Development of the Victorian Palliative Care Satisfaction Instrument

Final report

A Victorian Government initiative

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Final report

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Contents

Executive summary **1**

Introduction **3**

Section A: The Victorian Palliative Care Satisfaction Instrument **5**

Central core 5

Secondary core 7

Demographic and supporting information 9

Demographic information 9

Supporting information 11

Modules 12

Carer module 12

Health service module 14

Section B: Methodological overview **15**

Section C: Literature review **17**

Measuring satisfaction in palliative care: a review of the literature 17

Section D: Qualitative data **21**

Overview 21

Summary of findings 21

Section E: Pilot survey development **27**

Interview data 27

Existing questions 28

Development of client and carer pilot surveys 30

Section F: Quantitative data **33**

Data analysis – Core items 33

Factor analyses 35

Data analysis – Module items 39

Section G: Summary and conclusions **43**

Scoring and interpreting the VPCSI 43

Use and implementation of the VPCSI 44

Cohort (longitudinal) data collection 44

Best practice 44

Driving quality improvement 45

Summary and conclusion 45

Section H: References **47**

Section I: Appendices **49**
Appendix A: Final survey instruments – clients and carers 50
Appendix B: Advisory group and project team members 91
Appendix C: Question bank items 92
Appendix D: Pilot survey instruments (client and carer) 105
Appendix E: Pilot survey cover letters (client and carer) 235
Appendix F: Reminder/thank you letter 239
Appendix G: Descriptive statistics – core items 240
Appendix H: Correlations with overall satisfaction – core items 246
Appendix I: Factor reliability statistics 249

Executive summary

In 2007, the Department of Human Services Victoria (DHS) Cancer and Palliative Care Unit identified the requirement for a robust instrument to measure satisfaction of clients and carers of community and inpatient palliative care services. The two main drivers for development of a new satisfaction instrument were, firstly, to meet Australian Government key performance indicator reporting requirements and, secondly, to provide feedback to the palliative care sector that could drive quality improvement. This report details the development process of the new Victorian Palliative Care Satisfaction Instrument (VPCSI).

The VPCSI comprises five components. A central core taps four key dimensions important to the satisfaction of clients and carers with palliative care services. A secondary core assesses a further three dimensions. Demographic and supporting information are also measured, while the carer and health service modules tap areas specific to carers and inpatient care service recipients.

The VPCSI was developed using techniques in line with best-practice psychological instrument development. Two initial steps were to review the literature to identify existing instruments and to conduct qualitative data collection to identify issues of importance to clients, carers and key opinion leaders in the palliative care sector. From the literature review, it was concluded that while a number of validated instruments were available, few addressed all aspects of satisfaction relevant to this project. The interview data revealed a number of key themes; these themes formed the basis of new question development and informed inclusion of questions from existing instruments.

An initial question bank of 155 items was developed. Four different survey types, specific to individuals in each care setting, were constructed from the question bank items. These were: clients in the community; clients in health services; carers of clients in the community; and, carers of clients in health services. A total of 881 printed surveys were distributed to three Victorian palliative care services in mid-May 2008 for distribution to clients and carers. A total of 257 surveys were returned by early July 2008.

Data from core and module questions were analysed separately. Core item data were analysed using principal components and factor analysis. The initial pool of 80 core questions was reduced to 35 questions comprising seven key dimensions; the central core contains 21 questions in four dimensions, while the secondary core has 14 questions in three dimensions. Data from questions comprising the carer and health service modules were analysed using Pearson's correlations; these modules contain 30 and eight questions, respectively.

The VPCSI is intended to be used in a similar manner to other satisfaction instruments, such as the Victorian Patient Satisfaction Monitor (VPSM). Mean scores for individual questions can be determined and scores can be combined to form satisfaction indices. The VPCSI is designed for use across multiple modalities (hard copy, phone and online), and provides scope for the development of benchmark data as well as interventions for service quality improvement. This newly-created instrument can thus provide a reliable and accurate means for palliative care services to track their own performance in service provision.

Introduction

This report details the contents and development process of the newly-created Victorian Palliative Care Satisfaction Instrument (VPCSI). The first section presents the instrument details - the dimensions of assessment (factors), the instrument's questions and some implementation concepts. A full description of the project is presented in subsequent sections.

In 2007, the Department of Human Services Victoria (DHS) Cancer and Palliative Care Unit identified the requirement for a robust instrument to measure satisfaction of clients and carers of specialist palliative care services. The source population from whom to elicit satisfaction information included adults from an English-speaking background who were:

- Clients and carers of community palliative care services.
- Clients and carers of inpatient palliative care services.

The Department of Human Services released a Request for Quotation in June 2007 calling for organisations to submit a proposal to develop, pilot and statistically test an instrument to measure satisfaction in the population of palliative care clients and carers. UltraFeedback were awarded the contract to undertake this project in partnership with the Department of Human Services. An advisory group of sector and departmental representatives oversaw the project. Advisory group and project team members are listed in Appendix B.

There were two main drivers for the creation of a new satisfaction instrument. The first was to meet Key Performance Indicator reporting requirements for specialist palliative care to the Australian Government. The second was to act on feedback from the palliative care sector that the current satisfaction instrument was too long and was not providing information that allowed intuitive quality improvement. The newly-developed VPCSI instrument will be used in 31 inpatient palliative care services and 39 community palliative care services across Victoria.

The VPCSI has five components. The central core is comprised of 21 questions in four distinct factors and the secondary core contains 14 questions in three factors. Demographic and supporting information consist of (up to) 25 items. Two additional modules – carer and health service – are the final two components; the carer module contains 30 questions, while the health service module includes eight questions.

Section A:
The Victorian Palliative Care Satisfaction Instrument

The components of the Victorian Palliative Care Satisfaction Instrument (VPCSI) are described below. The final survey instruments for clients and carers appear in Appendix A.

Central core

The central core of the VPCSI comprises 21 items. These items fall into four factors, or dimensions.

Factor 1: Referral: Staff

The Referral: Staff factor contains six items. The factor describes the perceived nature of the interactive process between staff and the person receiving palliative care.

Factor 2: Referral: Explanation

The Referral: Explanation factor contains five items. The factor describes the information presentation and dissemination experienced by the person experiencing [about to undergo] palliative care.

Factor 3: Care staff

The Care staff factor comprises six items, and taps the constructs of communication, co-ordination and perceived skill of the staff involved in providing palliative care.

Factor 4: Symptom management

This factor contains four items pertaining to the management of key symptoms generally experienced by those undergoing palliative care.

Item list

Preceding the core list of items is a question assessing overall satisfaction with palliative care services.

The 21 items of the central core are presented here. Note that all items are scored on a five-point scale. Scale anchors depend on the wording of the item, and are either:

- satisfaction scales (one= very dissatisfied, five = very satisfied)
- agreement scales (one=strongly disagree, five=strongly agree)

Question wording specific to carers appears in italics.

Referral: Staff	
Prompt	**Item**
Would you agree that the staff involved in referring you *[the client]* to palliative care…?	Respected my *[the client's]* feelings and opinions
	Treated me *[the client]* like an individual and not just a number
	Showed sensitivity about my *[the client's]* readiness to accept palliative care
	Had my *[the client's]* best interests at heart
	Could see things from my *[the client's]* point of view
	Were helpful in answering questions
Referral: Explanation	
Prompt	**Item**
When you were *[the client was]* first told that you *[they]* could receive palliative care services, how satisfied were you with...? How clearly and simply palliative care was explained	The opportunity to ask questions about the range of available palliative care services
	The opportunity to ask questions about different care options, such as in-hospital versus in-home care
	The level of support provided to help you *[the client]* come to terms with the idea of receiving palliative care
When you were *[the client was]* referred to palliative care, how satisfied were you with information explaining…?	Information about the different options of care available, such as in-hospital versus in-home care
Care staff	
Prompt	**Item**
How satisfied have you been with the skills and attributes of health professionals involved in your *[the client's]* care, such as…?	The communication skills of nurses
	The professionalism of nurses
How satisfied have you been with the accessibility of people involved in your *[the client's]* care, such as…?	Accessibility of nurses during normal business hours
Thinking generally about the health professionals involved in your *[the client's]* care, how satisfied have you been with…?	The communication between different staff members about your *[the client's]* treatment
	The cooperation (teamwork) of people involved in your *[the client's]* care
	The level of expertise of people involved in your *[the client's]* care

Symptom management	
Prompt	Item
How satisfied have you been with the way these symptoms have been managed…?	Fatigue
	Eating or digestive problems such as loss of appetite, food aversions, feeling sick, bowel or incontinence issues
	Pain
How satisfied have you been with…?	The speed with which any symptoms have been treated

Secondary core

The analytic process identified a further 14 items that can be thought of as 'almost' core items (or secondary core items). These are items that probably belong in the central core, but the evidence to include them is currently lacking. In most cases, this is related to sample size. Future data gathering may reveal enough evidence to include some (or all) of these items in the central core.

The 14 secondary core items are all measured on five-point scales similar to the central core. There are three additional factors:

Factor 5: Access and involvement

This five item factor pertains to the accessibility and ease of starting palliative care, as well as the level of involvement extended to the client and family.

Factor 6: Social support

There are four items in the social support factor. It taps the constructs of emotional and psychological support

Factor 7: Information

The Information factor has five items relating to information (primarily written) provided to the client undertaking palliative care.

