the views of consumers and carers who had extensive experience of health and community pharmacy services. Nevertheless, the trends within the samples were similar. For example, cardiovascular and musculoskeletal conditions were the most prevalent long-term health conditions in both samples.

Table 4.4: Self-reported current health status

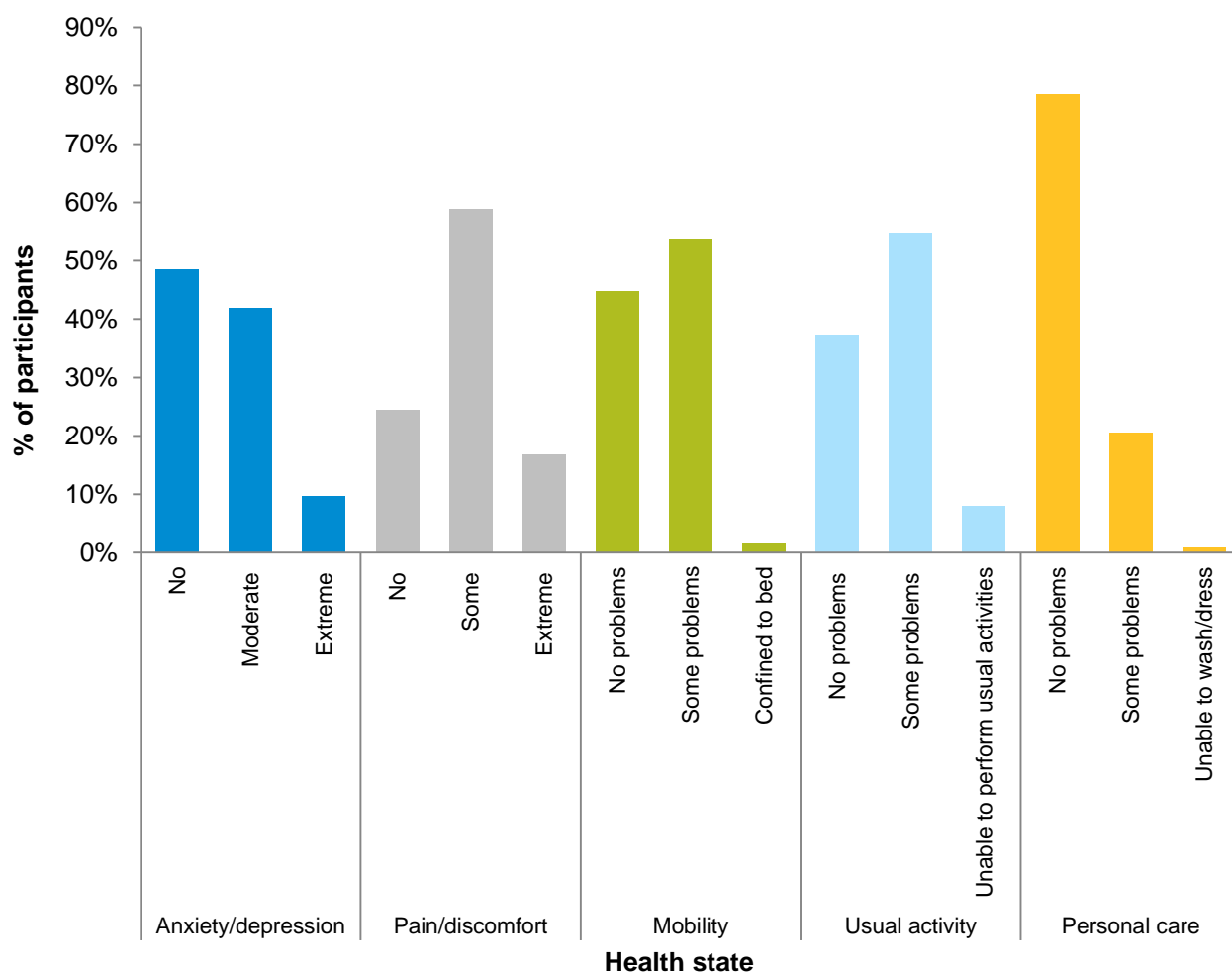
	Consumers (n=442) ^a	Carers (n=21)	Both (n=139)	TOTAL ^a (n=602)
Current health (EQ-5D-3L VAS)				
Mean (SD)	59.4 (20.7)	81.1 (15.7)	62.9 (19.7)	61.0 (20.7)
Median (IQR)	60.0 (50.0 to 75.0)	90.0 (72.50 to 90.0)	65.0 (50.0 to 80.0)	65.0 (50.0 to 75.0)
QoL utility weight				
Mean (SD)	0.60 (0.27)	0.93 (0.11)	0.66 (0.26)	0.62 (0.27)
Median (IQR)	0.68 (0.43 to 0.77)	1.00 (0.81 to 1.00)	0.71 (0.61 to 0.80)	0.69 (0.52 to 0.80)

^aExcludes one consumer who had missing data; Higher scores indicate better health state; SD=Standard Deviation; IQR=Interquartile Range. The VAS asked participants to rate their current health state on a scale from 0 (worst imaginable) to 100 (best imaginable). The QoL utility weights were assigned to EQ-5D health states using the Australian preference-based algorithm [105], and are interpreted on a scale from 0 (representing dead) to 1 (representing full health), with negative values representing states considered worse than death.

Quality of life

Participants reported high levels of morbidity (Table 4.4 and Figure 4.3). Mean health state utility scores were 0.60 (SD=0.27) for consumers, 0.66 (SD=0.26) for those identifying as both consumers and carers, and 0.93 (SD=0.11) for carers. A substantial number of participants (41.9%) reported being moderately anxious or depressed, while a further 9.6% reported being extremely anxious or depressed (Figure 4.3). More than half of the sample (55.3%) experienced problems with mobility (e.g. walking around). Nearly one-quarter of participants (21.4%) experienced problems with personal care, and 62.7% reported some problems with performing usual activities and/or being unable to perform them. Finally, a substantial proportion of participants (58.8%) reported experiencing moderate pain or discomfort, with 16.7% experiencing extreme pain or discomfort.

Figure 4.3: Quality of life among consumers and carers



As would be expected in a study of people with chronic condition(s), the consumer and carer participants generally reported poor levels of quality of life, when compared with the population norms for the EQ-5D-3L among Australian adults. In a study reporting the EQ-5D-3L population norms for a sample of 5,555 participants in Queensland, Australia, Clemens *et al.* [116] found that 15.3% reported some to severe problems with usual activities (vs. 62.7% in our study), 40.1% reported moderate to severe pain/discomfort (vs. 58.8% for our study), 16.2% reported moderate to severe anxiety or depression (vs. 51.5% for our study), 16.4% reported some to severe problems with mobility (vs. 55.3% in our study), and 3.1% reported some to severe problems with usual care (vs. 21.4% in our study). Clemens *et al.* also reported a mean utility score of 0.87, much higher than that reported by participants in this project [116].

Thus, it is clear that chronic conditions and/or caring for someone with a chronic condition are associated with significant reductions in quality of life. However, a range of participant characteristics were associated with poorer overall quality of life and/or the experience of moderate to severe problems with each of the quality of life domains (Table 4.5). These factors included increased age, higher levels of treatment burden, lower income and unemployment, increasing numbers of medications and high levels of service use (pharmacy and GP).

Table 4.5: Characteristics associated with moderate or severe problems in each EQ-5D-3L quality of life domain

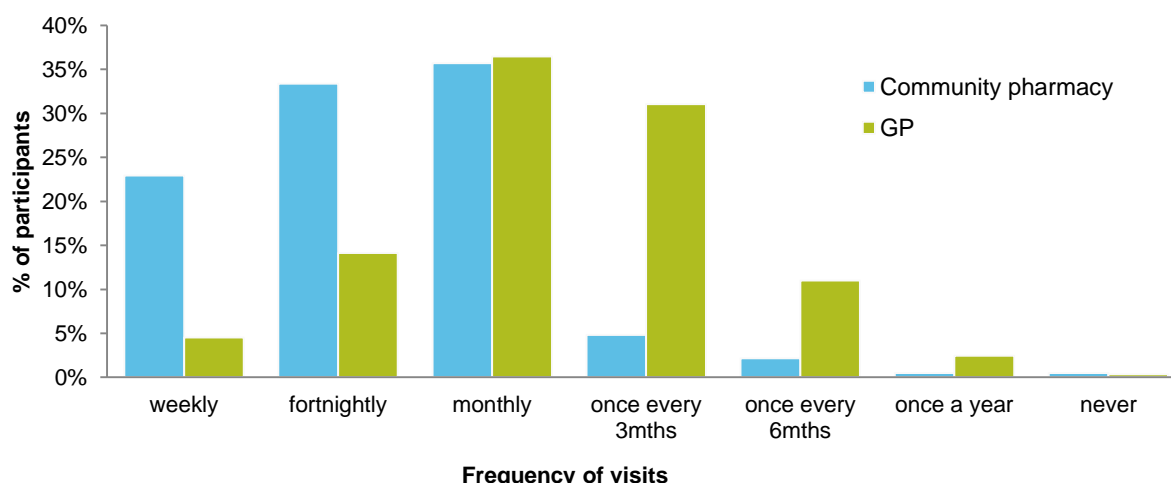
Characteristic	Anxiety/ depression	Pain/ discomfort	Problems with mobility	Problems with usual activities	Problems with personal care	TOTAL quality of life*
Experiencing ≥2 or more chronic conditions	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$
Taking medications ≥3 times a day	$p \leq 0.010$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$
Using ≥5 medications each day		$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$
Visiting a GP at least monthly	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$
Visiting a community pharmacy weekly/fortnightly	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$
Experiencing above median treatment burden	$p \leq 0.001$	$p \leq 0.010$	$p \leq 0.001$	$p \leq 0.010$	$p \leq 0.010$	$p \leq 0.001$
Having a total household income of ≤\$50,000		$p \leq 0.050$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.050$	
Not employed	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	
Being single			$p \leq 0.001$			
Being ≥41 years		$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.001$	$p \leq 0.050$	
Being ≤40 years	$p \leq 0.050$					
Being Caucasian with English as first language		$p \leq 0.001$	$p \leq 0.010$	$p \leq 0.001$	$p \leq 0.001$	
Having school qualification only	$p \leq 0.050$	$p \leq 0.050$			$p \leq 0.050$	$p \leq 0.050$
Reaching the PBS Safety Net**			$p \leq 0.001$		$p \leq 0.001$	

*≤65=low quality of life and >65=high quality of life out of a total score of 100 (higher score represents better quality of life); *PBS =Pharmaceutical Benefits Scheme; p value refers to Pearson's chi squared test for a difference in proportion between groups.

b. Health service use reported by consumer and carer participants

Overall, participants were relatively high users of primary health care services (Figure 4.4 and Table 4.6), including community pharmacies, with 92.0% visiting a community pharmacy at least every four weeks and 56.3% visiting at least fortnightly. Participants visited a GP less frequently (55.1% at least monthly), underscoring the frequency of contact that people with chronic conditions and their carers have with community pharmacy. Participants reported being loyal to one community pharmacy, with 69.2% reporting visiting one pharmacy most of the time.

