

Measurement Matters

Measuring experiences of palliative and end-of-life care

Creating patient and carer question sets

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The conclusions in this report are those of BHI and no official endorsement by the NSW Minister for Health, the NSW Ministry of Health or any other NSW public health organisation is intended or should be inferred.

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Summary

This report outlines the development of tailored question sets for palliative care patients and carers about their experiences of care. The question sets will support the collection of information about these patients' and carers' experiences with NSW healthcare services, which can be used to drive improvements.

The development of these question sets is the result of extensive research and consultation, including a literature review, a review of relevant NSW policy, focus groups with patients and carers, consultation with palliative care professionals, and cognitive testing with patients and carers. Through rigorous prioritisation and selection, core question sets were created. Inevitably, these processes of prioritisation and selection, and the sensitivities around conducting surveys in the context of palliative care, mean that the question sets are necessarily short and not all important issues can be covered.

The process has also been informed by the specialist expertise in palliative care of Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) at the University of Technology Sydney and the specialist expertise in measuring patient experience of the Bureau of Health Information (BHI).

The resultant question sets include:

- questions designed to be asked of patients about their own experience; of carers answering on behalf of a patient; and of carers about their own experience
- questions tailored, where appropriate, about experience in inpatient or community settings
- questions about care currently being received, and about experiences of care over the recent past (including how well care, for example from different providers or in different settings, has been coordinated)
- questions about patient characteristics, which are essential to inform analysis and interpretation of results (such as age and language spoken at home) – where this information is not available from local or central information systems.

The results of this work are presented in question sets, not full questionnaires. This is because finalised questionnaires can only be produced in the context of a specific survey approach, after clearly identifying a cohort of patients and/or carers and defining an analytics plan. These steps should determine the use of specific questions, allowing for some degree of flexibility in question selection and minor adaptations of wording.

Background

In 2020–21, BHI was funded by the NSW Ministry of Health, through the Health and Social Policy Branch, to develop and test approaches to measuring experiences of palliative care and healthcare at the end of life. This work was intended to address identified gaps in experience data, and to enhance the understanding of service provision and whether this has met patients' needs, from the perspective of carers and palliative patients.

This project was initiated in response to gaps identified by NSW Health in systematically collected patient and carer experience data to support the monitoring and evaluation of the NSW Health End of Life and Palliative Care Framework 2019–2024. Within NSW Health services, 'end of life care' refers to all the care that a person receives during the phase of life when they are likely to pass away within the next 12 months due to progressive, advanced or incurable conditions or old age. Palliative care is an approach to providing the best possible care for an individual as they near end of life, and to ensure their family and carers are well supported throughout that stage and beyond.

BHI is the statutory agency responsible for reporting on the performance of the NSW public health system. The agency develops reports and tools to enable analysis of the performance of health services, clinical units and clinical teams across the NSW public health system, and undertakes and commissions research to support the performance of these functions. It also manages the NSW Patient Survey Program on behalf of NSW Health. Every year, this statewide program gives thousands of patients the opportunity to provide feedback about their experiences of care in the healthcare system and subsequent outcomes, using evidence-based, validated survey instruments.

Development process

In developing a new questionnaire, BHI follows a rigorous process to ensure evidence-based and high-quality outcomes. Elements of this process may be adapted depending on whether the survey is new or established, the complexity or sensitivity of the survey topic, and the guidance and advice provided by key stakeholders.

Questionnaire development is guided by the following principles:

- a rigorous and systematic approach to questionnaire development considered best practice by Australian and international jurisdictions
- engagement with patients and stakeholders throughout the development process to ensure the survey measures what matters to those receiving and providing care
- development of questions that are actionable, unambiguous, unbiased and accurately reflect the quality of care
- cognitive testing of the questionnaire in partnership with people who have the lived experience appropriate for the survey topic.

This approach was applied to the development of the tailored question set/s for palliative care patients and carers.

The development process followed the following key steps:

1. Literature and policy review
2. Focus groups with patients and carers
3. Stakeholder consultation (clinical and managerial stakeholders)
4. Cognitive testing interviews with patients and carers.

BHI commissioned IMPACCT at the University of Technology Sydney to assist with several key steps of the development process, including the literature review, focus groups and cognitive testing of survey materials with patients and carers. All relevant ethics approvals for this work, as required by the university, were sought and obtained. Detailed reports from IMPACCT on each stage of the development process are available on request.

Literature review

IMPACCT undertook a review of the evidence in relation to patient- and carer-identified domains of importance for palliative care and potentially relevant questions for consideration in developing the question sets. This review aimed to:

- identify key domains of palliative and end-of-life care experience that matter to patients and/or carers in hospital and community settings
- match existing questions used internationally against these domains
- form the foundation of the survey tools and framework for analysis in the patient and carer consultation phases (focus groups and cognitive testing interviews).