Access and involvement	
Prompt	Item
Following your *[the client's]* referral, how satisfied were you with the time it took to commence services?	Satisfaction with speed of service commencement
Initially, how easy was it for you to gain access to palliative care services *[for the person you care for]*?	Ease of initial access to palliative care services

Access and involvement (continued)	
Prompt	Item
How satisfied have you been with…?	The way your *[the client's]* friends or family are included in treatment and care decisions
	The ability of staff to communicate clearly with you *[and the client]*
How satisfied have you been with the availability of palliative care services when you have *[or the client has]* required them?	Satisfaction with availability of palliative care services
Social support	
Prompt	Item
How satisfied have you been with…?	The level of genuine concern shown by staff
	The level of emotional support provided to you *[the client]*
	The level of respect with which you have *[the client has]* been shown
	The expertise of staff generally
Information	
Prompt	Item
Would you agree that the written information about palliative care was…?	Useful
	Detailed enough
	Clear and easy to understand
How satisfied have you been with…?	Information about your *[the client's]* prognosis
When you were *[the client was]* referred to palliative care, how satisfied were you with information explaining…?	How palliative care would be combined with existing medical or nursing care the client receives

Demographic and supporting information

The following items are not part of either the central or secondary core item sets. However, they provide important supporting and contextual information that will allow for greater utility and understanding in the analysis of the core questions. These items should be included in all surveys.

Demographic information

Demographic and descriptive items appear below, along with the response options presented. Question wording specific to carers appears in italics.

Question text	Response options
Your gender	Male
	Female
Your age	[enter age]
Are you of Indigenous or Torres Strait Islander origin?	Yes
	No
Would you agree that the written information about palliative care was…?	Useful
	Detailed enough
	Clear and easy to understand
Under which broad diagnostic category does your *[the client's]* diagnosis fall?	Cancer
	Stroke
	Heart disease
	Motor neuron disease
	Respiratory diseases
	Renal disease/failure
	Neurological condition
	Other (please specify)
How long have you *[has the client]* been receiving palliative care?	Less than 1 week
	Between 1 week and 1 month
	Between 1 month and 6 months
	Between 6 months and 1 year
	More than 1 year
[Client only] Do you have a carer?	Yes
	No

Question text	Response options
If you do have a carer, what relationship are they to you? *[What relationship is the person whom you care for to you?]*	Parent
	Child
	Grandparent
	Grandchild
	Other relative (e.g. uncle, niece, cousin)
	Friend
	Spouse/partner
	Other (please specify)
If you do have a carer, do they normally live with you? *[Do you normally live with the person whom you care for?]*	Yes
	No
Have you *[has the client]* had a recent stay in a hospital or health service (i.e. within the last 2 weeks)?	Yes
	No
	Not sure
What is the postcode, suburb or town where you usually live?	[enter postcode]
Where do you normally receive palliative care (i.e. where do you generally live)? *[Where does the person you care for normally receive palliative care (i.e. where does the client generally live?)]*	In my own home
	In a nursing home
	In a hostel
	In the home of a friend
	In the home of a relative
	In a palliative care facility (e.g. health service or hospital)
	Other (please specify)
Who completed this survey?	The person receiving palliative care
	Carer of the person receiving palliative care
	Family member who is NOT a carer of the person receiving palliative care
	Friend who is NOT a carer of the person receiving palliative care
	Volunteer
	Other health professional
	Other (please specify)

Supporting information

The following 13 items have been identified, via analysis and consultation, as having potential clinical relevance. Whilst they do not form part of the core satisfaction items, they augment the instrument and should be considered for inclusion in surveys based on their face value.

Question text	Response options
How satisfied have you been with the overall standard of care provided by the palliative care service?	[Five-point satisfaction scale]
When you were *[the client was]* referred to palliative care, how satisfied were you with information explaining what palliative care actually involved?	[Five-point satisfaction scale]
When you were *[the client was]* referred to palliative care, how satisfied were you with information explaining alternative support if you *[the client]* did not want to receive palliative care?	[Five-point satisfaction scale]
Has an interpreter been available to you *[or the client]* when required?	Yes
	No
To what extent do you agree that your *[the client's]* cultural or religious needs have been respected	[Five-point agreement scale]
To what extent do you agree that your *[the client's]* cultural or religious needs have been provided for	[Five-point agreement scale]
How often have you felt like you've had to repeat yourself or re-explain your story *[your own or the client's story]* to different people at different times?	1. Never
	2. Rarely
	3. Sometimes
	4. Often
	5. All the time
How often have you *[the client]* felt treated like you *[they]* are 'just a number' or 'just a disease'?	1. Never
	2. Rarely
	3. Sometimes
	4. Often
	5. All the time
How satisfied have you been with the skills and attributes of health professionals involved in your *[the client's]* care, such as…The communication skills of other staff, such as counsellors?	[Five-point satisfaction scale]
How satisfied have you been with the accessibility of nurses after hours?	[Five-point satisfaction scale]
How satisfied have you been with the accessibility of other health professionals, such as counsellors?	[Five-point satisfaction scale]

Question text	Response options
How satisfied have you been with the information received during your *[the client's]* care, such as the opportunities to ask about alternative medications or treatments?	[Five-point satisfaction scale]
Are you aware that there is an afterhours number you can call to get help at any time of the day or night?	Yes
	No
	Not sure

Modules

The two additional carer and health service modules assess specific aspects of palliative care. The carer module contains questions that tap into areas of specific interest to carers, while the health service module assesses different aspects of health services.

Carer module

Questions in the carer module have not been subject to the same statistical analyses as the core items and thus distinct 'factors' cannot be described. Nonetheless, four key themes or dimensions can be noted.

The 'initial support' dimension assesses satisfaction with the support provided when the client was initially referred to palliative care. The dimension of 'general support' taps into satisfaction with support related to day-to-day client care, such as access to medical professionals and resources to support oneself in the carer role. The component 'help with arranging' relates to satisfaction with assistance provided to gain access to carer-related goods or services, such as carer benefits from Centrelink and home alterations, while 'coping with' assesses general perceptions of how well a carer is managing different aspects of the care role.

Carer module	
Prompt	Item
How satisfied have you been with…?	The level of professional help you receive as a carer
	The level of respect you have been shown as a carer
	The level of support you receive from medical professionals
	The level of support you receive from the community
	The overall responsiveness of health professionals
	The ease of receiving urgent medical assistance from health professionals in general
	The efficiency of receiving urgent medical assistance from health professionals in general

Carer module	
Prompt	**Item**
When you first became a carer, how satisfied were you with…?	The level of information you received about what would be involved in supporting a person living with a terminal illness
	The sensitivity of staff about your readiness to start caring for the client
	The level of professional support you received in making the decision to become a carer
	The support provided to help you, as a carer, come to terms with the idea of the client receiving palliative care
	The level of support in deciding to place the client into a palliative care or aged care facility
	The level of support in determining HOW BEST to place the client into a palliative care or aged care facility
How satisfied have you been with the on-going support you have received as a carer, specifically…?	The availability of medical professionals to answer questions
	The availability of medical professionals to provide information
	The information provided to minimise your own physical burden
	The information provided to minimise your own psychological burden
	The level of access to psychological support services, such as a counsellor or psychologist, for you personally
	The level of concern for your own psychological wellbeing
	The level of training provided to enable you to carry out specific care functions, such as massaging, moving or bathing the client
	The opportunities to talk to someone about your own situation as a carer

Carer module	
How satisfied have you been with assistance in arranging matters related to client care, such as…?	Funeral arrangements
	Necessary equipment
	Home alterations
	Medical power of attorney
	Medications for the client not on the PBS
	Special dietary requirements for the client
	Transport to and/or from treatments
	Treatments for the client not covered by Medicare
To what extent do you feel you are coping with being a carer, specifically…?	The financial burden of caring

Health service module

The nine items recommended for inclusion in the health service module cover satisfaction with general aspects of the health service. These include the physical environment, service delivery and general level of comfort provided.

Health service module	
Prompt	Item
How satisfied have you been with these aspects of the palliative care facility…?	The explanation of routines (like meal times, visiting hours, etc)
	The activities provided to help you *[the client]* pass the time
	The attractiveness of the facility
	The quality of the food overall
	The general atmosphere of the facility
	The privacy of the room where you spend *[the client spends]* the most time
	The general level of comfort in the room where you spend *[the client spends]* the most time
	The amount of peace and quiet
How satisfied have you been with the communication skills of doctors?	Satisfaction with communication skills of doctors

Section B: Methodological overview

The Victorian Palliative Care Satisfaction Instrument (VPCSI) was developed using techniques in line with best-practice psychological instrument development. The development process and key implementation dates are described below.

Literature review

Following initial development and planning of the project during October 2007, a review of the literature was undertaken. Multiple databases, such as PsychINFO, Medline, PubMed and Web of Science were searched for publications pertaining to palliative care, and particularly assessment of palliative care services, client and carer needs and satisfaction. A number of existing instruments were identified. There appeared, however, to be little consensus on the factors influencing the satisfaction of palliative care recipients. It was therefore concluded that few validated instruments were available that addressed all aspects relevant to this project.

Qualitative data collection

Between January and March 2008, a number of interviews were conducted to ascertain the issues of relevance to clients, carers and key opinion leaders in the palliative care sector. Candidates interviewed were taken from a list provided by the Department of Human Services. Interviews were conducted by Mr Tom Holman and Dr Jenny Bartlett, and generally took between 30 and 60 minutes to complete. Recommendations were extracted from the interview material and were utilised in the survey development process.

Pilot survey development

An item (question) bank, drawing upon the existing literature and qualitative data, was developed during March and April 2008. Items of relevance to both clients and carers were compiled into a single list of 'core' items, while those specific to carers or to individuals receiving care in health services were compiled into two separate modules. The initial bank of questions was reviewed by a number of professional reviewers.