Figure 4.4: Frequency of visits to community pharmacy and GP*



*n=599 visited a community pharmacy, n=573 visited a GP.

The services currently accessed at a community pharmacy are reported in Table 4.6. Two-thirds of the sample reported having used a community pharmacy service to discuss medications with a pharmacist, nearly a third had used a pharmacy to decide whether to see a doctor, and over a quarter had accessed health screening or monitoring services (e.g. blood pressure monitoring, cholesterol testing etc.). This underscores the important role community pharmacy already plays, beyond medication supply, in providing medication-related advice and health care services to people with chronic condition(s).

High use of community pharmacy services (i.e. weekly or fortnightly) was associated with:

- using ≥ 5 medications per day ($p \leq 0.001$);
- being Caucasian with English as first language ($p \leq 0.001$);
- not employed ($p \leq 0.001$);
- taking medications ≥ 3 times a day ($p \leq 0.001$);
- experiencing above median (i.e. $\geq 54/150$) treatment burden ($p \leq 0.001$);
- being ≥ 41 years ($p \leq 0.05$);
- reaching the PBS Safety Net ($p \leq 0.001$);
- experiencing ≥ 2 chronic conditions ($p \leq 0.001$); and
- visiting a GP at least monthly ($p \leq 0.001$).

Table 4.6: Community pharmacy use among consumer and carer participants

	Consumers (n=442)		Carers (n=21)		Both (n=139)		TOTAL * (n= 602)	
	n	%	n	%	n	%	n	%
Frequency of community pharmacy visit								
Weekly	87	19.9	5	23.8	46	33.1	138	22.9
Fortnightly	158	35.8	5	23.8	38	27.3	201	33.4
Monthly	159	36.0	8	38.1	48	34.5	215	35.7
Once every 3 months	23	5.2	2	9.5	4	2.9	29	4.8
Once every 6 months	11	2.5	0	0.0	2	1.4	13	2.1
Once a year	2	0.5	0	0.0	1	0.7	3	0.5
Never	2	0.5	1	4.8	0	0.0	3	0.5
Loyalty to community pharmacy								
One pharmacy most of time	305	69.3	13	65.0	96	69.6	414	69.2
One pharmacy but visit others for specific needs	94	21.6	3	15.0	32	23.1	129	21.6
Different pharmacies	41	9.3	4	20.0	10	7.3	55	9.2
Type of pharmacy services accessed^a								
Deciding to see a doctor	135	30.8	6	30.0	54	39.1	195	32.7
Health screening/ monitoring	102	23.2	5	25.0	45	32.6	152	25.5
Quit program	22	5.0	1	5.00	13	9.4	36	6.0
Discussing medications at pharmacy	280	63.8	15	75.0	102	73.9	397	66.5
Discussing medications at home	58	13.2	3	15.0	23	16.7	84	14.0
Home deliveries	81	18.5	5	25.0	37	26.8	123	20.6
Dose administration aids	60	13.7	6	30.0	34	24.6	100	16.8
Weight management	36	8.2	1	5.0	13	9.4	50	8.4
Vaccinations	20	4.6	0	0	8	5.8	28	4.7
Needle and syringe exchange	33	7.5	0	0	11	8.0	44	7.4
Glucometer testing	22	5.0	0	0	9	6.5	31	5.2
Other service ^b	37	8.4	0	0	17	12.3	54	9.0
None of these services	78	17.8	3	15.0	15	10.9	96	16.0

*Loyalty to community pharmacy and type of services accessed at the pharmacy had missing/incomplete data. Percentages are based on actual number of individual responses; ^aTotal for the type of services accessed at the pharmacy exceeds 100% as respondents were asked to indicate all that applied; ^bIncluded returning unused medications, passport photographs, bone density testing, naturopath, etc.

c. Medication use reported by consumer and carer participants

Figures 4.5 and 4.6 show the number of medications participants reported taking per day and the frequency. This included over-the-counter medications and vitamins. Participants reported taking a mean of 7.1 different medications per day (SD=5.3, median=6), with a mean frequency of 2.7 times per day (SD=1.9, median=2). Consumers reported taking significantly more medications at higher dosing frequency, than participants who identified as being both a consumer and carer ($p \leq 0.01$; Appendix 6.7).

It was the original intent of the research team to identify what prescription, non-prescription and complementary medicines consumers were using. However, during the expression of interest process, it became evident that many participants were unable to identify by name what medications they, or their care-receiver, were using. They were however able to identify the number of different preparations they were taking and the frequency of these. Therefore this information was used in the study instead of names and types of medications. This finding underscores the importance of providing medication lists to assist people to understand, or at least recall, what medication they are using, particularly if taking multiple medications as identified by this study.

Characteristics found to be associated with taking a higher number of medications (≥ 5) included:

- being ≥ 41 years of age ($p \leq 0.001$);
- not employed ($p \leq 0.001$);
- taking medications ≥ 3 different times a day ($p \leq 0.001$);
- visiting a GP at least monthly ($p \leq 0.001$);
- visiting a community pharmacy weekly/fortnightly ($p \leq 0.001$);
- reaching the PBS Safety Net ($p \leq 0.001$); and
- experiencing above median treatment burden ($p \leq 0.001$).

Although medication use has increased steadily in Australia from 180 million community prescriptions in 1996 to 271 million in 2010 [17], the rate of medication use reported by the study participants was similar to that reported in the general Australian population. A 2009 report by the Australian Department of Health suggested that older Australians (65-75 years) were using an average of four prescription medications per day and predicted usage of approximately six per day by 2019 [117]. Our survey findings are consistent with this trend. However, a direct comparison cannot be made because our data included over-the-counter medications and vitamins which have become a more common feature of medication profiles in recent years.

Figure 4.5: Number of medications taken (per day)

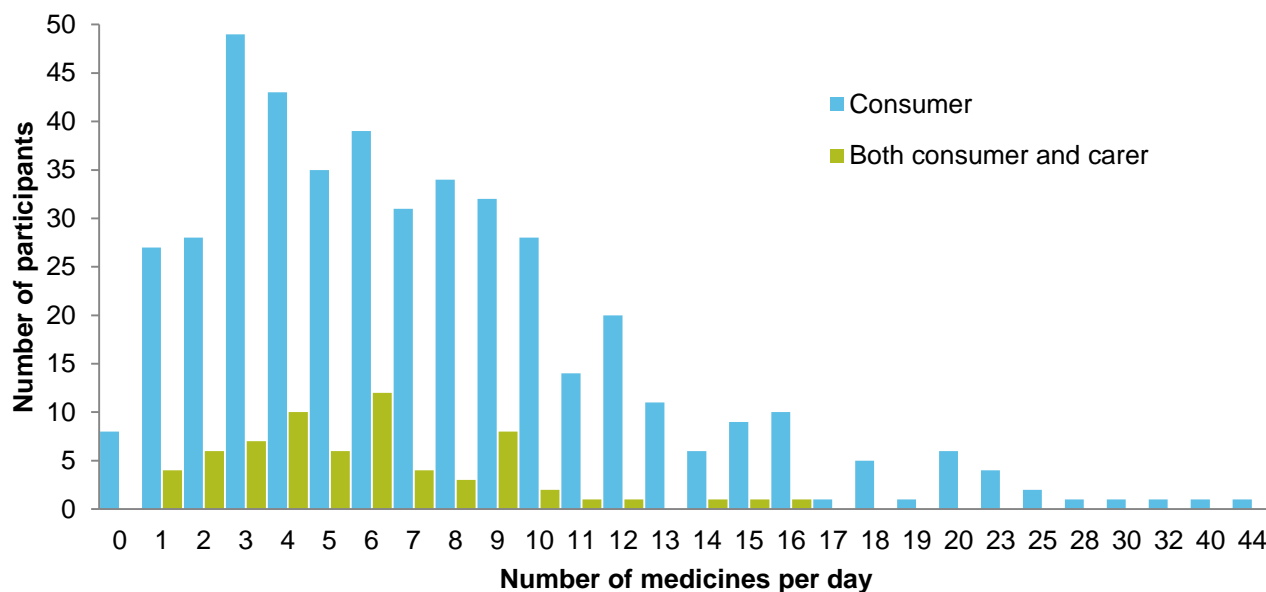


Figure excludes 22 consumers and 11 people (who were both a carer and consumer) who had missing data. Vitamins and over-the-counter medications were included.

Figure 4.6: Frequency of medication taking (per day)

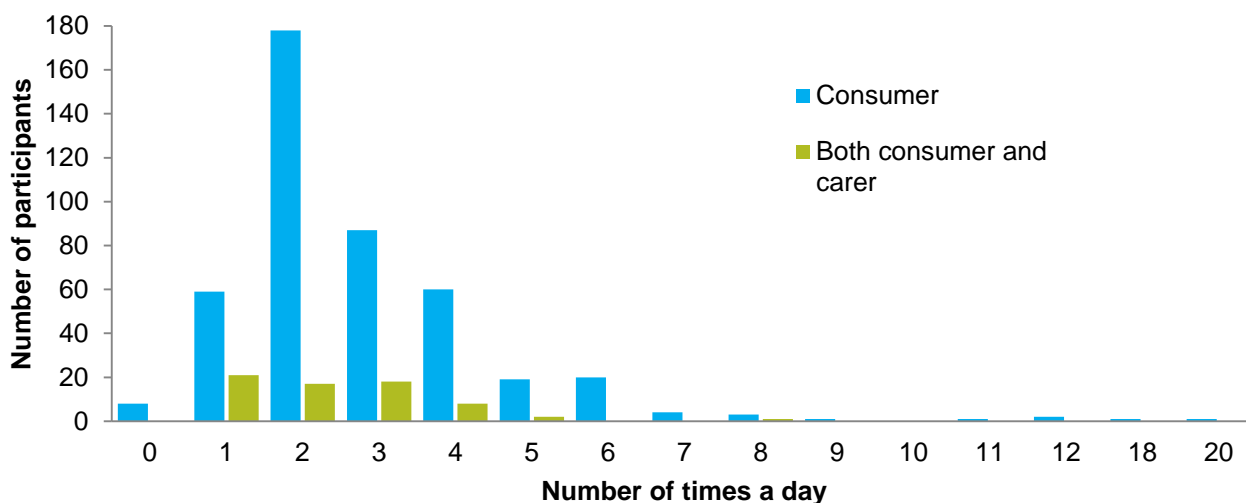


Figure excludes 24 consumers and 13 people (who were both a carer and consumer) who had missing data. Vitamins and over-the-counter medications were included.