The first search focused on identifying areas patients and carers determined to be most important for palliative care provision within hospital or community settings. Sixty-six studies were included in the review, of which 33 focused on surveys in hospital settings and 33 focused on surveys in community settings.

The second search focused on identifying existing questionnaires that measure experiences of care for patients with palliative care needs or their carers. The literature search identified 834 citations, of which 46 were selected after a multi-stage screening process and the application of exclusion criteria. From these 46 surveys, 946 questions that addressed patient or carer experiences of care received were extracted.

Findings

The first search identified 17 key domains of importance to experiences of patients and carers in relation to palliative and end-of-life care (Table 1). Five of these key domains relate to person-centred care (e.g. respectful and compassionate care), six key domains relate to expert care (e.g. patient safety) and three relate to optimal environments for care (e.g. cleanliness to support infection control). These three categories reflect research findings previously published by IMPACCT. However, three additional key concepts were identified as a result of this search strategy, including the burden of care, cultural and spiritual needs, and financial affairs.

This first search confirmed that many of the areas of importance for optimal palliative care are common across settings of care and were important to both patients with palliative care needs as well as their carers. The exceptions were the maintenance of a patient's role and identity, which patients emphasised, while financial affairs were attributed greater importance by carers. Accordingly, it is important to have different questionnaires for each group, or to ask who is completing the questionnaire (i.e. patient on their own behalf, carer on behalf of patient, carer on their own behalf). This issue is addressed in the recommended question sets proposed for use within NSW Health.

The research concluded that patient and carer experience in the very final days of life should be considered out of the scope of this work. This is because, clearly, patients cannot be asked to complete surveys in those final days, and any survey would need to be addressed to bereaved carers. There are also processes of care and concerns for patients and carers in the final days of life that are distinct from those in the earlier stages of a palliative journey.

The second search identified 946 questions across 46 surveys for measuring experiences of care among patients with palliative care needs and/or their carers. More than half of questions (60%) were designed for use with carers, compared with 40% for patients. A small number of questions (n=6) were identified that assessed experiences for both patient and carers. The greater availability of experience questions for carers, compared with those designed for patients, most likely reflects established barriers to collecting self-reported experiences for patients who may have a heavy symptom burden, cognitive impairment and/or deteriorating consciousness (in the end stages of disease).

Survey questions were mapped against key domains of importance from the patient and carer perspective, for optimal palliative care provision (Table 1). More than half (59%) of questions assess more than one domain of importance. The distribution of questions across domains of importance was very uneven, ranging from 321 available questions for effective communication and shared decision-making down to two (n=2) for patient safety. This imbalance reflects the relative importance that survey authors place on the different key domains. It also reflects that some domains contain multiple similar questions. Finally, it is not unusual to use other sources of data to measure important topics such as patient safety.

Table 1 **Key domains of importance and number of relevant survey questions identified in the literature review**

Categories	Key domains of importance and number of questions
Person-centred care	1. Respectful and compassionate care (n=241) 2. Maintaining role, meaning and identity (n=54) 3. Effective communication and shared decision-making (n=321) 4. Enabling family involvement (n=162) 5. Effective teamwork and coordination (n=62)
Expert care	6. Excellence in physical care (n=95) 7. Patient safety (n=2) 8. Supported access to senior clinicians (n=37) 9. Technical competence (n=10) 10. Effective symptom management (n=81) 11. Impeccable assessment and care planning (n=157)
Optimal environment for care	12. Structural factors – patient focused (n=42) 13. Structural factors – family focused (n=15) 14. Cleanliness to support infection control (n=3)
New domains	15. Carer burden (n=6) 16. Cultural/spiritual needs (n=18) 17. Financial affairs (n=8)

NSW policy review

The NSW Health End of Life and Palliative Care Framework 2019–2024 was developed based on consultation, roundtables and a survey of 2,000 people. It identifies five priorities which provide important context for the development of the question sets:

1. **Care is person centred.** Care should be based on the unique needs and preferences of the individual as an equal partner in decisions relating to their care and treatment.
2. **There is recognition and support for families.** Families and carers make significant contributions to the end-of-life and palliative care system, as they provide physical, emotional, social and spiritual support and care for patients. Families and carers need to be involved in planning and providing care, and to have access to the services they need to carry out this role.
3. **Across all settings, there is access to care providers who are skilled and competent in end-of-life and palliative care.** While not all patients require specialist palliative care, it should be available when needed.
4. **Care is well coordinated and integrated.** People needing end-of-life and palliative care may receive care from multiple services across a number of settings. Care should be delivered in an integrated and well-coordinated manner with seamless transitions between services and settings.
5. **Access to quality care is equitable.** Access should be based on individual and clinical need regardless of background and personal circumstances. Some groups need greater support to access end-of-life and palliative care services; these include but are not limited to people from cultural and linguistically diverse backgrounds, Aboriginal people, people with disability or a mental health condition, and young adults.

