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Community  
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The Pharmacy  
Guild of Australia

# *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

**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

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 16.12.13).
- 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:10.1111/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 catch them and keep them: the influence of patient centred care on pharmacy choice for Australian residents with chronic conditions. *International Journal of Pharmacy Practice* DOI: 10.1111/ijpp.12075 (published online 18.10.13).
- 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 (published online 26.07.13).
- 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.

# 1 Introduction

## Chronic health conditions

Chronic or long-term health conditions are characterised as having a complex causality, with long periods of illness and functional impairment or disability [1]. The World Health Organization defines chronic conditions as including non-communicable conditions (e.g. diabetes), persistent communicable conditions (e.g. HIV/AIDS), long-term mental health disorders (e.g. depression) and ongoing physical or structural impairment (e.g. blindness) [2]. Globally, chronic diseases are the leading cause of mortality [3], equating to more than 36 million deaths in 2008 [4]. The number of people with multiple chronic conditions is rising [4-6], particularly in the older population, with 8.0% of Australians over 65 years reporting more than four conditions [5]. For consistency, the term *chronic conditions* is used in this report.

## Treatment burden

Despite significant advancements in healthcare, people with chronic conditions still experience *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.* [7]. Learning about, adhering to and monitoring treatment and engaging with others are key aspects of burden, particularly medication use [8]. In 2010, 262 million medicines were prescribed in Australia, primarily to treat chronic conditions [9] and it is estimated that Australians aged 65-75 years, will be using on average six prescribed medicines by 2019. Treatment burden has received limited attention from researchers and health policy makers. Moreover there is limited knowledge about the ability of health professionals to recognise and respond when people feel overburdened. Research has neglected the experiences of those with more complex needs [10], and the issues unique to culturally and linguistically diverse populations, Aboriginal and Torres Strait Islander peoples and persons who are socially disadvantaged. Unpaid carers are another population that experience burden differently through their support of people with chronic conditions and greater insight is needed [11].

## Patient centred care

Providing consumers with the opportunity to become involved in their own care is considered a core element of healthcare quality [12, 13] and an 'ethical imperative' [14]. Although there has been little consensus on the definition of patient centred care, there is some agreement on its key attributes and domains (Table 1.1) [15]. There is limited concrete evidence of the benefits of patient centred care and additional research is needed.

**Table 1.1: Key domains of patient centred care**

<b>Holistic care</b>	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.
<b>Individualised care</b>	Considers the unique history, specific needs, preferences and health concerns of an individual and customises health care to meet their needs.
<b>Respectful care</b>	Recognises and acknowledges consumer competence in their own care, respecting their right to choose and supporting their strengths and abilities.
<b>Empowering care</b>	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.

Source: Adapted from Morgan and Yoder [15] and McMillan et al. [16].

## Role of community pharmacy

Increasingly, pharmacists are being expected to shift from a "product centred focus towards a patient centred

focus” [17]. Furthermore, the Australian pharmacy profession endorses professional standards and policies that promote the delivery of patient centred services [18]. These include the Community Pharmacy Service Charter and also the Pharmaceutical Society of Australia’s Code of Ethics which specifically states that pharmacists must encourage health consumers to actively participate in their health care, with informed consent [19]. Despite a drive towards more patient centred practice, scant data are available on the pharmacy services and attributes of patient centred care that people with chronic conditions and their carers expect, and/or want, from pharmacists and support staff. As medication is frequently used in the treatment of chronic conditions, pharmacy staff members are likely to have frequent contact with these consumers. The increasing rates of chronic conditions and comorbidities [4, 9], generated 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 overall **project objectives** were to:

- 1) Undertake a literature review regarding the burden of chronic 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 conditions and of multiple treatment regimens; health consumers’ expectations of community pharmacy services and how these can assist with health management; and
- 3) Make recommendations on: the role community pharmacy can play in assisting consumers with their chronic conditions; strategies and/or models of care for community pharmacists to use when assisting consumers with chronic conditions and complex treatment regimens.

The **specific aims** were to:

- undertake a systematic literature review to identify current research on the burden of chronic conditions, related treatment, the benefits of patient centred care and tools to assess this;
- conduct stakeholder interviews to explore organisational perspectives of the burden of chronic conditions, perceptions of patient centred care, and the role of community pharmacy;
- conduct interviews and nominal groups<sup>1</sup> with health consumers and carers to fully explore the diversity of perspectives of the burden of chronic disease, 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.

### Project design

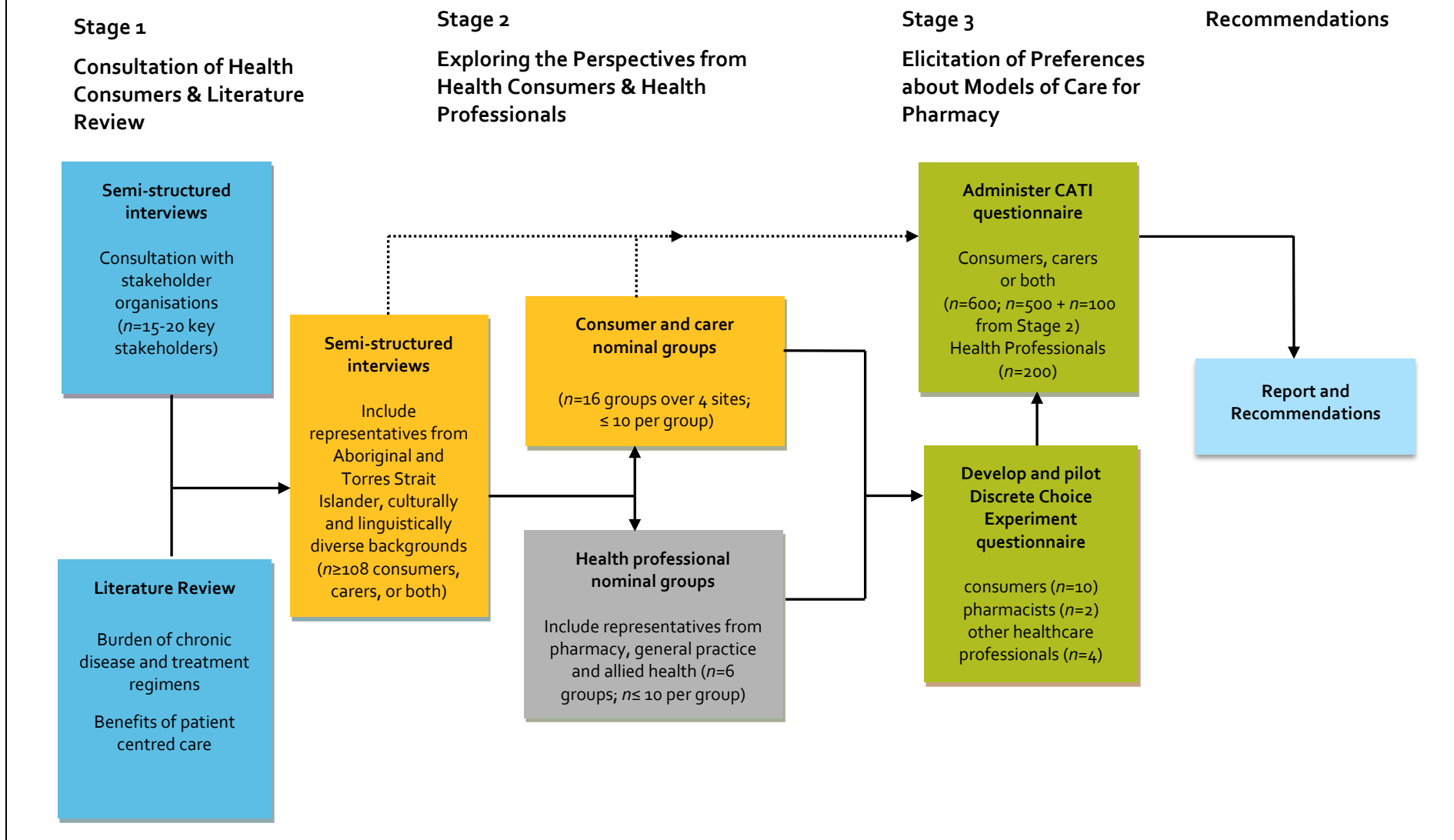
Commencing in November 2011, this 2.5-year project used a mixed methods approach over three stages (Figure 1.1). A total of 661 consumers with chronic conditions and their carers and 322 health professionals were recruited from four regions (Logan-Beaudesert and Mt Isa/North West in Queensland, Northern Rivers in New South Wales, Greater Perth in Western Australia) to participate in one or more stages of the research. Ethical approval was obtained from Griffith University and Queensland Health.