Four survey types were constructed, each providing a total set (core plus module(s)) of questions to clients or carers in different care settings. These were:

- Clients in the community.
- Clients in health services;
- Carers of clients in the community.
- Carers of clients in health services.

Two versions of each survey type were created, with questions presented in quasi-randomised order to counter any potential order effect of question presentation.

Quantitative data collection

Commencing 19 May 2008, printed versions of each survey type were distributed to Eastern Palliative Care, Melbourne Citymission and Wimmera Hospice Care. A total of 881 surveys were sent, with each palliative care service distributing the surveys to a random selection of clients and carers. A cover letter introducing the project was sent with each survey. A generic reminder/thank you letter was sent to each potential respondent approximately one week after survey distribution.

A total of 257 questionnaires (117 client, 140 carer) were returned by Friday 4 July 2008. The overall response rate was 29 per cent.

Quantitative data analysis

Core items and module items were analysed separately. Data were initially checked for quality and screened to ensure suitability of further analyses.

Initially, there were 80 core questions flagged for further investigation. Items where fewer than half of all respondents had provided a valid answer (n<100) were excluded. Testing of the suitability of the data for further analyses indicated that additional items lacking a sufficient number of responses would need to be excluded; thus all items with less than 200 responses were excluded (22 items). The remaining 58 items were entered into a correlation matrix to determine which had the strongest relationship (Pearson's correlation) with *overall satisfaction with palliative care*. Three items with the weakest relationships to overall satisfaction were removed; further testing indicated suitability of the remaining dataset for further analysis.

Principal components analysis and factor analysis were used to determine which of the remaining 55 items formed coherent subsets that would reflect the key elements of importance to recipients of palliative care services. An initial solution of 35 items was determined, showing seven factors (or seven dimensions of greatest importance). This solution was, however, based on responses from less than 30 per cent of all respondents (n=79, where total n=257) and was deemed adequate for the dataset but lacking statistical robustness. A final four-factor solution of 21 items was then determined; this solution was based on a larger proportion of the data (n=113) and was thus deemed statistically more robust.

Items contributing to the two modules (carer module and health service module) were analysed separately. Descriptive statistics for items in each module were determined, as were Pearson's correlations between each item and *overall satisfaction with palliative care*.

Of the 40 items in the carer module, 10 showed weak or non-significant correlations with overall satisfaction and were thus excluded. One item excluded from the core set was included in the health services module. Of the 19 items included in the health services module, nine items showed weak and non-significant correlations with overall satisfaction and were thus excluded.

Section C:
Literature review

A review of existing literature was conducted during November 2007. A number of existing instruments were identified that assessed various aspects of palliative care.

Measuring satisfaction in palliative care: a review of the literature

Palliative care services provide a range of support to patients diagnosed with terminal illness, and to their families. Palliative care is a patient-centred approach concerned with improving quality of life for patients and support for their families and carers (Sikora, 1999).

A review of the literature reveals that satisfaction with palliative care services or service quality and quality of care is not measured nearly as often as patients and carers need. Satisfaction with care services relates to factors such as needs, goals and quality of care in complex ways, making accurate assessment of satisfaction a difficult task (Wen & Gustafson, 2004). Satisfaction assessment is further compounded by methodological issues; direct or indirect questioning about satisfaction can influence responses, while patient illness or frailty and family distress can impede participation (Aspinal, Addington-Hall, Hughes, & Higginson, 2003).

To date, there appears to be little consensus about the factors that influence patient and family satisfaction. Access to information (Lecouturier, Jacoby, Bradshaw, Lovel & Eccles, 1999), staff competence and accessibility (Grande, Farquhar, Barclay & Todd, 2004) and expectations (Fakhoury, 1998) have been described by some authors as important determinants of satisfaction. However there appears to be few standardised and validated instruments available for assessment of all relevant aspects of satisfaction.

Meta-analysis overviews

A meta-analytic review of 80 studies was conducted by Aspinal et al (2003). Studies included in the review typically assumed satisfaction to be a proxy for quality of palliative care, and set out to determine whether quality of palliative care services could be accurately inferred through assessment of satisfaction with services.

The data in the meta-analysis indicated a wide range of definitions of satisfaction, with the concept often not defined at all, suggesting an underlying assumption that ‘satisfaction’ is a known and commonly agreed-upon quantity. Satisfaction is often associated with the fulfilment of needs or of expectations. Yet there appears to be no consistency in the degree of influence expectations have; some studies found satisfaction is directly related to unmet expectation while others have found no such relationship.

A great deal of methodological variation in assessment of satisfaction was also found. Studies tend to use a wide variety of measurement tools. Some utilised pilot study data or data obtained as part of a wider research program to develop questionnaire scales, while some studies used quality-of-life or symptom scales to infer satisfaction. Demographic data are frequently collected, yet tend to be utilised in different ways, with some finding correlations between satisfaction levels and demographic variables that are not present in other studies. Such methodological variations can impede understanding of the relationship between satisfaction and service provision by providing inconsistent and often incompatible data and interpretations.

The findings of Aspinal et al (2003) indicate a need to identify factors that influence satisfaction measurement in palliative care. Instruments that measure these factors and their degree of influence on patient and carer satisfaction must also be developed.

While there is currently little consensus on what these factors may be, some commonly identified factors include provision of information, pain control and staff competence. Information can be particularly important in palliative care settings where there are often high levels of emotional distress and confusion about what to expect. Pain has been often cited as a major concern of patients and family members, tending to have a negative impact on satisfaction when not managed appropriately. Staff competence appears to be another important factor, and includes aspects such as humanness, degree of support, confidentiality, respect for privacy and ability to reduce anxiety, as well as availability to discuss concerns. The authors also suggest that concepts such as quality of life, good death, good care and needs assessment should also be explored as possible contributors to satisfaction.

In another review, Wen and Gustafson (2004) assessed 24 needs assessment instruments (17 for patient, seven for families) for end-stage cancer patients. Conclusions reached were similar to those of Aspinal et al. (2003). Term definitions were inconsistent across instruments and a wide variety of content domains and approaches were utilised. There were few domains common to all instruments, and similar domain titles were often utilised where content items differed both operationally and conceptually. Methodological variations were also noted between instruments, with utilisation of Likert-type scales common. Instruments using Likert-type scales were prone to ‘ceiling effects’, with many items being rated high on the scale; such an effect limits understanding of needs by failing to separate high from low needs. Instruments also tended to fail in assessment of the different stages of care, such as ‘survivorship’, ‘bereavement’ and ‘prevention’.

Wen and Gustafson (2004) argue that patient and carer satisfaction is related to needs and quality of life in complex ways. Understanding these relationships is necessary in order to adequately assess satisfaction. However, a lack of conceptual theory addressing these relationships may be inhibiting the development of sound assessment tools.

Finally this review was limited to assessing the needs of end-stage cancer patients and their families. It is possible that the needs, quality of life and satisfaction of other patients receiving palliative care, and their families, may differ from those of cancer patients, suggesting that applicability of these findings to other palliative care settings may be limited. Nevertheless, this review does suggest that a more standardised approach to the assessment of satisfaction with palliative care services is necessary.

Instrument overviews

A number of instruments have been identified that assess the satisfaction of patients and carers with different aspects of palliative care. Psychometric properties of these instruments are generally good.

FAMCARE (Kristjanson, 1993) was developed to assess the satisfaction with advanced cancer care of patient family members. Items assess satisfaction using a five-point Likert scale, from very satisfied to very dissatisfied. Needs are not assessed.

A cluster analysis of pilot data (n=30) revealed four dimensions – provision of information, availability of care, physical care, and psychosocial care. Internal consistency (Cronbach’s alpha) during pilot testing was .93, with test-retest correlation of .91 (Kristjanson, 1993).

A subsequent validation study (n=183) indicated the presence of one primary factor with Cronbach's alpha of .96 (Ringdal, Jordhøy, & Kaasa, 2003). In comparing their factor analysis results with Kristjanson's (1993) conceptual model, Ringdal et al (2003) found that some items from the 'physical care' and 'psychosocial care' dimensions had strong factor loadings for their 'information' dimension, while one item assessing information about pain loaded strongly on both 'information' and 'general care' factors. The authors suggest that a reduction of items may be possible.

Usage restrictions and availability of FAMCARE are unknown; however the instrument is readily available via the internet. FAMCARE has been utilised in Australia (for example, Medigovich, Porock, Kristjanson & Smith, 1999; Flinders University, personal communication, 2007).

The Palliative Care Outcome Scale (POS) (Hearn & Higginson, 1999) was developed to assess physical, psychological, spiritual, organisational and practical concerns of patients with advanced cancer and their families. The POS is available in two versions: self-report for patients able to complete the survey and an adapted staff-rated version for patients unable to complete the survey. The scale is brief, taking less than 10 minutes to complete. The instrument includes assessment of symptoms as well as some pseudo-satisfaction items.

The 12 items have varying scales, most using a symmetrical five-point scale. The initial validation study (n=148) revealed variable construct validity (Spearman rho = .43 to .80), with acceptable internal consistency (Cronbach's alpha .65 for patients and .70 for staff) and acceptable test-retest reliability for seven of the 12 items. Subsequent validation studies using German and Spanish versions yielded comparable reliability and validity (Bausewein et al., 2005; Serra-Prat, Nabal, Santacruz, Picaza & Trelis, 2005).

The instrument appears to be freely available, although the user guide may be required for full instrument details and psychometrics (available for a fee). The instrument has been adapted for use in Australia (for example, Eagar et al., 2003).

