

TASMANIAN PALLIATIVE CARE COMMUNITY CHARTER PROJECT

FINAL REPORT PHASE 1

Prepared for the Better Access to Palliative Care Project Committee
Department of Health and Human Services
Tasmanian Government

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- Lois Berry, Hospice Care Association
- Rosie Crumpton-Crook, Canteen
- Margaret Hughes, University of Tasmania
- Colleen Johnstone, Palliative Care Tasmania
- Fiona Onslow, Hobart District Nursing Service/Hospice@home

Thank you also to Judy Clark for assisting us to hear the voices of Tasmanian Aboriginal community members.

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Acronyms and Abbreviations

Acronym/Abbreviation	Definition
ACP	Advance Care Plan
BAPC	Better Access to Palliative Care
CALD	Culturally and Linguistically Diverse
CDC	Consumer-directed Care
CINALH	Cumulative Index to Nursing and Allied Health Literature
DHHS	Department of Health and Human Services
GP	General Practitioner
HACC	Home and Community Care
HCP	Home Care Packages
LGBTI	Lesbian, Gay, Bisexual, Transsexual, and/or Inter-sex
NHS	National Health Service
OT	Occupational Therapist
RN	Registered Nurse
TAFE	Technical and Further Education
UK	United Kingdom
US	United States of America
WHO	World Health Organization

EXECUTIVE SUMMARY

The Tasmanian Government aims to improve access to quality palliative care across the Tasmanian community, through the Better Access to Palliative Care (BAPC) program, based on the Compassionate Communities framework¹. The Compassionate Communities model of palliative care has been used to describe engagement of communities in a range of matters related to death and dying, including setting up community support networks for people and their carers. This project, one of several that have been commissioned to help achieve the aims of the BAPC program, will develop a Tasmanian Palliative Care Community Charter

A charter is, in essence, an agreement between two or more groups within society. The Tasmanian Palliative Care Community Charter will be an agreement between the Tasmanian community and palliative care service providers. The Charter articulates what community members need and want in relation to palliative care and how the service system may be able to respond to these needs.

A reference group guided the KP Health project team during the project. The project incorporated a literature review, extensive consultation with organisational stakeholders, community consultations through group discussions and interviews and a survey. People consulted included Tasmanian Aboriginal people, people from culturally and linguistically diverse (CALD) backgrounds, lesbian, gay, bisexual, transsexual and inter-sex (LGBTI) people and people with disabilities. The draft Palliative Care Community Charter was developed and circulated for feedback and advice to inform its refinement.

The literature review identified that the best charters contain statements from both community members about their care needs and also corresponding commitments from care providers to incorporate those needs into the provision of care. The literature review provided the basis for the consultation that followed.

MAJOR FINDINGS

Main findings relating specifically to the Charter included:

- Community members want skilled staff to provide excellent/best practice management of pain and other physical symptoms, and other causes of distress. This was considered more important than any other concern.
- Community members felt strongly that such care, treatment and other support should be provided to everyone who needed them. This was of particular concern to Aboriginal and LGBTI people, people with disability and people in rural and remote areas.
- A Compassionate Communities approach can enable choice of place of care and place of death. Support networks of local community members and groups can reduce carer stress and burden and provide social interaction and reassurance for people who live alone.

¹ Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM. 2013 Dec;106(12):1071-5. Epub 2013 Sep 30.

Main findings in relation to service provision included:

- Community education about palliative care and pain management is needed, to reduce fear about the use of some palliative medications.
- Many health professionals also need better education regarding palliative care and pain management.
- Respect, dignity and person-centred care were major requirements for all groups and individuals consulted.
- Being treated with respect and dignity were particularly important to LGBTI people, people with disability and people from Aboriginal and CALD backgrounds.
- Service providers working together and good coordination of care were seen as essential for provision of high quality palliative care. Good care co-ordination can reduce distress for the person being cared for and their family members and carers.
- Good communication and provision of information was highly valued especially in relation to being told the truth about the person's diagnosis and likely prognosis.
- Poor communication and information provision impacted on other issues, including accepting that death was approaching and to allow the development of an end-of-life plan; the choice to die at home with the necessary formal and community supports; the carer's ability to cope with procedures during the care period; and security for carers of knowing what to do once death has occurred.
- Access to 24/7 urgent care and advice is particularly important.
- New e-learning options could provide educational opportunities to enhance skills of people currently providing palliative care and related support services, particularly in rural and regional areas.

Main findings in relation to system level issues included:

- Many participants thought it was important to have a written Advance Care Plan that expressed their wishes for what they do or do not want in the last stages of their life.
- Knowing that their wishes are legally binding on their care providers can give peace of mind to the person themselves and take away many concerns that they, their carers and other family members may have.
- Knowing what the person wants, or does not want, if they have lost capacity also provides guidance and security for health care providers.
- The majority of participants wanted to be cared for and to die at home but others did not. Both options need to be available.
- When someone is being cared for at home, carer-stress can be reduced if they have someone they can call at all hours; telehealth may be one option that could improve access to urgent advice and support.
- Many participants said that wherever death occurs, carers and others close to the person should be encouraged to participate in the care. This was especially important to LGBTI partners and specific members of Aboriginal or CALD community groups.

- This respect and recognition needs to continue once the person has died, with on-going bereavement support offered where needed; no carer should ever feel abandoned once the person has died.
- The palliative care workforce includes both highly-skilled health and allied health professionals and informal care providers, including family members, friends and volunteers. To maximise their effectiveness, regular training and education opportunities are required.

Recommendations

The recommendations that follow reflect the identified wishes of the Tasmanian community and will contribute significantly to better access to quality palliative care.

Charter Specific Recommendations:

1. That the BAPC project note the outcomes from the consultations and consider how they can be addressed both through the Charter initiative and other projects currently being implemented by BAPC.
2. That excellent/best practice management of pain, other physical symptoms and other causes distress be available to everyone who needs them
3. That in Phase 2 of the Community Charter project:
 - options to support the implementation of the Charter be explored in consultation with service providers, utilising existing structures and processes where possible, for example, quality and safety processes and standards
 - the scope of consultation includes service providers and organisations which play a key role in supporting members of the community with palliative care needs
 - consultation with young people is undertaken to determine if the Charter's principles adequately represent their needs and expectations
 - the concept of Compassionate Communities is explored with service providers and their advice sought as to how the Compassionate Communities approach may be implemented and developed in their service.

Service Level Recommendations:

4. That health professionals providing direct clinical care be offered regular continuing professional education (CPD) to update and improve skills, competencies, capabilities and understanding of pain management, medication use and related approaches to alleviate distress for people with palliative care needs.
5. That regular cultural-awareness in-service training be provided to front-line staff and volunteers to ensure that everyone is treated with respect and dignity, regardless of their age, gender, cultural background or support needs.
6. That opportunities for organisational care coordination strategies, which encourage everyone providing palliative care to work with other services in the coordination of care for their clients, be identified and promoted.
7. That options to improve access to and the delivery of ongoing education and professional development in the palliative approach to care be further explored.
8. That a range of options for providing palliative care, including using telehealth or other new technologies, be encouraged, especially where existing structural or geographic constraints are likely to limit access to care.
9. That access to 24/7 urgent care and advice be available for everyone who needs it.

System Level Recommendations:

10. That there is ongoing support and provision of information to encourage people to participate in End of Life Care and Advance Care Planning.
11. That initiatives to build the capacity of community and informal palliative care networks are supported and encouraged.
12. That the Compassionate Communities approach to palliative care continues to be supported and promoted.
13. That there is a stronger focus on workforce development across the whole palliative care sector to:
 - improve opportunities and support to access ongoing professional development and education
 - provide community education activities tailored to the needs of carers and volunteers;
 - develop communication skills across the workforce to support open and honest conversations about death, dying and planning for the end of life.

INTRODUCTION

The Tasmanian Department of Health and Human Services (DHHS) Better Access to Palliative Care (BAPC) program, based on a Compassionate Communities framework, aims to improve access to high-quality palliative care across the Tasmanian community. The Compassionate Communities model of palliative care is an extension of the World Health Organization (WHO) Healthy Cities / Communities concept and has been used to describe engagement of communities in a range of matters related to death and dying, including setting up community support networks for the person being cared for and their carer and family. To help achieve the aim of the BAPC program, a number of projects have been or are being conducted that focus on many of the issues involved in caring for people on their palliative care journey. One of these projects has, as its focus, the development of a Tasmanian Palliative Care Community Charter.

A charter is, in essence, an agreement between two or more groups or sectors of society. The Tasmanian Palliative Care Community Charter will be an agreement between the Tasmanian community and palliative care service providers. The Charter articulates what community members need and want in relation to palliative care and how the service system may be able to respond to those needs.

The aims of developing the charter are to:

- give a voice to community members about their palliative care needs
- assist to raise awareness about palliative care and how we can best support people to plan for death and dying
- provide guiding principles to inform and underpin the delivery of palliative care in Tasmania.

Developing a Palliative Care Community Charter also demands consideration of the role of the wider community in relation to community-based palliative care. This report covers Phase 1 of the Tasmanian Palliative Care Community Charter project. KP Health conducted consultations with Tasmanian community members between May and July 2016, and sought input from as wide a range of groups and individuals as possible.

METHODS

The development of the charter was guided by a reference group which provided advice to the KP Health project team through regular face-to-face and teleconference meetings. Feedback from reference group members was incorporated into the consultation plan, the survey questionnaire and the draft charter. The project plan was presented to, and accepted by, the Tasmanian Department of Health and Human Services (DHHS, Better Access to Palliative Care project team).

A literature review was undertaken to inform the development of the community survey. We reviewed academic literature and grey literature to find studies, reviews and reports on the development of community or patient charters both in Australia and internationally, in countries with similar health-care systems to Australia. (See Appendix 1 for a full report on the literature review context, methods, search results and an analysis of the literature, relevant to Phase 1 of the project). A basic draft charter was developed from the literature review for use in the consultations.

Drawing on local knowledge and networks of KP Health staff, and advice from the DHHS project team and reference group, a stakeholder list was drawn up and a general information document about the project was developed for distribution to all stakeholders. A final consultation plan was presented to the DHHS project team and accepted.

A total of 47 stakeholder organisations across all three Tasmanian Health Regions were contacted and provided with information about the project. These included government departments and services, non-government health and community organisations, church-based groups, volunteer organisations and service clubs. It was explained that the focus of this first phase of the project was to hear the voices of community members and that a proposed second stage would take the outcomes of Phase 1 to service providers, and ask for their thoughts on how the expressed needs and wishes of the community could be accommodated within service provision.

Not all organisations or groups contacted had the capacity to be involved in the project. Responses suggested that there was a degree of “consultation fatigue”, as a number of the organisations had already been involved in some of the other BAPC or similar projects.

Twenty-two organisations agreed to assist the project team to access their members or clients and, where relevant, they were provided with details of focus group venues, dates and times. Specific invitations for distribution to clients / patients / members were also sent to relevant organisations and groups. Community consultations were undertaken from May to July 2016. Focus groups were held in Southern and Northern Tasmania; very low response from community members in the North West Region precluded holding a focus group there.

Additional small group meetings or one-on-one interviews were conducted in all three regions across the state. Participants were provided with an Information Sheet about the project and completed a Consent Form (see Appendix 2), which included consent for the focus group, meeting or interview to be audio-recorded.

People from culturally and linguistically diverse (CALD) backgrounds, members of the Tasmanian Aboriginal community, lesbian, gay, bisexual, transsexual and inter-sex (LGBTI) people and people in the disability sector were also engaged and consultation was undertaken with a small number of general practitioners (GPs) and their patients. To ensure that Aboriginal people in Tasmania were provided with the opportunity to participate in a way with which they were comfortable, a consultant with strong links to the Tasmanian Aboriginal community was employed to undertake focus groups and interviews with members of the Aboriginal community. (See also Appendix 3 for a full report of the Community Consultations, including participants, and Appendix 4 for a Summary Consultation Report).

A Qualtrics on-line survey was developed, with a hard-copy option also available, based on the findings in the Literature Review (see Appendix 5 for a copy of the survey). Several stakeholders distributed the on-line survey to people on their databases or other networks. Hard-copy surveys were distributed at *Agfest* and other meetings as appropriate.

CONSULTATION OUTCOMES

Focus Groups, Meetings and Interviews

A total of 148 participants, ranging in age from late 20s to almost 90 years old, attended focus groups, meetings, discussions or interviews. Most participants had experience of caring for family members or friends at the end of life; in most cases this was positive but there were a number of participants who had had negative experiences.

Participants identified a range of issues as essential for the delivery of good palliative care in the community. A brief outline of these issues follows. (See also Appendix 3 for a full Consultation Report and Appendix 4 for a Summary Consultation Report).

Major issues in all focus groups

Relief from pain and other causes of distress

- Excellent / best-practice control of pain and other causes of distress is extremely important; if a person is in pain or experiencing other distressing symptoms, including psychosocial or spiritual issues, they can't appreciate anything else.

Respect, dignity and person-centred care

- People want to be treated as individuals, with dignity and respect for their values and beliefs; with empathy and compassion; and to die with dignity.

Good communication and provision of information

- Terminally ill people and their carers want honesty and truth-telling about: diagnosis (and prognosis as far as this is possible); options and choices around treatments and possible side-effects; a "plan of treatment / care" so they know what to expect; who will manage their care; reasons for tests and results; and the fact that they have the right to accept or refuse any tests or procedures.

Composition of the care team/coordination of care

- Coordination of care and services is important, so people do not have to tell their story over and over, and so each service provider knows what the others are doing.
- Services need to work together and involve the person, their general practitioner (GP), carer and other people nominated by the person receiving care. A skilled workforce at all levels is essential, from health care assistants or personal carers through to registered nurses and GPs.

Place of death and care

- People want choice about where they are cared for and where they die; if dying at home is not possible, people want their place of care to be a home-like environment.

Fair access to care that meets individual needs

- Community-based palliative care services need to be available to everyone who needs them, regardless of age, gender, income, culture, level of disability prior to diagnosis or usual place of residence and without the need to travel long distances, or go into a hospice or residential care away from family, friends or their community.

Support for the carer and other people who matter to the person receiving care

- Respect should extend to care for people important to the person, including after that person has died. However, access to respite for the carer shouldn't mean that the person being cared for has to go away from family, friends or community.

Bereavement support

- Carers and others close to the person need on-going support after the person has died; they should never feel abandoned.

Advance care planning

- It is important to have a written plan that describes a person's wishes for care and treatment at the end of life. A person's wishes, expressed through an Advance Care Directive or by their Enduring Guardian, are legally binding and therefore must be complied with if they reflect the person's current situation and the choices are allowed by law.

Additional cultural issues

Additional issues were raised by some groups in relation to cultural considerations.

For Aboriginal people in Tasmania issues included:

- Ask the person receiving care and their family or community group if there are specific cultural considerations in their care and planning for end of life that need to be addressed; for example, some people might want to go home or remain on country to die.
- Meaningful respect for the extended family and their role in the dying process is essential. When there is time and respect for cultural considerations, this can make a positive difference to the person and their family.
- After the death, people may need the opportunity for "sorry business".
- Community controlled Aboriginal organisations often have a multifaceted role in supporting the person, their family and community during palliative care, and with sorry business, and can be a valuable resource.

For the Bhutanese Community additional issues identified (which were also raised by people from other CALD backgrounds), included:

- These communities are as diverse as any other, they have different languages, adhere to different faiths and have different perspectives on end-of-life questions. Most wanted access to spiritual guidance offered by their respective faith.
- Family participation in end of life decision-making is critical but the person receiving palliative care, or their substitute decision-maker, should be asked which family members they want involved.

Responses to the Concept of Compassionate Communities

People consulted were asked their views about a 'compassionate communities' approach to supporting people with palliative care needs. Their responses included:

- Having a community response, where people could rally around when someone was dying and provide some support for the person and / or their carer(s) "would be amazing, especially for people with no family support or elderly people or people with no-one else".
- Local communities need to be involved in planning for services delivered in their community, especially services which rely on volunteers. Such things cannot be "imposed from the top".
- Where possible we should build on existing supportive relationships. Friends, social or cultural networks and good neighbours can make it possible for people to die at home.

Survey Process

The survey was completed fully or in part by 167 respondents. Demographic characteristics of respondents were as follows: 77% female; 35% aged over 79 years, 43% aged 50-79 years, and 22% aged younger than 50 years. Half of the respondents were from the Southern region, 42% from the North, with 8% from the North West and Western region; 71% were from urban areas and 29% from rural areas.

Overall 54% of respondents had experience of palliative care, either personally for a family member or through someone close, or as a health professional. More than 70% of respondents reported a positive experience (25% very positive, 46% somewhat positive). However, 10% had somewhat negative experiences and one person had a very negative experience.

Responses from the surveys reflected similar themes to those identified during the focus groups, meetings and interviews. Survey respondents identified the following issues as being important to them with respect to the delivery of community-based palliative care:

- Quality, availability and access to palliative care;
- Involvement of the person themselves and their carer and family in care planning, treatment and planning for death;
- Care and support for carers and significant others, including bereavement care;
- Preferred place to die, and what they would like in the place where they die; and
- Cultural and/or spiritual needs that they and/or their family might need.