While information derived from surveys of patients and carers is only one potential source of information for gauging progress against these health system priorities, surveys of experiences can offer information and actionable insights on priorities 1, 2 and 4, in particular. In relation to priority 5, it may be possible to compare experiences between population groups if enough people are surveyed.

NSW Health has also developed a framework to improve the human experience across the health system, focusing on both the patients and the health professionals and carers. Elevating the Human Experience: A Guide to Action was released in 2020 and places priority on:

1. Compassion, respect and kindness
2. Trust and confidence in care providers
3. Involvement in decision-making
4. Clear information and effective communication
5. Timely access to coordinated care and smooth transitions
6. Clean, safe, comfortable, culturally appropriate environments.

Focus groups

IMPACCT undertook a series of virtual focus groups in February and March 2021 with 21 patients and carers to identify topics that matter most to people with palliative care needs. Participants were recruited via organisations and groups including Healthcare Consumers NSW Palliative Care Network, Cancer Voices NSW, Palliative Care NSW and IMPACCT's own consumer advisory panel. The participants included 17 female and four male, with a similar number of people with experience of non-malignant and cancer/malignant illness. Two patients currently under the care of specialist palliative care services volunteered to participate. The focus groups aimed to:

- assess the face and content validity of survey questions for measuring the experiences of patients with palliative care needs and their carers
- explore the preferences of patients with palliative care needs and their carers regarding when and how they would like to be asked about their experiences of care.

The focus groups were conducted in the form of workshops – focusing on adults due to issues of consent and communication with children and their carers – who self-identified as having palliative care needs or as currently or previously caring for someone with these needs ('carer'). A mixed method approach was adopted, which included an online survey (quantitative) and virtual consumer workshops (qualitative).

For the purposes of the focus groups, the long list of questions identified through the literature review was refined by removing duplication, unduly complex questions (Flesch–Kincaid readability review), very generic questions, and those specifically designed for bereaved carers. Questions that used specific palliative and end-of-life care terminology were also removed. Participants were asked to complete a pre-workshop online survey in which they rated the importance and understandability of the remaining 246 survey questions previously identified as relevant to the 17 key domains.

After all workshops were completed, a post-workshop online survey was sent to all participants asking them to select their top five survey questions, from those that had been identified as 'very' important and easy to understand by more than half of participants attending each workshop.

Findings

The focus groups confirmed the relevance of the 17 key domains of importance identified in the literature review. They also added to a deeper understanding of other elements of care, which can be mapped against the domains as follows:

- a. Coordination/continuity/integration of healthcare, including the availability of a key contact/care coordinator/care navigator to enable access to support tailored to each patient or carers' unique needs (domain 5 in Table 1)
- b. Access to structured information, including patient/carer rights, hospital processes and financial supports (domain 3 in Table 1)
- c. Feeling fully involved in all decision-making (domain 3 in Table 1)
- d. 24-hour access to support for managing crises, often related to symptom distress or other stresses related to the complexity of living with palliative care needs (domain 8 in Table 1)
- e. The feeling of being heard and having your needs understood and promptly responded to by the healthcare team (domains 1 and 3 in Table 1)
- f. Timely access to personal care, delivered by consistent and regular health and social care workers, when living at home (domain 6 in Table 1)
- g. Having psychological and social needs assessed and valued (domain 11 in Table 1)
- h. Timely and responsive assessment and management of symptoms (domain 10 in Table 1)

- i. Safety, particularly with regard to medication management, feeling competent as a carer at home, and preventing falls (domain 7 in Table 1)
- j. Cleanliness of environment with a focus on infection control in patients who are immunocompromised and frail (domain 14 in Table 1)
- k. Clinical competence of the care team (domain 9 in Table 1).

Feedback from participants emphasised the complexity of survey design and administration in this population – given how unwell patients may be and how stressed carers may feel. It made clear the need for any questionnaire developed for this population to be brief, clear and easily understandable; provide a free-text option to provide additional information as required; be available in a variety of different formats to suit individual preferences (i.e. paper, online and face to face); and be worded flexibly enough to remain relevant to the differing needs of patients and carers living with varied complex illnesses and to appear non-judgemental.

Stakeholder consultation

Using the results from the focus groups, including the post-workshop survey results, BHI was able to create a short list of 71 survey questions of particular importance to patients and carers. BHI refined and reworded questions and, where possible, used relevant questions from existing surveys. This included using core questions from the NSW Patient Survey Program that had been previously extensively tested with patients, tailoring them where required for this patient/carer population.

Next, BHI undertook a round of consultation on the draft questions with a broad range of stakeholders including clinicians and other providers of palliative care services from across NSW Health, LHDs, pillar agencies, NSW Ambulance, local government and non-government agencies. Stakeholders were asked to review the questions to identify those which

would generate relevant and useful insights to inform improvements in palliative care across hospitals and health services, and any gaps or missing themes or questions that should be added.

