



## **Consumer and Carer Experiences and Expectations of Home-Based Palliative Care in the ACT**

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## **i. About the Health Care Consumers' Association**

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and now provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services
- research into consumer experience of human services.

## **ii. Acknowledgements**

HCCA thanks all the participants in this project, for their time and generosity in sharing their experiences with us.

HCCA also thanks the members of the Project Advisory Committee. Linda Trompf, Fran Parker and Shelley McInnis provided invaluable guidance and oversight of the project. HCCA member Dr Adele Stevens volunteered her time to provide advice to the project and to provide feedback on a draft report.

HCCA greatly appreciates the support of the community and consumer organisations that shared the invitation to participate in this research with their networks: ACT Retirement Village Residents Association, AIDS Action Council ACT, Alzheimer's ACT, Brain Tumour Alliance Australia, Carers ACT, COTA ACT, Lung Life ACT, Palliative Care ACT, Parkinson's ACT and Self-Help Organisations United Together (SHOUT).

Our thanks are also due to Calvary Health Care ACT and in particular Ms Nikki Johnston, Calvary Health Care Palliative Care Nurse Practitioner, for assistance in sharing the opportunity to take part in this project.

HCCA staff member Khalia Lee provided essential assistance with data analysis and the creation of *Health Experience Wheels*.

Finally, HCCA appreciates the partnership of ACT Health, Policy and Government Relations, which supported and resourced HCCA to undertake this work.

### iii. Main Messages

Consumers want person centred care and carers need more support. Quality of care, rather than the location in which palliative care is delivered, is the most important factor determining people's overall satisfaction with end of life care. While many consumers and carers have a strong preference to receive care at home, they also recognise that home-based care is not appropriate to everyone's circumstances. Across all locations of care, people value person centred care that supports and involves carers and is delivered in a home-like setting. For ACT policy makers and health care services, the challenge is to ensure that care with these qualities is consistently delivered in all care locations in the ACT.

To achieve this goal, HCCA recommends that:

- 1) ACT Health ensure future funding and policy settings support home-based palliative care services to **consistently deliver person centred care**, while meeting anticipated future increases in demand.
- 2) ACT Health **pilot and evaluate a dedicated palliative care area at The Canberra Hospital (TCH)**, to meet the urgent need for additional palliative care services in ACT public hospitals. This area should provide quiet, privacy, facility for carers to comfortably stay overnight, and skilled palliative care staff.
- 3) ACT Health **explore options to respond to unmet need for hospice care** in the ACT, including exploring the establishment of a second hospice, and identifying hospice models that would suit the circumstances of people who cannot receive home-based care, but who require in-patient care over an extended period of time.
- 4) ACT Health explore opportunities to **expand overnight respite services for carers** of people receiving home-based palliative care.
- 5) TCH and Calvary Public Hospital (CPH) **ensure that nursing and clinical staff who are likely to care for people at end of life are trained in palliative care and shared decision-making**.
- 6) TCH and CPH **introduce a care coordination approach** for all people admitted to hospital while living with late-stage life-limiting illness.
- 7) TCH, CPH and Clare Holland House continue to jointly **monitor and improve the timeliness of transfers from hospitals to hospice**, and share information about progress in this area at regular intervals.
- 8) ACT Health, hospitals and health services continue to **promote Advanced Care Planning** among healthcare professionals and in the community.
- 9) Home-based palliative care services **ensure all carers receive appropriate training and support to manage and administer medications**.

These recommendations are designed to ensure that more ACT residents can receive appropriate end of life care whether they are in hospital, hospice or their own home.

### iii. Executive Summary

Consumers want person centred care.<sup>1</sup> Quality of care, rather than the location in which palliative care is delivered, is the most important factor determining people's overall satisfaction with end of life care. Study participants valued the same aspects of person centred care across all the locations in which palliative care was delivered.

#### *Person centred care*

The domains of person centred care that were particularly important were:

- the support and involvement of carers;
- appropriate care (i.e. the right care, from the right person, at the right time);
- whole of person care;
- respectful care; and
- communication.

In hospice, hospital and at home, people expect and value care that **supports and involves carers**. Carers are most likely to feel supported when other elements of person centred care are present, especially good **communication** that provides them with the information they need to make informed decisions about end of life care. Sensitivity to diverse cultural preferences in relation to how death and dying should be discussed was particularly important in this context. **Whole of person care** that recognises and responds to an individual's mental, physical and emotional wellbeing is vital. Patients expect to receive care that demonstrates **respect** for their culture, beliefs, values and personal characteristics, and for their preferences and expressed needs. The physical environment in which care is delivered is also important. For care to be **appropriate** at the end of life, from the consumer and carer perspective, it should be delivered in a home-like setting that is private, affords the opportunity for quiet, allows loved ones to stay in comfort and ideally provides a view of nature.

#### *Care location*

People who received care in the location of their choice had more positive experiences than those who did not. Most participants had a clear preference to

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<sup>1</sup> The various definitions of patient, person and consumer centred care all describe "an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families" (Institute for Patient and Family Centred Care (2010) in Consumers' Health Forum of Australia (2012), *The Real People, Real Data Toolkit*). The *Real People, Real Data* method used in this project identifies twelve domains of person centred care, which reflect evidence-based typologies of the aspects of person centred care that are essential to safe, high quality care (among them the Picker Institute's (2013) *Principles of Patient-Centred Care*, the Australian Commission on Safety and Quality in Healthcare (2008) *Australian Charter of HealthCare Rights* and the International Association of Patients' Organisations (2006) *Declaration on Patient-Centred Healthcare*). These domains are defined at Appendix 2.

receive care either at home or in hospice. However, participants recognised that home-based palliative care was not appropriate or possible for everyone, nor was it the preference of every participant.

- *Home-based palliative care* was seen as a person centred approach that responded flexibly to the needs of consumers and loved ones, and supported and involved carers.
- *Hospice care* generally met the consumers' high expectations and provided positive experiences of care.
- *Hospital based care* provided inconsistent person centred care at the end of life, but when person centred palliative care was present, participant experiences were more positive.

#### *Home-based palliative care*

Delayed referral to home-based palliative care was the main barrier to access experienced by participants in this project. Additional [respite care options](#) would better support carers. Some participants would have benefited from [additional support to manage medications](#): this includes clearer communication about expectations on them to administer medications, assistance to dispose of unused medications, and more timely access to emergency supplies of medications. Some recipients of home-based palliative care were concerned that their loved ones' [wishes for end of life care might not be followed in the event of an emergency hospitalisation](#), but felt that having an Advanced Care Plan in place was a valuable strategy to increase the likelihood of their loved ones' wishes being honoured.

#### *Hospice care*

Like home-based palliative care, hospice was experienced as offering person centred care that supported carers in their role. [Delayed referral from hospital](#) to hospice was the most significant barrier to receiving care in this setting. Consumers and carers would welcome additional overnight respite care in the ACT to meet high levels of demand and need.

#### *Hospital based care*

Unfortunately people who received most of their care in hospital felt that it [often failed to deliver care person centred care](#). Nevertheless, when hospital services and hospital based health professionals did deliver person centred palliative care, participant experiences were more positive. The ACT's public hospitals can and do deliver excellent palliative care, and improvements can be made to ensure that care of this kind is more consistently delivered. However, this [demands a reorientation in how services are delivered](#).

Consumers and carers who must receive hospital care at the end of life hold the reasonable expectations that they will be **cared for by nursing and clinical staff who are skilled in a palliative approach**, and that they will have the **opportunity to make informed choices and take part in shared decision-making** about their treatment and palliative care. Consumers and carers would also like to see **changes to the built hospital environment**, such that people receiving palliative care can have privacy, the opportunity for quiet, space for loved ones to stay comfortably, and a view of the outdoors.

### **Areas for improvement**

The consumer and carer voices shared in this report indicate an unmet need for hospice care, as well as strong appreciation of and demand for home-based models that offer continuity of care over time. Based on these findings, the Health Care Consumers' Association makes several recommendations to improve consumer and carer experiences of palliative care that address:

- inconsistently delivered person centred palliative care;
- access to:
  - palliative care services in ACT public hospitals;
  - hospice care in the ACT;
  - overnight respite for carers;
- variable ability of health professionals in providing palliative care and shared decision-making;
- timeliness of referrals and transfers to palliative care and hospice;
- Advanced Care Planning promotion and understanding;
- care coordination for all people admitted to hospital while living with late-stage life-limiting illness; and
- challenges that carers face in managing and administering medications.

### **Background**

This report documents consumer and carer experiences of palliative care in the ACT. It identifies barriers and enablers of high quality, safe, home-based palliative care; and illustrates that many of these barriers and enablers also apply to end of life and palliative care delivered in hospital and hospice settings.

The research draws on in-depth interviews with one consumer and 16 carers who used palliative care services in the past five years. More than half (11 persons) received most of their care at home, with the remainder (seven persons) receiving most of their care in ACT public hospitals. Six of these participants also accessed hospice care. All the consumers were aged 55+, allowing a focus on the issues affecting older people as they and their loved ones' access palliative care.