Respondents were also asked to what extent they agreed with options by which they could contribute to their own care. There was almost unanimous agreement from respondents that they should be assisted to:

- Clearly document my wishes, including what treatment I want or do not want;
- Nominate someone to make decisions for me if I am unable to, and ensure that my health care team knows who that is;
- Let my health care team know as soon as possible if I have any pain, discomfort or emotional concerns that are impacting on my well-being; and
- Participate in my care and decisions about my care to the best of my ability.

(See Appendix 6 for a full Survey Report).

Developing the Draft Charter

Outcomes of the consultations were discussed and considered by the project consultants and developed into an initial 4-page draft Charter. This was then circulated to the DHHS project team and the project Reference Group, who provided feedback and advice. After a number of iterations, a final 2-page draft Charter (see below) was accepted to take forward into Phase 2, along with the Summary Consultation Report, for discussion with service providers.

THE TASMANIAN PALLIATIVE CARE COMMUNITY CHARTER

The Tasmanian Department of Health and Human Services aims to ensure that all Tasmanians have access to the best possible palliative care when they are approaching the end of life, to help them die peacefully with dignity, compassionate care, and support for them and their carers.

The Tasmanian Palliative Care Community Charter is the result of extensive consultations across the state with Tasmanian community members, including Tasmanian Aborigines and people from a range of cultures and social groups, which enabled them to say what they want and expect from palliative care.

The Charter is underpinned by a Compassionate Communities approach which accepts that palliative care is everyone's business. At the end of life, we all need to know that services and resources are available to us, our carers and other people who are important to us, to support us at this time. This approach was strongly endorsed by the people of Tasmania during the consultations.

The following principles reflect the voices of Tasmanians about what matters most to them, and together form *The Tasmanian Palliative Care Community Charter*. The Charter demonstrates our commitment to advocate for compassionate and quality palliative care.

STATEMENT OF PRINCIPLES

⊕ Relief of Pain and Other Causes of Distress

The most important thing is being free from pain and other distress, whether that distress is physical, emotional or spiritual; unless we are comfortable we can't appreciate anything else.

We need the right amount of palliative care and other support, at the right time and in the right place, delivered by skilled, qualified professionals.

We want to keep life as normal as possible, so we can participate in our usual activities, eat and drink what and when we want, express our sexuality and have pets with us if that is what we want.

⊕ Respect, Dignity and Person-centred Care

We want to be respected for our individual values, beliefs, culture, sexual orientation and choices of who we want involved in our care.

We want our carers and other people who matter to us to be treated in the same way;

respect the rights that our partners have to make decisions for us if we have lost capacity.

We want to be at the centre of planning at all times, with support to manage our care and make our own decisions if we want to, without pressure from health care providers to take a particular path.

We want to be cared for by people who are experienced and culturally respectful of our rituals of death and dying, the roles of our family or other people in our community, however those are expressed in the community groups to which we belong.

⊕ Good Communication

Give us, and our carers if we agree, information in honest, simple language about our illness, what treatment is available and, if possible, when we are likely to die.

Tell us and our carers what to expect when death is coming.

Explain to us what palliative care is and how it will help us.

Give us all the information and access to care and support that we, or our family or carers, might need.

⊕ **Coordination of Care**

Everyone providing care should talk to each other and share information, so everyone knows what everyone else is doing and so we don't have to repeat information over and over. Keep a balance between sharing our personal information and respecting our privacy.

Make sure we know who you are, what organisation you are from and what support you have come to provide. Don't assume we'll remember you from last time.

Our GPs and home carers are an important part of our care team. Make sure they are included in all communication.

⊕ **Place of Care and Place of Death**

We want choice and control over where death occurs. If care at home isn't possible, we need a peaceful, home-like environment where people who are important to us feel welcome and, where appropriate, encouraged to assist with care.

When death is close, we and our family need privacy, even if care is being provided in a hospital.

⊕ **Fair Access to Care that meets Individual needs**

We need access to palliative and other care when and where it is needed, without us having to travel away from family and friends.

Affordable care and support needs to be provided to everyone who needs it, regardless of age, physical or mental capacity, cultural background, religion or sexual orientation.

We need a clear, understandable pathway to access care and support.

⊕ **Support for People Important to Us**

Our palliative care journey will be easier if our carers and other people who are important to us are respected and cared for as well. In particular, our carers need:

- to have their knowledge of us and what brings us comfort acknowledged and respected.
- education about reasons for providing or not providing treatment options.
- contact details for 24/7 urgent care and advice, a check-list of what to do when we die, e.g., who to phone first, what needs to be done before the funeral home staff are called.
- support after our death, both immediately and in the weeks following the death. They should never feel abandoned.

⊕ **Help with Planning End-of-life Care**

Help us to plan ahead, as early as possible, for what treatment and care we want, or don't want, in case we can't tell you when we need the care and treatment. This includes assistance to complete an Advance Care Directive and to appoint an Enduring Guardian.

Give us information about who will have the legal authority to make decisions for us if we lose capacity and haven't appointed our own substitute decision-maker.

⊕ **Support for Aboriginal People in Tasmania**

Respect our wishes to go home or remain on country to die.

Take the time to understand and respect cultural considerations that affect us and our families, including the role of family and extended family in the dying process.

After the death, people may need the opportunity for 'sorry business'.

Give us a key contact person who we can go to if we are receiving mixed messages or don't understand something.

DISCUSSION AND RECOMMENDATIONS

Community members actively participated in the consultation processes that contributed to the development of the draft Tasmanian Palliative Care Community Charter. Many were responding from a perspective of having experienced palliative care for someone close to them; others expressed concerns and wishes relating to the end stage of their own lives and how they would like their palliative care journey to be.

Major issues which arose during the consultation process relating to the Charter are discussed in this section, with recommendations to address the issues raised. In addition, both during the consultation and in discussion with the expert Reference Group, there were issues discussed and views expressed that were beyond the scope of the Charter itself, but need to be addressed to help guide Phase 2. Recommendations specific to Phase 2 are therefore also included.

Charter Specific Recommendations

Main findings relating to the Charter included:

- Community members want skilled staff to provide excellent/best practice management of pain and other physical symptoms, and other causes of distress. This was considered more important than any other concern.
- Community members felt strongly expressed that such care, treatment and other support should be provided to everyone who needed them. This was of particular concern to Aboriginal and LGBTI people, people with disability and people in rural and remote areas.
- A Compassionate Communities approach can enable choice of place of care and place of death. Support networks of local community members and groups can reduce carer stress and burden and provide social interaction and reassurance for people who live alone.

Several attempts were made to engage young people in the consultations to inform the draft Charter. For various reasons, however, direct consultation with young people has not yet eventuated. Further work will be required in this area.

RECOMMENDATIONS

1. That the BAPC project note the outcomes from the consultations and consider how they can be addressed both through the Charter initiative and other projects currently being implemented by BAPC.
2. That excellent/best practice management of pain, other physical symptoms and other causes distress be available to everyone who needs them

3. That in Phase 2 of the Community Charter project:
 - options to support the implementation of the Charter be explored in consultation with service providers, utilising existing structures and processes where possible, for example, quality and safety processes and standards
 - the scope of consultation includes service providers and organisations which play a key role in supporting members of the community with palliative care needs
 - consultation with young people is undertaken to determine if the Charter's principles adequately represent their needs and expectations
 - the concept of Compassionate Communities is explored with service providers and their advice sought as to how the Compassionate Communities approach may be implemented and developed in their service.

Service Level Discussion and Recommendations

Main findings in relation to service provision included:

- Community education about palliative care and pain management is needed, to reduce fear about use of some palliative medications.
- Many health professionals also need better education in relation to the palliative approach to care, pain management and palliative medications
- Respect, dignity and person-centred care were major requirements for all groups and individuals consulted
- Being treated with respect and dignity were particularly important to LGBTI people, people with disability and people from Aboriginal and CALD backgrounds.
- Service providers working together and good coordination of care were seen as essential for provision of high quality palliative care. Good care co-ordination can reduce distress for the person being cared for and their family members and carers
- Good communication and provision of information was highly valued especially in relation to being told the truth about the person's diagnosis and likely prognosis.
- Poor communication and information provision impacted on other issues, including accepting that death was approaching and to allow the development of an end-of-life plan; the choice to die at home with the necessary formal and community supports; the carer's ability to cope with procedures during the care period; and security for carers of knowing what to do once death has occurred.
- New e-learning options could provide educational opportunities to enhance skills of people currently providing palliative care and related support services, particularly in rural and regional areas.

RECOMMENDATIONS

4. That health professionals providing direct clinical care be offered regular continuing professional education (CPD) to update and improve skills, competencies, capabilities and understanding of pain management, medication use and related approaches to alleviate distress for people with palliative care needs.
5. That regular cultural-awareness in-service training be provided to staff and volunteers to ensure that everyone is treated with respect and dignity, regardless of their age, gender, cultural background or support needs.
6. That opportunities for organisational care coordination strategies, which encourage everyone providing palliative care to work with other services in the coordination of care for their clients, be identified and promoted.
7. That options to improve access to and the delivery of ongoing education and professional development in the palliative approach to care be further explored.
8. That a range of options for providing palliative care, including using telehealth or other new technologies, be encouraged, especially where existing structural or geographic constraints are likely to limit access to care.
9. That access to 24/7 urgent care and advice be available for everyone who needs it.

System Level Discussion and Recommendations

Main findings in relation to system level issues included:

- Many participants thought it was important to have a written Advance Care Plan that expressed their wishes for what they do or do not want in the last stages of their life.
- Knowing that their wishes are legally binding on their care providers can give peace of mind to the person themselves and take away many concerns that they, their carers and other family members may have.
- Knowing what the person wants, or does not want, if they have lost capacity also provides guidance and security for health care providers.
- The majority of participants wanted to be cared for and to die at home but others did not. Both options need to be available.
- When someone is being cared for at home, carer-stress can be reduced if they have someone they can call at all hours; telehealth may be one option that could improve access to urgent advice and support.
- Many participants said that wherever death occurs, carers and others close to the person should be encouraged to participate in the care. This was especially important to LGBTI partners and specific members of Aboriginal or CALD community groups.
- This respect and recognition needs to continue once the person has died, with on-going bereavement support where needed; no carer should ever feel abandoned once the person has died.

- The palliative care workforce includes both highly-skilled health and allied health professionals and informal care providers, including family members, friends and volunteers. To maximise their effectiveness, regular training and education opportunities are required.

RECOMMENDATIONS

10. That there is ongoing support and provision of information to encourage people to participate in End of Life Care and Advance Care Planning.
11. That initiatives to build the capacity of community and informal palliative care networks is supported and encouraged.
12. That the Compassionate Communities approach to palliative care continues to be supported and promoted.
13. That there is a stronger focus on workforce development across the whole palliative care sector to:
 - improve opportunities and support to access ongoing professional development and education
 - provide community education activities tailored to the needs of carers and volunteers;
 - develop communication skills across the workforce to support open and honest conversations about death, dying and planning for the end of life.

DEVELOPING A PALLIATIVE CARE COMMUNITY
CHARTER FOR TASMANIA:
LITERATURE REVIEW

Prepared for the Better Access to Palliative Care Project Committee
Department of Health and Human Services
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Introduction

Context

The Tasmanian Better Access to Palliative Care (BAPC) program aims to improve access to high quality palliative care across the Tasmanian community. It includes a number of projects designed to help achieve that aim; one of these projects has, as its focus, the development of a Tasmanian Palliative Care Community Charter.

A charter is, in essence, an agreement between two or more groups or sectors of society. In this case the aim is to develop a charter between Tasmanian community members and service providers that elucidates what community members want and need in relation to the care and support provided to them at the end stage of life, and how the service system may be able to respond to those needs.

The aims of developing the charter are to:

- give a voice to community members about their palliative care needs and expectations of service providers
- assist to raise awareness about palliative care and how we can best support people to plan for death and dying
- provide guiding principles to inform and underpin the delivery of palliative care in Tasmania.

Developing a palliative care community charter demands consideration of the role of the wider community in relation to community-based palliative care.

Background

Since the 1990s there has been a growing awareness about the need to rethink the ways in which communities and service providers care for those facing life limiting illness and how society deals with death, dying, grief and loss.

Leaders in palliative care, such as Kellehear (1) advocate for a public health approach to palliative care (also known as health promoting palliative care), linking it to the World Health Organization's (WHO) Ottawa Charter for Health Promotion (2) which sees health as the responsibility of society as a whole.

Rosenberg and Yates (3) acknowledge that palliative care and health promotion appear at first glance to be conceptually incongruent fields.

Palliative care aims to achieve the best possible quality of life for dying people and their families (Palliative Care Australia, 2004), while health promotion aims to assist people to live as healthily as possible (WHO, 1986).

However, they argue that health-promoting palliative care is now widely accepted (3).

There is growing recognition that current approaches to end of life care are unsustainable. Demographic changes including an ageing population, increasing patterns of chronic disease and longer lifespans means that new ways of managing death, dying and support for people at end of life are required. One response to this is the creation of Compassionate Communities (4).

The Compassionate Communities model is an extension of the WHO Healthy Cities/Communities concept that:

encouraged ordinary people everywhere to adopt an understanding that 'health' was everyone's responsibility—not just their doctors and their health services. (4:1072)

In the last two decades, health promotion concepts have made their way into the area of palliative care; Kellehear refers to this as “knowledge transfer” (4:1072), noting that, in addition to physical problems, people living with life-limiting illness often experience social, psychological and spiritual problems that impact on their quality of life and are not easily addressed by health services. Enlisting the community in end-of-life caring can increase the effectiveness of such care. He concludes “that end-of-life care is everyone’s responsibility. Everyone has a role to play, however modestly” (4:1074).

The compassionate communities model has been used to describe engagement of communities in a range of matters related to death and dying, such as death education in schools and engaging public policy (4).

The goals of public health palliative care have been described as:

- Building public policies that support dying, death, loss and grief
- Creating supportive environments (in particular social supports)
- Strengthening community action
- Developing personal skills in these areas
- Re-orientating the health system. (1:20)

Kellehear (4) notes that many palliative care services are prioritising community engagement initiatives in their work, in most cases adopting a Compassionate Communities model, as a way of enhancing the effectiveness and reach of their clinical work.

Building community capacity, and not only supporting individual choice around end-of-life care but also embedding such choices within a broader policy and service framework, will also provide greater equity to people who are most vulnerable, and on the margins of society, including refugees, asylum seekers, people who are mentally ill or homeless, or who live in isolated indigenous communities (5).

The development of a palliative care community charter is one way that the Tasmanian government is seeking to engage with the community to rethink the approach to palliative care, death and dying, grief and loss.

Policy Changes

Reflecting this shift in provision of palliative care to some extent, aged and health care in Australia and internationally have moved strongly towards a person-centred approach (6,7), with consumer-directed care (CDC) being introduced into many Australian and State government policies and programs, including those focused on end-of-life care (8).

For many years, health-care consumers have been demanding more say in the treatment and care they receive. Along with people with disabilities, older people and those with a

chronic and/or life-limiting illness have been at the forefront of calls for a reform of government and medical systems, to ensure that consumers become partners in their health care (7).

One response to this is the Australian Government's Living Longer Living Better program (8). As part of this program, the Australian Government funded a number of projects directed at consumer-directed care (9) and mandated that all service providers offering care and support to community-based older people upskill themselves to move to CDC, with residential care expected to follow in the future.

From 1 July 2015, major changes were implemented with respect to aged care services and funding in Australia (10), including that Home Care Packages (HCPs) are now provided on a consumer-directed care basis, with a budget being allocated for each client who is in receipt of a package, but managed by the service provider. From February 2017, this move will be strengthened; funding of HCPs will follow eligible consumers who will be able to select any provider to deliver their care, with funding for the package paid to the provider selected by the consumer. The HCP will be portable between regions. Clients will be able to negotiate with service providers as to what they want or need, including community-based palliative care.

The Tasmanian government has been part of the move to CDC, including as part of the BAPC initiative (11), the overall objective of which is to increase Tasmania's capacity to increase access to high quality community-based palliative care for people with life-limiting illness nearing the end of their life. The Palliative Care Community Charter is an important component of the initiative that will support all of the BAPC action areas by engaging the community in consultations to better inform palliative care policy, service design and practices.

Understanding what community members in Tasmania want at the end stage of life is essential to ensure that the needs of dying people and their families and carers are understood, that services are designed to meet these expectations and that principles outlined in the Charter provide guidance for a Compassionate Communities approach to palliative care. Giving some control back to the community and fostering a culture of partnership between health professionals and community members will enable everyone to work together to achieve the best possible end-of-life care.