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<sup>1</sup> 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: Project outline (2011)**



## 1.2 Recruitment of participants

### Participant eligibility process

To ensure a diverse range of consumer and carer participants, at least one of the eligibility criteria needed to be satisfied:

- Health consumers with one or more chronic health conditions for at least six months;
- Health consumers recently diagnosed with a chronic health condition in the previous six months;
- Health consumers who had been self-managing their chronic health conditions and recently started using pharmacy services;
- Health consumers who are eligible for a Home Medicines Review;
- Health consumers who are high users of pharmacy or medical services;
- Health consumers who have or will reach the Pharmaceutical Benefits Scheme (PBS) Safety Net threshold;
- Aboriginal and Torres Strait Islander peoples who qualify for the 'Closing the Gap' PBS co-payment and have had at least one chronic condition diagnosed in the past six months; and
- Carers of health consumers with chronic health conditions.

For health professionals/workers to be eligible, they needed to be, or have recent experience of, working with consumers with chronic conditions, predominantly in the community setting, in one of the defined project regions. Interested individuals were asked to complete an expression of interest form by phoning a toll-free 1800 number, registering at the project website ([www.chronicillnessproject.com](http://www.chronicillnessproject.com)), or faxing a completed form to the research team.

### Recruitment strategies

Strategies involved targeted promotion of the study via consumer organisations (e.g. The Heart Foundation), professional organisations, and broader community based promotion (e.g. at community events). Pharmacy champions distributed project information in pharmacies. The project team distributed flyers in community and shopping centres, placed advertisements and media stories (e.g. regional newspapers), attended lunch meetings with health professionals in their workplace and presented at local conferences. Recruitment advice from stakeholders was sought (e.g. Medicare Locals, medical practices and health clinic visits). The research team engaged with community leaders and elders to ensure culturally appropriate engagement of certain populations. Participant recruitment continued throughout all stages of the project via snowballing, i.e. participant referrals.

### Participant incentives

Participants were offered reimbursement, based on their time, in the form of a supermarket gift voucher. Consumer and carers received: \$30 for Stage Two interview participation; \$50 for participating in a Stage Two nominal group; \$50 for Stage Three survey participation; or \$150 for all three parts. Health professionals/workers received: \$50 for Stage Two nominal group participation; and \$30 for Stage Three survey participation.

### Participants

In Stage One, 21 stakeholders from health consumer organisations, professional organisations, and four individuals with relevant expertise were consulted. In Stage Two, 200 consumers and/or carers participated; 97 in interviews and 103 in the 15 nominal groups. In Stage Three, 602 consumers and carers completed a survey.

More than 350 health professionals/workers were invited to participate in Stages Two and Three. In the Stage Two nominal groups, 61 individuals participated in 11 nominal groups. In Stage Three, 297 health professionals and health workers completed a survey.

## 2 Stage One: Literature review and stakeholder consultation

The following information is a summary of this stage; further detail is available in Appendices 3.1-3.7. This stage comprised two sections:

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

### 2.1 Systematic literature review and concept analysis

#### a. Patient centred care

Our systematic review revealed important insights for future pharmacy services (Box 2.1):

##### **Box 2.1: 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.

#### b. Treatment burden

Our concept analysis of the treatment burden literature revealed important elements of this poorly understood concept of importance to pharmacists (Box 2.2). Opportunities exist for pharmacy staff to reduce treatment burden, through improved communication with patients and medication management support.

### Box 2.2: 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. 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.

## 2.2 Stakeholder consultation

Insight into the views of mainstream health services and non-traditional service providers (e.g. consumer health organisations [CHOs]) is critical to development of truly patient centred services. In-depth consultation was conducted with health advocates and representatives of service providers to explore organisational perspectives on patient centred care, treatment burden, and pharmacy services, particularly as it related to their members.

### Method

Twenty-one semi-structured interviews were conducted from January to March 2012, either via telephone (n=11) or face-to-face (n=10). Stakeholders were purposively sampled to reflect diversity across the CHO<sup>2</sup>, pharmacy and health sectors. 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<sup>®</sup> to code transcripts into 'units' of data, and to categorise ('cluster') units until themes emerged. Interviews ceased once no more new ideas emerged (i.e. data saturation).

### Results

#### a. Patient centred care

There was a general consensus that patient centred care 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 inherent in the biomedical model of care.

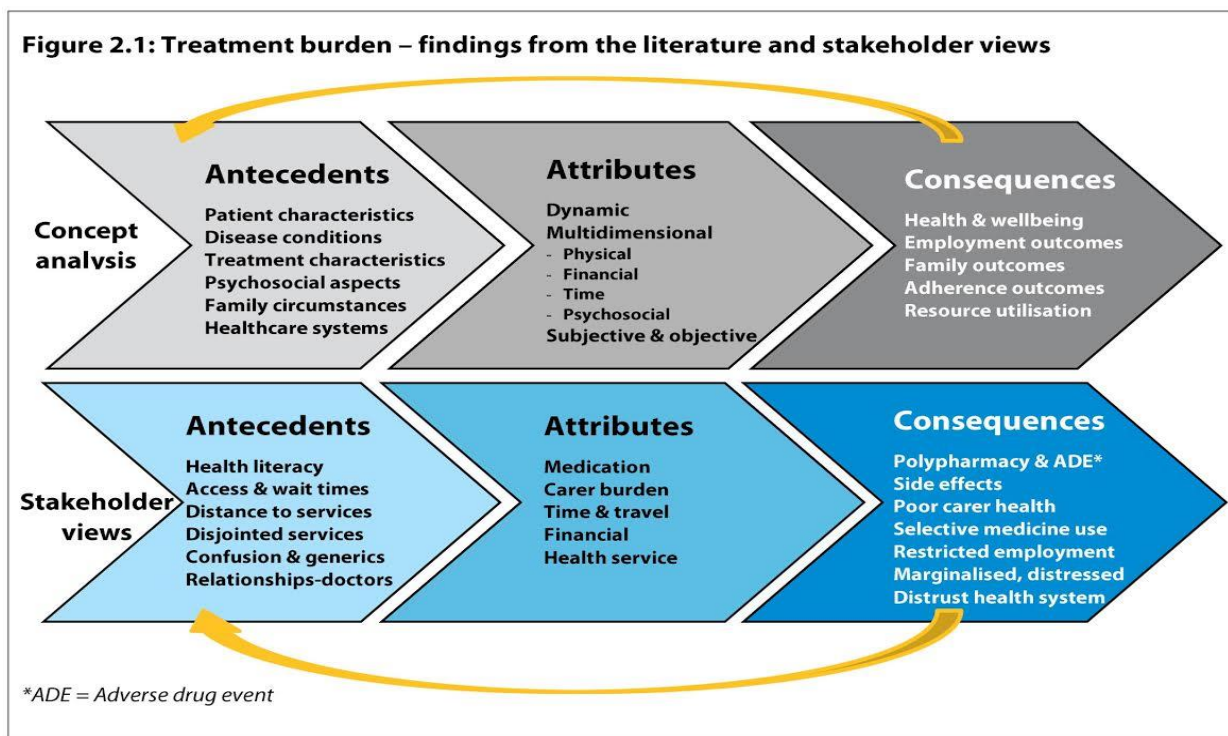
Organisational perspectives on patient centred care varied from a conceptual approach to the application of specific domains to services (holistic, respectful, individualised and empowering care) [15]. The latter approach delivered innovative, capacity building programs that encouraged consumers to take active control of their health. Participants described a wealth of innovative and under-utilised patient centred services delivered by their organisations, ascribing this to limited awareness and referral. It became clear that both pharmacy and CHOs are under-utilised health resources and that there is potential for them to work together to facilitate greater consumer access to patient centred services. It was acknowledged that significant changes in infrastructure, attitudes and behaviour are needed to facilitate widespread implementation of patient centred care and address potential barriers, such as health professional education and remuneration.