## The report

### 1. Context

This project investigates consumer and carer experiences and expectations of home-based palliative care in the ACT. It aims to identify barriers to, and factors supporting, the delivery of safe, high-quality home-based palliative care services.

Palliative care is “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness” by addressing the gamut of physical, psychosocial and spiritual challenges.<sup>2</sup> The defining characteristics of palliative care includes that it is non-curative, focused on managing and alleviating pain, distress and discomfort, and that it seeks to take a person centred and family centred approach to care.<sup>3</sup> Most palliative care is provided in institutional settings including hospital and hospices. However there is a slow shift towards more palliative and end of life care being provided in the home or usual place of residence. While it remains the case that a minority of people with life-limiting illnesses die in their own homes, much of the process of dying can take place in the home.

It is important to distinguish between specialist palliative care services and primary care services taking a palliative approach, as both can and do provide home-based palliative care. A specialist palliative care service focuses on patients with complex needs that are not well managed, and the needs of the patient’s family and carers. It can be offered both in institutions and to patients in their home environment, and operates in a consultative way providing support to primary care professionals.<sup>4</sup> Such a service usually comprises a medical director, clinical nurse consultant or nurse practitioner, and allied health professionals with specialist qualifications in palliative care. In the ACT specialist services are provided in-house by [Calvary Specialist Palliative Care Services](#), while the home based specialist services are provided by [Calvary Community Specialist Palliative Care Services](#).

In contrast, a palliative approach in the primary care setting is provided to patients with uncomplicated needs that are associated with a life limiting illness and end of life care. A palliative approach is used by primary care services and practitioners to

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<sup>2</sup> World Health Organisation 2016 *WHO Definition of Palliative Care*  
<http://www.who.int/cancer/palliative/definition/en/> accessed 02/03/2016

<sup>3</sup> Rosenwax and McNamara 2006, A method for defining and estimating the palliative care population, *J Pain Symptom Management* 2006 July; 32(1):5-12

<sup>4</sup> Palliative Care Australia, “Defining your Specialist Palliative Care Service, Fact sheet” National Standards Assessment Program, Accessed 17-05-2017.  
<https://www.caresearch.com.au/caresearch/LinkClick.aspx?fileticket=OcZ6fztlgDw%3D&tabid=2423>

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improve the quality of life for individuals with a life-limiting illness, and their family and caregivers.<sup>5</sup> This type of service provides clinical management and care coordination including assessment, triage and referral. It is usually delivered by general practitioners, nurse practitioners, registered nurses, generalist community nurses, Aboriginal health workers, and allied health staff.<sup>6</sup>

This project explores consumer and carer experiences of specialist palliative care services, primary care professionals and primary care services employing a palliative approach, and palliative care in hospital. The majority of participants in this project (nine people) experienced home-based care provided by a specialist palliative care service, one participant received home-based care provided by RACF nursing staff and a General Practitioner, one participant received care provided by ACT Health's community nursing team, and the remainder (seven people) received palliative care in hospital.

Consistent with the national experience, in the ACT there is a policy and practice shift underway toward delivery of more palliative care at home and in the community.<sup>7</sup> Home-based palliative care can deliver safe, high quality and cost-effective care. The benefits of home-based palliative care include consumer-reported improvements in quality of life and lessened emotional distress (when compared to palliative care in acute settings),<sup>8</sup> decreased hospital admissions, and a higher rate of completion of Advance Care Plans and Directives.<sup>9</sup> People who elect to receive care at home not only receive care in the location of their choice, they are also more likely to die in their location of choice,<sup>10</sup> which is associated with better consumer and carer experiences of end of life care.<sup>11</sup>

This project provides new evidence about ACT health care consumers' and carers' priorities, experiences, and expectations of home-based palliative care. This information is a necessary basis for decision-making about the future delivery of

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<sup>5</sup> Palliative Care Australia, Standards for Providing Quality Palliative Care for all Australians Edition 4. <http://palliativecare.org.au/national-standards-assessment-program/> Accessed 17-05-2017.

<sup>6</sup> Palliative Care Australia, "Defining your Specialist Palliative Care Service, Fact sheet" National Standards Assessment Program <https://www.caresearch.com.au/caresearch/LinkClick.aspx?fileticket=OcZ6fztIqDw%3D&tabid=2423> Accessed 17-05-2017.

<sup>7</sup> ACT Health *Palliative Care Services Plan 2013-2017*

<sup>8</sup> Hughes MT and TJ Smith 2014, *The growth of palliative care in the United States*, Annual Review of Public Health Vol.35:459-475

<sup>9</sup> Behm, B, *A synthesis of home-based palliative care on clinical effectiveness, cost effectiveness and quality of life: Policy implications explored*, Georgia State University

<sup>10</sup> Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., Gonzalez, J. (2007). *Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care*. Journal of the American Geriatrics Society, 55(7), 993-1000.

<sup>11</sup> Swerissen, H and Duckett, S., 2014, *Dying Well*. Grattan Institute, p2.

palliative care services in the ACT. With an ageing population and increasing numbers of people living longer with life-limiting illnesses, demand for high quality and safe home-based palliative care in the ACT is expected to continue to grow. Indeed, the major challenge for palliative care services in the ACT over the last five years relates to a steadily increasing demand for services, which has placed additional pressure on those services available.<sup>12</sup> In this context it is important to understand what people value about the services they receive, and what they perceive to be working well and less well in the current system.

The consumer and carer voices presented in this report confirm the importance of factors already known to contribute to good end of life care experiences. Participants in this research had better experiences when their clinicians were able and willing to start conversations about palliative care and the end of life, and referred them to palliative care services early in their experience of life-limiting illness.<sup>13</sup> Carers' experiences of home-based care were more positive when they were **supported and involved** in decision-making, when they had sufficient access to respite, and when services had strategies in place to respond to diverse cultural needs and preferences in relation to death and dying. Consistent with best practice, participants in this project had better experiences when they received continuity of care, including continuity in the clinicians making home visits and 24-hour access to specialist GPs. People's experiences were also better when clinicians collaborated across care settings, and shared information across care sites (particularly between home-based and acute settings).<sup>14</sup> This research also finds that people who have accessed home-based palliative care in the ACT would value earlier referral to palliative care, and enhanced support to manage and administer medications.

A key contribution of this project is to demonstrate that ACT consumers and carers valued the same aspects of person centred care in all the locations where end of life is delivered. While there was strong consumer and carer support and demand for home-based palliative care that offers continuity of care, people recognised that home-based care was not appropriate for everyone's circumstances. It is therefore important that wherever people experience their end of life care, services and health professionals consistently deliver care that **supports and involves carers**, provide **whole**

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<sup>12</sup> ACT Health *Palliative Care Services Plan 2013-2017* p1

<sup>13</sup> Rosenwax and McNamara 2006, *A method for defining and estimating the palliative care population*, J Pain Symptom Management 2006 July; 32(1):5-12; Hudson P, 2003 *Home-based support for palliative care families: challenges and recommendations* Med J Aust 2003; 179 (6 Suppl): S35

<sup>14</sup> Hudson P 2003 *Home-based support for palliative care families: challenges and recommendations* Med J Aust; 179 (6 Suppl): S35.

of **person care** and **respectful care** that responds to individuals' circumstances, culture and preferences, and **communicate** well about end of life care options.

## 2. Implications for policy and service delivery

These findings challenge policy-makers and service providers in the ACT to work in partnership with consumers to ensure that safe, high-quality and person centred care is delivered consistently across all care locations in the ACT. In particular, consumer and carer voices indicate an opportunity to improve the quality of person centred palliative care in the ACT's public hospitals. Consumers and carers would also welcome an expansion of hospice care in the ACT, to better meet the needs of people who cannot receive care at home but who require palliative care over a period of weeks or months. Consumers and carers would also welcome improved continuity of care, in particular in relation to transitions between care sites, specifically between hospice and hospital. Consumers and carers value home-based palliative care highly, and it is important that home-based services are resourced to continue to consistently provide the person centred care that consumers currently value.

## 3. Approach

This project used the applied qualitative research method *Real People, Real Data*, developed by the Consumers' Health Forum of Australia.<sup>15</sup> Consistent with this method, all participants took part in semi-structured qualitative interviews of approximately one hour about their palliative care experiences. Interviews addressed experiences of diagnosis with a life-limiting illness, treatment, receiving information about and referral to palliative care, receiving palliative care and overall perceptions of what worked well and less well in the care people received. Participants were recruited from HCCA's membership, through the networks of community and consumer organisations and with the assistance of the Calvary Health Care Palliative Care Nurse Practitioner.<sup>16</sup> This approach sought to involve people with diverse experiences of palliative care, and diversity in characteristics such as age, gender, and health condition.

In the *Real People, Real Data* method, participants' key experiences of care are presented as a *Health Experience Wheel*, a simple visual depiction of what mattered most for each person as they used services. This image is intended to clearly communicate areas for improvement as well as what individuals value about the services they received. Health Experience Wheels were created for 15 of the 17

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<sup>15</sup> More information about this method is available at: <https://chf.org.au/real-people-real-data-toolkit/real-people-real-data>

<sup>16</sup> Unfortunately, in this project it was not possible to recruit participants in partnership with TCH services.

participants in this project.<sup>17</sup> To create these images, HCCA provided each participant with a transcript of their interview. People were invited to review their transcript and identify their key positive and negative experiences, and were also advised that if they did not wish to do this the HCCA researchers could identify key experiences for their review. This choice was provided to protect against the possibility that participants would find it distressing to review their transcript. All participants elected for HCCA to identify key experiences, and each person had the opportunity to review their Wheel before it was finalised.