Tasmanian Health Regions Demographics

In the 2011 Census, Tasmania's resident population was 495,354 people, of whom 50% were in the Southern health region, 28% in the Northern region and 22% in the North West region (12). At that time 16.3% of Tasmanians were aged 65 or above, compared with 13% for Australia overall. In that Census, 4.5% of the Tasmanian population self-identified as Aboriginal and/or Torres Strait Islander, compared to 2.5% for Australia overall. Because of lower life expectancy among Aboriginal and Torres Strait Islander people, only 4.5% of this population group was aged 65 or above, with 17% aged 45-64 years.

Palliative Care Services in Tasmania

There are approximately 4,000 deaths per annum in Tasmania. It is estimated that 25 – 50 percent of deaths in Australia are “expected” (13); consequently, between 1,000 and

2,000 deaths each year in Tasmania could potentially benefit from a palliative approach to dying, even if the patient does not require Specialist palliative care service. These numbers also indicate why it is important that, as a community, people are equipped to deal with death and dying.

Specific/identifiable palliative care services in Tasmania include:

- Specialist Palliative Care teams (one in each region)
- The District Nurses – Hospice@home service (across the state)
- Whittle Ward – dedicated inpatient unit in the Southern health region
- Calvary Hospital’s Melwood Unit at St Luke’s Hospital in Launceston and Gibson Unit at St John’s Hospital in Hobart
- Community Palliative Care teams in each region.

There are also 11 rural hospitals with dedicated palliative care beds or suites across Tasmania.

In addition, it is widely recognised that families, friends and non-professional carers provide the bulk of care for people with a life-limiting illness, as do primary health care providers, including GPs and community nurses.

Methods

We reviewed academic literature and grey literature to find studies, reviews and reports on the development and/or implementation of Patient Charters both in Australia and internationally, in countries with similar health-care systems to Australia.

For academic literature, we searched the Cumulative Index to Nursing and Allied Health Literature (CINALH), Cochrane Library, Medline, PubMed and Google Scholar databases. Initial searches were limited to 2005-2016, but earlier publications were accessed where perusal of reference lists indicated they may be of value. Key words used were: "Patient Charter(s)", "Healthcare Rights" and "Community Charters"

Google was also interrogated and the reference lists of identified articles were scanned for additional relevant articles.

Other grey literature sites accessed were:

- www.greylit.org
- www.opengrey.eu
- www.lshtm.ac.uk
- www.ntis.gov
- www.kingsfund.org.uk
- www.nuffieldtrust
- www.phcris.org.au/search/index.php

Results

There was limited literature relating to patient or community charters on most of the grey literature sites. From those sites which did have relevant literature, charters were excluded if they: were not health-related; were for dental care; were for care in hospital; were for countries with very different health-care systems to Australia; or were punitive in nature (e.g., health insurance fund charters which set out penalties that would be applied to members who did not abide by specified health behaviours).

Of particular interest for this review was literature related to International patient charters and charters in Australia, New Zealand, Canada, the United Kingdom and Europe. A total of 25 Patient Charters or Codes/Bills of Health Rights and 4 related reports/implementation guidelines were selected for initial review (Table 1).

Table 1: Documents Selected for Initial Review

Ref No	Title	Geographic Location	Year	Type	Focus	Excluded* Yes/No
14	Alzheimer's Association and BUPA. Global Dementia Charter	International	2013	Charter	Dementia	N
15	World Care Council. The patients' charter for tuberculosis care	"	2006	Charter	TB	N
16	Lymphoma Coalition. International Lymphoma Patient Charter.	"	2006	Charter	Lymphoma	N
17	International Kidney Cancer Coalition (IKCC). Amsterdam Patient Charter for Global Kidney Cancer Care.	"	2014	Charter	Kidney Ca	N
18	Law and Government Division, Government of Canada (Smith M). Patient's Bill of Rights – A Comparative Overview of Initiatives in 6 Countries	"	2002	Report	Rights	Y
19	Qld Clinical Senate. A charter for care of adult patients at the end of life.	Australia	2015	Charter	End-of-Life (EoL)	N
20	Australian Government, Department of Social Services. Charter of Rights and Responsibilities for Home Care.	"	2014	Charter	EoL/Care at home	N
21	Kidney Health Australia. Patient Charter.	"	NF	Charter	Kidney Disease	N
22	Australian Commission for Safety and Quality in Health Care. Australian Charter of Healthcare Rights.	"	2009	Charter	Rights	N
23	Department of Health and Ageing, Government of South Australia. Cystic Fibrosis Patient Charter	"	2012	Charter	Cystic Fibrosis	N
24	SA Heart. Patient Charter.	"	NF	Charter	Heart	N
25	Swerissen H, Duckett S. Grattan Institute. Dying Well.	"	2014	Report	EoL	N
26	Health and Disability Commissioner. The Code of Health and Disability Services Consumers' Rights.	New Zealand	1996	Code/Charter	Rights	N
27	Minister's Advisory Committee on Health: A Foundation for Alberta's Health System. A New Legislative Framework for Health	Canada	2010	Legislative Framework	Law	Y

Ref No	Title	Geographic Location	Year	Type	Focus	Excluded* Yes/No
28	Canadian Arthritis Patient Alliance. Arthritis Patient Charter	“	2015	Charter	Arthritis	N
29	The National Council for Palliative Care (UK). The Dying Well Community Charter. Principles of care and support	UK	2014	Charter	EoL	N
30	Royal College of General Practitioners; Royal College of Nursing. End of Life Care Patient Charter	“	2012	Charter	EoL	N
31	Royal College of General Practitioners; Royal College of Nursing. Matters of Life and Death. Helping people to live well until they die. General practice guidelines for implementing the RCGP/RCN End of Life Care Patient Charter	“	2012	Guidelines	EoL	N
32	Voluntary Organisations Disability Group (VODG) Health Charter	“	2015	Charter	Disability	N
33	NHS Public Health Intelligence North East. North East Charter for a Good Death	“	2012	Charter	EoL	N
34	SIGN/Mental Health Foundation. Deaf mental health charter	“	2008	Charter	Deaf Mental Health	N
35	Federation of Independent Practitioner Organisations. A charter for patients and their doctors. Principles governing medical practice in the independent sector.	“	2007	Charter	Medical Practice	Y
36	The Orchard Partnership. Patient Charter	“	2007	Charter	Medical Practice	Y
37	Pan Birmingham Cancer Network. Patient Charter.	“	2012	Charter	Cancer	N
38	NHS Scotland. Your health, your rights The Charter of Patient Rights and Responsibilities	“	2011	Charter	Rights	Y
39	Choice in End of Life Care Programme Board. What's important to me. A Review of Choice in End of Life Care.	“	2015	Report	EoL	N
40	Charter of Rights for People with Dementia and their Carers in Scotland. Scottish Parliament Cross-Party Group on Alzheimer's	”	2009	Charter	Dementia	N

Ref No	Title	Geographic Location	Year	Type	Focus	Excluded* Yes/No
41	European Parkinson's Disease Association. Charter for People with Parkinson's	"	1997	Charter	Parkinson's Disease	N
42	Medical Center of Saint Martin (France). The Patient's Charter	"	NF	Charter	Medical Practice	Y
43	Nauck F, Dlubis-Mertens K. Germany has adopted a charter for the care of the critically ill and the dying. European J Palliative Care.	"	2011	Report: Peer-reviewed article	EoL	Y

*As the Tasmanian Palliative Care Community Charter project is not seeking to develop legislation or legally-binding Codes of Rights, four of the six documents related to legislation or codes of health rights were not considered further. The Australian Charter of Healthcare Rights (22) is included, as it provides an overarching framework for what consumers of the Australian healthcare system can expect in relation to their care. The New Zealand Code (26) is also included, though dating from 1996, as it was the only national or regional document found that addresses the rights of a First Nation's people in its country of origin.

The three charters relating to community-based general or specialist practice (35,36,42) were not considered further in this review; while good end-of-life and palliative care delivered in the community depends on strong links and communication between the palliative and primary care communities, these charters were directed more at the staff or were telling patients about procedural matters. In addition, a peer-reviewed article (43) originally considered in this section, set out key principles in a charter but as these were very organisationally focussed, rather than patient focussed this article will not be reported further.

Content of Fully-Reviewed Documents

Rights-based Charters:

Australia

The Australian Charter of Healthcare Rights (22) sets out three Guiding Principles which describe the rights of patients and other people using the Australian health system.

These are:

1. Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.
2. The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.
3. Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.

These principles are further developed into a series of statements and explanations, outlining what patients/consumers can expect from the Australian health system (Table 2).

New Zealand

The New Zealand Health and Disability Commissioner's Code of Health Rights (26) refers specifically to the First Nation people of New Zealand, the Maori people. Right 1 is the "Right to be Treated with Respect"; clause 3 in this Right says:

1. Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Maori.

Other Rights in this Code include the Right to:

2. Freedom from Discrimination, Coercion, Harassment, and Exploitation
3. Dignity and Independence
4. Services of an Appropriate Standard
5. Effective Communication
6. Be Fully Informed
7. Make an Informed Choice and Give Informed Consent
8. Support and
9. Complain.

Table 2: List of Rights and Meanings in the Australian Charter of Healthcare Rights

My Rights	What This Means
Access	
I have a right to health care.	I can access services to address my healthcare needs.
Safety	
I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect	
I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication	
I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation	
I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy	
I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment	
I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

Disease-specific Charters:

The quality and content of the disease-specific charters is variable and include:

- a series of “I should” statements (e.g., “I should have a say in the care and support that I am given”) but no corresponding commitment that the statements will be actioned (dementia - 14)
- a very comprehensive series of aspirational “you should” statements, many of which are laudatory (e.g., “You should be offered the opportunity to discuss your treatment with a member of the Multidisciplinary Team”). However, while this Charter was developed “with patients for patients” it does not have any evidence of commitment from service providers (cancer - 37)
- five dot points, mainly relating to referral, diagnosis and continuous care (Parkinson’s disease - 41)

- guidelines for the delivery of social care (disability - 32)
- a Vision Statement, followed by a paragraph of information relating to diagnosis, treatment, follow-up, information and support (Lymphoma - 16)
- a description of the health care services that patients have the right to expect (kidney cancer - 17)
- minimal statements about dignity, respect and compassion, the right to accept or refuse treatment and what information will be provided (heart disease - 24).

Four disease-specific Charters are more comprehensive:

1. **Dementia**

The Charter of Rights for People with Dementia and their Carers in Scotland (39) gives a detailed background on why such a charter is needed, concluding with a statement that it is needed to:

- empower people with dementia and their carers to assert their rights in every part of their daily lives and wherever they are
- ensure that those who provide health, social care and other services understand and respect the rights of people with dementia and their carers
- ensure the highest quality of service provision to people with dementia and their carers.

This is followed by a Preamble setting out the Scottish and International Human Rights Acts and Conventions which provide the key principles that guided the development of the Charter and concludes with a well-defined list of 15 “rights” which together address:

1. participation
2. accountability
3. non-discrimination
4. empowerment
5. legality.

2. **Arthritis**

The Canadian Arthritis Patient Alliance, Arthritis Patient Charter (28). This is a 1-page document which uses simple language to define the rights of people with arthritis, as follows:

People with arthritis have the right to:

- Be treated with dignity, respect and consideration. This includes being heard by healthcare providers who respect privacy and confidentiality.
- A timely and accurate diagnosis. Arthritis leads to significant joint damage when left undiagnosed and untreated.
- Timely access to all types of high-quality care. This includes access to all qualified healthcare providers and professionals.
- Readily available current information, education and support programs about arthritis and evidence-based arthritis care. People living with arthritis have the responsibility to learn about arthritis and arthritis care.

- Be informed and participate with their healthcare providers in all treatment decisions. This includes discussing treatment risks and benefits and timely access to medical records. People with arthritis have a responsibility to live a healthy lifestyle, speak openly with their healthcare providers, ask questions about treatment and follow the agreed upon course of treatment.
- Equal public reimbursement and timely access in all provinces and territories to available medication and non-medication treatments. Surgery and rehabilitation therapy that improve activities of daily living and quality of life should not be considered elective.
- Live their lives fully without discrimination. Enjoying life to its fullest potential includes taking part in family, social activities, school and employment. This may require removal of barriers and access to disability programs.
- See that research is underway to find a cure and improve quality of life. Arthritis research must: be funded to an amount equal to other chronic illnesses and include people with arthritis to help set priorities, participate as research partners or in clinical trials and benefit from its discoveries.
- Be included in the development of health policies and programs that affect them. The voices of people living with arthritis must be considered to develop the most relevant and meaningful policies and programs.

This Charter covers a wide-range of topics; although it was developed by a patient alliance it is based on rights that are legislated in Canada, giving patients more certainty about obtaining their rights

3. Kidney Cancer

The International Kidney Cancer Coalition, Amsterdam Patient Charter (17). This is a 2-page document which outlines the aims of the charter, the first of which is “to ensure that the more than one million people living with kidney cancer worldwide ... have access to the best available treatment, care, information and support” (2014; p1). This is followed by a brief history of the development of the charter.

The second page begins with the following statement: “Collectively, the global kidney cancer community declares that patients have the following rights”; it then lists 10 “rights” of which 1-7 are relevant to this review. These 7 rights address issues that patients and their support organisations had identified as being important to them during the charter development, i.e.

- timely investigation
- accurate diagnosis
- appropriate information and education
- access to a highly-skilled multi-disciplinary team
- appropriate and culturally sensitive psychosocial support
- information about available supports
- the right to play an active role in their decisions relating to their treatment and disease management.

4. Tuberculosis

World Care Council. The Patient's Charter for Tuberculosis Care (15). This final charter of the four comprehensive, disease-specific charters is actually a 4-page charter that has been produced to fold to a double-sided A5 booklet. This is the major problem with the document; while the content* is excellent, its value is destroyed by being reduced to a very small print size to fit the A5 booklet. This is difficult enough for someone with good vision to read but for many older, unwell patients, it would be almost impossible – and thus be fairly unusable in practice. It also breaches one of the usual inclusions about information provision, i.e., that it should be provided in an appropriate and accessible format – although it is noted that those words are not used in this charter.

(Extremely small font size is also a problem shared by one of the supporting documents of the Australian Charter of Healthcare Rights [22])

*Content of the Patients' Charter for Tuberculosis Care is set out under two headings: the first is Patients' Rights and comprehensively covers care, dignity, information, choice, confidence, justice, organisation and security. The second heading is Patients' Responsibilities; this covers the responsibility to share information, follow treatment, contribute to community health and show solidarity (with the latter being somewhat problematic in its presentation).

End-of-life Care Charters and Reports

The final group of six charters (19,20,29,30,33,40) focussed on end-of-life care. Two of these charters – Queensland's *A charter for care of adult patients at the end of life* (19) and the United Kingdom (UK) *End of Life Care Patient Charter* (30) begin with the same quote from Dame Cecily Saunders, who is usually credited with being the force behind the modern-day palliative care profession:

You matter because you are you and you matter to the last moment of your life and we will do all we can, not only to let you die peacefully but to help you live until you die.

Both charters are written from the perspective of the health professionals who provide end-of-life care. The UK Charter (30) has statements only from the health-care providers, which are very similar to the statements in the Queensland Charter detailed below.

A charter for care of adult patients at the end of life (19) was developed by the Queensland Clinical Senate and Health Consumers' Queensland, with input from a range of community and health professional groups. It is a 1-page document with a statement, following the Dame Cecily Saunders quote, which says: "We want to offer people who are nearing the end of their life the highest quality of care and support. We wish to help you live as well as you can, for as long as you can".

This is followed by “Our commitment to you – we will:

- Work together with you to support you openly and honestly.
- Respect your choices and your right to independence with compassion and understanding.
- Ensure your privacy, dignity and confidentiality.
- Talk with you and the people who are important to you as often as you feel the need, including (about) treatment options, diagnosis, prognosis and care.
- Co-ordinate care with treating teams across hospital and community – this will include referral, documentation and communication.
- Do our best to manage your pain and symptoms to ensure you are as comfortable as possible.
- Provide emotional, spiritual and cultural support in line with your wishes.
- Support the people who are important to you, both as you approach the end of your life and in their bereavement.”

This charter does what many others do not, that is, it reflects the true meaning of a charter as being an agreement between two groups; in addition to the commitments from the service providers it contains a series of commitments from patients (as determined during the meetings held during the development phase). Commitments from patients are:

- I will endeavour to let the health team and my family know my wishes about the remainder of my life. This might include:
 - the content of my advance care plan or directive
 - my preferred location of death and
 - who my preferred spokesperson(s) is.
- I or my designated spokesperson will:
 - let my treating team know if I am experiencing symptoms that are impacting my well-being, such as pain, discomfort or emotional concerns
 - let my health team know if I need information, direction and support
 - seek advice if I am uncertain of my current treatment or options
 - participate in my care to the best of my ability.

Good end-of-life care needs to be underpinned by principles of care and support that are understood and accepted by all services providers involved in patient care. Two charters (29, 33) set out Statements of Principles. *The Dying Well Community Charter* (29) was developed by the UK National Council for Palliative Care; it states that the Charter

provides a visible commitment by individuals, communities and organisations to work together towards the following principles, which should apply for all of us and our communities as we are affected by dying and death.