#### b. Treatment burden

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<sup>2</sup> Consumer organisations were selected to represent the chronic diseases identified as high priority areas by the Australian Government (National Chronic Disease Strategy; 2006).

Participants discussed treatment burden in the context of five broad attributes: *medication burden, carer burden, time and travel burden, financial and health service use burden* (Figure 2.1). Medication and financial burden were frequently discussed. Consequences included stigma, side effects, poor carer health outcomes and selective use of prescribed medications due to cost. Disjointed healthcare services were associated with consumer confusion, frustration, distress, and marginalised carers. Factors thought to contribute to burden (antecedents) included low health literacy, generic medication confusion, poor relationships with doctors, waiting and limited consultation times. Complexity of treatment burden was exposed when strategies introduced to address burden (e.g. dose administration aids) created another burden (e.g. financial).



### c. Community pharmacy

Community pharmacists were perceived to have an important role to play in the community. However, consumers may not be aware of the pharmacist's breadth of expertise and skills. One innovative solution proposed was for community pharmacy to expand beyond the provision of medication advice to become a health hub or healthcare destination. There was a strong perception that this more coordinated, holistic approach would promote greater uptake of community support programs and minimise treatment burden. Pharmacy was envisaged as becoming part of the *cycle of care*, through provision of medication support and referral to services, with three primary features: *healthcare system navigation, medication management and health advocacy*.

Participants acknowledged that structural and societal barriers face the pharmacy profession, particularly the current remuneration model, which emphasises product supply. They also raised concerns that limited consumer awareness of pharmacists' expertise could further impede role expansion. Other barriers described included the retail image of pharmacy, limited relationships between consumers, carers, and pharmacists, and a perception of pharmacists as reactive 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.'

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

The following information is a summary of this stage; further detail is available in Appendices 4.1-4.7 and 5.1-5.9. This stage comprised of two sections:

- in-depth, semi-structured interviews with consumers with a chronic condition(s), unpaid carers, or both;
- 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

##### Method

Semi-structured interviews ( $n=97$ ) were undertaken between May and October 2013. Questions explored the impact of chronic condition(s) on personal and professional life, managing the condition(s), and what they considered to be 'patient centred care' (Appendix 4.1). Participants were asked how pharmacy staff currently assist them and what other support they could provide. Participants reflected diversity in age, ethnicity and health condition (Table 3.1). Interviews were face-to-face ( $n=49$ ) or via telephone ( $n=48$ ), averaging 50 minutes (range 15-91 minutes). Three researchers analysed transcripts using the constant comparison method and QSR NVIVO 9<sup>®</sup> to develop 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	%		n	%
Participant type			Study location		
Consumer	70	72.2	Logan-Beauesert	41	42.3
Carer	8	8.2	Mount Isa and North West	15	15.5
Consumer and carer	19	19.6	Northern Rivers	21	21.6
			Greater Perth	20	20.6
Cultural background			Chronic condition(s) <sup>a</sup>		
Caucasian	55	56.7	One	10	11.8
Culturally and linguistically diverse	19	19.6	Two	19	22.3
Aboriginal and Torres Strait Islanders	23	23.7	Three or more	56	65.9

<sup>a</sup>Consumer and consumer/carers only. Source: adapted from McMillan et al. (64)

##### Results

##### a. 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 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 consumers' experiences and expertise. Participants had clear opinions about what was considered to be patient centred care and what was not (Table 3.2).

**Table 3.2: 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	Ongoing information exchange to inform and reassure
No consideration of individual health goals	Healthcare that is tailored to accommodate health and life goals

## b. Burden of illness and treatment

The impact of a chronic condition on a person was multifaceted, and the four inter-related components of treatment burden that emerged operated in a cyclical manner (Table 3.3). For example, contradictory advice from different health professionals (healthcare access burden) could lead to multiple medications (medication burden), requiring extra time to organise (time burden) and financial burden. Treatment burden was objective (e.g. number of medications) and subjective (e.g. medications perceived as a burden or praised as a source of relief and recovery).

**Table 3.3: 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 was described as highly problematic, particularly for those taking several long-term medications, or when multiple family members had chronic condition(s). Financial burden increased when medications were not subsidised on the PBS or costs varied between pharmacies. These findings align with



reports that financial burden reduces medication adherence [20, 21], particularly when co-payments are higher [21] or increase [22], with adverse effects on health outcomes [20]. Government subsidies, such as the CTG or the PBS Safety Net system, were perceived as alleviating financial burden. Limited awareness of eligibility for lower co-payments amongst some participants highlights the need for pharmacy staff to facilitate access to subsidies, particularly when circumstances change. Although pharmacy services were considered to reduce time burden (e.g. dose administration aids), this was offset by cost.

Restriction emerged as another particularly challenging issue, affecting employment and family life, with subsequent impact on psychological wellbeing and capacity to manage (Table 3.4). It was attributed to the chronic condition(s) (e.g. symptoms) or to employer and educator capacity to recognise and respond to specific needs. Certain aspects of restriction are unavoidable, while others can be improved through support from health professionals or community organisations.

**Table 3.4: Key elements of restriction**

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

### *Managing treatment burden*

Strategies to manage treatment burden encompassed CHO support, family support and self-management. Selected participants accessed CHO support, describing benefits related to knowledge of treatment options, practical coping strategies, connection to and learning from others [23]. However, limited referrals by some health professionals emerged as a barrier to CHOs. Aboriginal and Torres Strait Islander participants relied on family support over CHOs, and emphasised the importance of culturally appropriate health services. In rural areas, higher levels of organisation and planning were required to access treatment and there was a greater sense of community and self-reliance. Although self-management is important, for some it can contribute to treatment burden [24], and utility of standard self-management programs in the rural setting has been questioned [25, 26]. Alternative strategies include locally-directed and innovative forms of self-management devised between rural residents and health professionals [27-29]. Rural pharmacists are cognisant of the challenges experienced by local residents and able to help tailor self-management strategies [30], particularly if these strategies build on existing infrastructure.

These findings underscore the importance of alleviating treatment burden through individualised healthcare that considers each person's unique characteristics and preferences, and offers consumer-focused holistic care responsive to their needs. However, since treatment burden is a relatively new concept [24], health professionals may need additional skills to enable them to identify, explore and address treatment burden with consumers [31]. Furthermore, development of patient centred pharmacy services should consider both the attributes of



patient centred care that consumers and carers value, alongside how these address treatment burden in different contexts.

### c. Experiences of carer burden

When asked how community pharmacy could support them, most carers focused on medication supply issues similar to those described by consumers, and few were aware of potentially beneficial pharmacy services, such as dose administration aids (Table 3.5). They were often hungry for information [32, 33], about medications or organisations that could assist them in their role. Recognition of carers, especially those who do not self-identify, is not straightforward, as is ascertaining their role and responsibilities, and a 'carer card' could offer clarity [34].