The key experiences that appear on the Health Experience Wheels were coded according to which (if any) of 12 evidence-based domains of person centred care applied. Appendix 2 provides definitions of the criteria used in this project. These domains provide the themes around which the discussion and findings in this report are organised.

#### **4. The participants**

Participants had diverse palliative care pathways but there are some commonalities. All but one of the 17 participants were caregivers for a person aged 55 or older. Of these, 14 were bereaved while two were currently caring for a loved one.

A majority of the participants were women. Six men took part, of which five were carers and one was a palliative care consumer.

Just over half the participants (eleven persons) received most of their care at home, while the remainder (seven persons) received most of their care in hospital. All of those who received most of their care in hospital primarily used TCH services, though some participants also accessed Calvary public hospital.

A majority (eight) of those who received home-based palliative care accessed the Calvary Health Care Home-Based Palliative Care service. One person received care from staff of a Residential Aged Care Facility (RACF) with support of his own GP, and another received care at home from ACT Health community-based nurses. Of those who received care at home, three lived in RACFs.

Just over half the participants had cared for a person living with cancer. Of these, a majority had cared for a person who had died within a year after their diagnosis with an advanced cancer. Four participants cared for a loved one with a neurological

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<sup>17</sup> HCCA elected to interview every person who met the inclusion criteria for the project, including when interest was expressed late in the data collection phase of the project. This meant two people (Participants 16 and 17) were interviewed, but it was not possible to create Health Experience Wheels within the project timeframe. These two interviews nonetheless inform the discussion and findings presented in this report.

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condition: two had cared for a loved one with Parkinson's Disease, one for a loved one with Multiple Sclerosis, and other for a loved one with Alzheimer's Disease. One participant was the son-in-law of an elderly woman who died in hospital after suffering a suspected stroke, another participant's husband received palliative care for a cardiac condition. Another cared for her elderly mother.

For bereaved people, the place of death of a loved one also varied. Of the six bereaved people whose loved ones received most of their care at TCH, four died in hospice and two died at TCH. The single most common palliative care pathway was related by five carers whose elderly loved ones were diagnosed unexpectedly with an advanced cancer, received most of their care at TCH and died shortly after being transferred to hospice, all within a year of diagnosis. Of those who received home-based palliative care, six people died at home and two in hospice: therefore, as discussed in Section 5., all the participants who received home-based palliative care died in what can be considered a "home-like" environment.

The personal circumstances of the carers also varied. Some were full-time unpaid carers, others were also employed. They had been carers for varying lengths of time, ranging from 12 years to 3 months. Several of the carers themselves lived with chronic conditions or were older people, and felt this limited their ability to care for a loved one.

## 5. Results

### 5.1. Expectations and experiences of palliative care in different locations

Participants expected that home-based care and hospice care would provide high-quality, safe and person centred palliative care. With few exceptions, these high expectations were met.<sup>18</sup>

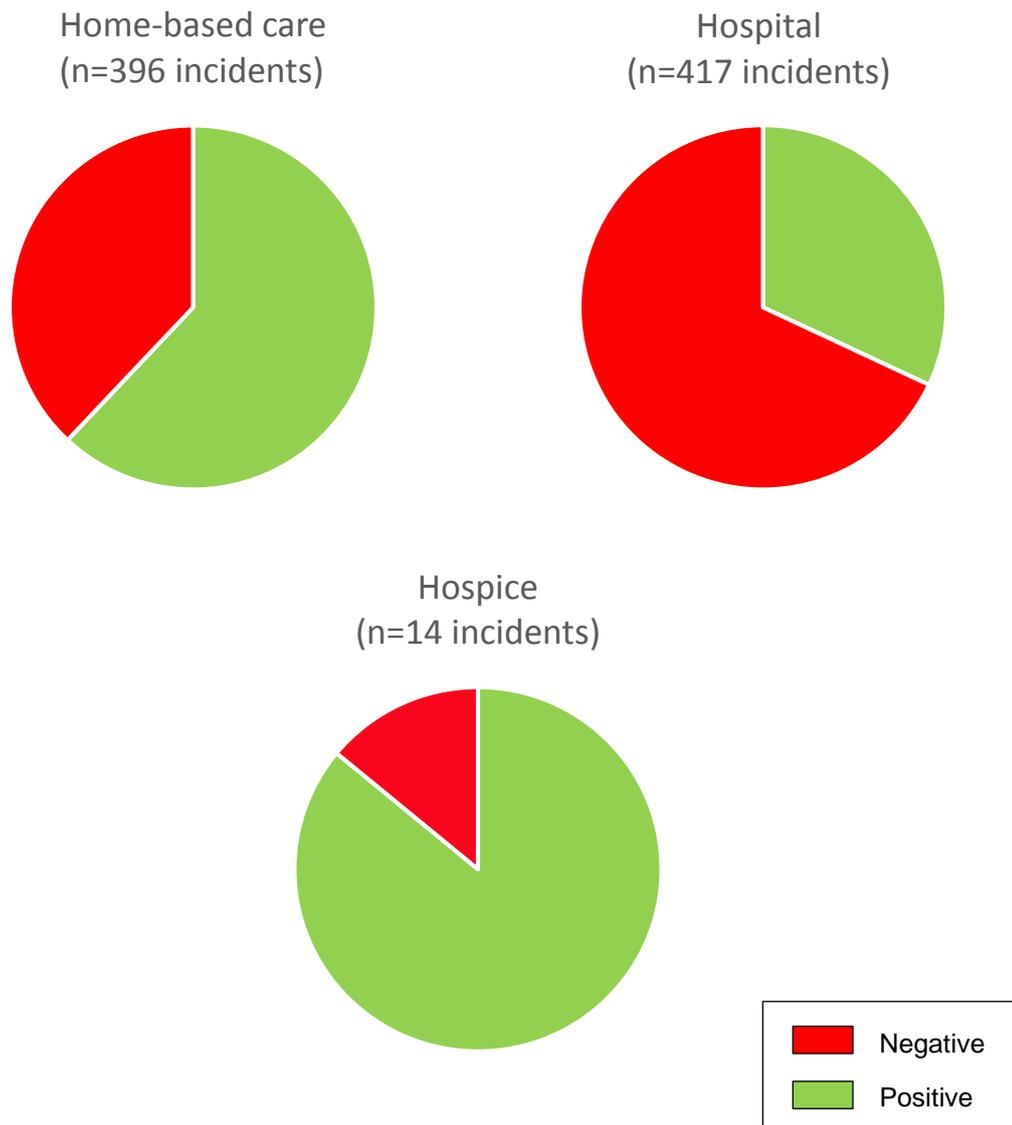
By contrast, people who experienced palliative care in hospital had more negative experiences of care than they did positive experiences of care. All the people who received palliative care in hospital expressed their preference to receive care at home, but they were advised, or themselves understood, that this was not possible in their circumstances. The reasons for this included a rapid decline in a loved one's health after a hospital admission, carers' own ill-health, carers' existing work and/or caring responsibilities, the requirement for extensive home modifications, and health care professionals' advice that a loved one's care needs were too high for home-based care. *Appendix 1* provides some more detail about these experiences. These people had a strong preference for earlier referral to hospice, in preference to an extended hospital admission.

While there was a strong preference for home-based and hospice care, across the cohort there were both positive and negative experiences of care in all locations. Diagrams 1-3 below demonstrate that there were both positive and negative experiences of care across all sites, but also show a clear trend toward overall more positive experiences for those who received most of their care at home. The diagrams also demonstrate the overall positive experiences of care that most people who accessed hospice had in this location.<sup>19</sup>

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<sup>18</sup> These expectations were most consistently met for people who accessed the Calvary Health Care Home-Based Palliative Care service, reflecting the value participants placed on the continuity of care usually offered by this service, including continuity of access to clinical and nursing staff with specialist knowledge and experience in palliative care. Experiences for the small number of people (2) who accessed other services, were overall less positive.

<sup>19</sup> These diagrams reflect the key experiences of care presented on *Health Experience Wheels* produced for 15 participants. Of the 15, nine people received most of their care at home, seven received most of their care in hospital. Five also accessed hospice care: four people who received most of their care in hospital also accessed hospice; and one person who received most of their care at home accessed hospice.



**Diagram 1. Proportion of positive and negative incidents in different care locations**

Ultimately the *quality of person centred care* was more important than the *location of care* in determining overall consumer and carer experiences. Across all locations, consumers and carers valued care that:

- supported and involved loved ones;
- provided appropriate care at the end of life;
- responded to the needs of the whole person and was delivered with respect for the person’s individual situation, preferences and culture; and
- was delivered by health care professionals who communicated well about end of life matters.

