

# Palliative care experience survey

Update: 1 May 2018

## Overview

The Department of Health and Human Services (the department) contracted Ipsos Social Research Institute (Ipsos) in December 2016 to assist with the development of palliative care client and carer experience questions.

These questions are intended to be incorporated into the department's Victorian Health Experience Survey (VHES) as an annual module (survey).

In accordance with the current VHES contract, the Victorian Agency for Health Information (VAHI) will oversee/lead the cognitive testing process and incorporation of the final questions into the VHES.

Ipsos will conduct a number of information sessions with the sector in the lead up to deployment of the survey.

## Reference Group

A sector reference group was established to advise on question development across multiple care settings.

Representation included:

- Regional palliative care services – Bendigo Health, South West Healthcare
- Community palliative care services – Peninsula Home Hospice, Eastern Palliative Care, Castlemaine Health
- Acute health services – Eastern Health, Peninsula Health
- Palliative Care Clinical Network
- Australian Centre for Grief and Bereavement
- Centre for Palliative Care; and
- Palliative Care Victoria.

## Process to date

- Ipsos conducted a literature review and an environmental scan of palliative care/end of life research and survey tools.
- Survey domains and groups were identified and agreed by the reference group
- 5 survey instruments were identified
  - In-home (community) client survey
  - In-home (community) carer survey
  - Hospital (inpatient) client survey
  - Hospital (inpatient) carer survey
  - Bereaved carer survey
- Experience questions were formulated by Ipsos based on literature review/environmental scan finding and other survey instruments
- Questions were presented, debated and refined with the reference group
- Ethics approval granted for cognitive testing process with clients, carers and bereaved carers
- Cognitive testing was completed in February 2018; final report was delivered to VAHI in late March 2018
- VAHI and the department met to finalise the cognitive testing report on 30 April 2018

- VAHI and the department are scheduled to meet with Ipsos in early May 2018 to prepare for implementation.

## Survey domains

Survey domains identified were:

- Access to care
- Person-centred care
- Communication, information and education
- Coordinated care
- Quality of care
- Demographics; and
- Carer (and bereavement) support.

A full over of the agreed survey domains are outlined in Appendix 1.

## Next steps

The department and VAHI will work with Ipsos to incorporate final questions into VHES and plan for implementation in late 2018 with the sector.

VAHI will lead implementation with input from palliative care policy area.

## Appendix 1: Survey Domains

### Access to care:

- Experience with the referral process
  - timeliness, understanding, participation in decision to be referred
- Ease of pathway into palliative care
- Commencement of service (waiting lists etc.)
- Travel / proximity of service (convenience)
- Access to health professionals with the requisite expertise

### Person Centred and Holistic Care:

- Participation in care planning and decisions (in accordance to their own wishes)
- Understanding of and respect for their preferences, including:
  - goals of care
  - “what matters most”
  - advance care plans
  - opportunity to refuse unwanted treatment
  - choice of place of care (includes place of death)
- Flexibility and responsiveness – tailored to person’s needs and individual preferences / situation
- Care as sensitive to client’s privacy, dignity, respect and values
- Care provided aligned with emotional, social, psychological, spiritual (broader than faith) and cultural needs

### Communication, Information and Education:

- Treatment / carer options clearly explained, including benefits and burdens
- Opportunities to ask questions
- Opportunity/freedom to change their mind (about place of death, goals of care, advance care plan)
- Choice about involvement of family and friends
  - Inclusion of family and friends in decision-making
- Education provided to support self-care and provision of care by family / carers
- Conversations are had around goals of care and priorities (current and future, includes advance care plan)
- Responsive to individual communication needs and preferences
  - Materials accessible in languages other than English
  - Assistance with understanding, if needed (e.g. low literacy)
  - Access to assisted communication
  - Access to interpreters
- Information provided is relevant and clear
- Information on different sources of care and support that can be accessed is provided (e.g. support networks)
- Conversations are aware of patient history and situation
- Communication is timely and responsive to needs
  - Availability / responsiveness outside of working hours / urgent needs

### Coordinated Care:

- Coordination and integration of care from all sources
  - Communication between all services being accessed, sharing of patient information (this includes hospital and GP)

- Roles of service staff clearly identified
- Experience of transitions between care providers and care locations
  - Including support for client and carer during transition

### **Quality of Care:**

- **For inpatient only:** service environment, cleanliness, hand hygiene
- Physical needs and comfort (including environmental factors – quiet, clean)
- Relief from pain and symptom management
- Responsiveness of care over time for those with prolonged care needs
- Care provided matches client's needs at that point in time
- Trust and confidence in service staff

### **Demographics:**

- Age, gender, language spoken at home, education, Aboriginal or Torres Strait Islander status
- Who completed the questionnaire
- Last contact with palliative care service
- Overall experience of care

### **Carer (and Bereavement) Support:**

- Access to information, communication and education to support carer needs and role
- Participation in discussion of client/patient
- Carer input into decision making
- Responsive to the needs of carers
- Adequacy of access to carer respite and support (ongoing)
- Adequacy of access to bereavement support
- Support with psycho-social needs of carers including grief and loss / bereavement.