The following five principles are then listed, each followed by a more detailed explanation:

- Recognition and respect
- Communicate
- Involvement
- Support
- Help us to Plan, and Do

The North East Charter for a Good Death (33) was prepared by the UK National Health Services (NHS) Public Health Intelligence. It contains four principles, as follows:

- Respect
- Time to plan
- Care
- Support.

As the statements under each principle in these two charters reflect charters discussed previously they are not repeated here.

A recent UK report, *What's important to me. A Review of Choice in End of Life Care* (39), published by the Choice in End of Life Care Programme Board, identified eight main themes on the kind of choices people would like to make at the end of life. These are:

Theme 1: I want to be cared for and die in a place of my choice.	Although most people said that they wanted to die at home, in most cases they did not do so unreservedly; many identified aspects of the dying environment, such as being calm and tranquil, feeling secure safe, respected and dignified, and having loved ones close by as more important than the actual physical location.
Theme 2: I want involvement in, and control over, decisions about my care.	This included timely access to support; involvement in decision-making, feeling in control over treatment choices (including treatment refusal); and honest communication and conversations.
Theme 3: I want the right people to know my wishes at the right time.	Advance Care Planning was highlighted under this theme but respondents noted the difficulty of initiating such discussions. (Other research has found that while many patients want to have such discussions they want their GP or other treating doctor to raise the issue (44). Some respondents also wanted access to their own medical records. However, a final point under this theme was that "it should not be assumed that all individuals wish to engage in decisions about their future care" (39:20).

Theme 4: I want access to high quality care given by well-trained staff.

Essential elements of good end-of-life care identified under this theme were: co-ordinated care; good communication; good pain relief; access to equipment; accurate care records; to be treated with compassion, dignity and respect; and care that was personalised to individual needs. All of these aspects were required to be delivered by skilled and well-trained staff.

Theme 5: I want access to the right services when I need them.

Services identified included: specialist palliative care; community care; hospice provision; and 24/7 care. All of these were seen as requiring good care co-ordination.

Theme 6: I want support for my physical, emotional, social and spiritual needs.

Although the majority of participants said that pain management and symptom control were the aspects of their overall wellbeing that mattered to them most, they also valued holistic support, emotional support and spiritual care.

Theme 7: I want the people who are important to me to be supported and involved in my care.

While outcomes under the previous themes related primarily to the dying person themselves, they were also concerned for family and other people who were caring for them and how they would be affected by their death. They wanted those people supported both during the caring phase and in alter bereavement.

The Australian Government, Department of Social Services, developed a *Charter of Rights and Responsibilities for Home Care* (20). As more care, including palliative care, is being provided in the community, in line with both ageing-in-place and consumer-directed care principles, this Charter is relevant to the current project.

The first section of the charter sets out care-recipient Rights, under seven headings: General; Participation; Care and Services; Personal Information; Communication; Comments and Complaints; and Fees. Although many of the rights listed under these headings have already been reflected in the charters above, the fact that this charter was developed by the Department of Social Services, rather than the Department of Health, is evidenced by the language used. For example, one of the rights listed under the "General" heading is that the recipient has the right "to full and effective use of all my human, legal and consumer rights, including the right to freedom of speech regarding my care. The two sections on "Comments and Complaints", and "Fees" are also not found in most health-related charters.

Headings in the second section of the charter, on Consumer Responsibilities, include statements about treating care workers without exploitation, abuse, discrimination or harassment, as well as further information about services, communication, access and fees. Presumably, the rights and responsibilities contained in this charter could be considered to apply to staff providing palliative care in the community.

An Australian report, *Dying Well*, prepared by the Grattan Institute (25:8) asks “What is a good death?” They propose that a good death includes the following:

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs (at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location including home, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives that ensure wishes are respected
- To have time to say goodbye, and control over other aspects of timing and
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

This list summarises the wishes and commitments found in many of the charters above.

As noted, no specific charter was found relating to community-based care for Aboriginal and/or Torres Strait Islander people and just one which specifically included Maori people (26). Some Australian hospital-based patient charters note that all patients, regardless of their culture, should be treated with respect, dignity and consideration, and most also specifically say “including Aboriginal and Torres Strait Islander patients”. However, Stewart et al note that “[t]here is little evidence to show how models developed for non-indigenous Australians or internationally might apply to Indigenous Australians (45). While this comment related to models of primary care, it is also relevant to community charters for palliative care.

Legal Status of Charters

Many of the charters identified in this review are “aspirational”; they have been developed by patient-support groups, or in some cases by health professionals, and state what rights a person “should have” or wish to have but are not specifically binding on service providers. There are some exceptions, where the rights espoused are also stated – at least in principle – in the legislation of the country or state in which they are based, including Australia (22) and Canada (28).

Schmidt (46) describes three charters which have varying degrees of enforceability – one in Scotland (aspirational only), one in Germany (codified in law) and one in the United States of America (USA) (provisions are unambiguously binding on enrolled Medicaid recipients). However, the focus in each case is on patient responsibilities, not patient rights, and the charters are worded punitively. It would appear that the Australian system provides a reasonable balance, as many provisions in patient charters are also covered by the Australian Government Charter of Healthcare Rights (22).

Preferred Place of Death, Expressed in Charters

This project has, as its focus, the development of a Community Charter; this does not only mean a Charter that reflects the views of the community but it also relates to palliative care that is delivered in the community. A number of the Charters reported above include a statement relating to preferred place of death. In most cases, people say that they would prefer to die at home but this may not always be the most appropriate place for death to occur because of factors including supports available, carer fatigue and/or distress, or the level of medical intervention that may be required to ensure that pain and other symptoms are well-controlled to allow a peaceful death.

However, there is increasing recognition about the importance of supporting people's choices about their place of death, to the extent that this is possible. A well-designed Charter should provide guidance about how people want to be cared for and supported, regardless of the place or location of their death. While the vast majority of Australians report that they want to die at home,

dying in Australia is more institutionalised than in the rest of the world; ... about half of Australians die in hospital, and about a third in residential care. ... Seventy per cent of people (in Australia) want to die at home, yet only about 14 per cent do so (25:2).

This compares poorly with many other countries in the developed world. "People are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France" (25: 2). Reasons for this include community and medical attitudes plus availability of funds for formal community care.

Swerisson and Duckett (25:2) challenge both the widespread assumptions about the cost of end-of-life care, noting that "only about \$5 billion a year is spent on the last year of life for older people in a health budget of \$100 billion", and the concern about the cost of community care. They provide evidence that doubling the funding for community-based support to allow people to die at home would be offset by the reduction in the cost of institutional dying. This would require a major increase in the availability of community-based palliative care but this can be assisted by changes to Government policy. In 2012, the Australian "Senate Community Affairs References committee recommended changes to Home and Community Care (HACC) funding to include palliative patients and their carers regardless of their age." (25:27).

These authors argue that three things are required for Australians to have better deaths (25:22):

- to be informed about the limits of health care and the importance of discussing our preferences for end-of-life care
- to ensure that greater incentives and encouragement exist for the development and implementation of Advance Care Plans
- to increase the availability of community- and home-based support for people who are dying, particularly for older people with chronic conditions.

This latter point is a major focus of the Better Access to Palliative Care project. To ensure that the Tasmanian Palliative Care Community Charter reflects the supports that the community of Tasmania wants, the project methodology will include focus groups and interviews with a wide range of community members, and both an on-line and hard-copy survey (see Implementation, below).

Emerging Technologies

One option for increasing equal access for all is to embrace some of the emerging technologies that are becoming increasingly available, such as telehealth. These can be valuable tools to address issues such as lack of transport, cost of accessing care and physical challenges that many older or very unwell people face, especially in rural communities. Embracing such options often requires addressing the prejudices of service providers about the capacity of some socio-cultural groups to learn to use the relevant equipment or being responsive to it.

Evaluation of a project using telehealth with four groups of older Aboriginal and Torres Strait Islander people in New South Wales and Queensland (47) found that: participants held very positive attitudes to technology; almost all participants were comfortable with the equipment installed in their homes and learned to use the equipment to monitor their vital signs with only 2-3 lessons; having the equipment at home increased the access to and choice about their health care; and significantly enhanced their health education, as they could see their own readings each day and began to make links between their life-style behaviours and the readings on their equipment. They also felt safer because they knew that their readings were also checked each day by the Community Nurse responsible for their project location, who would organise assistance for them if their readings indicated the need for that.

Use of technology, including electronic patient records, was also noted as important in the Choice report (40).

Implementation

A projected second phase of this project is to take the wishes expressed by Tasmanian community members to their service providers and explore with them options and strategies for implementing these wishes, where possible. Nationally there are mandated health standards which are currently being revised and likely to reflect and encompass the principles of the National End of Life Care Consensus statement (48).

Options and strategies for implementing expressed needs and wishes may include enshrining identified principles of care into organisational policy and ensuring that they become part of the culture of the organisation. This may require targeted staff education and training. For example, operationalising the principle of good communication will require service providers to not only be open and honest about the patient's diagnosis, prognosis and treatment options but also "how the health condition will affect their everyday life" (49:613). Henderson and Henderson (49:613) call for a recognition and valuing of patient knowledge alongside biomedical knowledge. This will assist health professionals to support patients to make decisions based on their own needs and values.

Becker, Clark et al (The International Work Group for Death, Dying and Bereavement) (50:402) also call for greater sensitivity to the individual needs of dying person, the people caring for them and the bereaved. Referencing Kellehear (2004), they note, in relation to death and bereavement, that “much of the expertise lies in the world of the dying person and their bereaved community”. They describe a new model for dying, death and loss that adopts a public health approach, based on the principles and actions of the World Health Organisation’s 1986 Ottawa Charter. Using this approach, they outline the essential elements of a Charter for Public Health Approach to Dying, Death and Loss (50:417).

These elements are:

- A culture of open discourse
- Sensitivity and adaptability to social and cultural differences across the life span
- A whole-context approach, including physical, spiritual, emotional, intellectual and psycho-social environments
- Social justice by promoting equal access for all
- A population health approach that focuses on the needs of whole communities
- Sustainability.

In the UK, the success of the Royal College of General Practitioners; Royal College of Nursing. End of Life Care Patient Charter (30) was seen to depend on close collaboration between community nursing teams and GPs (51).

However, for implementation to be effective and result in improvement in health care systems “it must have adequate accountability measures” (52: E264). A “Working Toward a Charter for Quality in Healthcare” panel in Canada noted that “a charter that can be ignored without consequence will be just that – ignored”. (52: E264). However, one panel member expressed the view that “[t]he very creation of a charter ... would provide clarity on what needs to be changed about the health system.” (52: E264).

Palliative Care Australia has developed a set of 13 standards to assist service providers to achieve “quality palliative care for all Australians” (53:9). The Standards can be used “to support quality management and improvement activities or benchmarking at a local, state or national level” (53:9), or as part of accreditation programs. They can be used across the care continuum.

While the standards were developed for service providers, they strongly support the person-centred, compassionate community approach to provision of palliative care. For example, Standard 9 says:

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.

Other standards, reflecting needs and wishes expressed in many charters above include:

Standard 1	Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver's and family's needs and wishes are acknowledged and guide decision-making and care planning.
Standard 2	The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
Standard 4	Care is coordinated to minimise the burden on patient, their caregiver/s and family.
Standard 5	The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes.
Standard 6	The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.
Standard 8	Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services.
Standard 10	Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Conclusion

As part of the Tasmanian Better Access to Palliative Care program, this project seeks to develop a charter between Tasmanian community members and service providers that elucidates what community members want and need in relation to the care and support provided to them at the end stage of life, and how the service system may be able to respond to those needs.

Developing a palliative care community charter demands consideration of the role of the wider community in relation to community-based palliative care, including taking a public health approach to the provision of such care. Adopting the concept of health-promoting palliative care and building community capacity to embrace the compassionate communities model can not only enhance the effectiveness of clinical care but can also help to address the social, psychological and spiritual concerns that are not easily addressed by health services. Enlisting the community in end-of-life caring can increase the effectiveness of such care.

An increasing commitment to consumer-directed care in Australia and internationally, in particular for care delivered in the community, has also given rise to the development of a number of patient and community charters. These range from statements outlining what patients can expect from a health service, or what health insurance organisations require of their members, through “wish lists” or expressions of what patients want or feel they should have access, to genuine agreements between patients and their care providers, with commitments on both sides.

An extensive literature review identified 25 charters and 4 related reports or guidelines that were relevant to this project. They included disease-specific charters from patient support organisations and or health service providers, legal frameworks and legislated statements of patients’ rights, as well as charters which focussed on care at the end of life. The charters reviewed included a range of principles covering many aspects of care provision, including:

<ul style="list-style-type: none"> • Quality care from skilled providers 	<ul style="list-style-type: none"> • Support
<ul style="list-style-type: none"> • Access 	<ul style="list-style-type: none"> • Safety
<ul style="list-style-type: none"> • Respect 	<ul style="list-style-type: none"> • Communication
<ul style="list-style-type: none"> • Participation 	<ul style="list-style-type: none"> • Privacy
<ul style="list-style-type: none"> • Choice (including in relation to place care and death) 	<ul style="list-style-type: none"> • Consent and Advance Care Planning
<ul style="list-style-type: none"> • Accountability 	<ul style="list-style-type: none"> • Non-Discrimination
<ul style="list-style-type: none"> • Empowerment 	<ul style="list-style-type: none"> • Legality

These principles were operationalised by a series of statements, reflecting how that principle is conceptualised and what is of particular importance to the people they are intended to serve.

The best of the identified charters contained not only statements from community members and patients of what they wanted and needed in their care, and the commitments they were prepared to make to assist in that process, but corresponding commitments from service providers to ensure that identified needs were incorporated into care provision.

The findings of this literature review provided the basis for the community consultations, through focus groups and a survey, that will inform the development of the Tasmanian Palliative Care Community Charter. This will operationalise the commitment of the Better Access to Palliative Care Project to:

- Give a voice to community members about their palliative care needs and expectations of palliative care services
- Assist to raise awareness about palliative care and planning for death and dying
- Provide guiding principles to inform the delivery of palliative care in Tasmania.

The proposed second phase of this project will present the community voice to service providers, and seek their response to the needs and wishes expressed by community members.

The final charter will contain principles and statements to guide the provision of palliative care in the Tasmanian Community, based on a compassionate community model underpinned by formal and informal care partnerships which reflect a whole-of-community approach.

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Tasmanian Palliative Care Community Charter

Community Perspective Focus Group Information Sheet

In Tasmania, the Better Access to Palliative Care (BAPC) project is working towards providing the best possible palliative care for people with life-limiting illness.

Palliative care aims to provide comfort and improve quality of life for a person living with a life-limiting illness. It looks after the whole person and address their physical, social, spiritual, emotional and cultural needs. It is sensitive to the needs and wishes of a dying person and those who care for them, providing support to family and friends involved in the person's care. Palliative care is active care, which helps a person to live as well as possible and when the time comes, to die in comfort in the place of their choosing.

As part BAPC project, the Tasmanian Department of Health and Human Services (DHHS) is supporting the development of a Tasmanian Palliative Care Community Charter. KP Health consultants have been contracted to undertake this project.

The Charter will be an agreement between Tasmanian palliative care service providers and the people of Tasmania about the way in which palliative care is provided in the community. The Tasmanian Palliative Care Community Charter is being developed to:

- Give a voice to community members about their palliative care needs and expectations of palliative care services;
- Assist in raising awareness about palliative care and planning for death and dying; and
- Provide guiding principles to inform the delivery of palliative care in Tasmania

It is very important that we understand the views of community members. Thank you for agreeing to take part in a focus group, which will be led by one of the KP Health consultants. The discussion will take approximately 2 hours. We will ask some specific questions relating to palliative care in the community but the aim of the focus group is to hear from you what you need or want from palliative care provided to you or your family members and friends in the community. You are therefore encouraged to join in the discussion on any issue, or to ask for an issue to be discussed that you think is important.

Consent

It is essential that you read the information sheet you have been given and sign the Consent Form before you take part in the focus group. All signed Consent Forms will be stored securely in the KP Health office in Hobart until the end of the project and then destroyed.

Confidentiality

The opinions or views that you share during the focus group will help with the development of the Community Charter. It may also be included in the final report from KP Health to DHHS but no information that specifically identifies you or the organisation you are representing will be reported.

Participation is entirely voluntary

If you choose to leave the focus group before it is finished you will not be asked for an explanation, nor will there be any negative consequences for you.

Possible Discomforts and Risks

If at any time during the focus group you feel distressed by what is being discussed, please let the facilitator know and she will provide support for you.

Feedback

If you would like to receive a copy of the Community Charter when it is available, please tick that box near your name on the Consent Form.