While home-based palliative care and hospice care were seen to *usually* provide this kind of care, consumers and carers identified an opportunity for hospital to *more consistently* deliver high-quality, person centred palliative care.

The people with the overall most positive experiences were those who received care from the Calvary Health Care Home-Based Palliative Care service. Only two participants did not receive home based palliative care from Calvary and their experiences were less positive.<sup>20</sup> In fact these two individuals' negative experiences accounted for more than twice the number of key negative experiences recounted by all the people who used the Calvary Health Care Home-Based Palliative Care service.

## **5.2. Person centred care at end of life**

People's experiences were strongly influenced by whether or not care was *person centred*. The domains of person centred care that most often recurred as relevant to people's key experiences of palliative care were:

- support for and involvement of carers (140 incidents),
- appropriate care (124 incidents),
- whole of person care (103 incidents),
- respectful care (95 incidents), and
- communication with health professionals (77 incidents).<sup>21</sup>

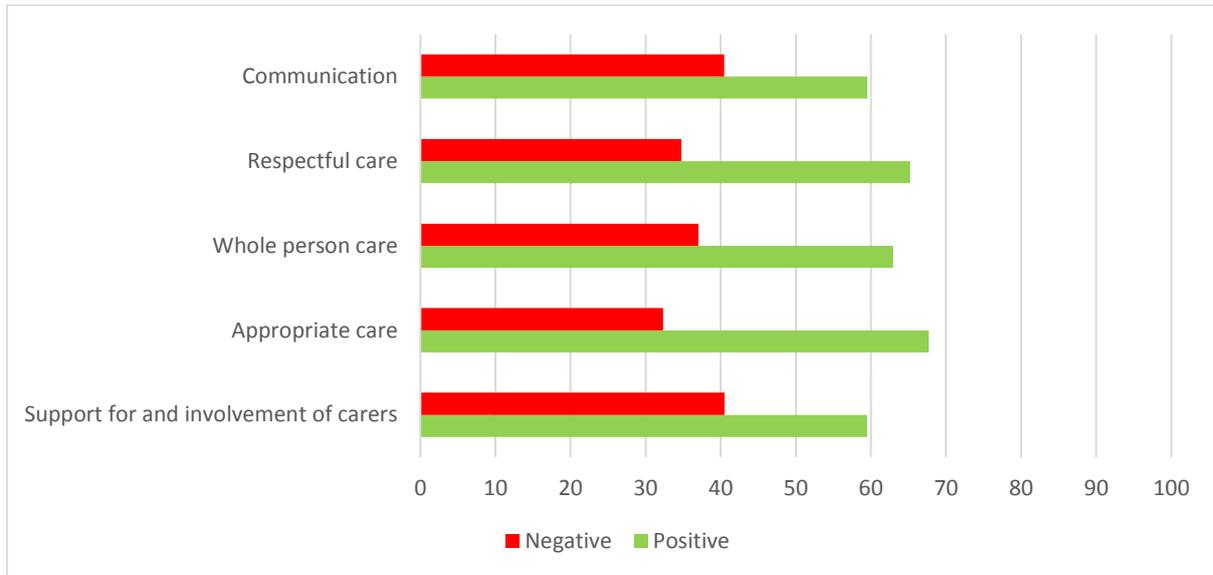
These aspects of care powerfully shaped people's overall experience of care in all care settings. Diagram 2 demonstrates that people who experienced most of their care at home had more positive than negative experiences across these key domains of care.

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<sup>20</sup> One person had a negative experience of care provided by ACT Health home-based nurses, while another had a very mixed experience of end of life care in an RACF in which care was provided primarily by RACF staff with the support of the patient's GP.

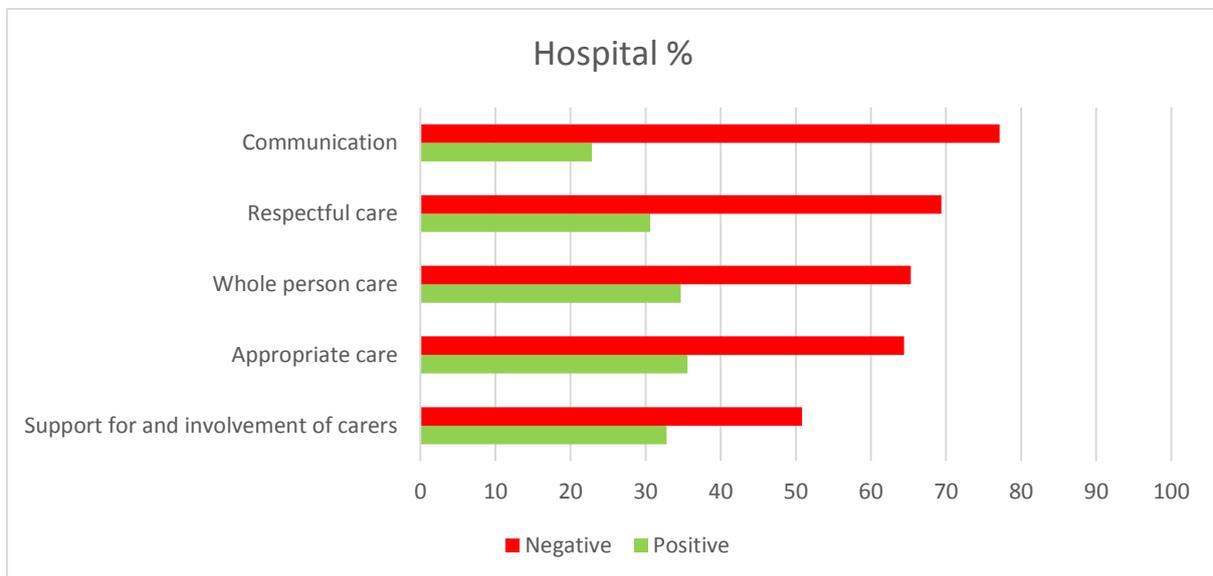
<sup>21</sup> The Real People, Real Data method analyses which domains of person centred care relate to people's key experiences. It uses 12 domains of person centred care that are widely recognised as essential to safe, high quality care. The key experiences appear on each participants' Health Experience Wheel, and each key experience may be coded as related to more than one domain of care (or none). Appendix 2 provides definitions of the domains of care used in this project.

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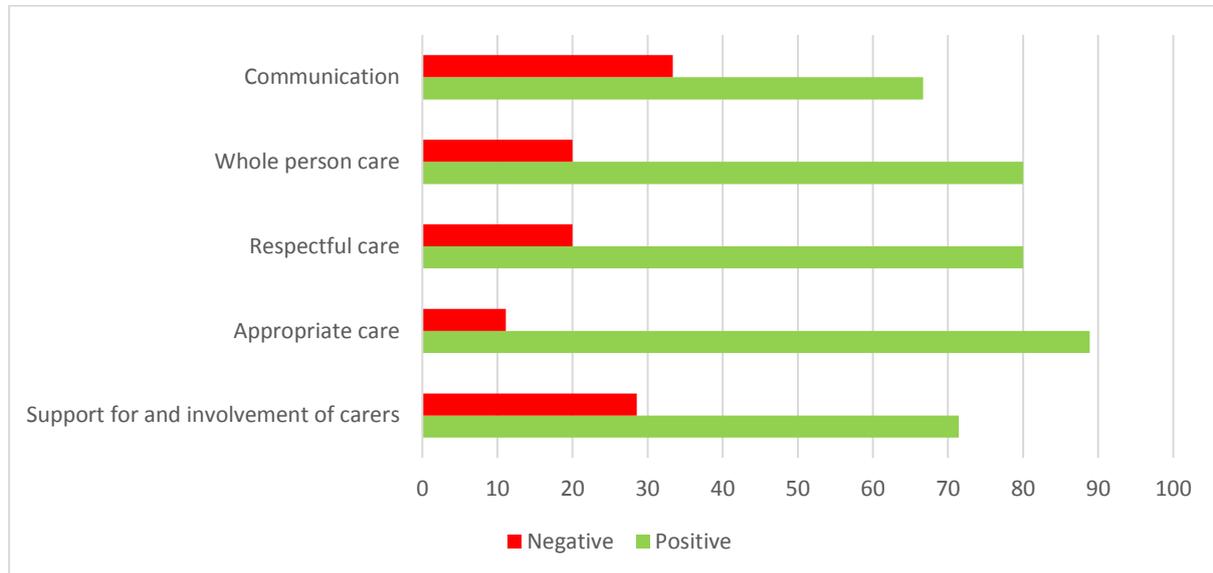
**Diagram 2. Proportion of positive and negative incidents of key domains in home based palliative care**

By contrast those who received most of their end of life care in hospital more often had negative than positive experiences of domains of person centred care (Diagram 3). While these people did have positive experiences of these domains of care, these were outnumbered by negative experiences.



**Diagram 3. Proportion of positive and negative incidents of key domains in hospital.**

Finally, Diagram 4 shows that those who experienced hospice care had overall positive experiences of these areas.