Given that the sample included a substantial proportion of people with low levels of total household income (60.5% reported $\leq \$50,000/\text{annum}$), relatively high medications use (mean=7.1 medications/day), and yet still reported substantial levels of morbidity, the impact of chronic conditions on financial burden required clarification. Thus, consumers were asked if they experienced difficulty purchasing medications for themselves because of financial cost. Over a quarter of consumers (25.8%) who reported taking medications experienced

difficulties obtaining medications because of the expense. These participants reported delaying or neglecting the purchase of prescribed medications for themselves during the past 12 months, as a result of cost.

Similarly, almost a quarter of participants (21.3%) delayed or neglected the purchase of medications for the person they cared for due to the expense. This finding is consistent with recent research in Australia and overseas, with an estimated 11-22% of people with a chronic condition delaying or deferring medication purchase because of cost [118-121].

Characteristics found to be associated with the reported delay or neglect to purchase prescribed medications during the last 12 months due to cost included:

- being ≤ 60 years of age ($p \leq 0.001$);
- being single ($p \leq 0.05$);
- experiencing above median treatment burden ($p \leq 0.001$);
- visiting a GP at least monthly ($p \leq 0.001$);
- not reaching the PBS Safety Net ($p \leq 0.001$); and,
- visiting a community pharmacy weekly/fortnightly ($p \leq 0.001$).

d. Treatment burden reported by consumers

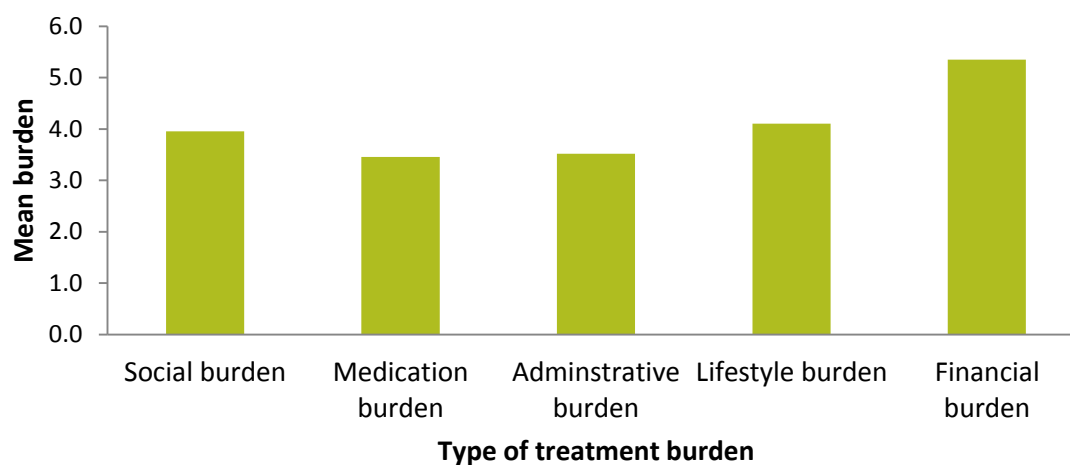
Participants rated their level of burden associated with their treatment regimens (i.e. treatment burden). Consumers and consumers who were also carers reported a mean overall treatment burden of 56.5 (SD=34.5) out of a total score of 150 (where higher scores represent higher burden). When analysed individually for the five domains of treatment burden (Figure 4.7), i.e. medication, time/administration, lifestyle, social and financial burden, the findings indicated that the highest level of burden was reported in the financial (mean=5.4, SD=3.6), lifestyle (mean=4.1, SD=3.0), and social (mean=4.0, SD=3.1) domains, reported as a mean out of a possible score of 10 for each question (higher score represents higher burden). However, the differences between the domains are quite small and it is difficult to discriminate between them.

Multiple linear regression was used to evaluate the association between treatment burden and a range of personal characteristics (including age, gender, marital status, income, employment status, educational background, cultural background, government concession, private health insurance, and whether a person had an unpaid carer to help with managing his/her conditions), and condition characteristics (including number of chronic conditions, and the type of chronic condition, which was represented by the following conditions: diabetes and other endocrine conditions, cardiovascular conditions, mental illness, musculoskeletal conditions, respiratory conditions, and cancer) (Appendix 6.8).

Characteristics that were associated with an increased level of treatment burden were:

- lower age ($p \leq 0.001$);
- presence of an unpaid carer ($p \leq 0.001$);
- experiencing an increasing number of chronic conditions ($p \leq 0.001$);
- experiencing diabetes or another endocrine condition ($p \leq 0.01$).

Figure 4.7: Treatment burden among consumer and carer participants



e. Ideal pharmacy characteristics

Table 4.7 shows the five highest and five lowest ranked characteristics of pharmacy services from a list of 22 possible characteristics derived in previous phases of the research (Appendix 6.g). The highest ranked (most important) three pharmacy characteristics for both groups of participants were identical. For consumers, carers and health professionals/workers, the highest ranked ideal characteristics were:

- treat me as an individual, not as a number;
- be respectful of my needs and personal values;
- provide personalised advice and information on prescribed medications.

Consumers, carers and health professionals/workers also reported similar perceptions about the lowest ranked (least important) pharmacy characteristics. For consumers, carers and health professionals, the following were the lowest ranked pharmacy characteristics:

- have other health providers working at the pharmacy;
- provide basic adult vaccinations or treatments;
- offer community health and wellness programs.

Table 4.7: Highest and lowest five preferred characteristics of pharmacy services for all participants

Participant	Preference	Participant	Preference
Consumers and carers	1st PCC (M= 86.32, SD= 21.808) <i>Treat me as an individual, not as a number</i>	Health professionals/ workers	1st PCC (M= 94.22, SD= 20.528) <i>Treat me as an individual, not as a number</i>
	2nd PCC (M=83.04, SD=24.432) <i>Be respectful of my needs and personal values</i>		2nd PCC (M=93.18, SD=12.623) <i>Be respectful of my needs and personal values</i>
	3rd Medication management (M=81.96, SD=23.856) <i>Provide personalised advice and information on prescribed medications</i>		3rd Medication management (M=86.17, SD=21.204) <i>Provide personalised advice and information on prescribed medications</i>
	4th Access (M=76.71, SD=29.902) <i>Have access to my prescription (dispensing) records from any pharmacy</i>		4th PCC (M=81.74, SD=19.194) <i>Be a partner in my health care (e.g. work with me and my family)</i>
	5th PCC (M=73.07, SD=30.342) <i>Recognise and value all parts of my life (e.g. holistic care).</i>		5th Health promotion (M=81.71, S=21.279) <i>Offer advice on the management of minor ailments</i>
Participant	Preference	Participant	Preference
Consumers and carers	18 Health promotion (M=59.04, SD=33.937) <i>Offer screening and monitoring service</i>	Health professionals/ workers	18 Access (M=67.63, SD=25.028) <i>Have access to my medical records, with links to my GP, specialist and hospital records</i>
	19 Referral and integration (M=58.32, SD= 34.190) <i>Be located in a large community clinic or medical centre as part of a 'one stop shop' health centre</i>		19 Innovation and prescribing (M=64.10, SD= 28.206) <i>Prescribe an extra 6 months of my repeat medications after my GP prescription runs out</i>
	20 Referral and integration (M=56.15, SD=32.165) <i>Have other health providers working at the pharmacy</i>		20 Referral and integration (M=60.94, SD=24.719) <i>Have other health providers working at the pharmacy</i>
	21 Health promotion (M=50.73, SD= 30.450) <i>Provide basic adult vaccinations or treatments</i>		21 Health promotion (M=60.03, SD= 27.060) <i>Provide basic adult vaccinations or treatments</i>
	22 Health promotion (M=42.33, SD= 33.136) <i>Offer community health and wellness programs</i>		22 Health promotion (M=47.47, SD= 26.935) <i>Offer community health and wellness programs</i>

Pharmacy service characteristics that consumers, carers and health professionals rated similarly are highlighted in blue. The mean (M) and standard deviation (SD) represent the total score on all 22 items of preferred pharmacy services; PCC=Patient Centred Care.

f. Preferences and priorities for pharmacy services

This section presents the findings of the discrete choice experiment about preferences for pharmacy services. Data analysis for the consumer and carer model was based on 2,396 choices, consisting of four choices made by each of the 602 consumers and carers (less 12 missing observations across five individuals). Data analysis for the health professional model was based on 1188 choices, consisting of four choices made by each of the 297 health professional participants. A similar number of participants (between 4.8% and 6.1% of each sample) completed each of the 18 survey versions.