Stakeholders were also asked to rank up to 10 questions they considered the ‘most important’, followed by a further 10 questions classified as the ‘next most important’. This way, each stakeholder could put forward up to 20 questions as candidates for inclusion in the final question set.

Feedback was received from 25 stakeholders in total, and included feedback on question prioritisation and free-text comments.

For NSW Health stakeholders, questions identified as ‘most important’ and ‘actionable’ included:

- a. Receiving information in an understandable way (domain 3 in Table 1)
- b. Receiving enough information about illness progression (domain 3 in Table 1)
- c. Health professionals discussing what is important to the patient in managing their care and treatment (domain 3 in Table 1)
- d. Patients being treated with respect and dignity (domain 1 in Table 1)
- e. Hospital staff respecting patients’ cultural and religious beliefs (domains 1 and 16 in Table 1)
- f. Symptom and pain management, including making patients comfortable (domain 10 in Table 1)
- g. Patients receiving care in their preferred location (domain 12 in Table 1)
- h. Adequate arrangements for any services needed at the patient’s preferred location of care (domains 12 and 13 in Table 1).

Cognitive testing

The next step was to use the findings from the literature review, focus groups and stakeholder engagement to further refine the question list and question wording so as to produce a manageable number of meaningful questions (with response options) that could be used for one-on-one cognitive testing in interviews with patients and carers.

BHI applied the following criteria required by BHI's questionnaire development procedure, in consultation with IMPACCT, to arrive at a set of 33 shortlisted questions:

- Patients must be able to describe their experience by choosing an answer from a number of response options.
- Questions should collect the experience and what occurred, rather than reporting satisfaction or collecting judgemental assessments.
- Validated questions should be used in preference to non-validated questions, especially if they address the same construct.
- Two questions should be used instead of a single, double-barrelled question.
- Balanced, rather than asymmetrical, response scales should be used for rating questions.
- Questions and instructions should be written in plain English (aiming for a reading age of 8–10 years).
- 'Don't know' and 'Not applicable' options should only be used where essential.
- Question wording should be clear, balanced and unbiased with leading questions avoided.

The question sets were formatted as lightly designed questionnaires to ensure feedback focused on the content rather than design.

BHI commissioned IMPACCT to undertake cognitive testing interviews with patients and carers. The interviews tested the extent to which the questions

were appropriate, easily understood and capable of accurately capturing the experience of palliative care. A total of 13 interviews (nine patients, four carers) were undertaken with selected adults who were receiving specialist palliative care as inpatients, outpatients or community patients at Calvary Health Care Sydney, and their carers. Interviews in the inpatient and outpatient settings were face to face, whereas those conducted with community participants were via telephone or videoconference. Of the patients, five were inpatients, one was an outpatient and three were community patients. Two of the carers were from the outpatient setting, one from the inpatient setting and one from the community.

IMPACCT gathered detailed feedback on participants' responses to each question including wording, perceived appropriateness and question value, and suggested modifications to the questions and response options. This included separating inpatient from community/outpatient questionnaires, reducing length by merging questions participants felt were repetitive, revising response options to provide respondents with a more direct 'yes/'no' response as opposed to an ordinal scale, and adopting a modular approach which would reduce questionnaire length and provide a way to tailor surveys to particular service areas of interest.

The interviews produced valuable insights which led to further refinements of the question sets to ease the burden on respondents and optimise the quality of data that could be collected in future.

Final question sets

The final question sets represent a synthesis of evidence from the literature, and directly from patients and carers, about what matters most to them about their experiences of palliative and end-of-life care. They also reflect the views of clinicians and providers of palliative care services in terms of key questions likely to generate relevant and useful insights to inform improvements in palliative care across hospitals and health services.

Inevitably, when compiling the final question sets presented here, careful decisions had to be made

about the questions to be included, while keeping them strictly limited in number. These decisions were informed by all the prior research and consultation.

The question sets are designed for four distinct potential survey cohorts: patients and carers during an encounter of care, and patients and carers across the journey of care (Figure 1). The identified core questions can be used in patient-reported information systems to collect point-of-care, rapid, reflective and population views about experiences of care.

Figure 1 Potential survey cohorts



These core question sets can be used to design questionnaires. When doing so, attention must be paid to the specific sampling and survey approach being taken to reach a clearly selected cohort of patients and/or carers, and a defined analytics plan must be in place. These steps should determine the use of specific questions, allowing for some flexibility in question selection and minor adaptations of wording.

The final question sets and development notes are summarised in Tables 2, 3 and 4.

Table 2 includes questions relevant to measuring current experiences in an inpatient or community setting from the perspective of the patient or carer.