**Diagram 4. Proportion of positive and negative incidents of key domains in hospice.**

### 5.3. Support for and involvement of carers

*Support for and involvement of carers* was the domain of person centred care that most frequently recurred in people's accounts of their key experiences of palliative care. This reflects the importance of support and involvement to the 16 carers who took part in this project. Many participants spoke frankly about the demands that caring can place on the loved ones of a person with a life-limiting condition. While this was true across all care locations, people who received most of their care at home usually felt that they received good support to undertake the caring role. Diagram 2 (above) illustrates carers' very high levels of satisfaction with the support they received while accessing home-based palliative care. Diagram 4 shows that hospice was also generally experienced as offering high quality carer support and involvement (with the notable exception of one consumer whose father experienced an adverse event as a consequence of a medication error). By contrast (as Diagram 3 shows), people who received most of their care in hospital had mixed experiences of carer support and involvement. In all three care locations, carers were more likely to feel supported and involved when the care their loved one received was:

- **respectful** of individuals' circumstances, culture and preferences;
- responsive to the needs of **the whole person**; and

- delivered by people who could **communicate** well about a loved one's situation

There is a close connection between these domains of person centred care: when health care professionals communicate well, this *demonstrates* to consumers and carers their respectful and whole-of-person approach to care, and their support for carers. Therefore, **respectful care**, **whole of person care** and **communication** are discussed together at Section 5.5. and 5.6.

People's largely positive experiences of carer support and involvement in home-based care reflect their understanding that this model is fundamentally designed to support them to care for a loved one at the end of their life. Home-based carers were able and willing to be the primary unpaid carer for a loved one and valued that they had access to a model of care that supported them in this role.

In very practical terms, home-based care provided carers with the equipment they required:

*I have a hospital bed. Hospital linen. I have all from the government. The staff over there is very, very nice. (Participant 6)*

*As soon as they came [for the first home visit], they arranged for the occupational therapist person to come out as well, the same day that they were coming, to have a look around the house and see what needed to be done because Mum was in a big queen sized bed and so then they organised for the shower chair and the hospital bed, for the chair in the lounge-room, all of those bits and pieces.*

One carer suggested that loved ones and families would benefit from easier and less costly access to the equipment necessary to keep a loved one at home for some days after their death and before their funeral. This would include access to a cold pad to keep a loved one's body cool after death.

Carers also received support and training so they could provide daily care and administer and manage medications:

*They'd say, 'this is the regime, what do you feel comfortable doing for your Mum and what do you want us to do, what do you need us to do for you that you don't feel comfortable to do because at the end of the day we're here to look after Mum. So, you need to tell us what you're comfortable doing and what you're not.*

*They taught us how to change her, how to roll her, how to move her into the bed and out of the bed so that we wouldn't hurt ourselves. (Participant 11)*

As this example makes clear, people appreciated it when home-based palliative care nurses flexibly negotiated which tasks family members were comfortable to take on.

Carers require training, and good support, to manage medications confidently and effectively. They also appreciated timely assistance when they required emergency supplies of medication, particularly out-of-hours:

*We sort had to find out which chemists were open late at night... We'd go 'oh my gosh we've run out of a script, and Mum's only got enough to last her until tomorrow morning. So, we would ring palliative care. They would get the Doctor to ring us and. She'd get Mum's file and.. she'd just ring the chemist and say "They're coming in. This is what it's for." (Participant 11).*

In the context of overall positive experiences of medication management, one participant felt that clearer information should be provided about what carers can do when a morphine driver needs to be changed overnight. Another, whose father received palliative care in an RACF<sup>22</sup>, recounted that lack of clinical staff authorised to change a morphine driver overnight meant her father received inadequate pain relief, waiting for more than an hour for someone to assist with this task. One carer was initially uncertain how often she was expected to administer a medication, and thought that while she may have been given clear information this was difficult to retain as carers receive a lot of information when they first take on this role. Two carers recounted that they were left with large quantities of unused medication, and were unsure how to dispose of this.

In the context of overall satisfaction with medication management arrangements, some carers would appreciate additional and consistent assistance to manage and administer medications. This includes clearer communication about expectations on carers to administer medications, assistance to dispose of unused medications, and more timely access to emergency supplies of necessary medications particularly outside of business hours.

Carers underscored the need to take "time out" from their caring role. Those who cared for a loved one at home over an extended period of time valued access to respite care very highly, but recognised that services were hard-pressed to respond to demand for this service. Participant 12 is typical of carers who faced long waits for respite care:

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<sup>22</sup> In this instance, palliative care was primarily provided by RACF staff along with the person's own General Practitioner.

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*“I got away twice when he was in hospital for a weekend at the farm which was good. And then [in September the social worker] said, “You need to get away. You need to have respite”. And I sort of said, “well I rang up about respite and they can’t offer me anything till next March’... That’s pretty useless. [Respite would have been good] but I mean the hospice just haven’t got that. They haven’t got the space. You need more respite rooms. And I think with the ageing population, you’re going to need more, aren’t you?”*

Other carers stressed that friendships and a strong social network were invaluable supports for them. Participant 6 recounted that:

*“When I go and see my daughter or my friend and I sit down I cry, a lot. A lot, a lot, a lot. And that help me. And the doctor all the time say, “You take care, when you feel you need something let me know, because you know you can have some respite, somebody can come in here and you can go for three days or whatever”. And I say, “Thank you very much but I never, never [did]. I don’t need [respite] because I got friends and when I go out I cry. Coming to my home and I sit and keep going.*

While not all carers availed themselves of respite care, it is an important aspect of carer support and involvement. Consumers and carers would welcome additional respite care options for people requiring palliative care in the ACT.

#### **5.4. Appropriate care**

*Appropriate care* was one of the most frequently recurring domains of person centred care that related to people’s key experiences. It was second only to **carer support and involvement** in terms of the frequency with which it recurred.

From the consumer and carer perspective, appropriate end of life care:

- Is provided in a *home-like setting*;
- Is delivered by *clinical staff skilled in a palliative approach*;
- Provides *timely referral to palliative care services*;
- Offers *continuity of care* over time and between care locations.

Participants who experienced home-based palliative care and hospice felt the care usually had these qualities. Hospital was experienced as delivering these qualities inconsistently.

##### *A home-like setting*

Those who received home-based care highly valued the provision of care in this location. It allowed both carers and loved ones to remain in a familiar, comfortable

and comforting setting, in which they could sustain the routines of daily life in a way that would not have been possible elsewhere:

*It was so much more relaxing [than being elsewhere]. It was basically being able to let Mum and Dad be at home where they wanted to be and not be dictated to by whether there was a bed spare for them in this ward or that ward or whatever and having to deal with that on a daily basis. We could take flowers in, we could have special pictures on the wall that would just be comforting but also, we could just walk away when they wanted to have a sleep or a rest, and go and put a load of washing on or sit and have a cup of tea with the palliative care [nurses]. (Participant 11)*

*In my own home, I was able to go out into the kitchen, I was able to do what I wanted. I could go out into the garden, if people wanted to come we could go and sit in another room. (Participant 9).*

One participant described home-based palliative care as allowing his wife the “space... to prepare herself for death” in way that hospital could not:

*I think dying in a hospital, if it's not a result of a car crash or something, is really a very poor option... For her, it was about having the space she needed to prepare herself for death and for the rest of us, particularly me, it was about making that space, creating the environment around her that she needed to be able to do what she needed to do. (Participant 3)*

Home-based care allowed carers and loved ones to remain in familiar environment in which they took comfort and over which they had a sense of control.

With one exception<sup>23</sup>, participants regarded hospital as an inappropriate end of life care setting. Those who received much of their care in hospital<sup>24</sup> felt the buildings were noisy, lacked privacy, were uncomfortable for visitors and disconnected from the world outside:

*There was nowhere to sit privately with him... It took him back to being a prisoner of war. He would sometimes ring me and say, “You need to get me out of here because this is just like being a prisoner of war again.” (Participant 14)*

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<sup>23</sup> Participant 12

<sup>24</sup> These experiences were consistent across both ACT public hospitals: Participant 14 quoted in this paragraph experienced care at CPH while Participants 4 and 7 experienced care at TCH.

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*They need to look at how [to help] people who want to stay, they've only got a few fold out chairs and they're really old and crappy. (Participant 4)*

*He was initially in a private room which was lovely but then... he was booted out into this converted corridor which had four beds with curtains a meter from the bed on all sides. He had no view beyond these curtains. It was for somebody who had loved the outdoors, who was a really keen bushwalker all his life, it was just dreadful to not even be able to see a tiny bit of sky. (Participant 7)*

*The wards are very noisy. This woman, she had the television up really loud and I said to her, "Look, would you mind turning it down a little bit?", and she had a friend who said, "It's a free world, she can do what she wants to" and I said, "Look, we need to respect one another in this place." "Oh, my friend's not well." I said, "I hope she hasn't just been given the diagnosis my husband's been given". And the nurse just let her do it. (Participant 4)*

Because of these characteristics of the hospital setting, Participant 7 found it was impossible to have the conversations she wanted to have with her husband at the end of his life.