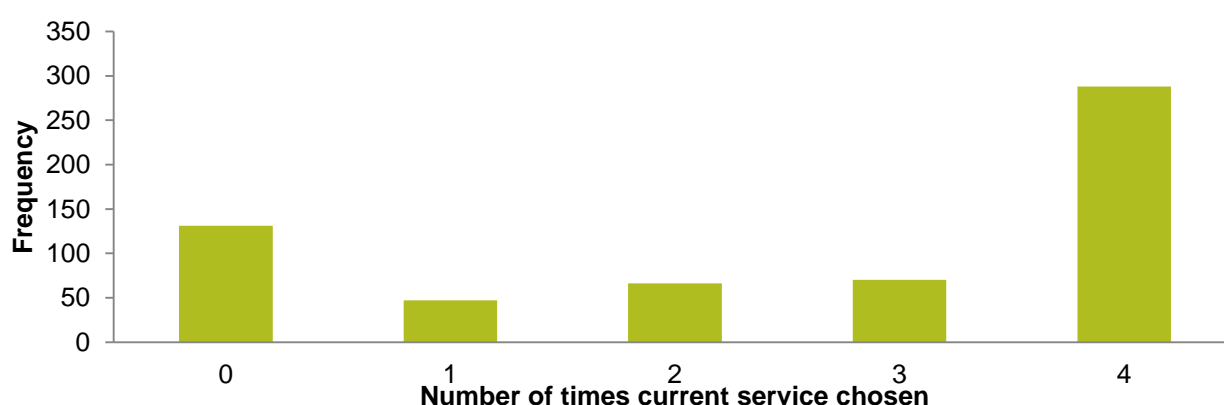
Uptake of a new pharmacy service versus retention of current service

There was a strong propensity for a participant to select their current service, rather than a new service, even though participants were told that the new service could be provided by their current pharmacist/pharmacy. For consumer and carer participants, a new pharmacy service (i.e. hypothetical service A or B) was chosen for 855 (35.7%) of all choices. Nearly one-quarter of all consumer and carer participants ($n=131$, 21.8%) chose one of the new services in all four scenarios (Figure 4.8). However, of the 602 consumers and carers, the majority elected to remain with their current pharmacy service rather than selecting one of the new services. Small numbers of participants chose their current pharmacy in one ($n=47$; 7.8%), two ($n=66$; 11%) or three ($n=70$; 11.6%) choices. Almost half the participants ($n=288$; 47.8%) selected their current pharmacy in all four choices. Thus, there appeared to be a consistent pattern in pharmacy choice in that many participants either selected a new service or their current pharmacy service in all four choices. Several characteristics were associated with the likelihood of choosing current pharmacy service over new service ($p \leq 0.05$):

- older age (≥ 66 years more likely and ≤ 25 years less likely compared to 26-65 year olds);
- lower education level (completed primary/secondary school only);
- not in employment;
- usually visit the same pharmacy;
- consumers with a recent diagnosis (≤ 6 months) of chronic condition(s); and
- residing in Greater Perth region.

There were also significant but small negative correlations between the number of times participants rejected new options and the extent of treatment burden they reported ($r=-0.15$; $p \leq 0.001$). Thus, the lower the sense of burden associated with one's current treatment, the more likely people were to reject new services.

Figure 4.8: Frequency of choice of current over new pharmacy service



Reasons for retaining current pharmacy service

Those who retained their current pharmacy provided reasons for doing so, although 10 participants provided no reason. Participants who retained their current pharmacy in at least one choice provided an average of 1.9 reasons for doing so (range 1-6). The provision of more reasons tended to be associated with increasing age ($r=0.16$; $p\leq 0.001$) and more consistent commitment to one's current pharmacy ($r=0.61$; $p\leq 0.001$), but also lower levels of treatment burden ($r=-0.11$; $p=0.004$) and fewer pharmacy visits ($r=-0.11$; $p=0.006$). This finding paints a picture of the role pharmacy may play in reducing burden and increasing satisfaction for older customers who are not overusing pharmacy.

In total, 907 reasons were supplied by participants who retained their current pharmacy in at least one choice, with the most common reasons being that their current pharmacy service was friendly and helpful ($n=161$), or offered continuity as a result of long-term knowledge about consumer needs and personal relationships with staff members ($n=188$). Participants were unlikely to consider any new pharmacy services if it meant a change to one of these two fundamental qualities.

A reasonably large group of participants ($n=97$) reported that their current pharmacy service already offered some or all of the new services (usually quality information and advice about medications), and often at no or low cost in a convenient location, making it a preferred option. Convenient location was a common reason for remaining with the current pharmacy ($n=148$) and low cost featured prominently as a reason for refusing new services ($n=95$), with many participants stating that they would not be prepared to pay for pharmacy services or that their current pharmacy service already delivered high quality services for no cost. Another small group of reasons concerned the speediness of service delivery, meaning that consumers did not have to wait ($n=16$).

Two important and related reasons for refusing new services involved the fact that the current pharmacy was perceived to be a good high quality source of advice, guidance, information and discussion about medications or symptoms that could not be replicated elsewhere ($n=92$) and a flexible, reliable and timely source of medication supply ($n=53$). These features were particularly important in times of emergency, when participants appreciated flexibility and cooperation from their pharmacy to ensure supply of medications.

Only a small number of participants reported that the new services were either not needed at all or not appropriate, some small aspects were valued or no reason was stated for opting out ($n=36$). An equally small number believed that the new services were not appropriate for delivery within or by pharmacy ($n=21$). These latter comments pertained to the safety and lack of personal contact associated with 'drive through' options, but mostly to preconceived beliefs about the roles of GPs versus pharmacists and an unwillingness to have their records shared between medical and pharmacy services.

Thus, when clustered into broader reasons, three main drivers of pharmacy choice emerged, namely patient centred services (i.e. a long-term personal and respectful relationship with pharmacy staff; $n=349$ of 907 reasons; 38.5%), easy access to pharmacy services (i.e. speed, convenience, location and low cost; $n=259$; 28.5%) and continuous reliable supply of medication and availability of timely, quality advice about medications and symptoms ($n=242$; 26.7%).

Consumer and carer preferences for the characteristics of pharmacy services

Statistical results for the consumer and carer preference model are included in Appendix 6.1.

Impact of service characteristics on choice

Four of the six attributes included in the DCE significantly influenced choice of pharmacy service (i.e. preferences for services other than current pharmacy service):

- *Continued medication supply:* The average participant preferred to have access to a pharmacist who could supply their regular medications and medications used previously for intermittent symptom flare-ups. This situation was preferred to having access to a doctor ($p \leq 0.001$).
- *Pharmacy location:* On average, a one-stop health centre was preferred over a pharmacy near a person's home/work ($p \leq 0.001$), and a pharmacy near home/work was preferred to a pharmacy near a person's GP practice ($p = 0.005$).
- *Getting your medications:* On average, participants preferred the availability of home delivery, over having face-to-face collection of medications alone ($p \leq 0.001$). They also preferred having face-to-face collection, over the availability of collection without going into the pharmacy e.g. by drive-through without personal contact ($p = 0.025$).
- *Average cost per month for the service:* The average participant preferred a pharmacy service that was available at a lower cost ($p = 0.002$).

The following two attributes did not have a significant impact on choice for the average participant:

- *Manage on-going condition:* There was a trend to prefer access to other health professionals employed in the pharmacy over pharmacy staff directing individuals to other services; however, this trend did not reach statistical significance ($p = 0.111$).
- *Access to pharmacist:* The availability of medications review or advice from a pharmacist in a pharmacy without having to ask, or with the additional modes of phone/email/internet or home visits by appointment, did not significantly impact on preferences, as compared to the availability of a medications review or advice from a pharmacist in the dispensary ($p = 0.183$ to 0.416).

Impact of participant characteristics on choice

There was substantial variation in the strength of preference across the sample for the attributes related to continued medications supply and cost. A number of participant characteristics significantly explained differences in preferences across participants for each of these two characteristics ($p \leq 0.05$):

- Characteristics associated with a preference for the availability of continued supply of regular medications by a pharmacist as opposed to a doctor alone:
 - frequent medications dosing (≥ 3 times per day); and
 - consumer with established chronic condition(s) (i.e. no condition(s) diagnosed ≤ 6 months).
- Characteristics associated with being less sensitive to increased cost per month for the service:
 - not in employment; and
 - residing in the Mt Isa and North West region.

Despite the observation that these participant characteristics significantly explained variation in preferences, a substantial amount of variation still remained around the preference for the preferred attributes of pharmacy services, even after considering the impact of participant characteristics.

Health professional perception of consumer preferences for the characteristics of pharmacy services

The statistical results of the health professional preference model are included in Appendix 6.1.

Impact of service characteristics on choice

Overall, fewer attributes significantly affected health professionals' perceptions about consumer choice, perhaps reflecting the difficulty of the task for health professionals (who were asked their perception of what others would want), the smaller sample size, or both.

Two of the six attributes significantly explained choice:

- *Pharmacy location:* On average, a one-stop health centre was expected to be preferred over a pharmacy near a consumer's home/work, and a pharmacy near home/work was expected to be preferred to a pharmacy near to a consumer's GP practice ($p \leq 0.001$). This finding was consistent with the preferences of consumers and carers.
- *Getting your medications:* On average, health professionals expected consumer and carer participants to prefer the availability of home delivery as an option to having face-to-face collection of medication alone ($p \leq 0.001$). This finding was consistent with the preferences of consumers and carers. There was a trend for health professionals to expect consumers to value the option to collect medications without going into the pharmacy e.g. through drive-through more than face-to-face collection alone; however, this did not reach statistical significance at the 5% level ($p = 0.085$). Such a trend was inconsistent with the preferences of consumers and carers, who preferred having face-to-face collection alone over the availability of collection without going into the pharmacy e.g. by drive-through in addition to face-to-face.

Four of the attributes did not have a significant impact on choice for health professionals:

- *Continued medication supply:* There was a trend for the average health professional participant to expect consumers to prefer to have access to a pharmacist for on-going supply of regular medications and for medications they have used before for symptom flare-ups rather than having access to a doctor alone. This relationship was stronger for regular and flare-up medications ($p = 0.075$) than for regular medications alone ($p = 0.396$), although this trend did not reach statistical significance. However, the direction and rank order of this trend was consistent with consumer and carer preferences.
- *Manage on-going condition:* There was a trend to expect consumers to prefer access to other health professionals employed in the pharmacy over pharmacy staff directing individuals to other services; however, this trend did not reach statistical significance ($p = 0.723$). This finding was consistent with the preferences of consumer and carer participants.
- *Access to pharmacist:* The availability of medications review or advice from a pharmacist in a pharmacy, or with the additional modes of phone/email/internet or by appointment at home, were not observed to significantly impact preferences, as compared to a pharmacist in the dispensary (p value ranging from 0.303 to 0.734). This finding was consistent with the preferences of consumers/carers.
- *Average cost per month for the service:* There was a trend for health professionals to expect consumers to prefer a pharmacy service that was available at a lower cost; however, this trend did not reach statistical significance ($p = 0.393$). This finding was consistent with the preferences of consumer and carer participants.