**Table 3.5: Carer burden, needs and how community pharmacy can help**

Key elements of carer burden	
<b>Medication related burden</b>	
<ul style="list-style-type: none"> <li>Supply related issues (PBS quantities, availability)</li> <li>Logistics of coordinating prescriptions</li> <li>Confusion about generic medications</li> </ul>	<i>...most of the time they don't have all the medications available...So that is a bit of difficult. [CC_1124]</i>
<b>What carers wanted</b>	
<ul style="list-style-type: none"> <li>Personal support and support for consumer</li> <li>Information on medication and where to access help</li> <li>Respite from carer burden</li> </ul>	<i>...listen to me and my troubles or worry what I got, and if they can help me in that way...[CA_1169]</i>
<b>How pharmacy can help</b>	
<ul style="list-style-type: none"> <li>Acknowledge the carer role</li> <li>Listen and check in on the health of the carer</li> <li>Optimise stock control to meet individual needs</li> <li>Providing information on medication/health services</li> <li>Informing carers about available pharmacy services</li> </ul>	<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>
<b>Impact of carer burden</b>	
<ul style="list-style-type: none"> <li>Feelings of guilt and stress</li> <li>Self-neglect and isolation</li> </ul>	<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

### 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.

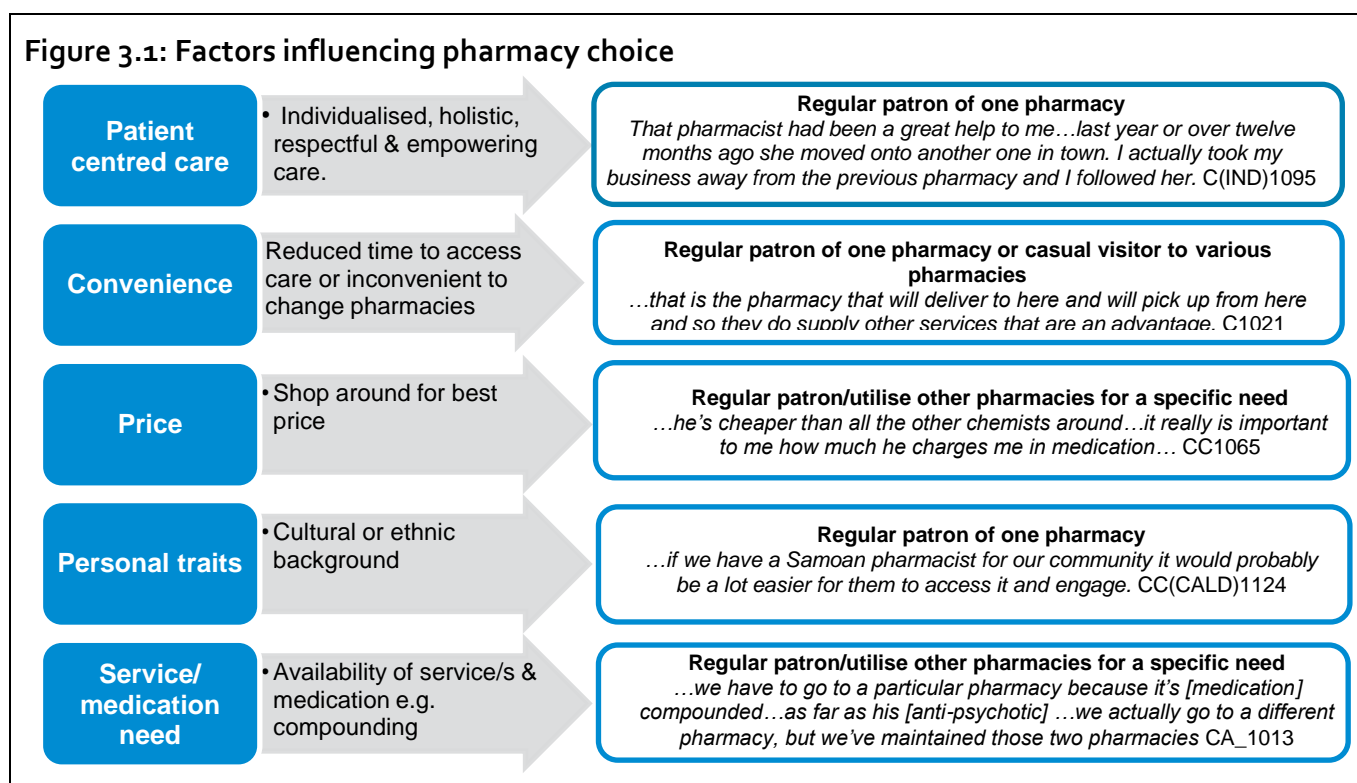
#### Consumer and carer experiences of community pharmacy

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 utilised another pharmacy to meet specific needs, and those who visited multiple pharmacies (i.e. casual user). Five key factors were identified as important to pharmacy choice (Figure 3.1) [35]. 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.

The importance of patient centred care featured prominently for regular pharmacy patrons, and was associated with supportive staff, caring and trusting relationships. Using one pharmacy was believed to promote medication

safety and individualised service through more complete medication history, and a similar 'protector' role emerged for mental health consumers [36]. The value placed on their relationship with pharmacy staff meant that a negative experience did not necessarily change their pharmacy choice. Convenience also remained important to pharmacy choice [37-39] and when service was poor, people did not change pharmacies if it was practically inconvenient.

Some participants did not expect or envisage a higher level of service elsewhere, and hence, did not perceive a reason to move pharmacies. Limited expectations were apparent in relation to medication management services; these were not drivers of pharmacy choice, reinforcing a need to explore consumer service awareness. However, patient centred pharmacy services that reduce treatment burden are likely to promote pharmacy loyalty.



### Consumer and carer knowledge and use of community pharmacy services

Low expectations of pharmacy services could be attributed to limited awareness of these services and a view that pharmacists were primarily medication suppliers with a technical (dispensing) role. It became apparent that consumers and carers *do not know what they do not know* about how pharmacy staff can support them and the services offered. Although participants were generally unaware of the breadth of the pharmacist's skill set, there was some discussion about seeking or obtaining the pharmacist's advice regarding new medication and drug interactions, or regular medication if they had additional questions. However, there was limited discussion about obtaining general health advice for their condition(s). Participants were less likely to seek advice from pharmacy support staff, yet acknowledged their broader role, including initial assessment of problems and triage to the pharmacist, provision of dispensed medication, and relaying pharmacist advice. Participants had limited understanding of the training and roles of support staff, particularly targeted use of their skills.

Barriers to seeking advice emerged, including a lack of awareness of the pharmacist's role, cultural barriers, lack of privacy and the retail focus of some pharmacies. 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 older participants, asked their GP instead. There was limited use of pharmacy services beyond dose

administration aids, home deliveries and blood pressure testing. It is possible that the pharmacies these participants used did not offer or promote additional services, they were considered too costly, viewed as providing no added benefit, believed unnecessary by consumers, consumers were unaware [40], or did not expect additional services [41].

### *New and expanded roles for community pharmacy in managing chronic conditions*

Few participants were able to provide specific recommendations about future roles for pharmacy. 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 care facilitators that promote effective referral of consumers to health and psychosocial support services. 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
<b>Access</b>	<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).
<b>Inform</b>	<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.
<b>Monitor</b>	<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).
<b>Connect</b>	<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), reduce treatment burden 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 in Australian regions where access to healthcare is limited [30]. However, any strategies for change need to address three fundamental factors: limited consumer expectations; innovation in pharmacy services and delivery methods; and capacity of pharmacists and pharmacy support staff.

## **3.2 Nominal groups with health consumers, carers and health professionals**

### **Method**

The NGT was chosen to identify what is valued by health consumers with respect to pharmacy services [42]. 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. In this study, the NGT was combined with an appreciative enquiry

approach to encourage consumers to be creative and solution-focused [43]. Participants were asked to propose and prioritise their ideas for ideal pharmacy services, while health professionals/workers were asked to reflect on what their clients would prioritise as ideal pharmacy services. Thematic analysis of initial group ideas was undertaken, with the resulting 12 themes used to code these ideas. The overall priorities for the entire consumer and carer sample, as well as for health professionals/workers were quantified (Table 3.8) using a framework by Van Breda [44]. The relative importance for each theme was identified for each group to allow for further group comparisons [45] and the qualitative data provided contextual insights into participant suggestions and preferences.