Should you wish to further discuss this project, please do not hesitate to contact

Professor Colleen Cartwright

Senior Consultant, KP Health

Email: colleen.cartwright@kphealth.com.au

Tasmanian Palliative Care Community Charter

Consent Form

Please tick the answer in each box that is correct for you, sign and date the form and give to the focus group facilitator

I agree to take part in a focus group about palliative care in the community.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand the information about my participation in the focus group, which has been provided to me by the facilitator.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my participation is voluntary.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that I can leave the focus group at any time.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that all information gathered in this project is confidential.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am aware that I can contact the Senior Consultant at any time with any queries. Her contact details have been provided to me	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Participant's name : _____

Participant's signature : _____

Date : _____

- Please tick this box and provide your email or mail address below if you wish to receive a summary of the project outcomes:

Email: _____

**Palliative Care Community Charter –
Community Consultations**

Consultation Report

September 2016



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Introduction

The Tasmanian Palliative Care Community Charter community consultations were undertaken throughout June and July 2016. The people who were able to participate were highly engaged in the discussions and keen to contribute to the development of the Charter. Focus groups were held in Southern and Northern Tasmania with additional small group meetings or one-on-one interviews conducted across the state.

People from CALD backgrounds, Aboriginal people in Tasmania, LGBTI people and people in the disability sector were also engaged and consultation was undertaken with a small number of GPs and their patients. A summary of the consultations outcomes follows:

(Note: Consultation records for the Bhutanese and Aboriginal community groups are presented separately, to ensure issues specific to these groups are noted).

Consultation Participants:

A total of 148 participants, ranging in age from late 20s to late 80s, attended focus groups, meetings, discussions or interviews. These included:

- 6 general practitioners and 10 patients from across Southern and Northern Tasmania
- 30 attendees at the Agfest rural event (of whom 22 completed a hard-copy survey)
- 17 people in the Huon Valley who were recipients of community aged care and/or disability packages
- 4 Council on the Ageing Tasmania Peer Educators
- 5 Hobart and 3 Launceston Focus Group attendees
- 16 people who provide care and/or services to people with disability
- 38 members of the Bhutanese community (including 3 interpreters)
- 17 Tasmanian Aborigines, across all areas of the State
- 1 member of the LGBTI community
- 1 young woman who had cared for her terminally ill husband

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Most participants had experience of caring for family members or friends at the end of life, some in the last 6-8 months, others were currently caring for a terminally ill person; in most cases this was positive (including where the care was being provided by the person's aged care provider) but there were a number of participants who had had negative experiences.

Themes that Emerged from Consultations (most were mentioned multiple times)

Relief from Pain and other Causes of Distress

- Excellent/best-practice control of pain and other causes of distress, by skilled professionals, is extremely important; if a person is in pain or experiencing other distressing symptoms, they can't appreciate anything else. Many carers said that good pain management was critical. Medication, massage, aromatherapy and music can be helpful.
- Community education is needed about pain management and what palliative care medications do – especially for men, as many think they should just “battle through”. One carer said “Control of pain was a real battle, they couldn't seem to get a balance, he was often uncomfortable.” Some of that was because the man resisted taking the medication; even though the palliative care nurse tried to explain to him how much it would help him, he thought he should be “tough enough” without it.
- Some health professionals have not had adequate pain management training and may not give adequate pain relief. “Making sure that pain is kept to a minimum is really important. Pain often gets in the way of good decision-making and quality of life. There are a lot of myths surrounding the use of medications, including the thought of addiction and health professionals need to allay people's fears”.
- When pain medication is not effective this can cause distress to both the person receiving care and the carer. The mother of a young man said: “He had bone pain, was in constant agony. He was given a range of medication, including through a syringe driver but the pain was almost never controlled and there were lots of side effects”.
- Carers may also require education where they are responsible for administering medication to the patient. One man, whose wife had “no pain but 7 systems shut down”; had to put his wife on a morphine drip, which he found really confronting.
- Another carer (RN) had the skills but said, “Pain was a constant challenge – it could go from 1/10 – 10/10 in 5 minutes”. She asked for a prescription for morphine for him; the GP said no, he would come but the first time he was needed he couldn't come. She took her husband to the hospital; they gave him methadone, and provided it to her for him – it worked well until near the end. “That was when it all fell apart.”
- Other causes of distress, including psychosocial and spiritual issues, also need to be understood and, where possible, ameliorated.

Respect, Dignity and Person-Centred Care

- People want choice – informed and supported
 - Provide treatment options and let me select what to receive/not receive
 - Who I want to have around and who I don't want to have around – both personally and professionally (e.g., I might not like some care providers)
 - Not wanting to feel like a burden
 - My choice who does what to/for/with me (this includes personal preferences relating to volunteers, such as family/friends + paid carers)
- Person-centred care should be the norm, managed by the person themselves or by the person they nominate, (who should be encouraged to be a strong advocate for the dying person).
 - Who I am – talk and listen to me
 - Who is important to me, who do I want involved in my care, who do I want - or not want – to participate, contribute, e.g., supported decisions
 - What is important to me – values and beliefs
 - Choices and decisions should reflect “person at centre” model of support
 - Acknowledge role/value of advocacy – including the possibility of employing an independent advocate
 - Decision-specific capacity – recognition of need for support and assistance
- (Wife): No problems with palliative care staff; some with community care staff. On the day her husband died, the community care nurse was due to come at 12 noon to change the syringe in the syringe-driver; she phoned them and told them that he had died, so they did not need to come. The person she spoke to said “Can we still come and pick our gear up?” She felt it was really callous response – no compassion. “They didn't need to word it like that”. Palliative care staff were wonderful.
- People want the right to be treated with dignity and respect and to die with dignity
- People wanted to be respected for their decisions and respected as an individual
- People in receipt of care need to be treated with empathy, dignity and respect
- The person themselves and those they care about should be treated with respect and their dignity maintained. Several participants expressed the wish that their life should remain as “normal” as usual, and that they be supported to continue to enjoy the things they always did, e.g., interacting with loved ones; expressing their sexuality but also for the care team to understand everyone's need for touch, hugs, comfort in non-sexual way; having food they like and a glass of wine or beer when they felt like it; having pets around; being treated like an adult, not a child – this related to the patronising way dying people are sometimes spoken to.
- Respect should be shown to both the patient and the family members/carers. It should extend to care for people important to the person after that person has died
- Control and independence are really important
- Wife had her dignity preserved, even after death. “The Community Nurses cleaned her, removed her catheter and dressed her in nice clothes before the funeral parlour people came”

- Husband retained his dignity because he was cared for by his wife, except for one episode in hospital when pads were not put on; he was incontinent and it upset him a lot.
- People want care that is culturally and socially respectful, especially about rituals relating to death, dying and the role of family and others in their community. This includes people with disabilities, Aboriginal and CALD people, LGBTI people and many people from the broader community.
- (LGBTI Person): Being treated with respect is important. Concerns were raised that “if the government of the day, including key ministers, is against LGBTI people, how does this then filter down to staff of the health department?” People who are important to the dying person should be respected and allowed to participate in the care and decision making without being judged. There is a fear that once you have been discriminated against in life, this will also carry forward for when you reach your end of life. It is important that a person’s partner does not have to fight to be recognised as a partner just because marriage equality is not recognised. Anyone who is important to the person dying, if that person consents, can participate in helping make decisions.

Good Communication/Provision of Information

- A number of participants provided examples of specialists not telling people when they are dying. This makes it hard to know when “palliative care” has actually started. Death then comes as a complete shock. One of the GPs interviewed said that patients don’t really understand that “being palliative” is not a yes/no thing, it is a dimensional concept, where the palliative approach increases over time and the intensity of active intervention decreases. Therefore, the Charter needs to encompass the concept that people need the right amount of palliative care at the right time, not just that they need palliative care at the right time.
- (Wife of young man who died): “Palliative care (staff) provided really good information but not about Carers’ Tasmania (she found out about that organisation through Canteen, which her two teenage sons had been connected to) or volunteer organisations in the community, or anyone who could provide respite. We told the Palliative Care nurse that we wanted to know up front, no matter how bad it was, no sugar-coating, what was happening and what to expect”. She was provided with a “fantastic document about the final stages of life”, so she could read that and understand what was happening and where things were up to and how fast it was progressing. The Palliative Care nurse phoned and emailed regularly, making sure everything was ok, and told them she was there to talk to them at any time if they needed her. The majority of Community Care nurses were good and they communicated OK with the Palliative Care nurses. The carer didn’t feel alone. Communication between palliative care and the oncologist was excellent.

- More explicit information is required about what the carer needs to do once death has occurred. One woman was told by Palliative Care staff, “Don’t call the ambulance or the police when he dies”, but she really needed a checklist because she called the funeral parlour – she thought that that was what she was supposed to do – but they told her that she had to call the community nurse to come and complete the “life-extinct” form before they could come and take his body away.
- Good communication from the health care team to the patient/person and carer is critical – many participants said that they wanted:
 - honesty and truth-telling with respect to diagnosis and prognosis
 - their options and choices around treatments explained properly, including the impact/side-effects they could expect from the treatment and
 - a “plan of treatment/care” (not advance care plan) so they knew what to expect, including what could be tried and in what time frames, as well as “what next?” if the treatment did not work. They also wanted to be kept informed about what was being looked for/found so if someone does an assessment, not just write it down and go away but tell the person what the assessment shows, or what the test results show.
 - to be told what is available but be supported to make their own decisions, with no pressure from health care providers to take the path they recommended.
 - to be told who would manage their care would it be the same person who was giving them the diagnosis?
- Good communication between health care providers is also critical – information needs to be shared between providers, to ensure continuity of care and decrease the burden on the family and person having to retell their story over and over. This is especially important in relation to handover of care. Linked to this was the issue of confidentiality; (this seems to be “a double-edged sword”; people need to know that their personal and health information will not be discussed with anyone who asks but some participants thought that confidentiality was sometimes used as an excuse between services so they did not share with other services). Consensus was that the patient should give consent for what can be shared, and with whom – including whether or not information can be provided to family members.
- Family members who are caring for the person, or are at the hospital regularly, need written notes of results of tests, or changes in what is happening. This also applied to things that cause family members great concern, e.g., when a person no longer wants to eat or drink, and why feeding tubes are not appropriate in such cases.
- **(The following case report highlights the problem of service providers assuming that the carer does not need help):** Because the carer was a RN, they thought she “already knew it all, left her to it. Community health phoned every few weeks but did not come”. She needed more information, especially about “What is going to kill him?” (Organs not affected at that time). She “needed a road map of what to expect”. She asked but nobody told her.

- (Husband caring for wife): Excellent communication, from team to patient and carer, and between all members of the team. However, early on he couldn't get a prognosis. 9 months before she died, palliative care person gave them "end of life" documents to complete.
- (The following case exemplifies how poor communication – potentially including checking with the patient and carer what they had/had not been told – can exacerbate both problems relating to the death itself and also to the carer's grief afterwards): Very poor communication: nobody told him or his mother that he was dying. They had a family conference with the doctor and other staff about 3 weeks before he died. The doctor who had been "head doctor" up 'till then just said that nothing they had done had worked. They did not see him again. They did not know who was in charge. A social worker came and said that he should make a Will (didn't say that death was imminent). A palliative care nurse she had never met before came in and said to her "He has only got a few weeks left" – total shock; she thought he was coming home. She then found out that, when he was completely on his own, the same nurse had asked him where he "wanted to pass". He also didn't know he was dying. Didn't have any support there with him. His mother stayed at the hospital almost all the time but still nobody told her what to expect at the end. Two weeks after being told that he only had a few weeks left she was told he only had a few days left.
- Having a written plan of care is important but it must be adaptable and flexible if circumstances change.
- Record who is providing care in a single place so the family are aware of who is coming and going.
- Have the same language – 'shared language, shared understanding'.
- Open, honest communication is critical. One participant said: "Being gay does come with some challenges and the way in which people communicate with you in life, so I do worry that this will be same in death. Language is so powerful and regardless of race, religion or sexuality, people need to be communicated with respectfully, honestly and openly."
- Information is needed about:
 - What supports are available to me?
 - Info relevant to my diagnosis, that is relevant and meaningful to me'
 - My rights, options, costs of these
 - Information should be given in a timely way and at a time and speed that I can absorb
 - Check in with me regularly – ensure key information and messages are repeated over time to give people a chance to hear it
 - Information should be available in a range of formats to support individual needs.

Composition of the Care Team/Coordination of Care

- GPs are often an important part of community palliative care teams. Palliative care specialists often play a greater role for people with more challenging problems.
- Services need to work together and involve the person, their carer and other family members.
- Having a skilled workforce is important at all levels, from health care assistants and personal carers through to registered nurses and GPs, not just specialist palliative care services. Participants viewed the GP and home care providers as key players in end of life care. The skills that were considered most important to most carers were:
 - Listening skills; Empathy; Approachability
 - Flexibility so that if the plan needs to change it can
 - Making the family and carers feel important and that they are in the 'driver's seat'
- Coordination of services was viewed as important so people did not have to tell their story over and over, and so each care provider knew what the others were doing.
- Family involvement in care and decisions making was seen as essential.
- Good care coordination and case management and right care from the right person at the right time is very important. One issue raised was that the case manager might not be clinically qualified, so may not be appropriate to manage the care coordination at all stages of the dying process.
- Coordination of care is really important; including between Community Nurse, the palliative care team and the GP. Participants thought that if the service providers had a good attitude, that helped a lot. (Some noted that "There needs to be a respect between providers because families can pick up on the disunity between service providers.")
- The team needs to work with the aim of what the person who is dying wants
- A woman who cared for her husband was a RN; she cared for him herself until the last 6 months. She was then connected to community health, palliative care, the hospital, a pharmacist, occupational therapist (OT), physiotherapist. Everything was really well coordinated; response was always rapid
- A carer's wife was on a Package organised by a rural hospital; this included palliative care, Hospice at Home, a neurologist, district nurse, and dietician. "Everyone worked together and the care was excellent". (NOTE: this couple lived in a rural area and he said all care was excellent, "Could not have better".)
- A woman who cared for her young son said that care was disjointed. "He had blood transfusions, chemotherapy, radiotherapy, all sorts of things – nothing worked." (Note: this latter comment probably relates to the difficulties encountered in his treatment, rather than care coordination).
- A carer who felt that her skills and understanding were ignored said: "The carer needs to be respected for their knowledge and understanding of the person. Often the carer has been married to the person for many years and they know what brings the person comfort."
- Several participants in a focus group in North West Region had experience with caring for family members at the end of life and one participant was currently caring for a terminally ill spouse. They reported a high level of satisfaction with the support

they were receiving from their aged care provider; they said that they were 'lucky' compared to other communities. Going to hospital was viewed as problematic as it was a break in care and often things went wrong and there was poor communication between the hospital and the family and existing providers.

- The palliative care nurse phoned and emailed regularly, making sure everything was ok, and told them she was there to talk to them at any time if they needed her. Majority of community care nurses were good (but not as good as palliative care nurses) and they communicated OK with the palliative care nurses. The carer didn't feel alone. Communication between palliative care and the oncologist was excellent.
- Having continuity of care and the same people involved in the care of a family member provides a level of confidence and comfort. It enables a good rapport and relationship to be built.

Place of Death and Care

- People may or may not want to die at home; the system needs to support both choices but needs to remain flexible if circumstances should change.
- People want community-based palliative care services to support them without the need to travel long distances to receive it, or go into a hospice or residential care away from family members or friends. (One option discussed was better use of technology, e.g., telehealth).
- People want access to services regardless of where they live, time of day
- Some people living in the north of the state thought that there were no hospice or hospital palliative care services available (although this was not the case), so access to palliative care services was seen as an issue.
- Providers visiting a person receiving care in their home need to have empathy and understanding.
- Going to hospital was viewed as problematic as it was a break in care and often things went wrong and there was poor communication between the hospital and the family and existing providers.
- Some participants want to stay at home until the end stage and then go to a palliative care ward. One man who had already spent some time in a palliative care unit was particularly impressed that, when a person is dying, the door to their room is closed to allow them and their family some privacy, which he wants.
- No matter where a person dies, they and others around them should be treated with respect: A carer provided an example of someone who died in an aged care facility and the funeral parlour people moved them out on a trolley through the dining room while other residents were having lunch, causing staff and residents considerable distress.

- Having the right equipment for use at home is very important; this had worked well in a number of cases. However, a woman who cared for her 24-year old son who died from a rapid, aggressive bone cancer, said they needed the equipment earlier; the bed that was needed arrived too late and her son could not use it by then. He spent the last weeks of his life – at home and in hospital – in a recliner chair.
- Access to services is needed for everyone (not just those who know the system).
- Equitable/Fair Access to Resources (to enable Choice)
 - Equitable access (this was discussed more in terms of fairness than to equal access) depends on more than just location – should be equitable regardless of person’s home address, support needs prior to diagnosis, age, gender, culture, income etc.
 - Clear, understandable pathway to support
 - Supported and informed GPs are needed to make dying at home a real option
 - Access should be financially viable
- “If Tasmania wants people to have the choice to die a quality death at home, the resources need to be there to support that choice”
- There needs to be a “central point” established as contact to provide information to GPs, community, to guide everyone through the ‘dying at home’ process – a “Maze Navigator”

Support for the Carer and Other People who matter to the person receiving care

- Carers and others close to the person receiving care need access to a social worker or counsellor – both for anticipatory grief and for bereavement support
- They need access to respite that is meaningful to them, and to the person they are caring for (i.e., respite for the carer shouldn’t mean that the person being cared for has to go away from family and friends)
- As well as support for the carer, support is needed for other people who live with the person being cared for and who are also being impacted on
- With consent of the person being cared for, give carers/others information, about diagnosis/ condition, probable prognosis, proposed treatment but also about Centrelink and other supports available

Bereavement Support

- (Negative example 1): After her husband died, nobody contacted her; she felt deserted at the end by everyone, including palliative care. “These people have been in your home every day for months, they’ve been a part of your life, and then nothing, from the day he died”. She felt deserted at the end, and really upset. (She is considering how to put together a non-profit organisation to help people through the end weeks and what to do after the person died).