Impact of health professional/worker characteristics on choice

Substantial variation was observed in how health professionals perceived their consumers would make choices about continued medications supply, managing an on-going condition, pharmacy location and cost. A number of participant characteristics explained this variation for each of these service characteristics:

- *Continued medication supply:* Health professionals who had been in their profession for under five years and those who were also a consumer with chronic condition(s) or carer themselves were more likely to report that consumers would value access to a pharmacist for on-going supply of regular medications and for

medications they have used previously for symptom flare-ups rather than having access to a doctor alone ($p \leq 0.05$).

- *Manage on-going condition:* Health professionals who indicated they worked in the private sector were more likely to report that consumers would prefer access to other health professionals employed in the pharmacy over pharmacy staff directing them to other services ($p = 0.004$).
- *Pharmacy location:* Health professionals identifying as being from an Aboriginal or Torres Strait Islander background themselves perceived their consumers to be more averse to a pharmacy near a GP practice compared to a pharmacy near their home/work ($p = 0.007$), as opposed to health professionals who did not identify with an Aboriginal and Torres Strait Islander background.
- *Average cost per month for the service:* Health professionals who were from Northern Rivers perceived their consumers to be less averse to cost than health professionals from Logan-Beaudesert ($p = 0.009$). Health professionals identifying as being from an Aboriginal and Torres Strait Islander background also perceived their consumers to be less averse to cost ($p = 0.006$).

Priorities for the provision of pharmacy services

Figures 4.10 and 4.11 show the relative importance of different features of service provision, according to the preferences of all participants. Sizes of the bar represents the relative importance of each feature after rescaling the model coefficients such that the most preferred service was given 100 points, and all other services were given fewer in proportion to their relative importance for that sample. The colours of bars represent the attributes, as per the colour code in Figure 4.09.

On average, consumers and carers placed the highest priority on continued medication supply from a pharmacist for regular medications and medications used intermittently to address symptom flare-ups (score 100). This was valued more than one-and-a-half times as much as pharmacy location in a one-stop health centre rather than near their GP practice (score 61), and twice as much as having the availability of home delivery in addition to face-to-face collection (score 52). Other characteristics were valued to a substantially lesser extent. This finding confirms the high priority of continued medication supply and providing convenient and coordinated care in a one-stop health centre. This is consistent with findings from Stage Two.

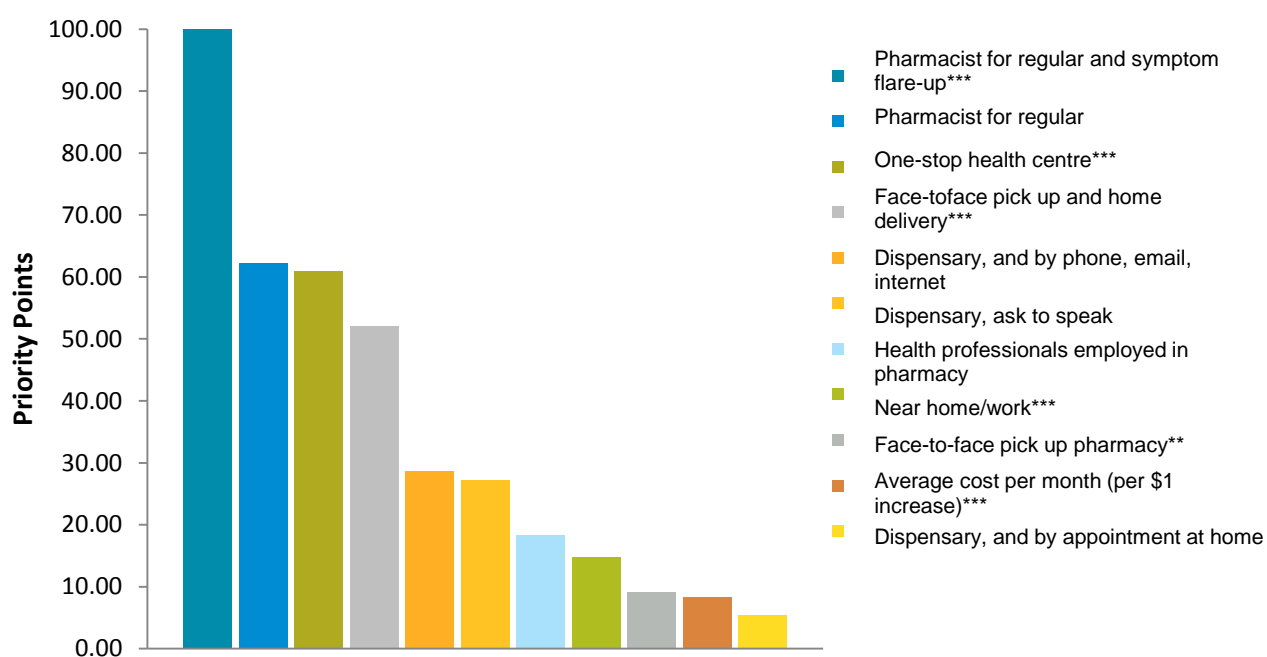
On average, health professionals expected their consumers to place highest priority on having a pharmacy location near their home/work (score 100) or in a one-stop health centre (score 88) rather than at a GP practice. Pharmacy location near home/work was expected to be valued one-and-a-half times as much as continued medications supply for regular and symptom flare-up medication (score 67), and more than twice as much as having the availability of home delivery in addition to face-to-face collection (42). Other characteristics were valued substantially less. Thus, although the attributes health professionals expected their consumers to prefer were largely consistent with consumers and carers actual preferences, some inconsistencies in the relative priorities were evident. Notably, continued supply was the most important priority for consumers and carers, whereas pharmacy location was perceived to be of the highest priority by health professionals.

Figure 4.09: Attribute colour coding for figures 4.10 and 4.11

	Key for Figure Bars	Least preferred level ^a
	Continued medication supply	<i>Doctor for all</i>
	Pharmacy location	<i>Near GP practice</i>
	Getting your medications	<i>Face-to-face pick up pharmacy and collect e.g. drive-through (consumers and carers)</i> <i>Face-to-face pick up pharmacy (health professionals)</i>
	Access to pharmacist	<i>Pharmacy, no need to ask (consumers and carers)</i> <i>Dispensary, ask to speak (health professionals)</i>
	Manage on-going condition	<i>Pharmacy staff direct to services</i>
	Average cost per month	<i>Per \$1 increase</i>

^aLeast preferred level aids interpretation of Figures 4.10 and 4.11.

Figure 4.10: Consumer and carer priorities for pharmacy services

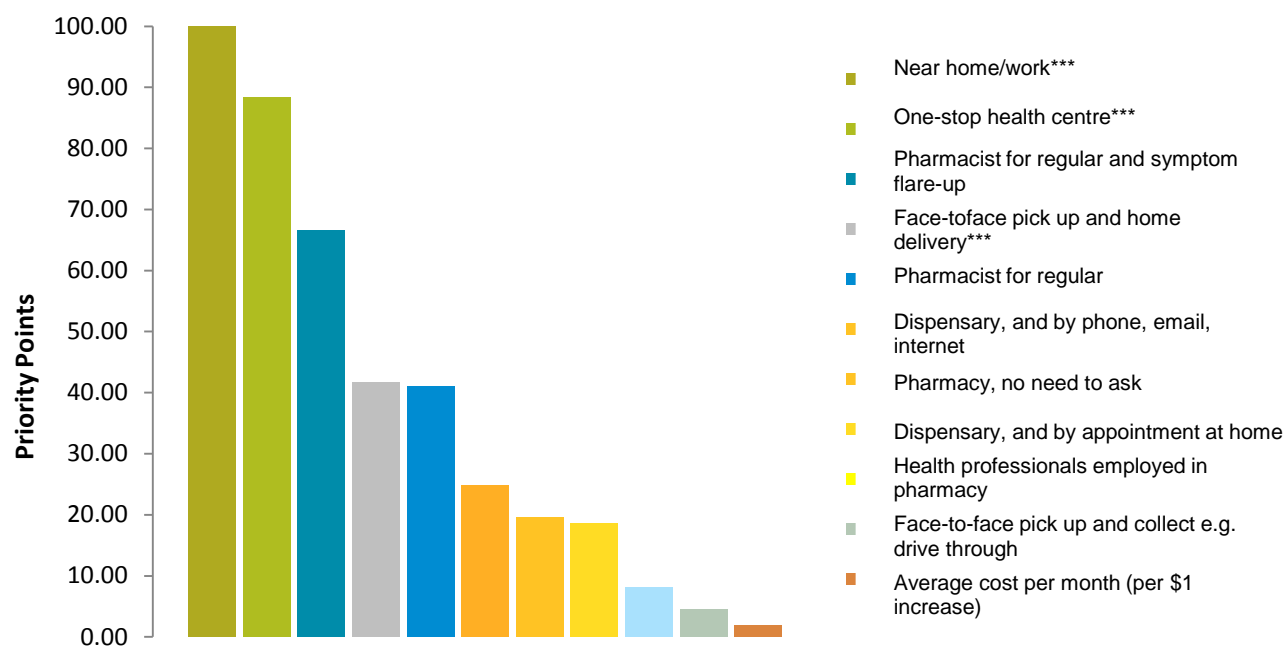


Bars are colour-coded for attributes; order of legend is consistent with order of bars.

Size of bar represents relative value of a gain in attribute from the least preferred level (defined in Figure 4.09).

***, ** ==> Relevant parameter (numerator) was significant in this model at the 1% and 5% levels.

Figure 4.11: Health professional perception of consumer and carer priorities for pharmacy services



Bars are colour-coded for attributes; order of legend is consistent with order of bars.

Size of bar represents relative value of gain in attribute from the least preferred level (defined in Figure 4.09).