## Results

Twenty-six nominal groups were conducted between December 2012 and May 2013, involving 103 consumers and carers (15 groups), and 61 health professional/workers (11 groups). There were on average six participants per group (range 2-14 people). Nine groups were conducted in Logan-Beaudesert, five in Mt Isa and the North West region, and five in the Northern Rivers and greater Perth areas.

### a. Top five priorities overall for 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 3.7). 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, suggesting that quality is assumed or that people are currently satisfied with pharmacy services. It appears that health professionals/workers 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, or assume that patient centred care is integral to quality.

**Table 3.7: 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.*

### b. Consumer and carer priorities

**Consumer information or education:** Emerged as the top priority overall for ideal pharmacy services and was an important theme across all project areas. This was 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 (e.g. privacy).

Medication-related information was sought on a variety of areas, including their indications, possible side effects and drug interactions, and any medication changes or treatment updates. Further explanation was sought about the expertise and qualifications of support staff, the range of pharmacy services and entitlements available and the differences with generic medication. Health professionals/workers, consumers and carers all perceived information provision as the primary role of pharmacists. 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 straightforward, consumer-friendly way.

**Access:** There was a clear need for continued or better access to quality medication and pharmacy services. This related to *what* pharmacies supplied (e.g. medication and devices), *how* to increase access (e.g. home deliveries and opening hours), and influencing *factors* (e.g. the pharmacy environment). Regular pharmacy users expected pharmacy staff to be aware of their individual needs and maintain sufficient stock of medication, equipment and devices, particularly in rural areas where options were more limited: *Better supply of medications in rural areas, because you don't have the choice you have in the city...* [C\_1222 (Group 16; ISA)].

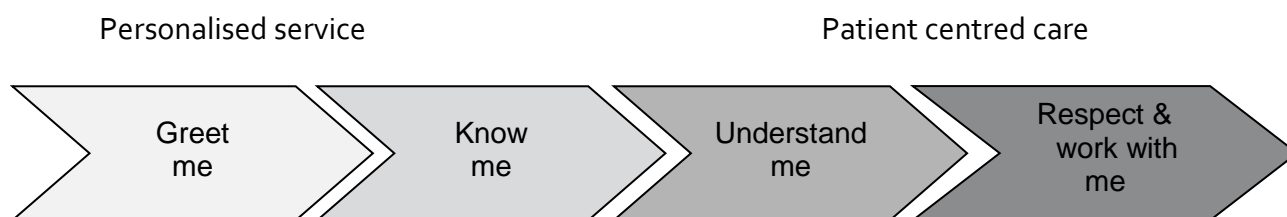
Convenience emerged as a key underlying theme to access, and consumer and carer suggestions for improvement included longer pharmacy opening hours (including 24 hours), being able to order medications from home and a drive-through service. A *pharmacy environment* conducive to healthcare access, such as a clean and comfortable environment (e.g. waiting area with chairs and water, no stock on the floor), increased privacy and more time with the pharmacist was also discussed: *I think if they [pharmacists] 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 (Group 7; L-B)].

**Affordability:** was the only consistent top five theme for all three carer groups, who are likely to be the financial support person for the care receiver. This was discussed as an 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. Consumers and carers appreciated the systems in place to reduce financial burden, and medication affordability was less of a priority or concern for Aboriginal and Torres Strait Islander participants, who attributed this to the CTG initiative. However, for other participants, affordability was a concern and subsequently, their ideal pharmacy services were described as being affordable: *More government funding for some of the different things that are provided. Like, you could make your Webster packing free....*[C\_1127 (Group 9; PER)].

A consistent discussion point was price discrepancies between pharmacies, particularly when pharmacies charged more for their products but did not provide a higher level of service. The need to increase staff knowledge about financial initiatives or schemes, and to introduce more payment options (e.g. direct payments via Centrelink), were also discussed: *[Pharmacy] could do a payment scheme because a lot of people aren't getting their medication because they can't afford...*[CC\_1184 (Group 2; L-B)].

**Patient centred pharmacy:** Consumer and carer views on patient centred care reflected a spectrum, from personalised service through to patient centred care that incorporated one or more attributes of patient centred care (empowering, respectful, individualised and holistic care) [15]. At a minimum, people wanted pharmacy staff to smile, be friendly, welcoming, attentive, and know their names (Figure 3.2). Participants appreciated staff who followed-up on their progress or provided services tailored to their needs. Respect was a collective need when interacting with pharmacy staff and included: maintaining privacy and confidentiality; respecting brand or medication preferences; and avoiding a patronising tone when questioning or providing advice. Respect was particularly important for Aboriginal and Torres Strait Islander participants; this could be facilitated by enhanced multicultural training for pharmacy staff and promoting opportunities for Aboriginal and Torres Strait Islander peoples to work in pharmacy.

**Figure 3.2: Spectrum of consumer preferences for patient centred care in pharmacy**



**Continuity and coordinated care:** Greater emphasis was placed on continuity and coordinated care in urban areas where more pharmacies are located. This was described from three key perspectives: co-location and coordination of health services or health professionals, healthcare records and communication. Suggestions included health professionals being located in a one-stop centre; having a coordinator, or other health care professionals, or both, located in the pharmacy; pharmacy staff situated within the medical centre; and pharmacy having the ability to directly refer to other services or specialists. The pharmacy was viewed as an ideal setting for this to be based, whether that was a pharmacist or another health professional: *They [pharmacists] could get paid to do care coordination through Medicare...[C\_1183 (Group 2; LB)].*

Some carers expressed frustration with being unable to obtain the medication for the person they cared for because of legal and confidentiality requirements. Although they acknowledge the legal constraints for pharmacies, a solution to address this issue was discussed in the form of a carer identity card; this would reduce the risk of being refused or 'interrogated' by pharmacy staff. Consumers and carers also 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: *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 (Group 9; PER)].*

**Innovative services and roles:** Continued medication supply was consistently identified as a new and desirable role for pharmacists. There was emphasis on continuing the supply of medications that were initially medically prescribed and that consumers were now stabilised on. This was described by various terminology, e.g. 'make', 'renew,' or 'prescribe' medication, within the proviso of a limited time frame, such as up to 12 months, thus ensuring an annual medical review. 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. 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: *Prescribe drugs, without having to go to your doctor...That would be one that would be helpful for me...[C\_CALD\_1069 (Group 5; LB)].*

Figure 3.3 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.