Table 3 includes questions relevant to measuring experiences of an individual patient or their carer across time and, potentially, different healthcare providers.

Table 4 includes sociodemographic and health characteristics that were identified in literature and consultations as being important to measure to best enable analyses and interpretation of survey results.

In Tables 2, 3 and 4, each question has been cross-referenced to the evidence outlined in this report, namely:

- key domains of importance identified through literature review
- policy priorities drawn from the NSW Health End of Life and Palliative Care Framework 2019–2024 (EOL & PC Framework)
- policy priorities drawn from the NSW Health framework Elevating the Human Experience (EHE)
- findings from focus groups (patients and carers)
- findings from stakeholder consultation (providers).

This cross-referencing confirms that the question sets are strongly informed by these sources of evidence. Where specific issues are not covered, this is because the evidence from literature and consultation did not prioritise them above those that were included. In some cases, sources of information other than patient/carer experience surveys could be used to measure the issue.

For ease of reference, the Appendix lists the questions by cohort (patient or carer) and setting of care (hospital or community).

Table 2

Patient and carer experience questions regarding current care in community or inpatient healthcare

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Preamble: Thinking about experiences of current care in hospital/at home:					
Q1	Patient	Is the room or ward where you spend most of your time as comfortable as you would like? Yes No	Inpatient	Question, tested during cognitive testing interviews, derived from: Victorian healthcare experience survey (Your palliative care hospital experience)	Domains from the literature: 12 (Structural factors – patient focused) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 6 (Safe, comfortable environment)
	Carer	Is the room or ward where the patient spends most of their time as comfortable as they would like? Yes No		As above	As above
Q2	Both	Is the room or ward suitable for a family member or carer to stay? Yes No Not applicable	Inpatient	Question, tested during cognitive testing interviews, derived from: Satisfaction Scale for Family Members Receiving Inpatient Palliative Care (SFIPC)	Domains from the literature: 13 (Structural factors – family focused) Priorities in EOL & PC Framework: 2 (Recognition and support for families/carers) Priorities in EHE: 6 (Safe, comfortable environment)
Q3	Patient	How would you rate the food and drink you are offered in hospital? Very good Good Neither good nor poor Poor Very poor I haven't been offered any hospital food	Inpatient	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q4)	Domains from the literature: 6 (Excellence in physical care) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 6 (Safe, comfortable environment)
	Carer	How would you rate the food and drink offered to the patient in hospital? Very good Good Neither good nor poor Poor Very poor They weren't offered any hospital food		As above	As above

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Q4	Patient	Do you have enough time to discuss your health or medical problems with the health professionals? Yes always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q9)	Domains from the literature: 3 (Effective communication and shared decision-making) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 4 (Clear information and effective communication) Priorities from focus groups: e
	Carer	Do you have enough time to discuss the patient's health or medical problems with the health professionals? Yes always Yes, sometimes No			Domains from the literature: 3, 4 (Effective communication and shared decision making; Enabling family involvement) Priorities in EOL & PC Framework: 2 (Recognition and support for families/carers) Priorities in EHE: 4 (Clear information and effective communication) Priorities from focus groups: e
Q5	Both	Do the health professionals explain things in a way you can understand? Yes always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q5)	Domains from the literature: 3 (Effective communication and shared decision making) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 4 (Clear information and effective communication) Priorities for stakeholders: a
Q6	Patient	If your family or someone close to you needs to talk to a health professional, do they get the opportunity to do so? Yes always Yes, sometimes No Not applicable	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Emergency Department Patient Survey 2020–21 (Q12)	Domains from the literature: 4, 8 (Enabling family involvement; Supported access to senior clinicians) Priorities in EOL & PC Framework: 2 (Recognition and support for families/carers) Priorities in EHE: 4 (Clear information and effective communication)
Q7	Patient	Are you treated with respect and dignity? Yes, always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q24)	Domains from the literature: 1, 2 (Respectful and compassionate care; Maintaining role, meaning and identity) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 1 (Compassion, respect and kindness) Priorities for stakeholders: d
	Carer	Is the patient treated with respect and dignity? Yes, always Yes, sometimes No			As above

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Q8	Patient	Are your cultural, religious and/or spiritual beliefs respected by staff? Yes always Yes, sometimes No Not applicable	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q25)	Domains from the literature: 1, 16 (Respectful and compassionate care; Cultural/spiritual needs) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 1 (Compassion, respect and kindness) Priorities for stakeholders: e
	Carer	Are the patient's cultural, religious and/or spiritual beliefs respected by staff? Yes always Yes, sometimes No Not applicable			As above
Q9	Patient	Are you given enough privacy during your care and treatment? Yes always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q10)	Domains from the literature: 12, 1 (Structural factors – patient focused; Respectful and compassionate care) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 6, 1 (Safe, comfortable environment; Compassion, respect and kindness)
	Carer	Is the patient given enough privacy during their care and treatment? Yes always Yes, sometimes No			As above
Q10	Patient	Do you have confidence and trust in the health professionals treating you? Yes, always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q11)	Domains from the literature: 9 (Technical competence) Priorities in EOL & PC Framework: 3 (Access to skilled/competent care providers across all settings) Priorities in EHE: 2 (Trust and confidence) Priorities from focus groups: k
	Carer	Do you have confidence and trust in the health professionals treating the patient? Yes, always Yes, sometimes No			As above