The Critical Care Family Satisfaction Survey (CCFSS: Wasser, Pasquale, Matchett, Bryan & Pasquale, 2001) was developed to assess satisfaction of family members with critical care outcomes as a proxy for patient satisfaction. The instrument comprises 20 satisfaction items each utilising a five-point Likert scale (very satisfied to very dissatisfied). Items form five subscales: assurance, proximity, information, support and comfort; however the comfort subscale includes only two items and performed relatively poorly in the initial validation study, suggesting a four-subscale instrument may be more appropriate.

The initial validation study (n=237) revealed a total score Cronbach's alpha of .93 for the five-factor solution and .91 for the four-factor solution. Internal consistency correlations for subscales ranged from .84 to .91 in the five-factor solution and .86 to .93 for the four-factor solution. Test-retest reliability was not assessed (Wasser et al., 2001). A subsequent validation study using data obtained via the internet revealed similar findings; Cronbach's alpha of .92 and internal consistency correlations for subscales ranging from .77 to .94 (Ray et al., 2005).

Usage restrictions and availability are unknown. The instrument has been utilised in Australia (for example, Concord Hospital, 2005).

Another survey instrument containing items relevant to the assessment of satisfaction with palliative care services is the Victorian Patient Satisfaction Monitor (VPSM). The VPSM has been used to assess patient satisfaction with care and services provided in Victorian public hospitals since July 2000 (Department of Human Services [DHS], 2007). The VPSM assesses satisfaction in areas such as

admission, physical environment, discharge, treatment, and complaints management. An independent review in 2003 found the instrument to be credible and methodologically sound, with internal consistency (Cronbach's alpha) of .91 (the Department of Human Services – personal communication, 2007). As palliative care involves components and outcomes that differ from those of generalised medical care, adapting medical care satisfaction instruments to palliative care settings must involve careful consideration of relevant items (Fakhoury, 1998). Nevertheless, some items of the VPSM do tap relevant aspects of satisfaction with palliative care and may be suitably adapted, for example, items assessing clarity and delivery of information, pain management, and staff responsiveness.

Other instruments

A number of other instruments have been developed that assess various aspects of palliative care. The Cambridge Palliative Audit Schedule (CAMPAS/CAMPAS-R: Rogers, Barclay & Todd, 1998; Ewing et al., 2004) is intended to assess palliative home-care patient symptoms and needs in the United Kingdom. Analogue scales are utilised to assess symptom severity and interference, either through patient self-completion or with assistance of a carer. It does not measure satisfaction with palliative care services per se. A sample of items included in the instrument is available.

Another instrument, the Self Assessment Service Audit (SASA), available from Palliative Care Australia (1999), provides a comprehensive set of guidelines for evaluation of most aspects of palliative care, such as symptom severity, care environment, psychological impact of illness and spiritual needs. It is not a survey instrument, but it does discuss concepts relevant to satisfaction and may be useful in the development of new satisfaction instruments.

A number of other palliative care assessment instruments that may contain relevant items have been identified. These include the Cancer Patient Need Survey (Wingate & Lackey, 1989), designed to assess self-selected needs of cancer patients; the Cancer Patient Need Questionnaire (Foot & Sanson-Fisher, 1995) intended to assess unmet needs of cancer patients; and the Home Care Study-Patient Form (McCusker, 1984), developed to measure patient attitudes toward medical care. However, as discussed, a focus on needs assessment is not perfectly congruent with measurement of satisfaction.

Conclusion

Assessing patient and family or carer satisfaction with palliative care services is a difficult and complex process. The components of palliative care differ to those of medical care, and it is important that these specific components be included in satisfaction instruments (Fakhoury, 1998).

From this review, it appears that there are few validated instruments available that address all dimensions relevant to this project. The FAMCARE instrument provides a well-validated means of assessing family member satisfaction with palliative care, and items may be readily adapted to a self-report measure. Items in the POS may also be usefully adapted. A number of other instruments may also provide useful items that can be adapted for the purposes of this project once appropriate domains of interest have been fully and formally identified.

Section D: Qualitative data

Overview

As part of the consultation process to develop the Victorian palliative care client and carer satisfaction survey, a number of interviews were undertaken to ascertain views and issues from key leaders in the sector. These interviews took place between January and March 2008, primarily as one-on-one conversations (a small number of interviews took place over the phone). This section of the report summarises the qualitative component.

The issues detailed in the report reflect the views of those interviewed and, at times, provide a range of perceptions. It needs to be noted that this is a sector which is extremely well regarded - high satisfaction rates are normal and, as such, the interviews aimed to pick up the subtleties that could help services learn from client and carer satisfaction surveys in order to improve.

Summary of findings

I – Issues for clients and carers:

The issues for clients and carers largely overlapped, with the emphasis differing rather than the issues. They include:

Referral: The process of referral was considered important with particular issues around delays in referral, referrals that were too early or too late; how the process was undertaken by the acute team to ensure clients and carers had a realistic understanding of what to expect and, in particular, how palliative care differs from the acute sector. The introduction of consultative services to major acute facilities was seen as a significant improvement in the way patients were assessed and prepared for community and inpatient palliative care. There remained a significant gap in patients being referred from private hospitals. Education and training for clinicians referring patients was seen as important, as was the gradual introduction of palliative care, rather than a sharp ceasing of acute care and a perception of abandonment by the acute team.

Access: Referral from acute services to community and inpatient palliative care was seen to have challenges across the sector, with some services able to pick clients up within 24 hours and others taking up to four weeks. In some circumstances where there were delays, patients waited in inpatient acute beds, which was not seen as an ideal or appropriate environment. Access to acute service's support was seen as problematic for some services. For example some palliative care clients still need pathology, radiology, radiotherapy and chemotherapy. In addition, access to specialist medical services for advice and support for both client and palliative care clinicians was seen as desirable.

Expectations of service: Community perception and understanding of palliative care was seen as requiring work because there is a poor understanding as to what to expect from the services. It is seen as the 'end of life' rather than 'preparation for the end of life'. This was compounded by the services differing in their models of care across the state. The language used was an issue with some preferring euphemisms about end of life [going to a better place versus dying]. The role of volunteers and what they offered was observed to vary considerably across services.

A clear expectation at the beginning of the process was seen as extremely important, with that information being documented for reflection and reminder. The information should be updated along the way as requirements changed. The timing of when information was given and the readiness of the clients and carers to hear and process it was seen as critical.

Appreciation of scope: Those clients and carers who were involved with palliative care services often didn't understand what was involved or how the complexities of the system fit together. This aspect sits between expectations of services and integration of care.

Integration of care: How clients and carers perceived the integration of the care being provided was seen as extremely important. The services all aim for interdisciplinary care at a professional level, which should include seamless communication between professionals so clients and carers are not repeating their stories. There was discussion about the number of clinicians providing care to clients and how that impacts.

The balance between 'talking services' and 'doing services' being provided to clients was highlighted as an area to explore within the survey. This picked up on the varying models of care being delivered, with care direction being decided and then delivered in pieces by many individuals. Scope for questions around whether the care meets their needs or whether there was anything else they would have liked to have happened, or to be offered that didn't happen, was identified.

There was discussion about the appropriate time to introduce issues and to offer services. Examples included when to offer volunteer, home help, social work or psychological services in order for them to be available at a time when they were most able to be accepted and beneficial.

There was some discussion about the ability to move out of palliative care, back to more general care in a period of stability of the disease process, and then back to palliative care and how that was something not well integrated in the client's continuum of care when re-entering palliative care in the event of a crisis via the Emergency Department.

Physical symptom management: The management of symptoms was seen as essential to good palliative care. It was considered that pain and bowel care were usually done well but other physical symptoms such as poor appetite and fatigue were not given as much importance or interest. It was considered important to determine whether dealing with symptoms was service focused, or client focused.

Psychological symptom management: The approach and management of psychological symptoms was seen as important with issues such as: stigma attached to needing a psychologist/psychiatrist; systems and processes put in the way to make such services less accessible than more mainstream services such as managing pain; others are doing the job so a specialist is not needed. There were issues around the balance between the value clinicians put on information, with views that clinical information was more valuable than social. The ability for patients to feel a level of control and be able to express their distress was important, as was the need to feel they exist as a person, not just a syndrome or disease. Exploring the maintenance of significant life connections such as the important 'self' connection, and aspects of keeping self intact, individual relationships and sense of place was also identified.

Choice of where services are delivered: Issues included care being undertaken at home or as an inpatient and whether a choice was clearly offered or available. There were some views that clients chose to die at home, as the alternative was an acute bed due to shortages of inpatient palliative care beds; the choice was thus not realistic. Palliative care services assume clients want privacy; however there is no evidence that that is the case in all circumstances.

The option of having the original acute care team still involved was seen by some as important in deciding where to receive care as clients did not want to feel abandoned by a team who may have looked after them for years. The original team's ongoing input was seen to be important as part of the clinical partnership in managing complex care needs.

II – Carer-specific issues:

Some issues from the interviews were specific to carers of palliative care clients.

Knowledge: Issues included the ability to access further information, how to deal with anger, where to get support and respite and, importantly, how bereavement is managed. Looking at when services were offered and how that offer was taken up at specific times in the continuum of care. Knowledge of palliative care was often obtained from friends and colleagues who may have had an experience in different circumstances where another model of care may have applied.

Carer needs: The ability of carers to deal with what is going on as well as have something left for themselves was highlighted in terms of a hierarchy of carer needs being; firstly dealing with the physical tasks, secondly spending time with their loved one and meeting their needs and finally having time/respite for themselves. Access to enough respite care to help carers keep going and the ability to feel safe that if there is a crisis there is someone to call. The issue of increasing lack of after-hours GP services was seen as a short to medium-term challenge to the sector.