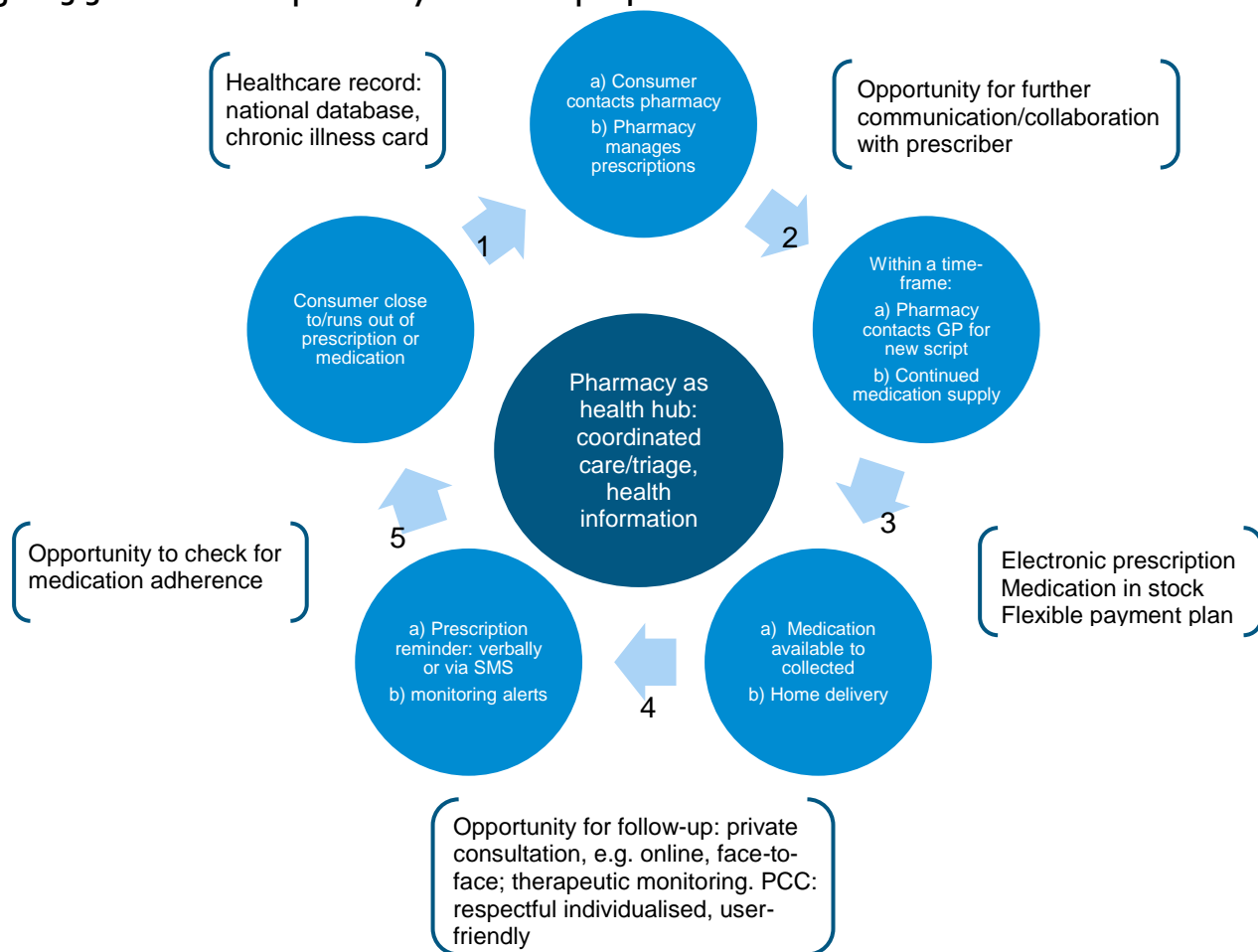
### c. Top five health professional priorities

Health professionals/workers believed that the following themes would be most valued by consumer and carers: continuity and coordinated care; consumer information or education; quality of service delivery; innovative services; and roles and affordability. While there were consistent views with respect to ranking consumer information or education and affordability, subtle differences emerged when describing what they involved. For example, 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 pharmacists ensuring the Quality Use of Medicines (e.g. medication reviews). Furthermore, GP and allied health professional groups focused on service quality; for pharmacists to provide quality, evidence-based advice and service, not driven by profit. Co-location of health professionals was mostly discussed by pharmacy-specific groups, and providing direct healthcare referrals was 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. Pharmacists also explored more innovative services and roles, such as the ability to adjust medication dosages, than other groups.

**Figure 3.3: Streamlined pharmacy access for people with chronic conditions and their carers**



PCC=Patient Centred Care

#### d. Comparison of consumer and carer and health professional/worker groups

Overall, priorities between consumer, carer, and health professional/worker groups were aligned with respect to certain themes. There was general agreement that consumers and carers would value a service whereby pharmacists renewed their chronic disease medication for a specified length of time. However, there were key differences, with consumers placing greater emphasis on access and patient centred care in contrast to health professionals, who placed a higher priority on quality of service delivery and innovative pharmacy services. 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.

In contrast to consumer and carer views, health professionals did not consider that their clients would prioritise patient centred care as part of their ideal pharmacy services. This could reflect a propensity to view pharmacy as

a business rather than healthcare destination, or an assumption that pharmacy services are already patient centred. The patient centred ideas that health professionals/workers did propose aligned with some consumer suggestions; being 'patient-focused,' supportive, providing professional customer service, and the development of a consumer-pharmacist relationship. Other examples of support included follow-up inquiries as to a consumer's progress, improved communication with consumers and families, and one GP group suggested that pharmacists facilitate self-management support groups. Although cultural awareness was not specifically discussed amongst health professionals as something they thought their clients would want from pharmacy, individualised care was.

Affordability was considered less of a priority by health professionals/workers, raising the question as to whether they were aware of the *extent* of financial burden for this consumer group. Providing pharmacy accounts or payment schemes were ideas raised solely raised by consumer and carer groups. 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. 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: *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; Brisbane)].

Quality of service delivery was viewed more of a priority by GPs and allied health professional than consumers and carers. 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 [46]. Particular emphasis was placed on ethical integrity, trust and for pharmacists to recommend evidence-based products based on consumer needs: *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.* [Allied Health Professional\_2108 (Group 26)].

Consumers and carers, other health professionals and GPs, all prioritised improved information provision as part of ideal pharmacy services: *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 (Group 24; LB)].

However, only one pharmacist group identified this as a priority, possibly because pharmacists perceived 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 complete healthcare/medication records, direct referrals to health professionals, and prescription and therapeutic monitoring (e.g. medical test) reminders. Implementation suggestions included installing a care-coordinator in the pharmacy (a pharmacist or other health professional). Streamlined care was further emphasised by health professional groups; pharmacists discussed having access to 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.



## 4 Stage Three: Elicitation of preferences from consumers, carers and health professionals about the delivery of pharmacy services

The overarching objectives of this stage were to: a) investigate health consumer **preferences for pharmacy services** to assist with the management of chronic conditions and multiple treatment regimens; b) quantitatively describe the extent to which treatment burden was reported by people with chronic condition(s); and c) compare perceptions of consumers and carers with health professionals about pharmacy services. For further details of the discrete choice experiment (DCE) see Appendix 6.1.

The survey consisted of the following parts:

- **Characteristics of pharmacy service(s) currently used (consumers and carers only)**
- **Importance of ideal pharmacy services (all participants):** Participants were requested to rate the expected impact of each pharmacy service using a scale of 0 to 100 (i.e. 100=very important service).
- **Preferences for characteristics of pharmacy services (all participants):** This part used a DCE to assess the preferred characteristics and relative priorities for pharmacy services, and relative priorities for implementing pharmacy services. Participants were each provided with four choice tasks, which asked a two-step question. All participants were initially asked to make a choice between two service alternatives, then consumers and carers only were asked to indicate whether they would access their preferred service if it were on offer, or remain with their current pharmacy service. Health professional participants were asked to indicate which service they thought consumers would prefer when making their choices.
- **Health conditions and treatment burden (for consumers and carers with a chronic condition):** This part asked the extent, duration, and the participant's experience of their chronic condition(s), as well as their use of medications, pharmacy and GP services. Treatment burden was assessed via a 15 item measure adapted from Tran *et al.* [47].
- **Health conditions (for carers only):** The questions related to the primary person they cared for.
- **Quality of life (for consumers and carers only):** The Australian version of the EQ-5D-3L was included to evaluate the quality of life [48].
- **Participant demographic characteristics (all participants).**

### Data collection and analysis

Surveys were mostly conducted by a Computer Assisted Telephone Interview (CATI) provider between October 2013 and January 2014 (Appendices 6.2-6.4). Some of the interviews (involving 54 consumers and carers, and 117 health professionals) were conducted face-to-face with participants (e.g. Aboriginal and Torres Strait Islander peoples). Data were initially analysed descriptively. The DCE was analysed using mixed logit regression analyses. Descriptive and thematic analysis was conducted and associations between respondent characteristics, including quality of life and treatment burden, were evaluated using routine statistical tests.