- (Negative example 2: Mother of young man). No contact or support after he died. She found a grief counsellor. A friend suggested going to a bereavement support group, which she now does.

(NB: The two cases above may indicate that younger carers are assumed to have more supports available, or that they are less impacted by the bereavement, than older carers).

- Positive example 1): He was treated really well after his wife died; community nurses, palliative care, everyone phoned regularly for a month or so. He also has seen a psychologist a few times since.
- Positive example 2): She was treated well afterwards and also has family support.

Advance Care Planning

- it is important to have a written plan that was available for everyone - family, services and GPs - that describes a person's wishes for end of life.
- People want their plans at end of life respected and adhered to.
- Service providers need to understand that a person's wishes, expressed through an Advance Care Directive or via their Enduring Guardian, are legally binding if they meet the current situation and are legal options within the law; they therefore must be complied with.
- Palliative Care staff went through the advance care plan (ACP) documents with the patient and his wife, so they understood what his and her rights were.
- Some misconceptions about Advance Care Planning were clarified (e.g., that a person holding Enduring Power of Attorney can consent to health-care, which they can't).
- Need information and help to say what you do/don't want.
- Having a plan in place and all the necessary paper work including wills, enduring guardian and power of attorney is always helpful.

Community and Service Provider Education

- A number of issues raised in the Communication/Information section above related to the need for patients, carers and the general community to receive education relating to end-of-life issues. One carer has undertaken some basic nursing training since her husband's death and obtained knowledge that she did not have at time of her his death, e.g., why a feeding tube was not appropriate. She noted that there were many such things that the average person in the community did not know about, and good information was hardly ever provided
- Carers could benefit from classes that included education about the patient's (and their) legal rights, including the right to accept or refuse any treatment
- Education is required in the general community because there is a lack of understanding of what palliative care is. Health literacy is low.

- Education is needed for medical professionals and other service providers to ensure that they recognise when a person is in a palliative phase of life and respond to people as individuals
- Relevant formal education curriculums should include a focus on being able to deliver/ provide information in plain and understandable manner and format
- Ensure care providers know and understand a clear pathway to access support.

Other Issues Discussed

- Polarisation of funding: this related to boundaries for when a person was/was not eligible for a service. A person who had received a referral for a package, and was applying through MyAgedCare website, had a diagnosis of cancer and was receiving palliative care. They were told that because they were receiving palliative care they were not eligible for a package and that referral was cancelled. They were told to “go back to your GP”.
Relating to this, concern was expressed that people on the end of the MyAgedCare phone or website usually do not have any clinical training and they are making decisions they are not qualified to make.
- There are new palliative care packages, but people are not being informed about this,
- Resourcing (e.g., adequate funding): Pro vs Reactive.

Aboriginal People in Tasmania

One-on-one interviews and small groups were conducted by a consultant known and well- respected within the Tasmanian Aboriginal community.

The consultant explained the purpose of the consultations, outlining that

“In Tasmania the Better Access to Palliative Care (BAPC) project is working towards providing the best possible palliative care for people with life- limiting illness, including through developing a Tasmanian Palliative Care Community Charter. The Charter will be an agreement between Tasmanian palliative care service providers and the people of Tasmania about the way in which palliative care is provided in the community.” I have been engaged by KP Health to talk to Tasmanian Aborigines about their views.

People were interviewed on Flinders Island x 3, north west x 1, north x 1, north east x 1, Hobart x 10, south east x 1 = 17. Four male, 13 female aged from 23 to 70+. 6 rural/remote, 11 urban. Four people declined or did not return emails/phone calls.

Most had some experience of someone close to them dying, three were directly involved in a community based palliative care “event” i.e. not formally a palliative provider but stood in and up when unmet needs were identified.

Culturally appropriate care

- All participants identified the importance and appreciation of the client AND family being asked if there were cultural considerations in their care and planning for end of life. Examples were given of people wanting to get home and/or remain on country, issues for family around a death in the home, traditional food, meaningful provision and respect for extended family, clarity around role of extended family and the need to ask as it may be different from person to person. Post death may include the opportunity for traditional “sorry business”.
- Community controlled Aboriginal organisations often have a multifaceted role in supporting the client and family (and community) during palliative care (and with sorry business) in a non-clinical role that could benefit from being formally recognised (with client consent) and could be a valued resource.
- Concern that local health providers “assume” they know who is an Aborigine and lots of examples of not being asked even though the understanding is that protocols are in place that this does occur.
- Concern about low levels of cultural sensitivity and casual (or not so casual) racism.
- Participants also identified examples of good practice when there was time and respect for cultural considerations; this made a positive difference to the client and their family.

Principles identified by Aboriginal people as underpinning good palliative care

Respect

For people’s differences and life choices, for differing levels of health literacy, for cultural differences.

Education

Enough education to make informed choices and be a partner in decision making. E.g. medication and treatment options and side effects, pros and cons of home based care, what “the end” might be like, how might you know it is getting close, what sort of supports are available for me and my support people. Having the client and not the busy health professional at the centre of thinking and doing. Better understanding of Advance Care Planning/Directives and support for interpreting medical language and education for ALL staff working in health e.g. “Mary? had decided she did not want further treatment (in a nursing home) and felt a staff member disagreed and said: What about your diabetes? What if you get pneumonia? She knew what she wanted but was not equipped for debate.

Comfort and pain relief

Participants wondered whether it was reasonable to expect pain could be managed. Confusion about “drugs of addiction” and what that might mean for the client; concern about medication being used to end life (or not); differing experiences about health professionals approach to suitable medication for pain relief. Wanting to know that “best practice” was being used. Value of non-medication for comfort e.g. music, view, pets, aromatherapy etc.

Communication

- To client and identified family members:

Lots of discussion and examples about a lack of clarity whether someone was dying or not and different health professionals telling different stories to different family members. Also a lack of communication about what the client and family may need to expect. “Many women are not told about child birth and we are not told about death either.” “Dad thought he could call us in and hold our hands as he drifted off and it was nothing like that.” “One staff member told my dying sister ‘death was imminent’, evidently staff thought we should have understood what was happening but none of us did and she died alone and we are still grieving and arguing about it”. “We would have really benefited from having a key contact person in the hospital who we could go to when we were receiving mixed messages or didn’t understand something”.

People had examples of not knowing who was responsible for what tasks e.g. mistaking the home help for the nurse, not knowing what to do when medication ran alarmingly low. “We needed better understanding of who was responsible for what”. “It is so tiring having to tell every person who visits the daily story let alone bigger picture issues”.

- Between health professionals:

Participants identified problems with their GP not sharing information with home visiting health professionals, felt that confidentiality was used as an excuse for not sharing information. Some reported the need for the client record to be held by the client/family so that each visiting service and family could see what and who had been before. “It is just as important that the volunteer who drops the kids off after school and gets tea sorted knows whether the nurse has been as it is for the nurse to know that a volunteer is preparing evening meal.”

Support for my family: People identified the need for partner/family support during and after.

Capacity in Aboriginal Communities

There were a couple of examples of communities not coping with a palliative family: “I don’t think they knew what to say or do so they avoided us”.

In the main participants identified that with a little education and support communities can (and do) make a significant difference in the life of a palliative client and their family. For this to work, people identified the need for a “lead” person either paid or not who was able to liaise with the client first (informed consent noted as key) and health professionals and volunteers. Examples of food and shopping rosters, outings for kids, time out for partner to have a bath or work in the garden, sleep over. It was identified that this needed to be valued by the professional care team and mechanisms for communication is needed especially where the client’s family may not be able to fill the “key contact” role. Participants noted that often health professionals did not know or understand about the role and services offered by the local Aboriginal community controlled organisation.

Rural/Remote Communities

Concerns were raised that the “specialisation” of palliative care may result in an expectation that people might need to move to regional centres to be cared for and die. Examples were given of small rural health services appearing to want to “move patients out to die”.

Lack of afterhours care was seen as a major obstacle to people remaining at home even in early stages. A couple of solutions were put forward: a) care \$’s being attached to the client to purchase out of hours home based care, b) better utilising the volunteer ambulance service that exists as part of the care planning. These were both framed within the constraint that very small communities may not have the physical resources to do this, funded or not.

Community Charter and Consultation

Participants all wished to have meaningful mechanisms for participating in palliative education, service development and delivery at a community level. Many spoke about feeling they were “informed” rather than meaningfully consulted or better still collaborated with. “Talk to us to tick a box” was a common refrain. Resources are thin on the ground a suggestion of using existing mechanisms or seeking participation on issues that are relevant.

Bhutanese Community, Launceston

KP Health were invited to attend a community gathering of members from the Bhutanese community. 29 participants, plus 4 staff, 1 student, 1 volunteer were in attendance. 3 interpreters were present to assist with the conversation.

The Bhutanese community is as diverse as any other, they have different languages, adhere to different faiths (notably Hindu and Christian), and they have different perspectives on end-of-life questions. The general themes were:

- some want to die at home whilst others in hospital where medical and nursing care was easily available
- family participation in end-of-life decision making was critical
- the elders of the community look to their children to support them but if they are unable other arrangements need to be made
- being pain-free or made as comfortable as possible was important
- few knew what services were available to them in Tasmania, or how to get them, but all knew they wanted access to spiritual guidance offered by their respective faith.

Responses to Concept of Compassionate Communities

- Having a community response, people who could rally around when someone was dying and provide some support for the person and/or their carer(s) “would be amazing, especially for people with no family support or elderly people or people with no-one” (Young wife). She would also like to see a volunteer service where people who knew about what happens and who could come and sit with the patient and/or carer and could check in with the carer/family in the weeks after the person died, to see how they were going.
- Rural and remote communities need to be included in any planning which could involve volunteers.
- Such things cannot be “imposed from the top”.
- Where possible, build on existing supportive relationships – friends, social networks (if any); one attendee said that good neighbours made all the difference for her mother when her father was dying, and allowed him to die at home.
- Care can be provided in the home by both paid/formal and unpaid/volunteer carers not necessarily known to the person/family beforehand but provided by community organisations. It was noted that formal/paid carers can be multi-skilled and perform a range of tasks, including personal care and domestic assistance; volunteer carers from community organisations are not allowed to provide personal care but can provide carer respite or transport. (Note: this raises the issue of how can someone provide respite for the carer if the person needing care requires on-going personal care and the volunteer is not allowed to provide that?).
- Many participants thought that it would be very helpful if people from volunteer organisations could go to the homes of family members/carers after the person has died – including some weeks after – to help the people with their grief.
- A man who was the main carer for his wife really liked this concept; he does not want his children to have to care for him the way he cared for his wife. He wants to die at home but his children live 2 hrs drive away. Maybe with community volunteers and family together he could do that. He really needed more respite than was available. He got 4 hrs/wk. for 6 weeks at one time in the 3 years. Was told, “no more. If more is needed, has to be paid for out of wife’s Package”. He didn’t want to do that, because the package was supposed to be for what she needed.
- A woman whose son had died said she had no preference for herself – depends on circumstances. She would have liked some younger volunteers to come and be with him in the hospital, “buddies” – not friends he already knew, just people his own age to visit. Everyone else in the ward were older people.



TASMANIAN PALLIATIVE CARE COMMUNITY CHARTER

SUMMARY CONSULTATION REPORT

September 2016

Acknowledgements

We sincerely thank everyone who participated in the consultations to inform the development of the Tasmanian Palliative Care Community Charter. Thank you for sharing your very personal stories of illness, grief, loss and death.

Tasmanian Palliative Care Community Charter

Summary of Community Consultation Outcomes, September 2016

This document provides examples of community responses for each of the principles in the Draft Charter. A full report of the Community Consultations is available on request or from

http://www.dhhs.tas.gov.au/palliativecare/better_access_to_palliative_care_project/project_activities/tasmanian_palliative_care_charter

PRINCIPLES AND SELECTED STATEMENTS FROM THE CONSULTATIONS:

Relief from Pain and Other Causes of Distress

- Excellent/best-practice pain and symptom control is extremely important; if a person is in pain or experiencing other distressing symptoms, they can't appreciate anything else. Medication, massage, aromatherapy and music can also provide comfort.
- Community education is needed about pain management and what palliative care medications do – especially for men, as many think they should just “battle through”. Some health professionals have not had adequate pain management training and may not give adequate pain relief.
- Carers may also require education where they are responsible for administering medication to the patient. One man who had to put his wife on a morphine drip, found that really confronting.

The most important thing is being free from pain and other distress, whether that distress is physical, emotional or spiritual. Unless we are comfortable we can't appreciate anything else.

- When pain medication is not effective this can cause distress to both the person receiving care and the carer. One woman who provided care for her husband said “He had bone pain, was in constant agony, almost never controlled; lots of side effects”.
- Other causes of distress, including psychosocial and spiritual issues, also need to be understood and, where possible, ameliorated.

People want to be treated as individuals – with dignity and respect for their values and beliefs; with empathy and compassion and to die with dignity

Respect, Dignity and Person-Centred Care

- People want choice – Informed and Supported
 - Provide treatment options and let me select what to receive or not receive
 - Who I want to have around and who I don’t want to have around – both personally and professionally (e.g., I might not like some care providers)
 - Not wanting to feel like a burden
 - My choice about who does what to/for/with me (this includes personal preferences relating to family/friends, informal carers and paid carers)
- Person-centred care should be the norm, managed by the person themselves or by the person they nominate, (who should be encouraged to be a strong advocate for the dying person).

- Who I am – talk and listen to me
 - Who is important to me, who I want involved in my care, who I want - or do not want – to participate, and contribute, e.g., supported decisions
 - Acknowledge the role and value of advocacy – including
 - seeking support from an independent advocate if necessary
 - Decision-specific capacity – recognising when the person needs support and assistance to make decisions and when they can make their own
- Life should remain as “normal” as possible, e.g., interacting with loved ones; having preferred food, a glass of wine or beer, having pets around; not being patronised.
 - Control and independence are really important.
 - Dignity can be preserved even after death (e.g., respectfully washing and dressing the person’s body before the funeral home staff arrive).
 - People want care that is culturally and socially respectful, especially about rituals relating to death, dying and the role of family and others in their community. This includes people with disabilities, Aboriginal and CALD² people, LGBTI³ people and many people from the broader community.
 - Being treated with respect is very important to LGBTI people; some fear that discrimination experienced through life will continue at the end of life. Allow people who are important to the dying person to participate in the care without being judged. The person’s partner should not have to fight for recognition as a partner just because marriage equality is not recognised.

² CALD refers to Culturally and Linguistically Diverse populations

³ LGBTI refers to Lesbian, Gay, Bisexual, Transgender and Intersex people

Good Communication/Provision of Information

- Some specialists don't tell people they are dying. This makes it hard to know when "palliative care" has actually started. Death then comes as a complete shock.
- Information is needed about support organisations and/or respite. A Palliative Care nurse provided a "fantastic document about the final stages of life" to a carer and it made all the difference.
- Explain what palliative care is and how it can help the person and their carer.
- Carers need explicit information about what to do once death has occurred (e.g., who to phone first).
- Terminally ill people and their carers want honesty and truth-telling about: diagnosis (and prognosis as far as this is possible); options and choices around treatments, possible side-effects; a "plan of treatment/care" so they know what to expect; who will manage their care; reasons for tests and results and the fact that they have the right to accept or refuse any tests or procedures.
- Information needs to be shared between providers (with consent of person/carers), so people do not have to repeat everything over and over. Record who is providing care in one document so the family is aware of who is coming and going.
- Family members/carers may need written notes about what is happening, e.g., when a person no longer wants to eat or drink, why feeding tubes are not appropriate in such cases.
- Open honest communication is critical. "Being gay comes with some challenges, including the way people communicate with you."
- Information about what supports are available; their rights, options, costs of these.
- Information should be given in a timely way and at a time and speed they can absorb.
- Check in regularly with the person and their carer – ensure that key information and messages are repeated over time to give people a chance to hear and understand it.
- Offer information in a range of formats to support individual needs

"Language is so powerful and people regardless of race, religion or sexuality need communication that is respectful, honest and open".

Composition of the Care Team/Coordination of Care

- GPs and home carers are an important part of community palliative care teams.