Family involvement: It was important to be aware of the family resources and the need for them to be 'centre stage' in the process rather than the clinicians. Ascertain what it is that the carers are really stressed about and help deal with that; that is, is it the death or the processes they need to deal with which causes the most stress. The issue of who had what knowledge across the family dynamics as well as the family and carers having different or more or less knowledge than the client. Family members being at different places and stages in their knowledge, involvement and acceptance was seen as important.

Emergency issues: Issues identified included knowledge that there is someone to call 24 hours a day in the event of an emergency, and the access to after-hours GP services, given the changing nature of how general practice is servicing the community.

Bereavement processes: Issues about support for carers and families after the death, including who is best to deliver that care, were raised.

Financial: The costs of dealing with caring for a loved one who is dying, including giving up work, home alterations, medications not on PBS, special food and so on, were raised by carers.

Training: There was a perception that carers would benefit from more training to help their loved ones with basic needs such as administering medications and personal care requirements such as transferring techniques. It was reported that when support had been sought from rehabilitation units, they were reluctant to assist, as these clients' long term prognosis was not positive.

III – Issues for services providing care:

There was a very clear message that services wanted the survey to deliver messages on 'what we should be doing' and 'what are we not doing well' rather than satisfaction with what we are currently doing - which previous surveys have shown to be very high. This suggests services want information about the palliative care client's experience while receiving care, in addition to their satisfaction with the care received.

Interdisciplinary care: The role individual disciplines play in the care team was seen as important to managers to be able to improve in certain areas and yet the model of care was not necessarily discipline specific, and the ability of patients and carers to differentiate between who was providing

which services was not clear. In addition, the models of care being delivered in the health services and coordinated by the consortia varied, which was felt to make benchmarking difficult. In general, care delivery-based questions were seen as more important rather than profession based.

Access: The ability to give access to all of those who would benefit from palliative care was seen as something to look at in the survey. It was considered that this would provide challenges given the view that currently only about one third of those who would benefit from palliative care were being referred. In addition the access for non-cancer patients was something to determine.

Referral process: Some of those interviewed from the community-based palliative care sector felt it was important to determine client satisfaction with the referral process. Their concern was that until the hospital-based consultancy services were established there had been difficulties with client perceptions and expectations of palliative care services. That is, was any dissatisfaction associated with the way palliative care was initially raised in acute health services, rather than the care being given by community and inpatient palliative care services?

IV - Palliative care in general:

Access: It was agreed that not all those who could benefit from palliative care had access and there was currently a debate in the sector as to how specialist palliative care can be extended to include those who need the services. In particular, this debate centred on the inclusion of clients with non-cancer diagnoses such as neurological conditions, for example Motor Neurone Disease and organ failure. It was agreed that in the past clients with non-cancer diagnoses may not have been given priority for access to palliative care. Care for palliative clients with no relatives available to look after them was also seen as an issue for access to appropriate services.

National agenda: The focus of improving palliative care services at the national and state government level was seen as positive with palliative care emerging as a speciality in its own right. This came with the challenge of increasing expectations of a limited workforce. There was discussion about the role of palliative care as 'end of life care' versus 'care at the end of life' and how that encompasses care across all specialties and conditions. The role of palliative care in aged care was discussed. Leadership in the sector was seen to fall on a limited number in the sector, who needed to be involved in committees and administration as well as providing the clinical input.

Staff education: The lack of palliative care education at an undergraduate level was highlighted as a concern. Part of the issue for resources was access to trained palliative care staff in a climate of an ageing workforce. The need for a framework to help up-skill nursing staff was being undertaken at a state level with national standards in the pipeline.

V– Issues facing palliative care (Victorian focus):

Resources: The availability and allocation of resources for palliative care was seen as the most critical issue. Underlying the resource issue was the availability of a suitably trained workforce to deliver care, even if funding was available. In particular medical, nursing and social work staff was highlighted. Workforce access in the rural sector was seen as particularly challenging.

Inpatient beds: Access to inpatient palliative care beds was seen as critical and there was a common view that additional beds were required in the sector, including an improved funding model for the beds. The lack of access to beds often meant the most vulnerable patients ended up in Emergency Departments when there was a crisis. Waiting lists for beds were seen by some as 'closely guarded

secrets', where the priorities of the health service managing the beds took priority over the patient care needs. Transition from specialist palliative care beds to residential aged care was seen as an issue which took considerable time and caused distress to families.

Consultation service: The recent recruitment of consultation services in the acute hospitals was seen as a significant improvement to the referral and education process. The differing models [medical/nursing; nursing only] was seen as a challenge when it came to validating the effectiveness of the services. These services were having a real impact on how prepared patients were when coming to palliative care, which was seen as being best when undertaken as a transition process. Education of health professionals referring patients was seen as a critical component of this service. How, and when, to refer were important issues for patient acceptance of palliative care, which was seen to be best delivered if it could be done as a transition arrangement with the acute team available if needs arise.

Model of care: The variation in the models of care being delivered across services in Victoria was seen as a challenge, in that it was difficult to assess outcomes, to benchmark between services and to be able to argue for additional resources based on validated needs. There were views that some of the current models of care were not best set to deliver seamless care from a client's perception.

VI – Expectations of the new satisfaction instrument:

Focus and language of survey

The language to be used was considered important with a balance between using too many euphemisms and being too confronting. The ability to differentiate between palliative care patients with a cancer diagnosis and those with other conditions was seen as important. There was some concern that a new survey would be too generic, too hospital focused and be designed and delivered in a way that would upset clients and carers.

Delivery of survey: Client and carer: There were differing views as to whether clients and carers would have the time, energy and ability to complete the survey. Alternative views were that they are at an important stage in their lives and most would be keen to participate and pleased to have their views sought. There was a majority view that, given the age and ethnicity of most of the clients, an online approach would not work. The preferred model of delivery was face-to-face interviews, followed by paper surveys being handed out by those providing care. There was a minority view that patients would be worried that if they said anything negative they would be denied the care they needed. It was felt a posted survey or cards with a number to call would not be as satisfactory. The bias in who responds was highlighted, with issues of language and cultural diversity being a challenge.

Delivery of survey: Service providers

Bank of questions: The approach of having a bank of questions able to focus on the relevant issues for clients and carers at various stages in the continuum of care [acute referral process, community, inpatient care and bereavement] was seen as important.

Longitudinal delivery: It was suggested that consideration should be given to delivering surveys in a longitudinal way to follow clients and carers from referral to end of life and carers after the death of the client. This could be considered for a subset of those surveyed or offered to all participants. Alternatively, surveys could be given to clients and carers on admission to the service and they could be asked to complete the survey at another stage during the continuum of care. Follow up surveys

could be sent to carers. The option of obtaining additional copies if clients and carers wanted to fill it out more than once, or if additional family members wanted to be involved, was suggested.

Benchmarking: Service providers were keen that the survey was undertaken state wide so there was an ability to benchmark with other services and to compare services that did particularly well in a dimension with the model of care they were using. A more qualitative and theme-based approach was needed to allow this to happen. Currently services felt it was difficult to benchmark with the information they had received in the past

Accreditation: The survey needed to meet the Australian Council for Healthcare Standards [ACHS] standards under EQuIP4 so there was no need to undertake additional surveys.

Qualitative information: The survey should have space for qualitative information, as well as the option to be contacted to provide further information and input either via a one-to-one or in a focus group. It was noted that given the information provided on the previous survey those reviewing the results of individual surveys had been able to identify clients in some cases.

Section E: Pilot survey development

Interview data

Interview data were collated and summary documents compiled by the interviewers. These summary documents were reviewed for common themes. Some issues were common to both clients and carers, some were important for carers only. Four key themes common to all were extracted.

1. **Referral**
   - Timing of referral.
   - How palliative care is introduced.
   - Information provided.
2. **Access to services, and awareness of what is available**
   - Access to palliative care.
   - Available services.
3. **Palliative care support and services provided**
   - What palliative care services are available?
   - Who has access?
     - Are services in regional areas sufficient?
   - How is palliative care integrated with other acute services?
   - Is there sufficient family involvement in decision-making processes?
   - Communication and continuity of care:
     - Retelling the same story is annoying.
     - Knowing what to expect is important.
     - Movement between facilities – does it occur easily?
     - Transition, and continuity of care, between home-based and health-service based care is important and often where problems occur.
   - Psychological support.
     - Acceptance of, and preparing for, end of life – is there adequate support?
     - People to talk to.
     - Being treated as a person, not just a symptom or disease.
   - After-hours support:
     - Access to staff (nurses and doctors particularly) after hours.
   - Cultural issues:
     - Availability of interpreter.
     - Respect and provision for cultural needs.

4. **Staff**
   - Staff with adequate training are vital.
   - 'People skills' are very important.

Four key issues specific to carers were also identified.

1. **Knowledge and family involvement**
   - Is enough information provided to make informed choices?
   - Are respite services accessible?
   - Are family members sufficiently informed and involved in the client's care?
2. **Carer needs**
   - Finding a balance between taking care of themselves and taking care of the client is important, but often difficult.
   - Are carers provided with enough physical and psychological support to care for the client as well as caring for themselves?
3. **Emergencies**
   - Access to GPs after hours (to avoid emergency waiting rooms) can be difficult.
   - Is there sufficient information given about after-hours support?
4. **General support**
   - Financial assistance.
   - Know where to get info about care-related issues (for example, legal documents, government departments).
   - Many thought more training in care-related activities (for example, personal care, administering medications) was needed.

Items for the question bank were developed based on these themes. It was assumed that a large number of questions would be excluded during analyses, thus a broad range of questions were developed that qualitatively seemed to tap every important dimension. Overlap of themes, and high inter-item correlations, were expected from the outset.

Question bank items appear in Appendix C.