### Results

Seventy percent of the 602 consumers and carers were female. The mean age was 57.0 years. Although 61.2% of participants reported being from an Australian (non-indigenous) background, participants came from diverse cultural backgrounds (e.g. 9.0% of participants identified as being from an Aboriginal or Torres Strait Islander background). In accordance with the high representation of participants over 65 years of age (33.6%), over one-third (35.8%) reported being retired or receiving an age pension. Sixty percent of participants reported a total household income of less than \$50,000/annum. Despite the survey being conducted mostly in the final quarter of

the year, half of all participants indicated that they had not reached the PBS Safety Net threshold. A further 8.3% did not know whether they had reached the PBS Safety Net threshold limit.

The mean age of the 297 health professionals/workers was 41.6 years, with more females (77.4%) than males. There were 89 pharmacists, 60 nurses, 40 doctors, and 108 other health professionals/health workers.

#### **a. Health status reported by consumer and carer participants**

*Chronic conditions:* Participants reported a wide range of conditions and 83.2% (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 on their lives were chronic neck/back pain, diabetes and arthritis.

*Quality of life:* Participants reported high levels of morbidity and poor quality of life, with a mean health state utility score of 0.62 (SD 0.27). More than half of the sample (55.3%) experienced problems with mobility and nearly one-quarter reported difficulties with personal care. A substantial proportion (58.8%) reported experiencing moderate pain or discomfort, with 16.7% experiencing extreme pain or discomfort. Finally, more than half of the sample (51.5%) reported experiencing moderate to severe anxiety or depression.

#### **b. Health service use reported by consumer and carer participants**

Participants were relatively high users of primary health care services: 92.0% visited a community pharmacy at least every four weeks and 56.3% visited at least fortnightly. Two-thirds 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. Characteristics associated with high use of community pharmacy services (i.e. weekly or fortnightly) included:

- using  $\geq 5$  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  $\geq 3$  times a day ( $p \leq 0.001$ );
- experiencing above median (i.e.  $\geq 54/150$ ) treatment burden ( $p \leq 0.001$ );
- being  $\geq 41$  years of age ( $p \leq 0.05$ );
- reaching the PBS Safety Net ( $p \leq 0.001$ );
- experiencing  $\geq 2$  chronic conditions ( $p \leq 0.001$ ); and
- visiting a GP at least monthly ( $p \leq 0.001$ ).

#### **c. Medication use reported by consumer and carer participants**

Participants reported taking a mean of 7.1 (SD=5.3, median=6) medications, 2.7 times (SD=1.9, median=2) per day.

*Impact of cost on access to medications by consumers and carers:* During the past 12 months, over a quarter of consumers (25.8%) reported delaying or not purchasing prescribed medications because of cost. Almost one quarter of carer participants (21.3%) delayed or did not purchase medications for the person they cared for because of the expense. Characteristics found to be associated with this included:

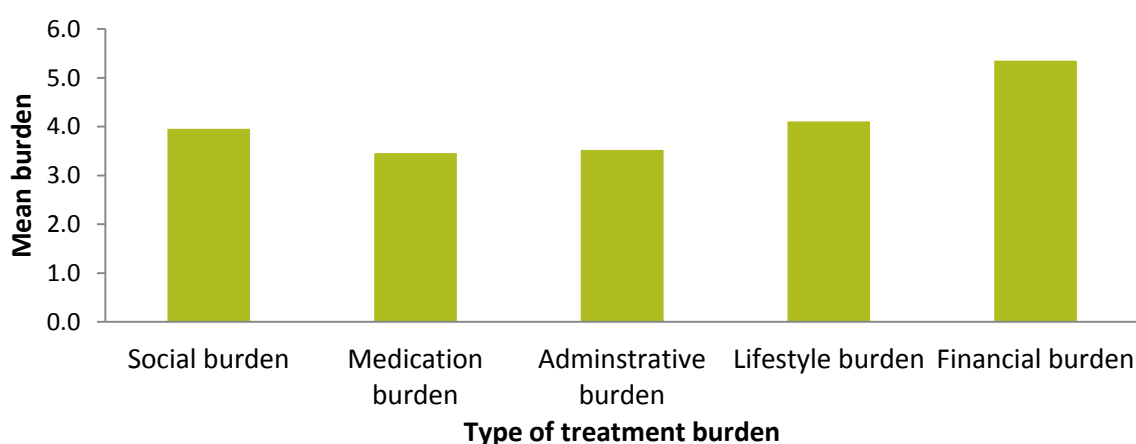
- being  $\leq 60$  years ( $p \leq 0.001$ );
- being single ( $p \leq 0.05$ );
- experiencing above median treatment burden ( $p \leq 0.001$ );
- visiting a GP at least monthly ( $p \leq 0.001$ );
- not reaching the PBS Safety Net ( $p \leq 0.001$ ); and,
- visiting a community pharmacy weekly/fortnightly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

#### d. Treatment burden reported by consumers

Participants reported a mean overall treatment burden of 56.5 (SD=34.5) out of a total score of 150 (higher score represents higher burden). Financial burden was the highest contributor to treatment burden (Figure 4.1). However, the differences between the types of treatment burden are quite small and it is difficult to discriminate between them. Characteristics that were associated with an increased level of treatment burden in a multiple linear regression analysis were (Appendix 6.8):

- lower age ( $p \leq 0.001$ );
- having an unpaid carer ( $p \leq 0.001$ );
- experiencing an increasing number of chronic conditions ( $p \leq 0.010$ ); and
- experiencing diabetes or another endocrine condition ( $p \leq 0.01$ ).

Figure 4.1: Treatment burden among consumer and carer participants



#### e. Ideal pharmacy services

The three highest ranked (most important) pharmacy services for both participant groups (consumers and carers and health professionals/workers) were identical: *treat me as an individual, not as a number; be respectful of my needs and personal values*; and *provide personalised advice and information on prescribed medications*.

Both groups awarded the lowest ranking to the following services: *have other health providers working at the pharmacy*; *provide basic adult vaccinations or treatments*; and *offer community health and wellness programs*.

#### f. Preferences and priorities for pharmacy services

**Uptake of a new pharmacy service versus retention of current service:** For consumer and carer participants, a new pharmacy service was chosen for 855 (35.7%) of all choices. The majority elected to remain with their current pharmacy service rather than select one of the new services. Nearly one-quarter of all consumers and carers ( $n=131$ , 21.8%) chose one of the new services in all four scenarios, with the remainder choosing to remain with their current pharmacy service in at least one scenario. Almost half of the participants ( $n=288$ ; 47.8%) selected their current pharmacy service in all four scenarios.

**Reasons for retaining current pharmacy service:** The decision to select their current pharmacy service (i.e. remain with their existing pharmacy service) was significantly associated with age: older participants were more likely to reject the new services ( $p \leq 0.05$ ). Those who rejected the new services were also more likely to report lower levels of education, not be in employment, have a recent ( $\leq 6$  months) diagnosis of a chronic condition(s), report being loyal to their current pharmacy, or reside in the Greater Perth region ( $p \leq 0.05$ ). The most common reasons for retaining existing pharmacy services related to patient centred services (38.5% of all reasons given),

easy access to pharmacy services (28.5%) and continuous reliable supply of medication and availability of timely, quality advice about medicines and symptoms (26.7%).

*Consumer and carer preferences for the characteristics of pharmacy services:* The following four of the six DCE attributes 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 ( $p = 0.002$ ).

A number of participant characteristics explained significant variation in preferences ( $p \leq 0.05$ ):

- 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 ( $\geq 3$  times per day); and
  - consumer with established chronic condition(s) (i.e. no condition(s) diagnosed  $\leq 6$  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.

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

Although only two attributes significantly affected health professional perceptions about consumer choice, they did so in a direction that was consistent with consumer and carer preferences:

- *Pharmacy location:* 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 ( $p \leq 0.001$ ).
- *Getting your medications:* 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 ( $p \leq 0.001$ ).