When hospital did afford privacy, quiet and a view of the outdoors, experiences was much more positive. For example, one participant felt that his loved one's room at TCH:

*"was not really a bad room in that there was an external window and so there was some sunlight. It was near a courtyard". (Participant 3)*

Another person (Participant 12) was very appreciative when a TCH doctor suggested that her husband move from a shared ward to an empty four-bed ward nearby so that his family could sit and be with him in privacy before his death. This experience demonstrates that better use of the existing hospital environment can support positive end of life experiences.

Changes in how in-patient areas are designed and used would deliver more consistently positive experiences. The upcoming move of facilities from TCH to the University of Canberra Public Hospital creates an opportunity for TCH and ACT Health to establish a dedicated palliative care area that would deliver on consumer expectations of quiet, privacy, a connection to the natural world, and facility for loved ones to remain in comfort including overnight. As discussed immediately below, consumers would expect a facility of this kind to be staffed by nurses and clinicians with expertise in palliative care.

*Clinical staff skilled in a palliative approach*

People who received care at home valued round-the-clock access to palliative care nurses and doctors:<sup>25</sup>

*“It’s a special doctor, when ... he is very sick at 2.00am I can call”  
(Participant 6)*

*The doctor used to come out very frequently and check on Mum and that was great. The doctor would say to us, “Any questions?” ... [We were] able to pick up the phone any hour of the day or night, even if they’d just been an hour before, just to clarify something. (Participant 11)*

In addition to round-the-clock access to specialist advice, several participants spoke of the excellent pain management offered by home-based palliative care. Participant Nine is typical of respondents who saw this as a defining strength of this model:

*[My husband] had a lot of pain in his back and both his GP and his haematologist were saying “Take more pills”. The doses weren’t excessive but he slept all of the time. I thought this was stupid and... so we were referred [to home-based palliative care] and we saw a doctor and she worked with him and saw him every month or so and reduced his painkillers up and down. The idea was to get him on the least amount so he had the appropriate amount of pain-free care. (Participant 9)*

Home-based clinical and nursing staff were also generally regarded as responding sensitively and appropriately to end of life circumstances, including sensitively discussing an impending death.<sup>26</sup>

By contrast, most participants would have welcomed a more consistent palliative approach to their care in hospital. This includes timely access to clinical staff skilled in a palliative approach, and earlier referral to palliative care services (both within and beyond hospital). For example, one participant believes that earlier involvement of palliative care clinicians or nurses would have assisted her husband and herself to better weight up the potential benefits and risks of the chemotherapy program suggested by their hospital oncologist at TCH:

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<sup>25</sup> While most people who received home-based care enjoyed this continuity of care, the small number of people who received care from ACT Health community-based nurses (1) and RACF staff (1) had less positive experiences in this area.

<sup>26</sup> This is discussed in more detail at 5.3, *Support for and involvement of carers*, and 5.6, *Communication with healthcare professionals*.

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*Had we at that stage, if it had been said to us, "Perhaps you might like to consider an alternative to chemo drugs and this six month program I'm suggesting? Perhaps you need to talk to people in palliative care or radiation?" So collaboration, it sounds wonderful, but in my husband's experience it just did not happen. (Participant 1)*

Some people who received most of their care in hospital felt that clinicians' orientation toward treatment rather than palliation was a barrier to getting the care their loved one required. Three participants recounted that it was difficult to elect to cease unnecessary or unwanted procedures. Participant 1 explained that:

*There was this struggle... I mean, palliative care was operating in that they're trying to control his pain. My husband had decided to be palliative and... yet you can't believe that you could be that sick and you're still given ten [chemotherapy] tablets a day. He was so sick. He was on thickened water because he couldn't swallow, but somehow or other, he expected him to swallow and he managed to, because somebody was standing over him saying "Do it. Take these ten tablets".*

Participants 4 and 2 would have preferred that their loved ones not undergo routine observations and routine procedures while they were close to death in hospital:

*It wasn't going to make a blind bit of difference taking his blood pressure all the time, doing his diabetes stuff, all that kind of interventional stuff. There should have been a little flag that went up automatically... [so that there were]... no interventions. (Participant 4)*

*The major problem was she wasn't getting access to palliation and she was routinely having ob.'s taken and inappropriate care at the end of life, to what I felt she have had it she'd been in the hospice or a palliative care setting. Essentially the palliative care nurse knew what to do, which was to keep her mouth moist and a whole range of other things which she would do when she came, but in between, the regular nurses were not skilled enough to do that or too pressured to do that. (Participant 2)*

People valued palliative care nursing and clinical staff highly. Participant 14 for example related that "the palliative care nurse and her understudy" at TCH:

*"They were wonderful. My husband related very well to them. When I had an issue, the palliative care nurse heard about it she said, "Why didn't you call me?" and I said, "I couldn't have called you at that time of night", and she said, "I wouldn't have minded." She was very generous with her time.*

The fundamental concern for carers was that hospital did not consistently offer a palliative approach. In contrast to home-based care, ACT public hospitals were seen not to offer sufficient staff skilled in palliative care, nor a service culture sufficiently open to palliative care.<sup>27</sup> Establishing a dedicated palliative care area at TCH would assist to improve people's access to a palliative approach within the ACT's public hospital system. Palliative care training for nursing and clinical staff would increase both the skills of the workforce delivering end of life care in ACT hospitals but also their confidence and ability to communicate well with people about end of life treatment options.

#### *Continuity of care and smooth transitions*

Carers appreciated the **continuity of care** that home-based palliative care usually offered. Participant 10 is typical in appreciating that the level of care offered responded flexibly to his family's circumstances:

*[Initially] they would come... every six months or so and we'd have a chat and a cup of coffee and see how [my wife] was going and then as she got into her final weeks and so forth, they were far more perceptive of this than I was. In the last week of two they were there pretty much every day keeping an eye on her. So, my experience with palliative care is they were just fantastic. (Participant 10).*

People who received home-based care also generally experienced smooth transitions between home and hospice, when this was appropriate to their circumstances. For example Participant 16 felt that the home-based nurse introduced the idea of hospice at an appropriate time, and presented the benefits of hospice (in particular, increased medical support) effectively. By contrast, some people were concerned that transitions between home and hospital were not always smooth. In particular, two people were worried that their loved one's preferences in relation to end of life care would not be followed if they were hospitalized in an emergency. For example, when Participant 5's father developed pneumonia while receiving palliative care in an RACF:

*I got a phone call from the nursing home saying we've called an ambulance for your father and we're about to take him to hospital and I said hang on a minute, he's got an advanced care directive that says he [doesn't want to be hospitalised], and then I called the doctor and then*

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<sup>27</sup> While most participants who expressed this concern received most of their care at TCH, this was also raised by one participant whose father received care at CPH. This suggests the issue applies to both ACT public hospitals.

*raced up there and I managed to stop them sending him in the ambulance. (Participant 5)*

Participant 3 was “terrified” that his wife would be transferred to hospital in an emergency and ensured that her Advance Care Plan was “everywhere” in the house so that ambulance officers would view it if called. These accounts illustrate both that information sharing and continuity of care between home-based care and acute hospital settings could be improved, and that having an Advanced Care Plan in place can support smoother transitions between care sites. In turn, this suggests the value of ACP promotion and education both for community members and for healthcare professionals. Without an ACP in place it is less likely that a person’s end of life care wishes can be known and honoured in the event of an emergency or unexpected transition between care locations.

Delayed or unpredictable transfer from hospital to hospice was the most pressing care continuity challenge for consumers and carers. Those who received most of their care in hospital had a strong preference for earlier referral to hospice, because they perceived that hospice would offer the palliative care their loved one required but had not received in hospital. Unfortunately, several participants experienced long and unpredictable wait times. Participant 7’s husband was:

*Scheduled to go to the hospice and I kept asking when can he go and they kept bumping him back in the queue while they gave priority to people in the community who’d had their loved one at home and could no longer manage... But they also kept telling me he’s too well to go to hospice. (Participant 7)*

Participant 2’s family was told that his mother-in-law was too unwell to be discharged but that she was not an “appropriate candidate” for hospice:

*We were frustrated about their not being a bed in the hospice which would have been appropriate.... The family had been told that she was not an appropriate person to be in the hospice, which was not correct. She was entirely appropriate. She was palliative. (Participant 2)*

Some participants felt that the lack of a clear pathway to discharge from hospital negatively impacted their loved one’s health. For example, Participant 8’s mother’s health deteriorated during a long hospitalisation:

*When am I coming home? When am I coming home? That’s the first question she’d ask when you go in.. She’d lose her train of thought, her train of speech... She couldn’t even make a sentence because she had no interaction with anybody for three weeks. (Participant 8)*

Participant 7 was told she must find a high-care nursing home so that her husband could leave hospital:

*One person at one point said, Well, you know, we can't keep him here indefinitely and you better start looking at aged care". I was sort of appalled at the thought of high-care nursing home. However, we thought if he's going to get booted out and not to the hospice... We rang every nursing home. Everyone was full up with a waiting list except for one. We left thinking no, we just can't put him there. Anyway, that sort of lapsed [and he was eventually transferred to hospice] but it was yet another stress... [and] time-consuming, yes indeed. (Participant 7)*

As her account illustrates, the lack of predictable pathways from hospital to hospice (or an alternative hospice-like facility) added to the stress of an already-difficult experience.