Existing questions

Questions from existing satisfaction instruments examined in the literature review were assessed for their potential to be included in the new instrument. The relevance of these items was considered based on the key themes identified in the interview data. Three surveys contained questions that were included.

Patient Outcome Scale (POS)

Three questions were adapted for inclusion. Questions were not able to be used in their original format as the preceding text of each question (Over the past three days…) was deemed to set too narrow a context to adequately capture the experiences of palliative care recipients.

1. How much information have you and your family or friends been given?
2. Have any practical matters resulting from your illness, either financial or personal, been addressed?
3. How did you complete this questionnaire (on my own, with help from family/friends, with help from staff)?

FAMCARE Scale

Of the 20 FAMCARE items, 14 were adapted for inclusion. The original five-point satisfaction scale was retained (one=very dissatisfied to five=very satisfied), and some items were included with minimal or no changes. Some items were, however, reworded to ensure consistent use of tense (for example, speed with which symptoms are treated was reworded to speed with which symptoms have been treated). Question bank items, including question origin, are shown in Appendix C.

FAMCARE items included in the question bank were:

1. The patient's pain relief.
2. Information provided about the patient's prognosis.
3. Answers from health professionals.
4. Information given about side effects.
5. Availability of a hospital bed.
6. Family conferences held to discuss the patient's illness.
7. Speed with which symptoms are treated.
8. Availability of doctors to the family.
9. Availability of nurses to the family.
10. Coordination of care.
11. The way the family is included in treatment and care decisions.
12. Information given about how to manage the patient's pain.
13. How thoroughly the doctor assesses the patient's symptoms.
14. Availability of the doctor to the patient.

Victorian Patient Satisfaction Monitor (VPSM)

Some items relating to staff and health services were drawn from the VPSM. The five-point response scale used in the VPSM (one=poor to five=excellent) was replaced with a five-point satisfaction scale (one=very dissatisfied to five=very satisfied) to maintain consistency of response scales across the questionnaire.

Items derived from the VPSM were:

1. The cleanliness of the room where you spent the most time.
2. The cleanliness of the toilets and showers.
3. The quality of the food overall.
4. The restfulness of the hospital (amount of peace and quiet).

5. The privacy of the room where you spent the most time.
6. The way the hospital routines and procedures (such as meal times, visiting hours, doctors' visits) were explained to you.
7. How well your cultural or religious needs were respected by the hospital.

Development of client and carer pilot surveys

It was envisaged that a set of core items, applicable to all respondents, would be supplemented by additional questions that were specific to particular sub-populations of palliative care recipients. This conceptualisation, illustrated in Figure 1, formed the basis of survey development.

Figure 1: Illustration of client and carer survey development, with a core set of items plus two additional modules.

	Client	Carer
Community	Core questions	Additional carer module questions
Health service	Additional health service module questions	Additional carer module questions plus health service module questions

Newly-developed items and those adapted from existing instruments were compiled into a question bank (Appendix C). Items identified as relevant to both clients and carers were flagged as 'core', while items specific to carers or to individuals receiving care in health services were aggregated into modules. There were 155 items in total; 84 core items, 12 demographic, 19 in the health services module, and 40 in the carer module.

Four different survey types were constructed:

- Clients in the community (the 'base model'; every question included in other versions).
- Clients in health services.
- Carers of clients in the community.
- Carers of clients in health services.

The shortest survey was *Clients in the community* with 96 items (core + demographic), while the longest was *Carers of clients in health services* with 153 items (core + demographics + health services module + carer module).[1]

Two versions of each survey type were created, with questions presented in quasi-randomised order to counter potential order effect of question presentation. Therefore, there were a total of eight different pilot survey instruments (two clients in the community; two clients in health services; two carers of clients in the community; two carers of clients in health services). These instruments appear in Appendix D.

1. Two items in the health services module were not relevant to carers of clients in health services: *How satisfied have you been with assistance in arranging matters related to client care, such as* (1) *medications for the client not on the PBS (in other words, not subsidised by the government)*, and (2) *treatments for the client not covered by Medicare*. These services are provided to clients residing in health services, and were thus excluded from the *Carers of Clients* in Health Services questionnaire.

The initial bank of questions was compiled in Word format and was reviewed by a number of professional reviewers:

- Dr Tracey Dagger, University of Queensland (acknowledged expert in patient satisfaction and survey construction, particularly in relation to oncology patients).
- Members of the Palliative Care reference group, including:
    - Kevin Larkins, CEO of Palliative Care Victoria.
    - Sue Salau, Policy Officer, Palliative Care Victoria.
    - Kirsten Campbell and Dr Darren Harris, Department of Human Services.
- Peter Hudson, Director, Centre for Palliative Care Education & Research, St Vincent's Hospital and Melbourne University.

Feedback was collated and items amended, added or removed accordingly. Revised versions of the questionnaires were sent to the Department of Human Services for approval.

The final versions of each pilot survey included a version number in the bottom corner; codes to identify respondents or their palliative care service were not included to ensure anonymity of respondents.

Section F: Quantitative data

During the week commencing 19 May 2008, a total of 881 surveys were sent to three Palliative Care services for distribution to clients and carers; 49 per cent (n=433) client surveys, 51 per cent (n=448) carer surveys. The three palliative care services were:

- Eastern Palliative Care
  - 313 client surveys
  - 317 carer surveys
- Melbourne Citymission
  - 106 client surveys
  - 106 carer surveys
- Wimmera Hospice Care
  - 14 client surveys
  - 25 carer surveys

The total number of surveys distributed was fewer than originally planned. This was largely due to decreases in potential respondent numbers following client death.

A cover letter introducing the project was sent with each survey (Appendix E); the letter was printed on palliative care service letterhead and signed by Jackie Kearney, Manager of Palliative Care, the Department of Human Services. A generic reminder/thank you letter (Appendix F) was sent to each respondent approximately one week after survey distribution.

A total of 257 questionnaires (117 client, 140 carer) were returned by Friday 4 July 2008, with an overall response rate of 29 per cent. There was a slight difference in response rates for client and carer surveys (27 per cent and 31 per cent respectively).[2]

Responses from returned surveys were entered manually into Excel; data from each survey type and version were collated. Analyses were conducted using SPSS v14.01.

Data analysis – Core items

Of the 84 core items, one open-text and three categorical items were excluded from factor analyses due to an inappropriate variable type. Initial factor analyses thus contained 80 scale variables (79 items plus one item assessing overall satisfaction with palliative care). There was some slight difference in wording for some questions (for example ‘you’ versus ‘the client’), but for the purposes of analysis these items were treated as the same.

Descriptive statistics were determined for the 80 scale variables (Appendix G). A large proportion of data were missing, with some seemingly not missing at random; for example, some items, such as the availability of an interpreter, were deemed *not applicable* by the vast majority of respondents (Appendix G shows the number of respondents deeming each question *not applicable*). This rendered some questions fundamentally ineligible for further analyses.

2. Response rates for each palliative care service could not be calculated as codes identifying each service were not included on the questionnaires.

Missing data and consequent ineligibility of some items for further analysis does not mean the questions themselves were necessarily of no value. Such items may be of great value for subsamples, or specifically targeted populations. Given the goal of the current project was to produce a general satisfaction instrument, the loss of these items was not considered to be problematic.

Data were then checked for quality. Screening for outliers, normality, linearity, homoscedasticity, and multicollinearity/singularity was also undertaken.

Outliers

Data were inspected for univariate outliers (using Z scores), and for multivariate outliers (using Mahalanobis distance with $p < .001$). No outliers were detected.

Normality

All core variables were negatively skewed; five variables showed kurtosis values below zero with 75 variables showing kurtosis values above zero, violating the assumption of normality. Transformation was not undertaken as variables measuring psychological phenomena are typically not transformed as this can blur interpretation compared with variables such as time or physiological readings that are more commonly transformed. When the assumption of normality is violated, a factor analyses or principal components solution may be degraded but still viable (Tabachnick & Fidell, 2007).

Linearity

Skewness values indicated increased likelihood of some pairs of variables having curvilinear relationships. However the large number of variables included the analyses made inspection of all possible variable pair scatterplots impractical; following Tabachnick and Fidell (2007), spot-checks of variable pairs likely to hold curvilinear relationships were performed and there appeared to be no evidence of curvilinear relationships that would undermine the final solution.

Homoscedasticity

Due to the strong negative skewness of all variables, the assumption of homoscedasticity was also likely violated. However, Tabachnick and Fidell (2007) argue that violation of the assumption of homoscedasticity does not result in an invalid solution, but may weaken the solution. Compensatory measures were applied (see the Factor analysis section).

Multicollinearity

A number of strong and significant correlations were detected between items in the initial batch of 80. Due to the relatively small sample size and large proportion of missing data, multicollinear items were included in factor analyses.

The final solution was screened again for multicollinearity. Two pairs of highly correlated items were detected in two factors: (1) Factor 'Referral: Staff', item *Referral staff treated me (the client) like an individual and not just a number* and item *Referral staff had my (the client's) best interests at heart* ($r = .836$, $p<.001$); and (2) Factor 'Symptom management', item *Pain* and item *Fatigue* ($r = .771$, $p < .001$). Further inspection revealed strong and significant correlations between all items within these two factors. It was determined that the highly correlated items would be retained for clinical reasons.

Factor analyses

The intention was to reduce the item set to an optimal mix of around 25 to 30 items. This was considered to be enough items to achieve baseline validity for satisfaction purposes, but still manageable from a respondent demand perspective.

The initial list of 80 items was considered for factor analysis. It is generally recommended that a sample of at least 300 cases is desirable for factor analyses, with a sample of 200 considered 'fair' (Tabachnick & Fidell, 2007). These criteria were used in exclusion of the first set of items; those with n<100 were excluded (nine items).