Health professional/worker characteristics that significantly explained the variation in health professional perceptions about consumer choice included ( $p \leq 0.05$ ):

- *Continued medication supply:* Those 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 indicate their consumers would value access to a pharmacist for ongoing 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 ongoing condition:* Health professionals working in the private sector were significantly more likely to indicate their consumers would prefer access to other health professionals employed in the pharmacy over pharmacy staff directing individuals to other services ( $p = 0.004$ ).

- *Pharmacy location:* Health professionals identifying as being from an Aboriginal and 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 NSW 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 ( $p=0.006$ ).

*Relative strength of preference or priority for pharmacy services:* Consumers and carers placed the highest priority on continued medications supply for regular and symptom flare-up medications (score 100). This was valued more than one-and-a-half times as much as pharmacy location in a one-stop health centre instead of 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). Alternatively, 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 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 (score 42).

## 5 Key Findings and Recommendations

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 and patient centred care that reduces treatment burden and promotes 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 and consumer and carer interviews demonstrated that consumers value, desire and benefit from patient centred services that are holistic, individualised, respectful and empowering. Our findings indicate that pharmacy could positively impact upon treatment burden by providing patient centred services that promote informative and respectful relationships with consumers. 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.

Consumers and carers were clear about their requirements of patient centred services, nominating this as a top priority and a primary reason for remaining loyal to one pharmacy. It was described as healthcare that accommodates individual goals, proactively delivers information and monitors progress. Stakeholder participants reported that patient centred services constituted more than just friendly, personalised service, and required a shift of power and control of health to consumers.

Stakeholders expressed the view that while many barriers hamper patient centred care, pharmacy services are not limited by structural or financial barriers and do not require a greater investment of time to be successful (Box 2.1). 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. In Stage Three, health professionals identified features of patient centred pharmacy services as high priority for consumers and carers, 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. It should develop understanding of the continuum of patient centred and assist pharmacies to progress to the highest level possible within the constraints of their settings. Examples of support strategies:

- 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 a consultation room);
- 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:

- 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 implementation and impact of patient centred care across pharmacy settings is needed.

## **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, often used five or more medications, experienced high treatment burden and valued a pharmacy capable of providing reliable access to continuous, safe and quality supply of medication, particularly in rural areas. There was a strong preference for continued medication supply by pharmacists (without visiting a doctor) for regular medications for a predefined period as well as medications previously used to relieve symptom flare-ups. 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 [30]. The ability to easily obtain medication acted as an underlying driver of pharmacy patronage that is critical to community pharmacy planning. Solutions proposed to improve medication supply included home delivery, extended opening hours, and other flexible, practical options. There have been reports that many pharmacies intend to either discontinue, reduce availability or increase the cost of many of these services (e.g. home delivery) [49].

Provision of quality advice was viewed as a primary role for pharmacy, and personalised explanations about medication from a qualified and credible source was valued. Stakeholders described confusion over generic medication and low health literacy as predictors of treatment burden, suggesting 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 5<sup>th</sup> CPA *Continued Dispensing service*, 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 visited at least fortnightly. Access to pharmacy services was a key consumer priority, 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. This was articulated along a spectrum of service that can be tailored to individuals and pharmacy service offerings. Consumers and carers described pharmacy as an important physical location where they could be connected to relevant community services based on their individual needs. This role required pharmacists to play an active part in the coordination of health information, personal records, prescriptions, follow-ups and a range of other services. Alternatively, there was discussion of co-locating health professionals in a one-stop shop.

#### **Recommendations**

- a. Research should trial a range of models of developing and implementing a flexible health hub service that can be tailored to individual pharmacies and their customer base. It would reflect a spectrum of services including information on medicines, symptoms, and referrals sign-posting to services to support self-management.
- b. The use of portable health records that can be shared with other health professionals and community organisations, purposefully selected by consumers, is needed. Advocacy for this would allow pharmacists to work collaboratively in the chronic care team [30].
- 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. with community organisations, health professionals).



#### 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.

Several subgroups 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. Recognition of opportunities for pharmacy to alleviate unmet health needs of young people [50] was tempered by calls to involve young people in the design of youth-friendly services [51]. Similarly, carers were not fully recognised in their role and this group represents an important focus for pharmacy, given their importance to the wellbeing of care recipients, and that many carers (139 out of a total of 152) managed their own chronic conditions.

Many participants accessed pharmacy at alarmingly high rates and this was associated with high levels of burden and poor quality of life. Two-thirds of consumers visited the same pharmacy most of the time, indicating that it is an ideal healthcare setting for identifying those who are experiencing burden and providing targeted and personalised support. Potential roles suggested for pharmacists in collaborative chronic care management include adjusting doses, discontinuing therapy and continued medication supply [30].

##### Recommendations

- a. Research funding should be made available for conducting trials of innovative services directed at high risk groups, such as the younger users, low income earners, high pharmacy users (particularly those with diabetes) and carers. Evidence gathered in earlier Pharmacy Agreements should inform research and subsequent services.
- b. Classification of their consumers according to frequency of visit, sociodemographic factors and burden, could enable pharmacies to effectively target new initiatives. Examples could include:
  - Targeting new initiatives (e.g. on-line), to younger or 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 dates and wellness checks;
  - Carer support systems (e.g. information and connections/referrals, regular wellbeing check-ups); 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. Three factors to perceived affordability: decreased costs through low prices or prescription subsidies; maintaining price consistency across pharmacies; and responsive payment methods that accommodate financial stress. Financial burden was significant, and a quarter of the participants reported that cost had resulted in deferred use of medication. Government subsidies were considered vital, yet there was limited awareness of the PBS Safety Net system. Cost was a barrier to accessing new pharmacy services for many in the discrete choice experiment. Advocacy is needed on behalf of consumers, particularly with recommendations to increase medication co-payments [52], and evidence that a \$2NZD increase limited medication access in New Zealand [22].

##### 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 [53].
- 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 emphasised the timely and reliable coordination of medication and services within a patient centred and responsive relationship. If these characteristics were present, most consumers and carers would remain loyal to their pharmacy.

Consumers and carers encouraged pharmacy to embrace a consumer-driven approach that responds to the cultural, economic and service delivery circumstances of each region and individual consumers. Health professionals' awareness of consumer and carer preferences provides a receptive environment within which to nurture innovation. Since perceived service quality has the potential to reduce burden, increase medication adherence, and maintain pharmacy loyalty, engaging consumers in service design will promote meaningful and viable solutions for all.

Although many innovative and plausible services were recommended by consumers and carers, creative solutions are required within the context of shrinking financial resources. Pharmacy needs to resourcefully capitalise on and improve the central characteristics of service already appreciated by consumers and carers. Delivering a fundamental individualised response is relatively inexpensive and easy to develop with adequate support.

#### Recommendations

- a. Pharmacy should seek consumer input into the design of solutions and engage them in quality improvement cycles.
- 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 that can easily be used in the context of pharmacy. Research should explore ways of addressing barriers to change.
- 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 broad range of stakeholders, consumers and carers across widespread geographical areas, reflecting diversity in types, severity and stages of chronic conditions, cultures,

socioeconomic and demographic groups. Carers are often under-represented in research and we purposively recruited unpaid carers, identifying their integral role in supporting consumers.

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 pharmacy staff, GPs, allied health professionals and other health workers. This enabled a direct comparison of consumer and carer preferences with the perspectives of health professionals. 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.

On-going discussions were held with a Reference Group and a consumer researcher was involved throughout to ensure that findings were valid, reliable and grounded in consumer experiences. Each stage of the research informed the next and the consistency in the findings from all stages attests to their credibility.

The DCE presented a limited number of innovations. It was not possible to examine every alternative using this methodology, as the resulting questionnaires would have been unwieldy and the sample sizes impossible to satisfy. As not all services in the DCE currently exist, some people may have found it difficult to estimate the value of those services. What consumers and carers say they would choose for the purposes of research environment does not necessarily reflect what they would choose in a real-life situation.

## 5.2 Conclusion

The results 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 reduced 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 local needs, but also accommodates and/or alleviates existing treatment burden without inadvertently adding further burden.

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