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Q11	Patient	If you need help with personal care (e.g. eating and drinking, moving around, going to the bathroom), do staff help you within a reasonable time frame? Yes, always Yes, sometimes No Not applicable	Inpatient	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q26)	Domains from the literature: 6 (Excellence in physical care) Priorities in EOL & PC Framework: 1, 3 (Care is person centred; Access to skilled/competent care providers across all settings) Priorities in EHE: 5 (Timely and coordinated care)
	Carer	If the patient needs help with personal care (e.g. eating and drinking, moving around, going to the bathroom), do staff help within a reasonable time frame? Yes, always Yes, sometimes No Not applicable			
Q12	Patient	Are adequate arrangements made for any services or aids you need at your home or place of care (e.g. equipment, home care, community care, follow-up appointments)? Yes, always Yes, sometimes No	Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q39)	Domains from the literature: 5, 11 (Effective teamwork and coordination; Impeccable care assessment and planning) Priorities in EOL & PC Framework: 4 (Care is well coordinated and integrated) Priorities in EHE: 5 (Timely and coordinated care) Priorities from focus groups: f Priorities for stakeholders: h
	Carer	Are adequate arrangements made for any services or aids needed at the patient's home or place of care (e.g. equipment, home care, community care, follow-up appointments)? Yes, always Yes, sometimes No			
Q13	Patient	Do you think the health professionals do everything they can to help manage your pain? Yes, always Yes, sometimes No Not applicable	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q28)	Domains from the literature: 10, 1 (Effective symptom management; Respectful and compassionate care) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 1, 2 (Compassion, respect and kindness; Trust and confidence) Priorities from focus groups: h Priorities for stakeholders: f
	Carer	Do you think the health professionals do everything they can to help manage the patient's pain? Yes, always Yes, sometimes No Not applicable			

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Q14	Patient	Do you think the health professionals do everything they can to help manage other symptoms? Yes, always Yes, sometimes No Not applicable	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q28)	Domains from the literature: 10, 1 (Effective symptom management; Respectful and compassionate care) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 1, 2 (Compassion, respect and kindness; Trust and confidence) Priorities from focus groups: h Priorities for stakeholders: f
	Carer	Do you think the health professionals do everything they can to help manage other symptoms the patient may have? Yes, always Yes, sometimes No Not applicable			As above
Q15	Patient	Do the health professionals respond to your needs in the evenings and on weekends? Yes, always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: Victorian healthcare experience survey (Your in-home community palliative care experience)	Domains from the literature: 5, 8 (Effective teamwork and coordination; Supported access to senior clinicians) Priorities in EOL & PC Framework: 4 (Care is well coordinated and integrated) Priorities in EHE: 5 (Timely and coordinated care) Priorities from focus groups: d
	Carer	Do the health professionals respond to the patient's needs in the evenings and on weekends? Yes, always Yes, sometimes No			As above

Table 3 Patient and carer experience questions regarding experiences over time across NSW health services

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
		Preamble: Thinking about experiences of care over recent weeks...			
Q16	Patient	Do you feel your care has been well coordinated? Yes, always Yes, sometimes No	Inpatient/ Community	BHI Longstanding Health Condition Survey	Domains from the literature: 5, 11 (Effective teamwork and coordination: Impeccable assessment and care planning) Priorities in EOL & PC Framework: 4 (Care is well coordinated and integrated) Priorities in EHE: 5 (Timely and coordinated care) Priorities from focus groups: a
	Carer	Do you feel the patient's care has been well coordinated? Yes, always Yes, sometimes No		BHI Longstanding Health Condition Survey	As above
Q17	Patient	Have you been involved, as much as you wanted to be, in decisions about your care and treatment? Yes, always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q20)	Domains from the literature: 3, 2 (Effective communication and shared decision-making; Maintaining role, meaning and identity) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 3 (Involvement in decision-making) Priorities from focus groups: c Priorities for stakeholders: c
	Carer	Have you been involved, as much as you wanted to be, in decisions about the patient's care and treatment? Yes, always Yes, sometimes No		As above	Domains from the literature: 4 (Enabling family involvement) Priorities in EOL & PC Framework: 2 (Recognition and support for families/carers) Priorities in EHE: 3 (Involvement in decision-making) Priorities from focus groups: c Priorities for stakeholders: c
Q18	Patient	Have the health professionals given you the support you need to help with any worries or fears related to your care and treatment? Yes, always Yes, sometimes No I haven't had any worries or fears	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q19)	Domains from the literature: 1 (Respectful and compassionate care) Priorities in EOL & PC Framework: 1 (Care is person centred) Priorities in EHE: 1 (Compassion, respect and kindness) Priorities from focus groups: e, g
	Carer	Have the health professionals given you the support you need to help with any worries or fears related to the patient's care and treatment? Yes, always Yes, sometimes No I haven't had any worries or fears		As above	Domains from the literature: 1 (Respectful and compassionate care) Priorities in EOL & PC Framework: 2 (Recognition and support for families/carers) Priorities in EHE: 1 (Compassion, respect and kindness) Priorities from focus groups: e, g