Nor were transitions from hospital to hospice always smooth. As participant 14 recounted, when her father was moved by ambulance from TCH:

*He'd been transferred with just a blanket on. Got the hospice with no pyjamas, nothing. You could imagine the distress for my mother with that. And for me. (Participant 14)*

When transitions between hospital and hospice were smooth and timely, consumers were very satisfied with this experience:

*So, by chance the doctor in charge of the hospice was on the ward [at TCH]. So, they brought him in to see him and he just sat down next to his bed and said, "I'd really like to look after you over at the hospice. What do you think?" And he said, "That'd be lovely." And so, the very next day the bed was there. (Participant 4).*

In short, timely and predictable access to hospice as an alternative to hospital-based palliative care was highly valued, as were smooth transitions between these sites. Given that delayed transfer from TCH to the Clare Holland House was a concern for some consumers and carers, it is suggested that these agencies collaborate on an ongoing basis to ensure protocols and practices deliver seamless transfers between these sites of care, and report regularly to consumer organisations about progress on this issue.

### *Experiences of hospice care*

People who received hospice care were overall very satisfied with the care delivered to them here. Hospice was seen to be peaceful, quiet, to have a view of trees, sky and water, and provide opportunity for family and friends to visit and stay:

*He was given a room [of his own]. It was large enough to have a double sofa bed and another area where people could sit, so it could easily accommodate my son who over by then and my daughter and I could open up the double bed at night time and stay on that. (Participant 1)*

The quality of medical care was generally regarded as excellent, with the notable exception of one participant whose family experienced a serious adverse event because of medication error. People transferred from hospital to hospice appreciated the consistent palliative approach that hospice provided, while carers whose loved ones moved from their own homes to hospice valued the greater level of medical care available there.

The consumer and carer experiences gathered in this project suggest that there is significant unmet demand for hospice care in the ACT, and that consumers would welcome an expansion of hospice care. HCCA encourages ACT Health to explore options to meet unmet need and demand for hospice care in the ACT. This should include investigating the option of establishing a second hospice in the ACT, and exploring hospice models that would suit the situation of people who cannot receive home-based care, but who require in-patient care over an extended period. A review of models of this kind in place in other jurisdictions would provide a basis for policy and service development in the ACT.

### **5.5. Respectful care and whole-of-person care**

Home-based palliative care as a model was generally regarded as responding well to people's individual circumstances and to their whole-of-person care needs. Several carers appreciated home-based clinicians' and nurses' respectful broaching of end of life conversations. For example, Participant 9 appreciated that a palliative care doctor broached the issue of death with her husband when he was at the end of his life:

*"He took a long time to die because he did not want to die. He struggled on. The [home-based GP] tried to have conversations with him. You know, "Is there anything that's worrying you? Are you ready to die?" He wouldn't go there...."*

Participant 11 appreciated a palliative care nurse tactfully navigating differences of opinion within her family about whether her mother should have ceased chemotherapy treatments.

In the context of overall very positive experiences in this area, one expressed that home-based nurses and clinicians could better anticipate cultural influences and individual variation in preferences for how death and dying should be discussed. Participant 16 and her family migrated from Lebanon, where she feels clinicians “don’t tell the person” about a life-limiting diagnosis and families often prefer not to directly address an impending death:

*“Before our family had even conceptualised the whole process [of home-based care] and accepting that he was dying, we were in denial. One of the [home-based] nurses came in and started talking to my mum about it. My mum was angry. Really angry... It was almost to the extent it felt like, “Oh, so where are you going to bury him?”*

*It was shocking and my sister and I were talking about it afterwards and my sister’s like, “Oh, well, maybe she’s just trying to be realistic,” but I think there is that fine line. The assessment that I can give is that it’s always good to audit the situation. If you audit the situation and know what level that person is up to [that’s good], because if they’re in denial there’s no point going and asking where you’re going to bury that person.*

Regular training in culturally responsive care for all palliative care nursing and clinical staff (including but not limited to those providing home-based care) would support the consistent delivery of **respectful care** and **whole of person care**.

Participant 13 had a negative experience of home-based care<sup>28</sup> in which home-based nurses were unable to assist him to apply a prescription cream (which he could not himself apply) to ease skin irritation caused by cancer treatment. This left him feeling that he “lacked the willing support network” he had expected on discharge from hospital. This example highlights the importance of a person centred approach in which people’s reasonable needs can be flexibly met. Future funding and policy settings should ensure that home-based palliative care services can consistently deliver **respectful care** and **whole of person care**, while expanding to meet anticipated future increases in demand for these services.<sup>29</sup>

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<sup>28</sup> In this instance, care was provided by ACT Health community-based nurses.

<sup>29</sup> ACT Health’s *Palliative Care Services Plan 2013-2017* (p1) makes clear that growing demand for palliative care services is placing growing pressure on those services available.

## 5.6. Communication with health professionals

One participant who had an overall negative experience of home-based care was disappointed with how a nurse communicated when a medication unexpectedly ran out. The nurse and carer agreed that the carer would leave her loved one, who was very close to dying, to drive to a pharmacy and fill a script. The carer felt the nurse did not communicate clearly why the medication was needed, whose responsibility it was to obtain it, or why she had not brought it with her. The carer's loved one died while she was away collecting the medication. This experience underscores the challenge, and the importance, not just of excellent medication management but also excellent *communication* with carers and loved ones about medication issues.

People who received most of their care in hospital had mixed experiences of carer support and involvement, and this was often related to their experience of the closely-linked issue of communication with health professionals. Many people found it difficult to get the information they needed about their loved one's situation:

*If you could find someone they would answer your questions but you could never find out when the oncologist was doing his rounds, it was very hard to find out who was in charge when and who to talk to (Participant 7)*

*It was really, hard to get to see a doctor (Participant 14)*

In contrast with home-based care, hospital staff did not always acknowledge the reality that consumers and carers were facing an impending death, and this also contributed to people's sense that care did not respond well to their individual circumstances. Many participants would have appreciated more open recognition and discussion of their situation:

*I know the [nurses] were saying, "Oh, we have to get your husband in a single room and I said, "Why? You know, like, why?" It's OK to talk about death and dying and it's part of the natural process. (Participant 4)*

Carers appreciated it when hospital clinicians respectfully acknowledged the reality of an impending death. For example, when a hospital doctor advised Participant 12 that her husband was so close to death he was unlikely to be discharged, she appreciated that this was relayed directly and with sensitivity. In all care locations, consumers valued open conversations that matched their readiness for discussion about end of life.

Consumers and carers were more satisfied with their end of life care when they had the opportunity for open conversations and involvement in decisions about treatment and care at the end of life. One participant speculated that time pressures on her mother's clinicians was a barrier to this occurring:

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*He [the TCH oncologist] was so busy you would wait for three hours past your appointment time. He wouldn't even look at her. He'd just go "Oh your results are blah blah blah, but chemo won't show anything until you've had at least three rounds" and that was it. And we'd say "Oh but what are your thoughts? We were thinking that we would engage palliative care, and we're not actually even sure if Mum is well enough to continue with chemo?" and he said, "Oh well, you won't get any results for blah blah blah", but he said "That's your call". ...We wanted somebody to tell us straight, "Do we keep pushing her?" We wanted to have the information behind us". (Participant 11)*

This participant would have valued more time to discuss the issues with a treating clinician, to inform her family's decision-making.

In some instances, clinicians appeared reluctant to countenance cessation of treatment and were unwilling to discuss this option. Participant 1 perceived that a TCH oncologist feared "losing control" when her husband requested to cease chemotherapy, while Participant 3 related that:

*She really resisted [our decision to cease treatment], but she rang me back a couple of weeks before my wife died. She rang me back to say, "You guys made a really good decision", because we were never going to slow it down, so that was great getting that validation from her. (Participant 3).*

This participant valued the oncologist's frank admission, demonstrating the positive impact that open communication about treatment choices can have on consumer experiences.

Improved communication and better information flow would improve overall experiences of care within ACT public hospitals, and assist carers to feel involved and supported in the care of a loved one. All patients admitted to hospital with late-stage life limiting illness would benefit from a care coordination approach. Beginning early after admission and continuing until departure from hospital, care could be coordinated by a patient care navigator or nurse coordinator, and involve at least one family conference bringing together the treating team, the family or loved ones, a social worker and a palliative care doctor or nurse. HCCA encourages ACT Health to consider trialling and evaluating an approach of this kind at TCH.

## 6. Future research

The consumer and carer experiences gathered in this project addressed several areas that fall outside the scope of this work, and/or warrant further investigation. These include:

- The ethics of healthcare for older people, in particular how well older consumers and carers in the ACT are supported to make informed decisions about the risks and benefits of medical interventions such as surgery;
- The role of GPs in palliative care in the ACT; and
- Consumer attitudes towards assisted dying in the ACT.

Two participants raised issues relating to the safety and quality of RACF care. These participants had experienced what they perceived to be poor quality care for a loved one, particularly at the end of life. One participant also expressed that he had not been provided with sufficient information to make an informed decision about entering a retirement living facility. While these concerns were expressed by a small number of participants, they do suggest areas for possible future research, namely:

- Consumer and carer experiences of quality and safety in RACFs, both at end of life and more generally; and
- How to best support informed decision-making by consumers as they consider entering a retirement living facility and/or RACF.