***, ** ==> Relevant parameter (numerator) was significant in this model at the 1% and 5% levels.

Key Findings

- **Relatively poor level of quality of life:** Chronic condition(s) appear to have a substantial impact on participants with chronic condition(s) and carers. Consumers reported a high level of morbidity across all dimensions of quality of life;
- **High users of health services:** Consumers and carers were generally high users of community pharmacy, with 56.3% visiting a community pharmacy at least fortnightly. Participants were also high medication users, taking an average of seven different prescribed or over-the-counter/complementary medications, across almost three times per day;
- **Financial burden is an important domain of treatment burden:** Participants described treatment burden across all five burden domains, including financial burden. Further, the cost of medications affected medication adherence for our participants, with about a quarter of consumers reporting they have delayed the purchase or not purchased prescribed medications during the last 12 months due to expense;
- **Uptake of entitlements designed to relieve financial burden:** Despite a high proportion of participants having below average household income and qualifying for a concession card, fewer than half reported reaching the PBS safety net threshold. This is surprising, given the survey was primarily conducted in the last quarter of the entitlement year and participants reported a comparatively high level of medication use;
- **Key characteristics associated with reduced quality of life and/or increased treatment burden:**
 - High users of health services and medications reported lower levels of quality of life. Experiencing two or more chronic conditions, taking medications three or more times per day, and frequent visits to a community pharmacy or GP were all associated with reduced quality of life;
 - The burden of treatment including financial burden appears to fall disproportionately on younger consumers. Older consumers reported worse quality of life in some domains and reported taking a higher number of medications each day. However, younger age was associated with higher levels of treatment burden, and middle-aged consumers (41-60 years) were more likely to delay access to or not obtain medications, because of cost;
 - Consumers who reported diabetes or another endocrine condition reported higher levels of treatment burden;
- **Loyalty to community pharmacy:** Over two thirds of consumers and carers reported visiting the same pharmacy most of the time. Furthermore, when offered hypothetical choices between different pharmacy services and their current service, nearly half always chose their current pharmacy service. Key reasons given for this loyalty were:
 - The patient centred approach of their current pharmacy service;
 - The responsiveness of their current service to their medication needs in terms of continuity of care and knowledge associated with their current provider; and
 - Convenience;
- **Priorities for characteristics of pharmacy services:** Consumers and carers exhibited strong preferences for the opportunity to access continued supply of medications from a pharmacist, a “one stop health centre”, and home delivery of medications. They placed the highest priority on

access to continued medications supply from a pharmacist for regular and symptom flare-up medication, which was valued more than one-and-a-half times as much as a pharmacy location in a one-stop health centre instead of GP practice and almost twice as much as having the availability of home delivery in addition to face-to-face pick up:

- Younger consumer and carer participants and those with higher treatment burden were more likely to choose to take up a new pharmacy service. Younger participants were also more likely to have a higher level of treatment burden. Providing services addressing their preferences is an important avenue to explore in the management of treatment burden;
- **Health professional/worker perceptions of consumer priorities:** Overall, health professionals/workers appear to have a good level of understanding about what services they believe their consumers would like from community pharmacy.

Insights for community pharmacy: New or extended services

- Prioritise and advocate policies to enable the continued supply of regular prescription medicines and those used previously by consumers to manage a symptom flare-up, by pharmacists within an appropriate framework of regulation and protocols to ensure quality and safety. Target these towards the needs of younger consumers, those in employment, and those with more established rather than newly diagnosed conditions. Key health professional champions of these policies are likely to be those who have most recently entered their profession or who have personal experience of chronic conditions;
- Promote strategies that support the establishment of community pharmacy as part of a one-stop health centre;
- An important goal is to provide pharmacy services that address the needs of younger consumers, who have the highest treatment burden and who are most likely to take up a new pharmacy service;
- Extending pharmacy services for consumers with diabetes and other endocrine conditions who are likely to have high levels of treatment burden;
- Further research should be prioritised into the needs and preferences of younger consumers with chronic conditions related to the provision of pharmacy services and medicines management.

Insights for community pharmacy: Improvements to existing services

- Provision of patient centred care, which is within the internal control of the pharmacy (i.e. not subject to regulatory or cost barriers), is likely to be a key driver of consumer loyalty and satisfaction with a pharmacy service;
- Frequent contact by consumers and carers with community pharmacy provides an ideal opportunity for consumer engagement and enhanced medicines and health management;
- An evidence-based review of the co-payment and other financial benefit systems for individuals with chronic conditions, with a view to optimising the needs of consumers (reduced financial burden and improved compliance) and the health system (sustainability), should be considered.

Insights for community pharmacy: Training and education

- Education of consumers with chronic conditions to ensure they understand financial entitlements related to their medicines use and treatment, could help improve compliance and alleviate financial burden;
- There is a need to increase consumer and carer awareness of the medications they use. Community pharmacy staff have an opportunity to promote the use of individualised medication lists (such as National Prescribing Service Medicines List) for people with chronic conditions and their carers. This should include the medication name, dose, frequency and details of the indication in each case;
- Increase the specific focus on patient centred care in the learning outcomes and content for health professional and pharmacy education and training programs.

5 Key Findings and Recommendations

This section provides the:

- a) Key findings regarding the perspectives of health consumers' and their carers' on the burden of chronic disease and multiple treatment regimens, and their expectations of community pharmacy; and
- b) Key recommendations regarding the role that community pharmacy can play in assisting consumers with their chronic conditions and complex treatment regimens.

The findings of this research should be widely disseminated to professional and consumer organisations, pharmacists and support staff to promote awareness and implementation of pharmacy services that reduce treatment burden and promote wellbeing among people with chronic conditions.

1. Whole-of-pharmacy patient centred services are of prime importance to consumers and carers and influence pharmacy choice and loyalty, satisfaction, perceived quality of service and treatment burden.

Our systematic literature review demonstrated that consumers value, desire and benefit from patient centred services that are holistic, individualised, respectful and empowering (pg.28, Box 2.2). Interviews with consumers and carers confirmed the central importance of patient centred health services, which can influence choice of pharmacy (pg.43, Figure 3.1). This is particularly important, given that medication use is a key contributor to treatment burden (pg.27, Box 2.1) and pharmacy is a critical point of intervention to reduce burden for consumers with chronic conditions (pg.32, Box 2.3). Our findings indicate that pharmacy could positively impact upon this burden by providing patient centred services that promote informative and respectful relationships, clear communication, and engagement with consumers (pg.28, Box 2.2). Empowering consumers through small but consistent practice changes can promote consumer and carer satisfaction, pharmacy loyalty, perceived quality, a relationship of trust and facilitate medication adherence, ultimately translating into improved outcomes for all parties (pg. 28, Box 2.2). These findings align with a key finding of the 5th CPA project, *Consumer Needs Project*, that knowing and trusting the pharmacist or staff is a key reason for consumers remaining loyal to a pharmacy [122]. Importantly, the interaction with the pharmacist was the second most important factor influencing pharmacy choice for those consumers aged 50 years or older [122]. Thus, pharmacy is a critical point of intervention for reducing burden of consumers with chronic conditions.

Consumers and carers were clear about their requirements of patient centred services (pg.41, Table 3.5) and nominated this as a primary reason for remaining loyal to one pharmacy (pg.43, Figure 3.1; pg.107, Section 4 Summary). Central elements of patient centred care were nominated as a top priority for consumers, and health professionals recognised its importance to their consumers and carers (pg.52, Table 3.9; pg.53, Table 3.10; and pg.99 Table 4.7). Stakeholder participants reported that patient centred services constituted more than just friendly pharmacists and pharmacy staff and personalised (patient focused) service, and required a shift of power and control of health to consumers (pg.33, Section 2.2 Summary). Consumers described this as being recognised as individuals, having their needs understood, experiencing healthcare that accommodates their goals, delivers proactive information and monitors their progress (pg.41, Table 3.5).

Stakeholders expressed the view that while many barriers hamper patient centred care (pg.33, Section 2.2 Summary), pharmacy services are not limited by structural or financial barriers and do not require a greater investment of time to be successful (pg.28, Box 2.2). However, education and training about patient centred care and the nature of treatment burden will be required to ensure a whole-of-pharmacy approach to service delivery.

Training and improved workforce development strategies were identified as important responses for pharmacy, particularly in the context of cultural and remote communities (pg.79, Section 3.2 Summary). Importantly, in the Stage Three survey, health professionals identified features of patient centred pharmacy services as high priority for consumers and carers (pg.99, Table 4.7), indicating a fertile environment for change and improvement.

Recommendations

a. To assist pharmacies in developing patient centred services, an implementation support unit should be established. The support unit should develop understanding of the continuum of patient centred services (see pg.61, Figure 3.5) and assist pharmacies to progress to the highest level possible within the constraints of their settings. Examples of support strategies could include:

- Site visits and mentoring;
- Telephone coaching;
- Online resources and support;
- Training opportunities for pharmacists and pharmacy support staff;
- Advocacy for inclusion of patient centred training in tertiary curricula;
- Advice on methods for facilitating privacy and respect within pharmacy contexts (beyond implementing a separate consultation area [123]);
- Case studies of new innovative patient centred services from the profession;
- Economic analyses and business models to support pharmacy in adopting new services; and
- Consumer and carer stories of success through patient centred services.

b. A range of patient centred tools and processes should be developed, but must be sufficiently flexible to accommodate diverse pharmacy settings and the unique needs of particular customer bases. Examples could include:

- Personalised medication labels with empowering messages to consumers;
- Personal greetings and introductions to staff members;
- Methods for retaining historical knowledge of consumer conditions and personal contexts;
- Appropriate storage and monitoring of personal records and prescriptions;
- Respecting consumer medication brand choice;
- Prompts for questions pharmacists and pharmacy support staff can ask consumers and carers;
- Methods for tailoring pharmacy services to knowledge of consumer conditions; and
- Prompt sheets for consumers ("questions to ask your pharmacist").

c. Existing programs that encourage a culturally diverse workforce and facilitate cultural sensitivity should be promoted and supported within pharmacies and the profession.

d. Research exploring application of patient centred care within a pharmacy context is limited. Investigations need to determine how it can be effectively implemented across different pharmacy settings and subsequent pharmacy and consumer outcomes.

2. A continuous and reliable supply of medication and high quality advice achieved through creative, personalised, responsive, flexible and proactive services is highly valued by consumers and carers.

High users of pharmacy services were often using five or more medications (pg.107, Section 4 Summary) and experienced large levels of treatment burden. Consequently, they valued a pharmacy capable of providing

reliable access to continuous, safe and quality supply of medication, particularly in rural areas (pg.58, Figure 3.3; pg. 72, Figure 3.9; and pg.107, Section 4 Summary). This was described from two perspectives, continued supply of prescription medications by the pharmacist (without visiting a doctor), and convenient medication supply from the pharmacy.