Question #	Cohort	Question and response options	Care setting	Question source	Relevant domains of importance and priorities
Q19	Patient	Have health professionals given you the support you needed to be in the place of your preference? Yes, always Yes, sometimes No	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: Victorian healthcare experience survey (Your in-home community palliative care experience)	Domains from the literature: 3 (Effective communication and shared decision making) Priorities in EOL & PC Framework: 1, 3 (Care is person centred; Access to skilled/competent care providers across all settings) Priorities in EHE: 3, 6 (Involvement in decision-making; Safe, comfortable environment) Priorities for stakeholders: g.
	Carer	Have health professionals given the patient the support they needed to be in the place of their preference? Yes, always Yes, sometimes No			
Q20	Patient	What most needs improving about the care you have received? [FREETEXT]	Inpatient/ Community	Question, tested during cognitive testing interviews, derived from: BHI Adult Admitted Patient Survey 2021 (Q59)	
	Carer	What most needs improving about the care the patient has received? [FREETEXT]			

Table 4 Information required to inform interpretation and ensure results are actionable

The following questions should be included for all care settings if the information is not available from local or central information systems.

Question #	Question and response options	Comments
TBC	What year were you born? Write in (YYYY)	Priorities in EOL & PC Framework: 5 (Equitable access to care) It is important to be able analyse patient experience by age group.
TBC	How do you describe your gender? Please X <u>one</u> option Man or male Woman or female Non-binary Prefer to use a different term. Please specify. [Fretext box] Prefer not to answer	It is important to be able analyse patient experience by gender.
TBC	Which language do you mainly speak at home? English A language other than English What is that language? Please write below. [Fretext box]	Priorities in EOL & PC Framework: 5 (Equitable access to care) It is important to be able analyse patient experience by language spoken at home.
TBC	Are you of Aboriginal origin, Torres Strait Islander origin, or both? Yes, Aboriginal Yes, Torres Strait Islander Yes, both Aboriginal and Torres Strait Islander No	Priorities in EOL & PC Framework: 5 (Equitable access to care) It is important to be able analyse patient experience by Aboriginal or Torres Strait Islander origin.
TBC	Do you have any of the following longstanding conditions: Mental health condition (e.g. depression) A physical disability An intellectual disability	Priorities in EOL & PC Framework: 5 (Equitable access to care) This may be included if there is a clear intention to analyse results by condition and likely to be sufficient data.

Information to enable analysis of the following should be derived from local or central information systems in the process of sampling:

- location of care (hospital, community setting)
- severity of illness/palliative care phase
- diagnosis, especially cancer vs other conditions.

Appendix

Question sets by cohort and setting

Question set for a patient in hospital

Preamble: Thinking about experiences of current care in hospital...

1. Is the room or ward where you spend most of your time as comfortable as you would like?
2. Is the room or ward suitable for a family member or carer to stay?
3. How would you rate the food and drink you are offered in hospital?
4. Do you have enough time to discuss your health or medical problems with the health professionals?
5. Do the health professionals explain things in a way you can understand?
6. If your family or someone close to you needs to talk to a health professional, do they get the opportunity to do so?
7. Are you treated with respect and dignity?
8. Are your cultural, religious and/or spiritual beliefs respected by staff?
9. Are you given enough privacy during your care and treatment?
10. Do you have confidence and trust in the health professionals treating you?
11. If you need help with personal care (e.g. eating and drinking, moving around, going to the bathroom), do staff help you within a reasonable time frame?
12. Do you think the health professionals do everything they can to help manage your pain?
13. Do you think the health professionals do everything they can to help manage other symptoms?
14. Do the health professionals respond to your needs in the evenings and on weekends?

Thinking about experiences of care over recent weeks...

15. Do you feel your care has been well coordinated?
16. Have you been involved, as much as you wanted to be, in decisions about your care and treatment?
17. Have the health professionals given you the support you need to help with any worries or fears related to your care and treatment?
18. Have health professionals given you the support you needed to be in the place of your preference?
19. What most needs improving about the care you have received?