It was also beyond the scope of this project to explore in detail the process by which consumers and carers were advised that home-based palliative care was not appropriate to their circumstances.

Only one participant in this project had received care from ACT Health's community nursing team. Consumer and carer experiences of this important provider of palliative care services could usefully be explored in more detail.

These area areas that could be explored in future applied qualitative research with ACT consumers and carers.

## Appendix 1: Consumer and carer perspectives on circumstances in which care at home may not be appropriate

The most significant barrier to home-based care affected those who were advised, or themselves judged, that home-based care was not suitable in their circumstances. Several participants who experienced most of their care in hospital would have preferred to care for a loved one at home but concluded that this would not be appropriate in their circumstance. For example, one participant explored home-based palliative care after his elderly mother-in-law was hospitalised following a stroke but ultimately decided this would not be possible:

*She had this huge aversion to nursing home and to hospital. Her mother had died in a hospital with short notice back in the 50's and she clearly didn't want to be in hospital, but she wasn't communicating at all, until... [suddenly] she was sat up in bed and said, "Take me home!" That was obviously very traumatic, because we knew she didn't want to be there, but it was totally impractical to go home, but nonetheless, we knew that's what she would have wanted.*

*We did our best. She did not have a hospital bed [at home], so she wasn't really safe to go back to her own bed. It was a tri-level place, trying to get her to the toilet, all those sorts of things would have been difficult. Nevertheless, we did explore that, but it was not feasible. (Participant 2)*

In addition to the need for home modifications in some instances, participants drew attention to the time, physical demands, and confidence required of unpaid caregivers. One participant who cared for a loved one receiving palliative care at home observed that:

*She was young, 55 and I was 56, a year older and fit and able. My daughter came to live with us as well, and she was training to be a nurse at that point, but we were both able to give injections, all the rest of it and her illness was very short, was only three months. There was no dementia or anything involved. She was very accepting of her illness and we didn't have any division in the family around it. I was able to pick her up whenever I needed to, and I could actually carry her. (Participant 3)*

A number of the caregivers lived with chronic conditions that they felt would limit their ability to care for a loved one, or were themselves elderly. Some were in full-time employment; one participant cared for an adult child with significant health needs. These circumstances informed their view that they were unable to provide the care their loved one would require to remain at home.

In some instances, the care needs of a loved one were very considerable, and participants recognised that these care needs could not be met at home. For example, one participant observed that:

*If he was at home... yes, certainly I could not have managed by myself full stop. I just couldn't have. If he was at home you'd pretty much wasn't someone there at least for half the day, at least through the night so you could have some kind of a rest. So, yes. (Participant 4)*

Another had planned to care for her husband at home while he received home-based palliative care after his diagnosis with cancer, but the rapid deterioration of his health made this impossible:

*He was discharged and so then palliative care got involved. And they were lovely but by the time the first [palliative care] doctor came she was really, really shocked at how poorly he was and she said, 'No, he has to go to hospital'. So, at that stage he was taken to TCH and he never was discharged from there.*

*We did investigate whether I might be able to manage him at home but once his spine collapsed and he became paraplegic it really was impossible. (Participant 4).*

This circumstance underscores that in some circumstances home-based palliative care cannot provide the level of care required.

One participant who was unhappy with the quality of care her father was receiving in an RACF considered bringing him to live with her but was advised that his care needs were too high:

*Everyone, the palliative care people, all the nursing team, just said don't do it, you can't do it at home. Because Dad was well off I was going to use his resources to care for him here [at my own home], and they said put more resources into the RACF, so we employed a private physio person to come three times a week, we tried to employ someone to come twice a week to take Dad for a walk and read him books on top of my sister and I coming every day. (Participant 5)*

As these examples illustrate, when participants were advised that HBPC was not suited to their circumstances they accepted this advice. However, this research did not explore the process used to assess the appropriateness of HBPC in every circumstance. This point notwithstanding, people recognised that home-based palliative care was not possible or appropriate for everyone. Those who explored but decided not to pursue to home-based palliative care made this decision various

reasons, including on the advice of healthcare professionals, recognition of the limitations on their ability to undertake the caring role, and the very high care needs of a loved one.

## Appendix 2: Domains of person centred care used in this project

The domains of person centred care used in the project, and the definitions of these domains, were developed by the Consumers' Health Forum of Australia for use in the *Real People, Real Data* method. The domains and definitions were developed drawing on evidence-based typologies<sup>30</sup> of the aspects of care that deliver safe, high quality care and positive consumer and carer experiences. The original table can be accessed at: <https://chf.org.au/real-people-real-data-toolkit/analysing-and-presenting-consumer-stories-shape-decision-making-2-1>

Criteria	Definition
1. Access, equity and affordability	<ul style="list-style-type: none"> <li>• People can access services to address their healthcare needs and to manage their condition/s. This includes access to safe, quality, timely and appropriate services, treatments, preventative care and health promotion.</li> <li>• Healthcare services, professionals and the healthcare system recognise and address dimensions of health inequality such as those related to geographic location, socioeconomic status, language, culture or Indigenous status.</li> <li>• People can afford the treatment and care that they require.</li> </ul>
2. Information and understanding	<ul style="list-style-type: none"> <li>• People are provided with accurate, relevant and comprehensive information, that considers their individual condition, language, age, understanding, abilities and culture. This healthcare information is open, timely and appropriate and delivered in a way the consumer can understand. This information includes (but is not limited to): discharge information, information about medicines, treatments and devices, danger signs to look out for and clear, comprehensible information for self-care.</li> </ul>

<sup>30</sup> The Australian Commission on Safety and Quality in Healthcare (2008) *Australian Charter of Healthcare Rights*; International Association of Patients Organizations (2006) *Declaration on Patient-Centred Healthcare* (IAPO: London); Picker Institute (2013) *Principles of Patient-Centred Care*; the *Patient Activation Measure* (see Hibbard, Judith, Jean Stokard, Eldon Mahoney and Martin Tusler (2004) Development of the Patient Activation Measure (PAM): Conceptualising and Measuring Activation in Patients and Consumers (*Health Services Research August 2004, 39(4 Pt1): 1005-1026*)); and the *World Health Organisation (2001)*'s multi-country study on health and responsiveness 2000-2001 (*WHO: Geneva*).

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3. Informed consent (including informed financial consent)	<ul style="list-style-type: none"> <li>• Patients are provided with all the relevant information to support their agreement (or not) to any medical or health procedure. This involves being informed by their treating professional/s about their options, understanding the benefits and any risks associated with the procedure and being supported by their treating professional(s) to make a decision about their care.</li> <li>• Patients are provided with clear, timely and comprehensible information about the cost of treatments and procedures.</li> </ul>
4. Appropriate care	<ul style="list-style-type: none"> <li>• Patients receive the right care, at the right place, at the right time, and from the right professional.</li> </ul>
5. Respectful care	<ul style="list-style-type: none"> <li>• Patients receive care that demonstrates respect for their culture, beliefs, values and personal characteristics, and for their preferences and expressed needs.</li> </ul>
6. Whole of person care	<ul style="list-style-type: none"> <li>• Patients receive care that recognise and responds to their mental, physical and emotional wellbeing.</li> </ul>
7. Coordinated care and supported transitions	<ul style="list-style-type: none"> <li>• Patients experience care that is coordinated and integrated of care, with smooth transitions between different services.</li> </ul>
8. Safety and quality	<ul style="list-style-type: none"> <li>• Care and treatment do not harm the consumer.</li> <li>• Any harms and risks involved in treatment are clearly communicated and understood by the consumer.</li> <li>• If an adverse event occurs, this is openly disclosed.</li> <li>• Consumers who have not received appropriate care can make complaints and seek restitution through complaints and oversight mechanisms.</li> <li>• Healthcare organisations have a culture of openness and transparency around safety and quality, and processes to respond to complaints and feedback.</li> <li>• Healthcare organisations have a learning culture and processes to support continuous quality improvement.</li> </ul>
9. Control and choice	<ul style="list-style-type: none"> <li>• Consumers are involved in self-management of their health and any health conditions. This can involve having the knowledge, skills and confidence to manage one's own health, and having a choice of healthcare provider.</li> <li>• Patients have opportunities to be involved in health policy, and take shared responsibility for policy-making</li> </ul>

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	through meaningful and supported engagement in all levels and at all points of decision-making.
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10. Social, economic and community participation	<ul style="list-style-type: none"> <li>• Consumers receive healthcare that supports their social, economic and community participation – for example studying, training, working and/or taking part in community activities.</li> <li>• Consumers have safe, secure housing; freedom from stigma and discrimination; and a sense of connection to culture. These enable and underpin participation and good health.</li> </ul>
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11. Carers and support	<ul style="list-style-type: none"> <li>• Consumers are supported by family, friends or other carers.</li> <li>• Carers, family and friends are supported to care for the patient.</li> <li>• Family, friends or other carers should be involved in decision-making and care planning in support of the patient.</li> </ul>

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