To examine the suitability of the remaining data set for factor analysis (71 items), anti-image correlations between items were determined in order to inspect Measures of Sampling Adequacy (MSA) values (Kaiser & Rice, 1974). An error was returned,[3] indicating insufficient sample size for some items that prevented extraction of the anti-image correlation matrix (and thus unsuitability of the data set for factor analysis). Items with the lowest n were removed one at a time, and anti-image correlations re-run. Following removal of all items with n<200 (22 items in total), the error was still returned.

In order to determine which items to remove next, Pearson's correlation coefficients were determined for the remaining 58 items (Appendix H). Items that showed the weakest correlation with *overall satisfaction with palliative care* were removed, one at a time, until the anti-image correlation matrix was successfully extracted. A total of 55 items remained, including *overall satisfaction with palliative care*. The overall satisfaction item was then omitted from further analyses on the basis that it would automatically be included in the final survey regardless.

Principal components analysis was run on the remaining 54 items. The overall MSA value was 0.499, indicating the dataset was not suitable for factor analysis and further items should be removed. A seven-factor solution, accounting for 83.3 per cent of the variance, was determined but was based on n=62 (this reinforced the problematic nature of large portions of missing data).

Items were added and removed, one at a time, in an iterative manner. Criteria for exclusion were low factor loadings and/or low corrected-item total correlations; a minimum four items loading on each factor was also desirable. A further 18 items were removed.

One final item was additionally flagged for exclusion due to question re-wording. This item appeared in the initial question bank as *How satisfied have you been with the skills and attributes of health professionals involved in your [the client's] care, such as the communication skills of other staff, social workers, physiotherapists, or occupational therapists?* Upon further consideration, it was deemed that the latter section of this item would be more appropriately worded …*communication skills of other staff, such as counsellors*. As this re-wording was considered after the data collection period, there were no data available to determine the statistical suitability of the revised item. It was thus excluded from further factor analyses and included as a supporting item.

The remaining 35 items were entered into a principal components analysis (with varimax rotation) and an initial seven-factor solution extracted (Figure 2). The number of factors was confirmed by a MAP test (Velicer, 1976). The overall MSA value was 0.891, with all MSA values above 0.8, indicating the dataset was suitable for factor analysis. This seven-factor solution accounted for 85.3 per cent of the variance and revealed clean factors, yet was based on a relatively small portion of the data (n=79).

3. Error returned: *This matrix is not a positive definite.*

Solutions using other extraction methods (Principal Axis Factoring and Unweighted Least Squares) with varimax rotation yielded similar solutions, accounting for 82.1 per cent of the variance. Reliability of factors was excellent, with Factor five showing Cronbach's alpha of 0.846 and all other factors with Cronbach's alpha 0.9 or above (Appendix I).

Figure 2: Initial seven-factor solution showing factor loadings of each item.

	1	2	3	4	5	6	7
Referral staff respected my feelings and opinions	0.867						
Referral staff treated me like an individual and not just a number	0.842						
Referral staff showed sensitivity about my readiness to accept palliative care	0.822						
Referral staff were helpful in answering questions	0.790						
Referral staff could see things from my point of view	0.779						
Referral staff had my best interests at heart	0.755						
When referred, satisfaction with how clearly and simply palliative care was explained		0.909					
When referred, satisfaction with the opportunity to ask questions about the range of available palliative care services		0.886					
When referred, satisfaction with the opportunity to ask questions about care options (e.g. in-hospital versus in-home care)		0.881					
When referred, satisfaction with support provided to help you come to terms with the idea of receiving palliative care		0.852					
When referred, satisfaction with information explaining care options (e.g. in-hospital versus in-home care)		0.647					
Satisfaction with communication skills of nurses			0.828				
Satisfaction with professionalism of nurses			0.753				

	1	2	3	4	5	6	7
Satisfaction with accessibility of nurses			0.729				
Satisfaction with communication between staff			0.708				
Satisfaction with level of expertise of care staff			0.688				
Satisfaction with cooperation (teamwork) of care staff			0.672		0.461		
Symptom management – fatigue				0.857			
Symptom management – eating or digestive problems				0.787			
Symptom management – pain				0.704			
Satisfaction with speed of symptom treatment				0.639	0.434		
Ease of access to palliative care					0.758		
Satisfaction with speed of service commencement					0.747		
Satisfaction with inclusion of friends or family care decisions			0.412		0.620		
Satisfaction with the availability of palliative care services					0.575		
Satisfaction with the ability of staff to communicate clearly					0.521		
Satisfaction with level of genuine concern shown						0.783	
Satisfaction with the level of emotional support provided						0.749	
Satisfaction with the level of respect shown						0.696	
Satisfaction with the expertise of staff generally				0.438		0.621	
Written information about palliative care was useful							0.774
Written information about palliative care was detailed enough							0.751
Written information about palliative care was clear and easy to understand							0.702

	1	2	3	4	5	6	7
Satisfaction with the information about prognosis							0.535
Satisfaction with information explaining integration of palliative care with existing care					0.415		0.446

With a sample of 200 considered 'fair' for factor analysis, further analyses were conducted to determine if a suitable solution – based on a larger proportion of the data – could be found. Tabachnick and Fidell (2007) suggest that if factors have at least two items with high factor loadings (above 0.8), a sample size of 50 or 100 may be adequate. With this in mind, items loading on factors that had the poorest overall factor loadings and lowest reliability (Cronbach's alpha) were removed and re-added in an iterative fashion and the principal components analysis re-run.

The final 21 item, four-factor solution was extracted using principal components analyses with varimax rotation, and accounted for 83.87 per cent of the variance (Figure 3). The number of factors was confirmed by a MAP test. This solution was based on n=113, and solutions utilising other extraction methods (Principal Axis Factoring, Maximum Likelihood and Unweighted Least Squares) with varimax rotation yielded similar solutions. Each factor had at least two items with factor loadings above 0.8, suggesting the four-factor solution to be statistically more robust than the seven-factor solution, based on the available sample size.

Figure 3: Final four-factor solution showing factor loadings of each item.

	1	2	3	4
Referral staff respected my feelings and opinions	0.996			
Referral staff treated me like an individual and not just a number	0.902			
Referral staff showed sensitivity about my readiness to accept palliative care	0.901			
Referral staff had my best interests at heart	0.867			
Referral staff could see things from my of view	0.836			
Referral staff were helpful in answering questions	0.822			
Satisfaction with communication skills of nurses		0.934		
Satisfaction with cooperation (teamwork) of care staff		0.896		
Satisfaction with level of expertise of care staff		0.889		
Satisfaction with communication between staff		0.882		
Satisfaction with accessibility of nurses		0.857		
Satisfaction with professionalism of nurses		0.793		
When referred, satisfaction with how clearly and simply palliative care was explained			0.982	
When referred, satisfaction with the opportunity to ask questions about the range of available palliative care services			0.967	

	1	2	3	4
When referred, satisfaction with the opportunity to ask questions about care options (e.g. in-hospital versus in-home care)			0.939	
When referred, satisfaction with support provided to help you come to terms with the idea of receiving palliative care			0.903	
When referred, satisfaction with information explaining care options (e.g. in-hospital versus in-home care)			0.707	
Symptom management - fatigue				0.994
Symptom management - eating or digestive problems				0.923
Symptom management - pain				0.892
Satisfaction with speed of symptom treatment				0.726

Data analysis – Module items

Analysis of module items was more difficult than core items due to a considerably smaller sample size. While preliminary analyses indicate which items could potentially be dropped from the final questionnaire, a larger sample size will provide a better indication of valuable items.

Items contributing to the two modules (carer module and health service module) were analysed separately. Descriptive statistics for items in each module were determined, as were Pearson's correlations between each item and *overall satisfaction with palliative care*. These appear in Tables 1 and 2.

Table 1: Carer module questions – descriptive statistics and correlation with overall satisfaction (Pearson's correlation co-efficient).

Carer module				
	N	Mean	Standard deviation	Correlation with overall satisfaction
Help with arranging: Transport to and/or from treatments	66	3.88	1.45	0.62**
Help with arranging: Special dietary requirements for the client	56	3.96	1.29	0.55**
Help with arranging: Treatments for the client not covered by Medicare	23	3.52	1.56	0.55**
Help with arranging: Medications for the client not on the PBS	35	3.89	1.41	0.52**
Help with arranging: Funeral arrangements	37	3.46	1.63	0.50**
Initial support: The sensitivity of staff about your readiness to start caring for the client	109	4.14	1.27	0.40**
General support: The level of access to psychological support services, such as a counsellor or psychologist, for you personally	78	3.76	1.33	0.40**

Carer module				
	N	Mean	Standard deviation	Correlation with overall satisfaction
General support: The level of training provided to enable you to carry out specific care functions, such as massaging, moving or bathing the client	68	3.56	1.63	0.39**
General support: The level of support you receive from the community	104	4.10	1.19	0.38**
Help with arranging: Medical power of attorney	42	3.62	1.65	0.37**
General support: The information provided to minimise your own physical burden	92	3.67	1.46	0.36**
General support: The efficiency of receiving urgent medical assistance from health professionals in general	119	4.27	1.04	0.36**
Initial support: The support provided to help you, as a carer, come to terms with the idea of the client receiving palliative care	116	3.97	1.34	0.35**
General support: The information provided to minimise your own psychological burden	100	3.62	1.44	0.34**
Help with arranging: Necessary equipment	94	4.38	1.07	0.33**
Help with arranging: Home alterations	60	3.90	1.27	0.33**
General support: The level of professional help you receive as a carer	120	4.26	1.15	0.33**
Initial support: The level of support in determining HOW BEST to place the client into a palliative care or aged care facility	67	3.96	1.27	0.32**
General support: The level of support you receive from medical professionals	123	4.22	1.12	0.30**
Initial support: The level of support in deciding to place the client into a palliative care or aged care facility	72	4.06	1.29	0.30**
Coping with: The financial burden of caring	107	3.93	1.19	0.30**
Initial support: The level of information you received about what would be involved in supporting a person living with a terminal illness	120	3.76	1.38	0.30**
General support: The level of respect you have been shown as a carer	126	4.45	1.04	0.30**
General support: The overall responsiveness of health professionals	120	4.31	0.98	0.29**
General support: The ease of receiving urgent medical assistance from health professionals in general	121	4.25	1.08	0.29**