Question set for a carer of a patient in hospital

Preamble: Thinking about experiences of current care in hospital...

1. Is the room or ward where the patient spends most of their time as comfortable as they would like?
2. Is the room or ward suitable for a family member or carer to stay?
3. How would you rate the food and drink offered to the patient in hospital?
4. Do you have enough time to discuss the patient's health or medical problems with the health professionals?
5. Do the health professionals explain things in a way you can understand?
6. Is the patient treated with respect and dignity?
7. Are the patient's cultural, religious and/or spiritual beliefs respected by staff?
8. Is the patient given enough privacy during their care and treatment?
9. Do you have confidence and trust in the health professionals treating the patient?
10. If the patient needs help with personal care (e.g. eating and drinking, moving around, going to the bathroom), do staff help within a reasonable time frame?
11. Do you think the health professionals do everything they can to help manage the patient's pain?
12. Do you think the health professionals do everything they can to help manage other symptoms the patient may have?
13. Do the health professionals respond to the patient's needs in the evenings and on weekends?

Thinking about experiences of care over recent weeks...

14. Do you feel the patient's care has been well-coordinated?
15. Have you been involved, as much as you wanted to be, in decisions about the patient's care and treatment?
16. Have the health professionals given you the support you need to help with any worries or fears related to the patient's care and treatment?
17. Have health professionals given the patient the support they needed to be in the place of their preference?
18. What most needs improving about the care the patient has received?

Question set for a patient in a community setting

Preamble: Thinking about experiences of current care in hospital...

1. Do you have enough time to discuss your health or medical problems with the health professionals?
2. Do the health professionals explain things in a way you can understand?
3. If your family or someone close to you needs to talk to a health professional, do they get the opportunity to do so?
4. Are you treated with respect and dignity?
5. Are your cultural, religious and/or spiritual beliefs respected by staff?
6. Are you given enough privacy during your care and treatment?
7. Do you have confidence and trust in the health professionals treating you?
8. Are adequate arrangements made for any services or aids you need at your home or place of care (e.g. equipment, home care, community care, follow-up appointments)?
9. Do you think the health professionals do everything they can to help manage your pain?
10. Do you think the health professionals do everything they can to help manage other symptoms?
11. Do the health professionals respond to your needs in the evenings and on weekends?

Thinking about experiences of care over recent weeks...

12. Do you feel your care has been well coordinated?
13. Have you been involved, as much as you wanted to be, in decisions about your care and treatment?
14. Have the health professionals given you the support you need to help with any worries or fears related to your care and treatment?
15. Have health professionals given you the support you needed to be in the place of your preference?
16. What most needs improving about the care you have received?

Question set for a carer of a patient in a community setting

Preamble: Thinking about experiences of current care in hospital...

1. Do you have enough time to discuss the patient's health or medical problems with the health professionals?
2. Do the health professionals explain things in a way you can understand?
3. Is the patient treated with respect and dignity?
4. Are the patient's cultural, religious and/or spiritual beliefs respected by staff?
5. Is the patient given enough privacy during their care and treatment?
6. Do you have confidence and trust in the health professionals treating the patient?
7. Are adequate arrangements made for any services or aids needed at the patient's home or place of care (e.g. equipment, home care, community care, follow-up appointments)?
8. Do you think the health professionals do everything they can to help manage the patient's pain?
9. Do you think the health professionals do everything they can to help manage other symptoms the patient may have?
10. Do the health professionals respond to the patient's needs in the evenings and on weekends?

Thinking about experiences of care over recent weeks...

11. Do you feel the patient's care has been well coordinated?
12. Have you been involved, as much as you wanted to be, in decisions about the patient's care and treatment?
13. Have the health professionals given you the support you need to help with any worries or fears related to the patient's care and treatment?
14. Have health professionals given the patient the support they needed to be in the place of their preference?
15. What most needs improving about the care the patient has received?

About the Bureau of Health Information

The Bureau of Health Information (BHI) is a board-governed organisation that provides independent information about the performance of the NSW healthcare system.

BHI was established in 2009 and supports the accountability of the healthcare system by providing regular and detailed information to the community, government and healthcare professionals. This in turn supports quality improvement by highlighting how well the healthcare system is functioning and where there are opportunities to improve.

BHI manages the NSW Patient Survey Program, gathering information from patients about their experiences and outcomes of care in public hospitals and other healthcare facilities.

BHI publishes a range of reports and information products, including interactive tools, that provide objective, accurate and meaningful information about how the health system is performing.

BHI's work relies on the efforts of a wide range of healthcare, data and policy experts. All of our assessment efforts leverage the work of hospital coders, analysts, technicians and healthcare providers who gather, codify and supply data. Our public reporting of performance information is enabled and enhanced by the infrastructure, expertise and stewardship provided by colleagues from NSW Health and its pillar organisations.

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