- Services need to work together and involve the person, their GP, carer and other people nominated by the person receiving care.
- It is important to have a skilled workforce at all levels, health care assistants or personal carers through to registered nurses and GPs. The skills that were considered most important by participants were:
 - Listening skills; Empathy; Approachability
 - Flexibility so that if the plan needs to change it can
 - Making the person receiving care, their carer and others important to them feel important and that they are in the 'driver's seat'
- Coordination of care and services is important, so people do not have to tell their story over and over, and so each service provider knows what the others are doing.
- A carer who was connected to community health, palliative care, the hospital, a pharmacist, OT, physiotherapist said that "Everything was really well coordinated; response was always rapid".
- A carer's wife was on a Package organised by a rural hospital; this included palliative care, Hospice at Home, a neurologist, community nurse, and dietician. "Everyone worked together and the care was excellent".
- Families can pick up on disunity between providers.
- A carer who felt that her skills and understanding were ignored said: "The carer needs to be respected for their knowledge and understanding of the person. Often the carer has been married to the person for many years and they know what brings the person comfort."
- Several carers in the North West reported a high level of satisfaction in relation to care from their aged care provider. Going to hospital was problematic; often things went wrong and there was poor communication between the hospital, the family and existing providers.
- Another carer noted that "communication between palliative care and the oncologist was excellent".

Place of Death and Care

- People may or may not want to die at home; the system needs to support both choices but remain flexible if circumstances should change.

- People want community-based palliative care services, regardless of location, support needs prior to diagnosis, age, gender, culture, income or time of day, without the need to travel long distances, or go into a hospice or residential care away from family, friends or their community. (Better use of technology may help, e.g., telehealth).
- No matter where a person dies, they and others around them should be treated with respect. One participant provided an example of a person who died in an aged care facility and the funeral parlour staff moved the person through the dining room when residents were at lunch, causing staff and residents considerable distress.
- When death is close, families need privacy, even if the person is in hospital.
- Having the right equipment for use at home, early in the care process, is very important.
- GPs need on-going palliative care education and support, so they are well-informed to make dying at home a real option
- A central contact point is needed to provide information to GPs and other service providers, and to the general community, to guide everyone through the 'dying at home' process – a "Maze Navigator"

People want choice about where they are cared for and where they die and preferably it is in their own community

Support for the Carer and Other People who Matter to the Person Being Cared for

- Respect should extend to care for people important to the person, including after that person has died.
- Access to a social worker or counsellor may be needed, both for anticipatory grief and for bereavement support.
- Access to respite for the carer shouldn't mean that the person being cared for has to go away from family, friends or their community.

Bereavement Support

- Negative example: nobody contacted the carer after her husband died; she felt deserted by everyone, including palliative care.
- Positive example: Carer was treated really well after his wife died; community nurses, palliative care, everyone phoned regularly for a month or so.

Advance Care Planning

- It is important to have a written plan, available for everyone - family, services and GPs - that describes a person's wishes for end of life.
- People want their plans at end of life respected and adhered to.
- Service providers need to understand that a person's wishes, expressed through an Advance Care Directive or via their Enduring Guardian, are legally binding and therefore must be complied with if they meet the current situation and are choices that are allowed within the law.
- The person and their carers need information about options and help to communicate what they do or do not want.

Support for Aboriginal people in Tasmania

In addition to many issues above:

- Ask the person receiving care AND their family or community group if there are cultural considerations in their care and planning for end of life, e.g., some people might want to get home/remain on country to die; issues for family around a death in the home; traditional food; meaningful respect for the extended family and their role in the dying process is essential, (it may be different from person to person). When there has been time and respect for cultural considerations, this made a positive difference to the client and their family.
- After the death, people may need the opportunity for "sorry business".
- Community-controlled Aboriginal organisations often play several roles in supporting the client, family and community during palliative care (and with sorry business) in a non-clinical role; if the client consents to their involvement, this could be a valuable resource.
- Provide a key contact person who people could go to if they were receiving mixed messages or didn't understand something.
- Some service providers "assume" they know who is an Aborigine and don't ask, despite protocols in place for this to occur.

Capacity in Aboriginal communities:

- Some communities don't cope well and are unsure how to support people with palliative care needs and their families: "I don't think they knew what to say or do so they avoided us". However, with a little education and support communities can (and do) make a significant difference in the life of a person with palliative care needs and their family. This needs to be valued by the professional care team; community support may be very

helpful, especially where the client's family may not feel confident enough to ask questions of the health professionals.

- Meaningful consultation/collaboration is needed, not just "being informed".

Ask us about our cultural needs and how we want to be cared for. Keep checking to ensure you understand what is being asked of you.

Bhutanese Community

Many issues were the same as for the general community.

Additional Issues: (These are also likely to apply to many other CALD groups).

- This community is as diverse as any other, they have different languages, adhere to different faiths (notably Hindu and Christian), and have different perspectives on end-of-life questions. All wanted access to spiritual guidance offered by their respective faith
- Family participation in end of life decision-making was critical
- The elders of the community look to their children to support them but if they are unable to do so, other arrangements need to be made
- Few of the participants knew what services were available to them in Tasmania, or how to get them.

Responses to the Concept of Compassionate Communities:

People involved in the consultations were asked their thoughts about a 'compassionate communities' approach to supporting people with palliative care needs. Their responses included:

- Having a community response, people who could rally around when someone was dying and provide some support for the person and/or their carer(s) "would be amazing, especially for people with no family support or elderly people or people with no-one".
- Local communities need to be involved in planning for services delivered in their community, especially services which would rely on volunteers.
- Such things cannot be "imposed from the top".
- Where possible, build on existing supportive relationships. Friends, social or cultural networks and good neighbours can make it possible for people to die at home.
- It would be helpful if volunteers could go to the homes of family members/carers after the person has died – including some weeks after – to help the people with their grief.
- Young people with life-limiting illness need younger volunteers who can talk about things of interest and importance to young people.

Appendix 5: Community Perspective Survey

In Tasmania the Better Access to Palliative Care (BAPC) project is working towards providing the best possible palliative care for people with life-limiting illness.

Palliative care aims to provide comfort and improve quality of life for a person living with a life-limiting illness. It looks after the whole person to address their physical, social, spiritual, emotional and cultural needs. It is sensitive to the needs and wishes of a dying person and those who care for them, providing support to family and friends involved in the person's care. Palliative care is active care, which helps a person to live as well as possible and when the time comes, to die in comfort in the place of their choosing.

As part of the BAPC, the Tasmanian Department of Health and Human Services (DHHS) is supporting the development of a Tasmanian Palliative Care Community Charter. KP Health consultants have been contracted to undertake this project.

The Charter will be an agreement between Tasmanian palliative care service providers and the people of Tasmania about the way in which palliative care is provided in the community. The Charter is being developed to:

- Give a voice to community members about their palliative care needs and expectations of palliative care services
- Assist to raise awareness about palliative care and planning for death and dying
- Inform the delivery of palliative care in Tasmania

It is very important that we understand the views of community members. Information from this survey will assist with the development of the Charter

How to complete the Survey

Please take whatever time you need to complete the survey. We would be grateful if you could return it by 30 June 2016, either to the person who provided it to you or post it to KP Health, 69 Letitia St. Hobart. Please do not write your name anywhere on the survey, as all responses are anonymous. Thank you for completing the survey that follows.

We appreciate your time and valuable comments. If you would like to have input but would rather not complete the survey, or if you require any further information please contact

Professor Colleen Cartwright, Senior Consultant, KP Health

Email: colleen.cartwright@kphealth.com.au

Or phone Rosie Beardsley on 0459 141 221

Tasmanian Palliative Care Community Charter

Community Survey

SECTION 1

Please read each question carefully and follow the instructions for each question.

Q1. Which of the following best describes your situation? (*Please select all that apply*)

a	I am a palliative care patient	
b	I am a carer/family member caring for a palliative care patient	
c	I am a carer/family member who previously cared for a palliative care patient	
d	I am a current or former health professional	
e	I am a current or former palliative care volunteer	
f	I am a current or former community service provider	
g	I am a member of a community group funded by Palliative Care Tasmania (Please specify which group)	
h	I have never had personal experience of palliative care	
i	Other (please state))	

If you or someone close to you has received palliative care, please go to Q2 and then Q3.

If you have never had personal experience of palliative care, please go directly to Q3.

Q2. How would you describe your experience with the palliative care services that were provided?

(Please tick the box that best describes your experience with the palliative care services provided).

- Very Poor
- Poor
- Satisfactory
- Good
- Excellent

Please tell us about your experience

.....

.....

Q3. The Tasmanian Palliative Care Community Charter will include a list of statements that reflect what the Tasmanian community want when they receive palliative care. Below

is a list of statements that have been included in other patient or community charters in Australia and overseas.

Please read the list of statements below and rank how important you think each one is, with 1 being the most important to 11 being the least important. (If you prefer, you may just rank from 1-3 the three that are most important to you).

	Which of the following statements are most important to you?	Rank
a	I want the best possible care and support for my physical, emotional, social and spiritual needs, given by well-trained staff.	
b	I want access to the right services when and where I need them	
c	I want care and support that is provided equally to everyone who needs it, regardless of age, ethnic background, religion or sexual orientation	
d	I want people who are involved in my care to communicate with me in a clear, honest and compassionate way about all aspects of my care and what I can expect.	
e	I want involvement in and control over decisions about my care	
f	I want help to record my wishes and decisions, so that everyone involved in my care knows what I want or don't want	
g	I want my right to accept or refuse any treatment to be understood and respected	
h	I want people involved in my care to always treat me, and people who are important to me, with dignity, respect and compassion.	
i	I want those involved in my care to talk to one another to ensure that my care is well-coordinated	
j	I want to be cared for and die in a place of my choice	
k	I want the people who are important to me to be well supported, both during my illness and after my death.	
l	Is there any other care or support you want or think you might need if you had a life-limiting illness?	

Q4. The statements below are some of the things that people can do to help their health-care team to provide them with the best care. How much do you agree or disagree with the following statements:

	If I have a terminal illness it is important for me to:	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
a	Clearly document my wishes, including what treatment I want or don't want					
b	Nominate someone to make decisions for me if I am unable to, and ensure that my health care team know who that person is.					
c	Let my health care team know as soon as possible if I have any pain, discomfort or emotional concerns that are impacting on my well-being					
d	Participate in my care and decisions about my care to the best of my ability					

SECTION 2: Your thoughts about your care

Q5. In this section, please tell us in your own words, your thoughts and expectations about a range of issues related to end-of-life care. Feel free to write whatever comes to mind for each heading.

- (a) Quality, availability and access to care
.....
- (b) Involvement of you and your family and carers in care planning, treatment and planning for death
.....
- (c) Care and support for your carers and significant others, including bereavement care
.....
- (d) Your preferred place to die and/or what you would like in the place where you die
.....
- (e) Any cultural and/or spiritual support that you and/or your family might need
.....

SECTION 3: About you

Now we would like to ask a few questions about you to help us understand the ideas and opinions of specific groups of community members

For all questions in this section except Q13, please select one number only.

For Q13, please provide the requested information.

Q6	What is your age group? Less than 18 1 18-29 2 30-49 3 50-69 4 70 or better 5	Q7	What is your gender? Male 1 Female 2 Other 3
Q8	In which Tasmanian Health Region do you live? North 1 North West 2 Southern 3	Q9	Do you live in an urban or a rural area? Urban 1 Rural 2
Q10	What is your highest level of education? Less than high school 1 Completed high school 2 Certificate or Diploma 3 University Degree 4	Q11	What is your income level? Less than \$30,000 per year 1 \$30,000 - \$49,999 per year 2 \$50,000 - \$69,999 per year 3 \$70,000 or more per year 4
Q12	Do you regularly use a computer to obtain information about your health or other issues of interest to you? Yes 1 No 2	Q14	What religious affiliation, if any, do you have? (a) Anglican 1 (b) Buddhist 2 (c) Catholic 3 (d) Jewish 4 (e) Muslim 5 (f) Uniting Church 6 (g) Not applicable 7 (h) Other (please specify) 8
Q13	What is the culture with which you identify?		

**Palliative Care Community Charter –
Survey of Opinions**

Results of survey



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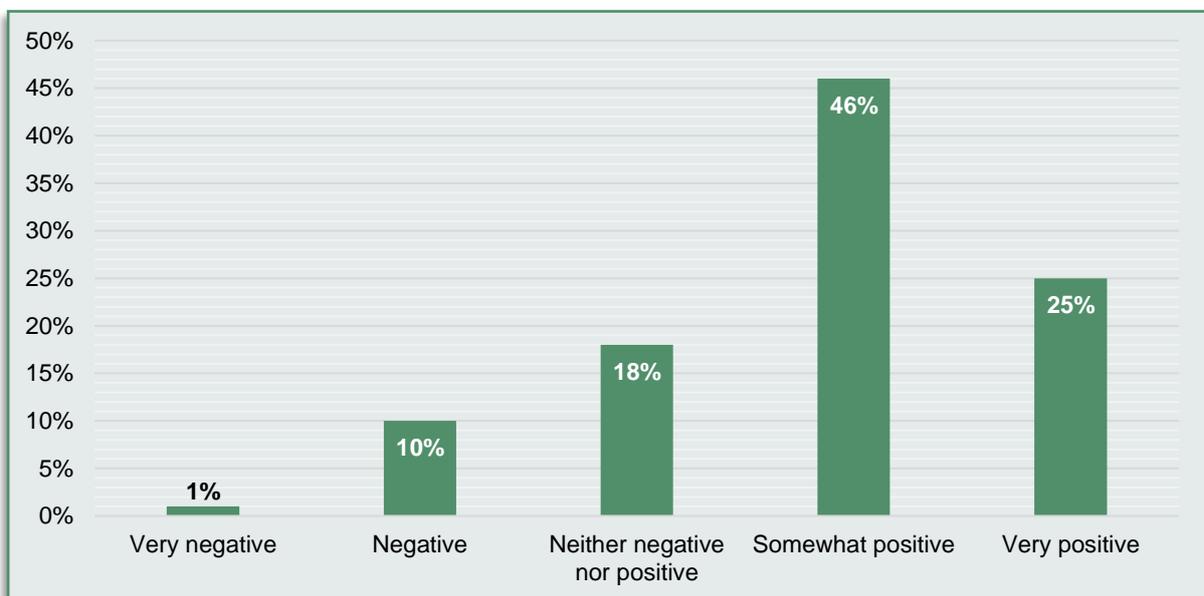
Introduction

The survey to inform the development of the Tasmanian Palliative Care Community Charter was completed fully or in part by 167 respondents with approximately on average 150 answers provided for each question about palliative care. There were on average 120 answers to the demographic questions.

Experience of palliative care

Overall 54% of respondents either personally had experience of palliative care or had someone close to them with experience of palliative care, as a family member, carer, or as a health professional.

When asked about their experience of palliative care, more than 70% of respondents had had a positive experience (25% very positive, 46% somewhat positive). However, one person had a very negative experience and 10% had somewhat negative experiences



(Figure1).

Figure 1: Experiences of Palliative Care

When asked to amplify their views of their experience of palliative care, the following matters were described.

Good care, poor care, opportunities for improvement of care

Good care was characterised by:

- The person with a life limiting illness, family and carer involvement in decision-making
- explicit conversations with the medical staff about expectations of care, progress and outcomes
- informed and involved general practitioners
- access to specialist community and residential palliative care services
- timely access to equipment

- education and support for families and carers, that was adaptable to the stage of care.

In turn poor care was characterised by:

- lack of information, openness, coordination and respect for the person nearing end of life and family at transitions of care especially within and from the acute sector
- lack of understanding of palliative care outside specialist palliative care services, which includes hospitals, residential aged care facilities and community care
- lack of knowledge and understanding about pain management for people in need of palliative care and
- lack of understanding and empathy for people with specific issues, including HIV and disabilities.

Care could be improved by:

- clarity about the expected course of the illness
- early referral to palliative care services
- advice about available resources, eligibility criteria, costs
- continuity of care from a small number of staff from a limited number of organisations
- access to and certainty about after-hours phone and in-home support especially towards the end of life
- agreement as to how the end-of-life situation will be managed
- respite for family and carers and
- access to support and advice for family and carers after the person dies.

Expectations of palliative care

Survey respondents were asked to rank in importance to them features of a palliative care system. These characteristics were identified from a review of the literature.

Ten per cent of respondents judged that all the elements identified were necessary in a high quality system, a further 18% ranked their top three priorities equally. Table 1 sets out in descending order from the highest ranked features. The Top Rank column is the number of times the feature was ranked number one and includes the 18% of responses noted above but not the 10% which ranked all options as number one rank. The Top 3 rank is when the feature was ranked 1-3.