Carer module				
	N	Mean	Standard deviation	Correlation with overall satisfaction
General support: The availability of medical professionals to answer questions	118	4.06	1.20	0.25**
General support: The level of concern for your own psychological wellbeing	103	3.95	1.28	0.23**
General support: The availability of medical professionals to provide information	118	4.08	1.19	0.22**
General support: The opportunities to talk to someone about your own situation as a carer	103	3.89	1.29	0.22**
Initial support: The level of professional support you received in making the decision to become a carer	105	3.72	1.44	0.21**
Items below have weak and/or non-significant correlations with overall satisfaction and are unlikely to be useful				
Help with arranging: Refusal of Medical Treatment certificate	33	3.36	1.67	0.32
Ongoing support: The level of psychological support provided to you personally	85	3.75	1.34	0.22
Help with arranging: Carer benefits from Centrelink	93	3.69	1.50	0.21
General support: The level of support you receive from the government	97	3.30	1.55	0.17
Coping with: The physical burden of being a carer, such as lifting, feeding, running errands	108	3.83	1.12	0.14
Coping with: The emotional burden of caring, such as putting on a brave face for the person whom you care for	122	3.53	1.25	0.13
General support: The level of support you receive from your family and friends	127	4.46	0.95	0.12
Coping with: Managing the stress associated with being a carer	124	3.66	1.18	0.10
To what extent do you feel a 'balance' between caring for the client and looking after yourself?	133	2.30	0.81	0.05
Coping with: Putting the client's needs ahead of your own	123	4.05	1.22	0.03

Table 2: Health service module questions – descriptive statistics and correlation with overall satisfaction (Pearson's correlation co-efficient).

Health service module				
	N	Mean	Standard deviation	Correlation with overall satisfaction
The explanation of routines (like meal times, visiting hours, etc)	34	4.41	1.02	0.62**
The activities provided to help you *[the client]* pass the time	25	3.84	1.43	0.47*
The attractiveness of the facility	36	4.44	1.05	0.43**
The quality of the food overall	33	3.79	1.39	0.42*
The general atmosphere of the facility	35	4.26	1.09	0.42*
The privacy of the room where you spend *[the client spends]* the most time	35	4.29	1.13	0.37*
The general level of comfort in the room where you spend *[the client spends]* the most time	35	4.29	1.05	0.36*
The amount of peace and quiet	34	3.91	1.29	0.34*
Items below have weak and/or non-significant correlations with overall satisfaction and are unlikely to be useful				
The level of socialisation you have *[the client has]* with other clients	25	3.92	1.19	0.36
The general attitude of staff toward clients	36	4.47	0.97	0.31
The amount of paperwork to be completed	39	4.26	1.04	0.27
The choice of facility	47	4.51	1.02	0.27
The cleanliness of the room where you spend *[the client spends]* the most time	36	4.50	1.03	0.22
How long you (the client) had to wait to be admitted to the facility	39	4.31	1.06	0.22
The cleanliness of the toilets and bathroom	36	4.42	1.02	0.22
How prepared in general the facility was to receive you *[the client]*	47	4.53	0.95	0.18
The time taken to get a bed	43	4.37	1.00	0.15

** Correlation is significant at the 0.01 level (two-tailed)

* Correlation is significant at the 0.05 level (two-tailed)

Of the 40 items in the carer module, 10 showed weak or non-significant correlations with overall satisfaction ($r \leq 0.32$, $p > 0.05$) and are flagged as potential items for exclusion. Analyses of items in the health service module is purely exploratory due to the very small sample size ($n=25$ to $n=52$). Of the 19 items included in this module, nine items showed weak and non-significant correlations with overall satisfaction ($r \leq 0.36$, $p > 0.05$) and may potentially be excluded.

One core item may additionally be included in the health service module. The question How satisfied have you been with the *communication skills of doctors* was excluded from factor analyses of core items due to lower correlation with overall satisfaction than other core items. Upon further consideration, it was, however, deemed that this item may be important in the specific context of health services and was therefore included in the health services module.

Section G:
Summary and conclusions

Scoring and interpreting the VPCSI

The VPCSI was developed with the intention that a means-based index (factor) scoring system be used. This system is widely used in instrument scoring across a range of disciplines and is familiar to users of the Victorian Patient Satisfaction Monitor (VPSM).

The scoring approach works as follows:

1. The scores of each item within a factor are summed.
2. A total score for the factor is derived.
3. Scores are pro-rated to a common denominator (for example, 100) to allow for inter-factor comparison.

This simple approach is very robust, can easily take into account missing data (for example, if not all questions within a factor are answered), and allows for more sophisticated analysis of data if required (for example, regression and ANOVA).

Individual item scoring

The five-point scoring scale used for all the core items in the VPCSI lends itself to means reporting. That is, the average score (between one and five) is reported as the result. It is also possible to present scores as percent based (for example "percent satisfied") by counting the proportion of respondents who endorsed a particular point or points on the scale, such as four and five. It is recommended that means reporting be used as the primary technique, as such an approach is both more precise and more likely to change to reflect interventions (for example, improvements in service quality).

Example of reporting

The follow table illustrates how the factor results might be displayed. Colouring of scores can be used to represent significant differences between scores, so in the example below the Referral: Staff factor current score is significantly higher than it was on the previous survey, and also significantly higher than the current state average.

Factor score (20-100 scale)	Your current score	Your previous score	Current state average
Care staff	81	81	82
Referral: Staff	**83**	77	80
Referral: Explanation	84	84	86
Symptom management	76	80	82
Overall satisfaction	81	83	83

Use and implementation of the VPCSI

The VPCSI is intended to be used in a similar manner to other satisfaction instruments, such as the Victorian Patient Satisfaction Monitor (VPSM). However, some key points should be noted. The VPCSI is a new instrument so benchmark and normative data are not available, which is true of any newly-developed test. The implications of this will need to be explained to some users. These key implications are:

- There will be no historic data, so users will be unable to directly compare previous satisfaction data with VPCSI findings at the first usage.
- Normative data (for example. age or diagnosis-specific benchmarks) may not be available until the instrument has been used often enough to capture enough data for specific groups.

These issues will disappear once the VPCSI is in common usage.

The instrument itself is designed with a hard-copy data collection process in mind. This is consistent with the current needs and capabilities of the target population. However, alternative data collection methods were also considered in the survey construction, and the instrument is well suited to both phone interview and online methods. Online methods are likely to be an increasingly preferred option over time.

The VPCSI is a tailored solution to a specific population, but the needs of that population should always be kept in mind when using the instrument. While the final instrument (Central Core + Secondary) is 36 items, the supporting questions can increase the length of the survey. The survey is still short by most standards, but the target population may need some patience and understanding from survey administrators during data collection.

Cohort (longitudinal) data collection

There is scope for intervention and service quality improvement with the VPCSI. For example, there is the possibility that those in early stage palliative care have differing satisfaction needs and issues compared to those experiencing end-stage palliative care. Comparing the two different groups will be straightforward if the supporting item *How long have you (has the client) been receiving palliative care?* is presented and used to segment data.

Best practice

Continued use of the instrument will allow for the collection of benchmark data for subgroups, confirmation of core components, and other psychometric consolidation measures. Additionally, administration of the instrument can be relatively proactive (rather than reactive); clients can be provided with the survey to complete as part of a ‘start of care’ package, and can be asked to complete it at a time that suits them. This will potentially minimise sampling complications and lead to increases in data capture rates.

While the advantage of having an ‘opt-in’ sampling frame is that clients and carers are free to complete the survey at time that suits, there is a real risk that the information provided back to services would be biased. The bias arises from the clients and carers potentially being able to submit multiple survey instruments when they are either feeling very satisfied, or highly dissatisfied. In addition, the distribution of instruments at predetermined events in a palliative care episode may be difficult in that not all episodes of palliative care are likely to have events other than episode start and end.

An ‘opt-out’ sampling of the palliative care client and carer population would see regular surveying of the population, with every person having the same chance of receiving an instrument to complete. The client or carer could then decide if they wanted to complete the instrument but they would only be able to submit feedback once. This sampling may provide the palliative care service with a more representative cross section of views about the domains explored in the instrument’s factors.

Driving quality improvement

With the VPCSI being designed to be usable across multiple modalities (in other words, hard copy, phone, and online), there is scope for using the data for quality improvement purposes, especially via online reporting to services. Palliative care services would have the capability to track their own performance and detect notable trends or issues with minimal delay. This style of feedback process helps to facilitate continuous improvement.

Summary and conclusion

The development of the VPCSI represents an important landmark for the measurement of palliative care satisfaction in Victoria. The instrument is the result of a wide-ranging and thorough consultation process, a robust testing and piloting process and appropriate statistical and psychometric analyses. The end result is a tool that will allow for reliable and accurate measurement of the key components that are integral to satisfaction of those receiving palliative care, and those who assist in providing that care.

Section H: References

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