Continued medication supply was the most important priority identified in Stage Three (pg.105, Figure 4.10) and was frequently discussed in nominal groups (pg. 65-66, Table 3.13). There was a strong preference for pharmacists to supply regular medications for a predefined period as well as medications previously used to relieve symptom flare-ups. Health professionals acknowledged the importance of continued medication supply, yet failed to fully grasp its significance to consumers (pg.105, Figure 4.10; and pg.106, Figure 4.11). These findings align with recommendations that pharmacists could reduce GP workloads in underserved areas, by repeat prescribing regular medications used to treat chronic conditions, for up to 18 months [77]. There is potential for this identified priority to expand the 5th CPA *Continued Dispensing* service [124]. Currently *Continued Dispensing* allows a pharmacist to provide a repeat supply of only two eligible medicines (statins and oral contraceptives) that have been previously prescribed, but this supply mechanism could be extended to include other medicines for people with chronic conditions (i.e. where the treatment is stable and the prescriber supports continuation of the medicine).

The ability to easily obtain medication acted as an underlying driver of pharmacy patronage (pg.72, Figure 3.9 and pg.107, Section 4 Summary) that is critical to community pharmacy planning. Solutions proposed to improve medication supply included home delivery, extended opening hours, and other flexible, practical options (pg.67, Figure 3.6). Although consumers valued home delivery over face-to-face pick-up of medications (pg.105, Figure 4.10; and pg.106, Figure 4.11), they wanted to be able to contact their pharmacist when the need arose (pg.74, Box 3.2). However, according to the 2014 *Pharmacy Services Expectations Survey* conducted by The Pharmacy Guild of Australia, many pharmacies intend to either discontinue, reduce availability or increase the cost of many of these services (e.g. home delivery) [125]. Moreover, a quarter of pharmacies surveyed indicated that they are likely to shorten their opening hours [125].

Provision of high quality advice was viewed as a primary role for pharmacy (pg.51, Table 3.9; and pg.56, Figure 3.2), and consumers valued individualised explanations about medication from a qualified and credible source. Knowledgeable pharmacists that provide *good and accurate advice* was a key reason for 58% of consumers reporting satisfaction with their interaction with the pharmacist in the 5th CPA project, *Consumer Needs Project* [122]. In our study, absence of adequate information was evident in consumer reports of feeling overwhelmed, lack of privacy to ask difficult questions and misunderstanding about generic medications (pg.56, Figure 3.2). Consumers and carers were largely unaware of the range of services available from community pharmacy. Stakeholders described confusion over generic medication and low health literacy as key predictors of treatment burden (pg.33, Section 2.2 Summary), suggesting that high quality advice could reduce this.

Recommendations

- a. The feasibility and effectiveness of expanding the role of pharmacists in continued medication supply should be explored and advocated by the profession and consumer groups. International experience with pharmacy prescribing initiatives and extension of current mechanisms such as *Continued Dispensing* [124], can inform a streamlined introduction of this service priority in Australia.
- b. Funding streams should be identified for important services that facilitate supply, including home delivery of medications; repeat reminders (e.g. text messaging, email or telephone) and dose administration aids.

c. Innovative ways to streamline consumer medication supply should be investigated and implemented where possible. Examples could include:

- E-prescriptions and online/telephone orders;
- Pharmacy alignment of supply dates in cases of multiple prescriptions (in consultation with GP/specialists);
- Streamlining medication supply when doses are changed to reduce the burden of collecting new prescriptions or medication on different days. This requires funding and legislative flexibility for pharmacists to change medication supply quantities, as prescribed, to meet the needs of people with chronic conditions;
- Identifying when repeat prescriptions are not filled and exploring contributing factors;
- Providing personalised explanations about medication effects and interactions;
- Medication lists for consumers with multiple prescriptions (including promotion of existing lists (e.g. National Prescribing Service Medicine List);
- Dispensing software 'flags' that trigger personal contact with the customer;
- Ensuring adequate pharmacy stock for regular consumers;
- Increasing access to medication traditionally supplied via hospitals;
- Increasing staff awareness and use of interpreter services; and
- Training staff on culturally appropriate resources and responding to low literacy.

d. Develop a campaign and methods to raise consumer and carer awareness of the range of services available from community pharmacy. There is opportunity to extend the work of previous campaigns through collaboration with other organisations such as the National Prescribing Service.

e. An implementation package of case studies and economic analyses is required for service adoption.

f. Research should evaluate consumer and pharmacy experiences, economic feasibility and impact of new services that promote accessible, affordable and quality use of medicines. Examples include:

- Consumer and carer experiences of new and extended services and the impact on treatment burden;
- Consumer and carer willingness to pay for new services;
- Insight into service uptake and implementation processes in pharmacy and staff experiences;
- Potential for innovative funding streams for new services;
- Economic modelling of potential funding frameworks that utilise healthcare savings or extending existing allied health funding (i.e. Chronic Disease Management) to include pharmacist services.

3. Pharmacy is a convenient, accessible and trusted location that can act as a health hub or central point for appropriate referral, access to other health professionals and timely multidisciplinary information.

Almost a quarter of consumers and carers visited a pharmacy weekly and over half of them visited at least fortnightly (pg.93, Figure 4.4; and pg.107, Section 4 Summary). This was associated with treatment burden and highlights the important role of pharmacy. Access to pharmacy services was a key consumer priority (pg.52, Table 3.9; and pg.58, Figure 3.3), particularly in relation to pharmacy being a safe health space offering innovative or after-hours access to the pharmacist.

Community pharmacy was proposed as being a central hub for information and referral to other support services. There is already an expectation that the pharmacist will refer consumers to other health professionals for treatment when they believe it is needed, as reported by 74% of consumers surveyed in the 5th CPA project, *Consumer Needs Project* [122]. However, in our study the pharmacy as a health hub was articulated as a more

structured concept along a spectrum of service that can be tailored to individual consumer and carer needs and pharmacy service offerings. Consumers and carers sought consistency and continuity over time, familiarity with staff and informed advice tailored to their needs. This role required pharmacists to play an active part in managing health information, personal records, prescriptions, follow-ups and a range of other services. Consumers and carers described pharmacy as an important physical location where they could be connected to relevant services, particularly community organisations, based on their individual needs (pg.32, Box 2.3; pg.46, Section 3.1 Summary; and pg. 63, Table 3.12). The potential for pharmacy to provide sign-posts to consumer support emerged as an important theme and was viewed as a useful strategy for directing referrals to the multitude of available community resources. Furthermore, this could reinforce pharmacy loyalty observed when consumers reported that their needs were met in a convenient and timely way (pg.107, Section 4 Summary). Alternatively, there was some discussion about having a one-stop shop where health professionals are co-located (pgs.105-106, Figures 4.10 and 4.11).

Recommendations

- a. Research should trial a range of alternative models of developing and implementing a flexible health hub service that could be tailored to individual pharmacies and their consumer population is recommended. As a concept the health hub reflects a spectrum of services including information about medications, symptoms, services, referrals and sign-posting to community-based support, tools and resources to support self-management (e.g. audiovisual displays, free telephone points to contact other professionals and referral letters).
- b. The use of portable health records that can be shared with other health professionals and community organisations, purposefully selected by consumers, is needed. There has been advocacy for greater uptake of Personally Controlled Electronic Health Records (PCEHR), which would address this need. This would allow pharmacists to work collaboratively in the chronic care team, as recommended by the Gratton Institute report [77].
- c. The feasibility and impact of different co-location models for pharmacy across a range of regions and cultures to inform new services should be investigated (i.e. co-located with community organisations, health professionals within pharmacy).

4. Pharmacy has great potential to prevent or limit burden for specific populations, particularly for younger people who are more willing to adopt new initiatives, for carers, frequent pharmacy users and individuals experiencing financial distress or high levels of burden.

Treatment burden is an important issue identified in this study. Throughout the qualitative and univariate quantitative analyses, treatment burden was revealed as an important indicator of openness to new services. However, when included in a multivariate analysis, treatment burden did not significantly predict service preferences beyond other important variables such as age, education level, employment status, and duration of diagnosis. It is likely that this finding reflects the fact that treatment burden and service preference are both related to these important variables. Given the challenges associated with identifying treatment burden, and the complexity of this concept as found in our concept analysis, it may not be helpful for pharmacy staff to make judgements about need based on their assessment of burden. Thus, despite the importance of this concept, our results suggest that further research is needed to understand this complex association more accurately.

Nevertheless, several subgroups within the sample emerged as areas of opportunity where proactive pharmacy services could prevent or reduce treatment burden. Younger people were more likely to take up new and

innovative services than older consumers (pg.107, Section 4 Summary). Opportunities exist for pharmacy to reduce burden and address illness progression through innovative services for young people, particularly those in the early stages of their chronic condition(s) who are not using as many medications. However, recognition that pharmacy services could alleviate unmet health needs of young New Zealanders [126] was tempered by calls that new services are youth-friendly and developed in consultation with young people [127]. Middle-aged consumers, who were high health service users experiencing treatment burden, delayed or avoided obtaining prescribed medication due to cost (pg.107, Section 4 Summary). Pharmacy is in a unique position to identify this consumer group and provide supportive and timely interventions (i.e. flexible supply of medication, assistance to access financial support). Similarly, carers were often hidden from view, not fully recognised in their role by health professionals, including pharmacists and pharmacy support staff. Given the importance of carers to the wellbeing of care recipients, and the fact that many carers (139 out of a total of 152) frequently visited pharmacies to collect medication and also reported managing their own chronic conditions, this group represents an important focus for pharmacy.

Many participants accessed pharmacy at alarmingly high rates (pg.93, Figure 4.4; and pg.94, Table 4.6), possibly due to having to collect repeat prescriptions on different dates and because they used a high number of medications (pg.107, Section 4 Summary). Irrespective of the reason for high visitation rates, frequent pharmacy use was associated with high levels of burden and poor quality of life (pg.107, Section 4 Summary). High levels of burden were associated with the presence of diabetes (or other endocrine conditions) in particular, a chronic condition for whom pharmacy already represents an important service. Pharmacy represents the best healthcare setting for identifying and supporting those who are experiencing burden. Furthermore, two-thirds of consumers visited the same pharmacy most of the time (pg.94, Table 4.6), indicating that pharmacy is a frequent and consistent point of intervention for a large number of people with chronic conditions. As the frequency and duration of contact with pharmacy is not limited by funding structures, such as those associated with GP visits, these frequent attendances at pharmacy provide an opportunity for targeted and personalised support. Potential roles suggested for pharmacists in collaborative chronic care management could address these issues. These include adjusting doses, discontinuing therapy, treating acute conditions and continued medication supply [77].