Table 1: Palliative Care Systems Features - Rank of Priorities

Palliative care system feature		Top rank	Top 3 ranks
1	I want the best possible care and support for my physical, emotional, social and spiritual needs, given by well trained staff	42	67
2	I want care and support that is provided equally to everyone who needs it, regardless of age, ethnic background, religion or sexual orientation	22	47
3	I want involvement in and control over decisions about my care	19	42
4	I want access to the right services when and where I need them	16	44
5	I want people who are involved in my care to communicate with me in a clear, honest and compassionate way about all aspects of my care and what I can expect	15	49
6	I want the people involved in my care to always treat me, and people who are important to me, with dignity, respect and compassion	12	44
7	I want to be cared for and die in a place of my choice	11	23
8	I want my right to accept or refuse any treatment to be understood and respected	8	34
9	I want the people who are important to me to be well supported, both during my illness and after my death	8	29
10	I want those involved in my care to talk to one another to ensure that my care is well-coordinated	6	25
11	I want help to record my wishes and decisions, so that everyone involved in my care knows what I want or don't want	2	21

All the features were thought to be important, but unsurprisingly the highest rank was for 'best possible care and support' which given its breadth could encompass most of the more specific aspects of care. Otherwise, when the Top 3 ranks are considered the first six appear to rate at a higher strata of importance than the remaining five. It was also noted that priorities change over the course of the episode of care.

Other features of palliative care

Respondents were asked to identify other aspects of care which were important to them. These included:

- person-centred care, that embeds self-determination wherever possible
- access to the breadth of services close to home, in both urban and rural areas
- access to spiritual and or psychological support for the person and carers
- access to pain relief when needed; the family do not need or want to pester the care staff; prescribing needs to be flexible to meet a person's needs
- certainty that help will arrive when requested
- people need an opportunity to identify special, but apparently minor needs, that would provide comfort, such as massages, extra pillows
- the ability to incorporate alternative therapies and
- the right to die when ready; this was a consistent theme that was raised by a significant proportion of respondents at various stages in the survey.

Respondents were also asked to rate the importance to them of certain aspects of a care if they have a terminal illness. There were 150 responses to these issues (Table 2). There was universal agreement with the statements.

Table 2: Importance of aspects of care to respondents with a terminal illness

Issue	Strongly agree	Agree	Neither Agree nor Disagree	Disagree, Strongly Disagree
Clearly document my wishes, including what treatment I want or not	76%	23%	1%	0%
Nominate someone to make decisions for me if I am unable to, and ensure that my health care team knows who that is	79%	20%	1%	0%
Let my health care team know as soon as possible if I have any pain, discomfort or emotional concerns that are impacting on my well-being	79%	19%	2%	0%
Participate in my care and decisions about my care to the best of my ability	83%	17%	0%	0%

Survey respondents were then asked to identify issues of importance to them with respect to certain aspects of palliative care.

Quality, availability and access to palliative care

Issues identified included:

- early referral to high quality care that is freely available close to where people live
- comprehensive early assessment and planning, with effective coordination of care
- no unreasonable or artificial barriers to care
- specialist and general practitioner working in tandem with the palliative care team
- education for general practitioners about palliative care and availability of services
- best information about services available and likely illness progression
- pain and symptom control
- trained staff who understand the importance of respecting the wishes and choices of people even if they are in conflict with staff views
- continuity of staffing, need to see the same faces, not lots of strangers and
- all-hours, on call access to nursing services / specialist palliative cares who know the person.

Involvement of you and your family and carers in care planning, treatment and planning for death

Respondents advised that:

- the involvement of the person and their family and carers was integral to their well-being, and this involvement could be facilitated by palliative care staff and perhaps volunteers
- however the involvement needed to be modulated by the persons explicit wishes, which are not be over-ridden by family preferences
- the family may need help and tools to manage their own emotional issues so that in turn they can support the person who is dying
- people with disabilities may be either the person with a life limiting illness or a family member of someone who is dying and every effort must be made to enable their participation in decision-making
- an end of life care plan can help clarify ones wishes, but needs to be reviewed regularly because of changes in circumstance and perspective.

Care and support for carers and significant others, including bereavement care

Respondents advised that families and carers:

- need to be able to access support during care and after the death of the person
- need access to useful information and to be aware of services available which can be initiated easily and at short notice.

Special consideration needs to be given to tailored support for family members with an intellectual disability and carers in residential aged care facilities.

Preferred place to die, and/or what you would like in the place where you die

Consistently respondents wanted to be cared for where they would be treated with dignity and compassion, where their opinions and decisions would be respected and with symptom control.

Ideally this would be at home or in familiar surroundings, but if that was impractical then in a high quality palliative care setting with access to familiar food, drinks, friends, pictures, with facilities for family and carers, and with staff who don't perceive the person as a burden.

Cultural and/or spiritual needs that you and/or your family might need

Respondents would like the opportunity to decide whether they want access to spiritual support or not. Love, care, honesty, sympathy, clear unbiased and professional advice and overall a strong sense of being held safe and supported were identified as priorities.

Survey respondents – demographic profile

This section sets out some of the demographic profile of survey respondent. On average about 120 responses were provided to these questions.

Figure 2 sets out three demographic features.

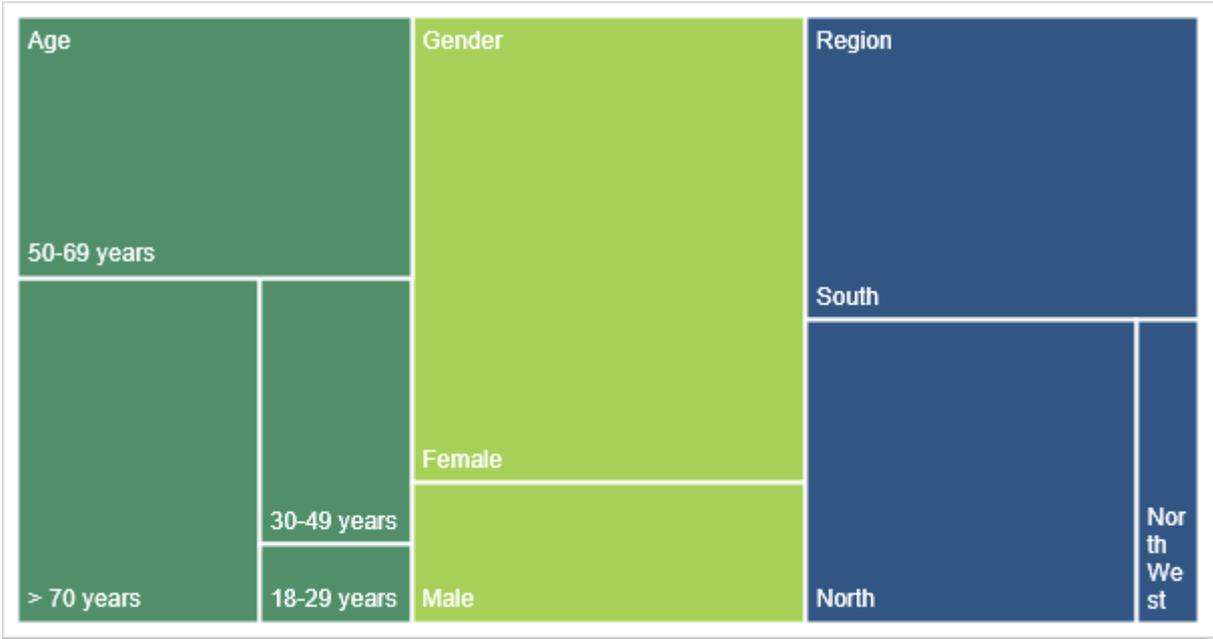


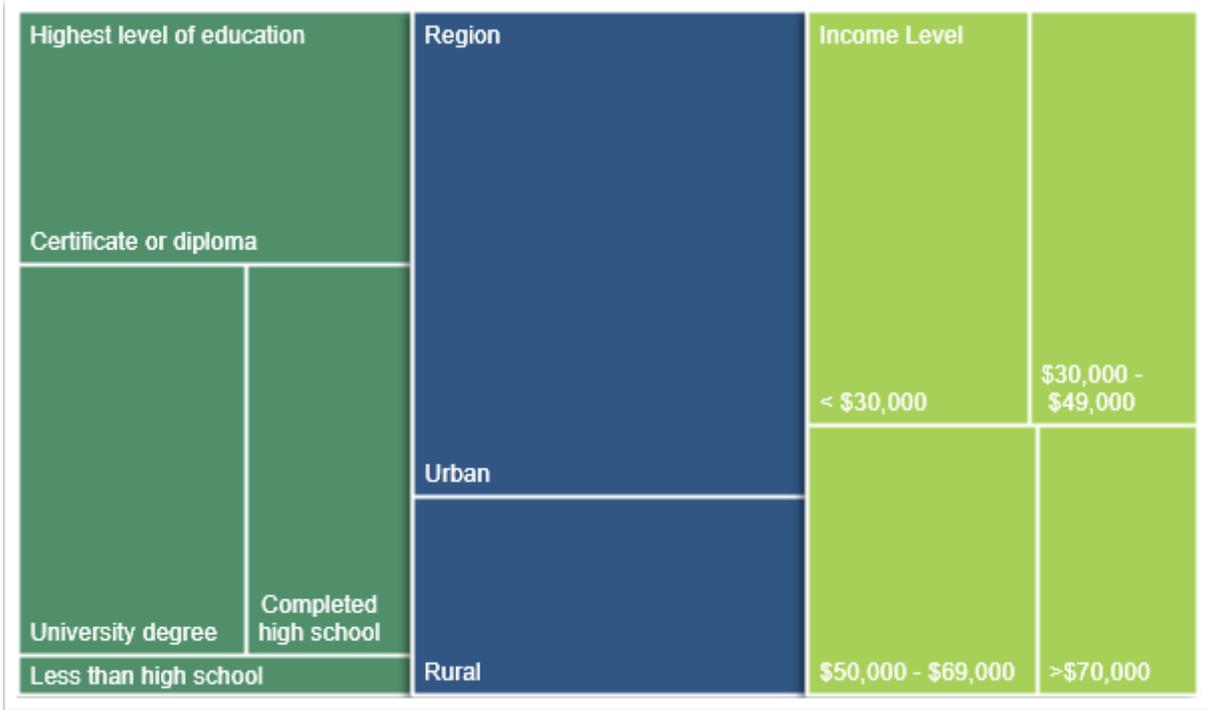
Figure 2: Respondent Demographics by Age, Gender, Region

Seventy-seven per cent of respondents were female. Thirty-five per cent of respondents were aged over 79 years, 43% were aged 50-79 years, with the remaining 22% being under 50 years of age. Half of the survey respondents were from the Southern region, 42% were from the North, with 8% from the North West and Western region.

Figure 3 sets out a further three demographic domains.

Seventy-one per cent of respondents were from urban areas and 29% from rural areas. The level of education ranged from 6% who did not complete high school, to 24% who completed high school, 37% had a post-school certificate or diploma and 33% had a university qualification.

Income level no doubt in part reflected that a significant proportion of respondents were retired or absent from the workforce, with 34% having annual income below \$30,000; there were 26% with income between \$30,000-49,000 and 23% with income between



\$50,000 and \$70,000. The remaining 17% had income exceeding \$70,000.

Figure 3: Respondent Demographics - Region, Education, Income.

Respondents were also asked about cultural identification and religious affiliations.

More than three quarters of respondents identified as Australian, Anglo-Celtic or Anglo-Saxon; 10% identified a European heritage such as Polish, German, Dutch, Croatian and Scandinavian. One person identified as indigenous and about 11% were of other cultural groups, most notable from Bhutan (Figure 4).

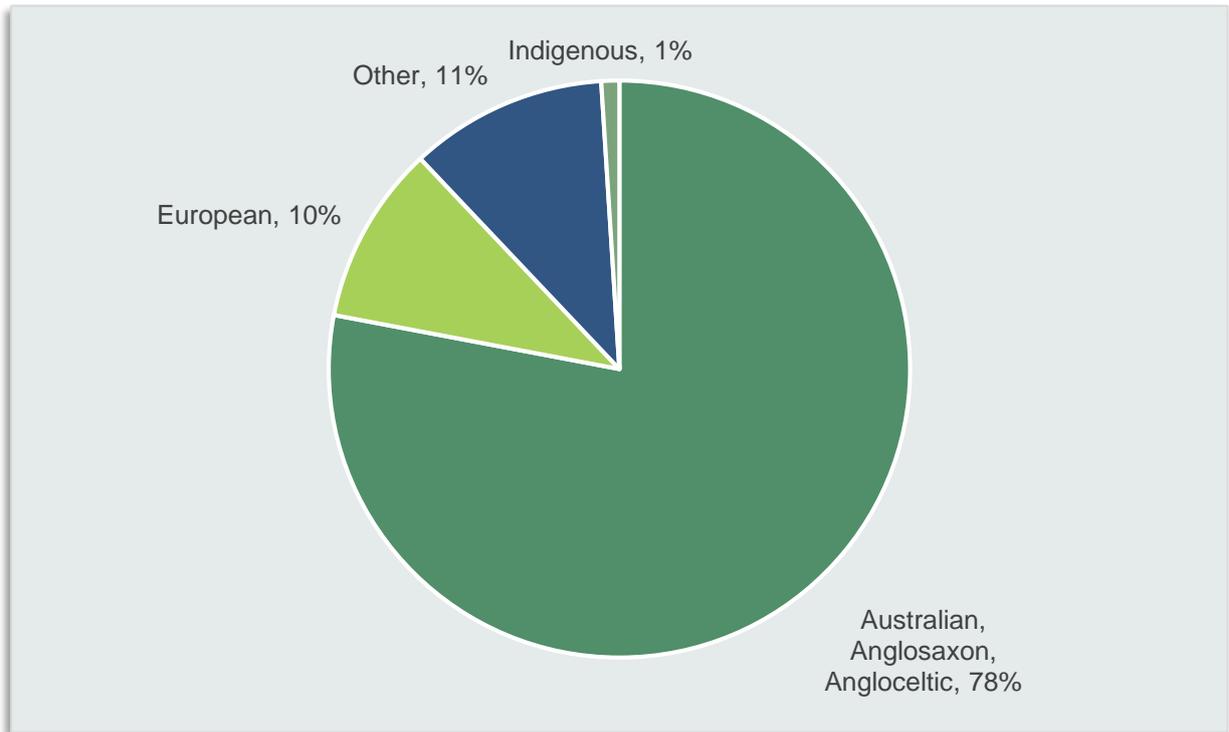


Figure 4: Respondents' Cultural Identification

When asked about religious affiliation, 43% identified no affiliation, 27% identified as Catholic, 13% Anglican, 10% other Christian religions, 4% were adherents to an Eastern religion with 3% secular, humanists (Figure 5).

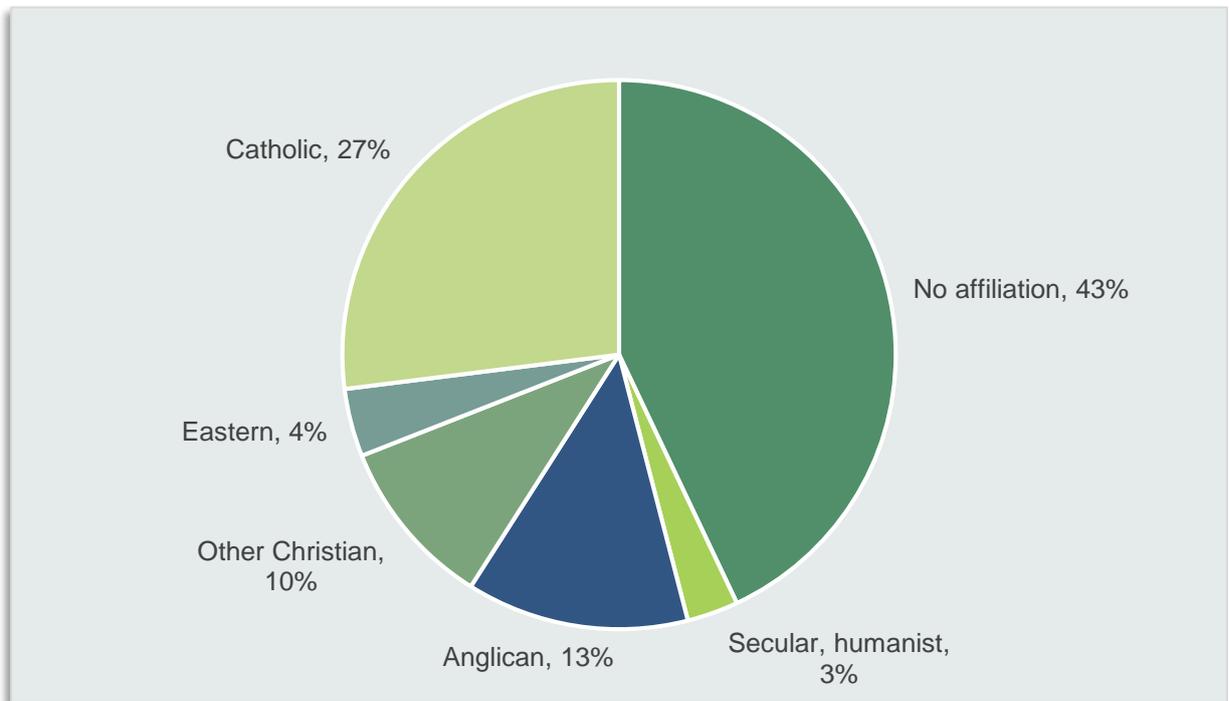


Figure 5: Respondents' Religious Affiliations