Recommendations

a. Research funding should be made available for conducting trials of innovative services directed at high-risk groups, such as younger users, low-income earners, high pharmacy users, (particularly those with diabetes) and carers. Evidence gathered in earlier Pharmacy Agreements (e.g. diabetes, adherence) should inform research and subsequent service implementation.

b. Classification of their consumers according to regularity/frequency of visits, sociodemographic factors and burden, could enable pharmacies to effectively target new initiatives. Examples could include:

- Targeting new initiatives, particularly those delivered through online modalities, to younger or new consumers not yet locked into a pattern of service use;
- Strategies to prevent burden in frequent pharmacy users, such as flexible supply responses, streamlining of prescription refill dates and wellness checks;
- Implementation of carer support systems (e.g. information packages and connections/referrals, wellbeing check-ups and carer cards to enable easy collection of medications by identified carers); and
- Review and broader implementation of existing disease management programs (e.g. diabetes) is needed.

5. Financial burden is inherently linked to medication use/non-use and in the absence of broader systemic changes can be identified and addressed by pharmacy.

Affordability emerged repeatedly as a key priority from the perspectives of consumers, carers and health professionals (pg.52, Table 3.9; pg.53, Table 3.10; and pg.60, Figure 3.4). Loyalty to a particular pharmacy was influenced by medication expense (pg.43, Figure 3.1), availability of affordable retail items and pharmacy flexibility in response to financial burden (pg.107, Section 4 Summary). Three factors contributed to perceptions of affordability: decreased costs through low prices or prescription subsidies (e.g. CTG); maintaining price consistency across pharmacies; and responsive payment methods that accommodate financial stress (pg.60, Figure 3.4).

Financial burden was a key component of overall burden experienced by consumers and carers (pg.37, Table 3.2; pg.98, Figure 4.7; pg.107, Section 4 Summary), and about a quarter of participants reported delaying or not purchasing prescribed medication in the preceding 12 months due to cost (pg.107, Section 4 Summary). This indicates the need for information on and access to financial support, as well as medication information for informing consumer choices. Government subsidies were considered vital by consumers and carers, yet there was limited awareness of these subsidies and the PBS Safety Net scheme (pg.56, Figure 3.2; pg.60, Figure 3.4; and pg.79, Section 3.2 Summary). Cost was a barrier to consumers and carers accessing new services, with many participants electing not to pay for any new pharmacy services in the discrete choice experiment. Advocacy is needed on behalf of consumers, particularly in the light of recent recommendations to increase medication co-payments and introduce a mandatory co-payment for GP services [128]. The New Zealand experience of a \$2 NZD increase in prescription co-payments acted as a barrier to medication access [63]. Cost has been identified as a significant barrier to medication access particularly for those self-reporting poor health, high psychosocial stress, and two or more comorbidities [129]. A quarter of the participants in our study reported that cost was a barrier resulting in deferred use of medication. Any co-payment increase is therefore likely to significantly impact on consumer long-term health, and increase morbidity and mortality rates.

Recommendations

- a. Financial barriers to medication access, especially co-payments should be capped, reduced or removed for certain populations. Research should examine and monitor the impact of any changes.
- b. More flexible medication payment options should be explored, such as direct Centrelink repayments to the community pharmacy, consistent pricing for common medications and supports to use existing entitlements, such as the PBS Safety Net and CTG.
- c. Consumers and carers who are likely to experience financial burden should be identified and informed about financial entitlements and subsidies, such as PBS Safety Net requirements, and links to community assistance schemes, to promote adherence. Pharmacy staff should be aware of, and promote the use of, existing smart phone technology linking family Safety Net records [130].
- d. Consumer and carer understanding of generic brands should be promoted to facilitate informed and affordable choices. This should include education by pharmacists and support staff.
- e. In the event of changes in medication co-payments, research must investigate and monitor the impact of these changes on rates of delaying or deferring purchase of medications.

6. Pharmacy services need to be tailored to economic, personal, cultural and geographical circumstances of their customer base, as prevailing needs and values differ depending on the environment in which the pharmacy is accessed.

There is no single model of pharmacy service that is capable of addressing the needs of diverse consumers and carers across various regions of Australia. In this study, ideal pharmacy service did not reflect a particular model, but focused on the timely, reliable and coordinated provision of medication and sign-posting to services within a patient centred and responsive relationship. If these characteristics were present, most consumers and carers would remain loyal to their pharmacy (pg.107, Section 4 Summary).

Consumers and carers clearly recognised that structural and societal barriers limit the flexibility of pharmacy services. Nevertheless, they articulated that pharmacy needs to embrace a consumer-driven approach that responds to the cultural, economic and service delivery circumstances of each region and individual consumers (pg.51, Table 3.9; and pg.99, Table 4.7). Health professionals generally identified and were sympathetic to the preferences of consumers and carers (pg.99, Table 4.7). This level of understanding of consumer needs provides a receptive environment within which to nurture innovative service designs. Given that the perceived quality of the service environment has the potential to reduce treatment burden, increase medication adherence, and maintain pharmacy loyalty, the engagement of consumers in a consumer-driven service design offers the potential for meaningful and viable solutions for all parties. This is especially pertinent in the light of the differences existing between regions, which confirm that no single service model is capable of addressing the needs of all regions (pg.54, Table 3.11).

Although many innovative services were recommended throughout this project, such recommendations necessitate creative solutions within the context of shrinking financial resources. Community pharmacy also needs to identify innovative ways of capitalising on existing services and opportunities to improve the fundamental characteristics of pharmacy already appreciated by consumers and carers. Importantly, consumers and carers revealed many innovative suggestions for pharmacy that warrant further investigation (pg.65-66, Table 3.13). Selected services are plausible (e.g. continued medication supply, increased home delivery and health hubs), and the delivery of a fundamental individualised response is relatively inexpensive and easy to develop with adequate support from The Pharmacy Guild of Australia and higher education institutions.

Recommendations

- a. Pharmacy should engage its consumers in quality feedback and improvement cycles, and seek consumer input into the design of solutions to ensure responsive practices.
- b. The Pharmacy Guild of Australia should focus on workforce development in terms of education, career pathways, role models and case studies, with the establishment of industry champions to motivate change and support normative shifts in practice.
- c. Attention should be given to implementation and evaluation strategies (i.e. appropriate change management tools and valid outcome/process measures) that can easily be used in the context of pharmacy. Research should explore ways of addressing barriers to change (e.g. financial pressures and interprofessional rivalries).
- d. Professional bodies, pharmacists and support staff should work with consumer and health professional organisations to advance public awareness about pharmacy services and their potential role in supporting the management of chronic conditions.

5.1 Strengths and limitations

Strengths of this research include the size and diversity of the sample and the combination of qualitative and quantitative methods. Stages One and Two involved a wide range of stakeholders, and a wide range of consumers and carers experiencing different types, severity and stages of chronic conditions representative of diverse cultures, widespread geographical areas and multitude of socioeconomic and demographic groups. Carers are often under-represented in healthcare research. We purposively recruited unpaid carers in this research, identifying that they play an integral role in supporting the healthcare of the care recipient.

In Stage Three, predominantly quantitative methods were used, in which generalisability becomes more important. We sought a representative sample of older consumers who were extensive health service users. Greater insight is required into the specific needs of this population to inform effective allocation of health resources. The sample size was large, with over 600 consumers and carers from all regions included in the study. Within this sample, we used various strategies to ensure recruitment from diverse sources. Thus, our sample was both representative and generalisable despite being restricted to high-frequency pharmacy users.

The use of more than one data collection mode (CATI and face-to-face) could be considered a limitation, given that there may have been a systematic effect of the mode of data collection on participant responses. However, there was no evidence that this occurred. Further, this approach ensured the size, diversity and inclusivity of the sample.

We recruited a diverse range of health professionals and workers consisting of pharmacists, pharmacy support staff, GPs, allied health professionals and other health workers. Due to the limited numbers of GPs and pharmacists in rural and remote areas, the absolute numbers were small even though a high proportion of eligible participants responded.

To ensure the validity and reliability of our findings, on-going discussions were held by the research team with a Reference Group. A consumer researcher was involved throughout the project to ensure that the findings were grounded in consumer experiences. Each stage of the research informed the next, enabling a convincing and triangulated argument to be developed. The high level of consistency in the findings across all stages attests to the credibility of the study.

The discrete choice experiment (Stage 3) required the presentation of only a limited number of service attributes. It was not possible to examine every alternative, as the resulting questionnaires would have been unwieldy and the required sample size impossible to satisfy. As not all services in the DCE currently exist, some people may have found it difficult to rate the value of those services. Further, it should be noted that consumers and carers choices in a research environment may not necessarily reflect choices that would be made in a real-life situation. Nevertheless, the study provided an important indication of consumer and carer preferences that should inform future decision-making regarding pharmacy services.

5.2 Conclusion

The results of this research reveal many opportunities for community pharmacies to assist consumers with chronic conditions and their carers. The creative solutions proposed by consumers and carers in this project have real potential to positively impact on treatment burden. Overall, there is no single model of care that can be recommended for community pharmacists to deliver; tailoring patient centred services to consumers and their carers should be a priority for all community pharmacy staff. Ideally, care should be delivered within a holistic,

individualised, respectful and empowering environment that links effectively with other services to reduce treatment burden.

Consumers and carers wanted streamlined access to medication, both in consolidation of existing services such as home deliveries and innovative services such as continued medication supply. They valued the innovative pharmacy service of continued supply of regular medications by a pharmacist for a designated time period because it allowed streamlining of access to treatment and reduction of burden. Another key service to emerge from all stages of the research was the potential for pharmacy to provide quality advice and health information, identify specific consumer needs and connect them to relevant support services. These activities have been collectively described under the umbrella of a health hub and we acknowledge that the degree of uptake by pharmacies will depend on their capacity, capability and customer base. Any new service should be developed in consultation with service recipients to ensure it meets the local needs, but also accommodates and/or alleviates existing treatment burden without inadvertently adding further burden.

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