

Measuring experience of care in end of life care: An overview

This paper gives an overview of measuring experience in end of life care and available resources. The underpinning principle is to use measurement/data to drive and support continuous quality improvement. The content of this overview is based on a round table discussion with people with lived experience and professionals, and contributes to the delivery of [Actions for End of Life Care 2014–16](#) (NHS England, 2014).

Patient or service user experience has been defined as “the sum of all interactions [with care], shaped by an organisation’s culture, that influences patient perceptions across the continuum of care” (the [Beryl Institute](#), 2015). There is an interplay between experience, choice, and involving patients in decisions about their care, ensuring what is important to the patient and those important to them is central to care planning (The [Choice in End of Life Care Programme Board](#), 2015).

The intended audience includes:

- Experts in measuring patient experience who want to know more about applying this to end of life care.
- Experts in providing/commissioning end of life care who want to know more about measuring experience.

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

[Every moment counts](#), a narrative for person centred coordinated care for people near the end of life.

National Voices

“Sometimes, it's the little things that matter, and that is what you remember.”

Expert with lived experience

Why is measuring peoples experience important?

Measurement in this area can help us to:

- Understand how to improve experiences for a person and those close to them;
- Consider how improving experience of care might contribute to improving clinical outcomes, safety and effectiveness of care;
- Improve the services we commission and provide;
- Critically analyse and demonstrate the quality of care interventions and assess if changes we make are an improvement;
- Build the evidence base about what really matters to individuals and those close to them and how best to measure this;
- Understand population based needs, including aspects of cultural diversity and 'hard to find' groups.

“What you experience is different from the clinical care, services are our safety net, we need to feel welcome and may need permission to ask questions, and help us and our families to walk into the unknown.”

Expert with lived experience

“People will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

Maya Angelou

1. Overview of measuring patient experience

How experience measures differ from outcome measures

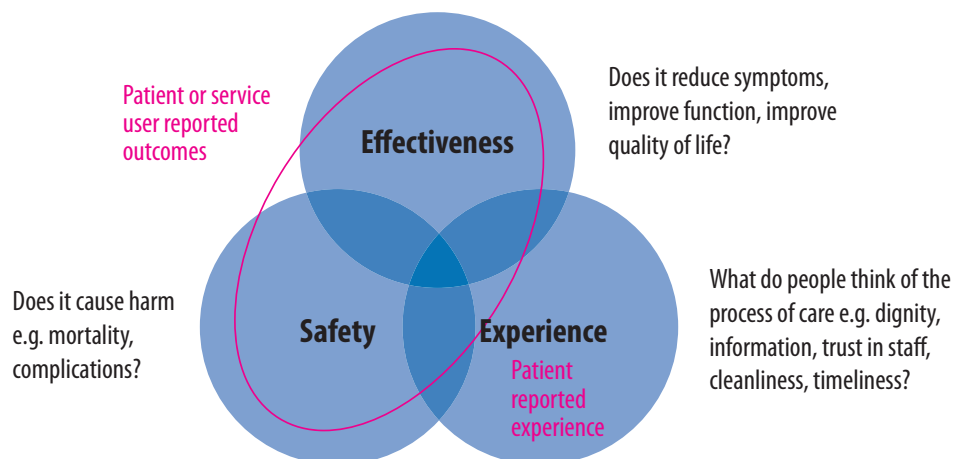
It is possible for a patient to have a positive experience but poor outcomes and vice versa. Ideally, both would be good but in end of life care, particularly at an advanced stage of illness when a person's health is rapidly deteriorating, it may not always be possible to achieve outcomes that are positive.

"Outcome measurement is a way of measuring changes in a patient's health over time. An outcome can be described as "the change in a patient's current and future health status that can be attributed to preceding healthcare".

A patient's experience can be related to physical (for example, symptoms and functional status), psychological (for example, cognition and emotions), social and cultural (for example, family and friends, organisational and financial), and spiritual (for example, beliefs, meaning and religion) domains, which are all interlinked.¹

There is clearly an overlap between experience and outcome, as shown in Figure 1. In particular for end of life care, it may be difficult to differentiate between the two.

Figure 1: Domains of quality of care: the relationship between experience and outcomes



Adapted from: [Relationship between patient reported experience \(PREMs\) and patient reported outcomes \(PROMs\) in elective surgery](#). Kings Fund.

¹ Bausewein C, et al 'Outcome Measurement in Palliative Care. The Essentials', Cicely Saunders Institute, Kings College London, London. The emphasis is on outcome measurement more than experience.

Is experience the same as satisfaction?

The quick answer is no, although clearly they are connected. This is because satisfaction requires someone to make a judgement against prior expectations.

The following illustrates the difference:

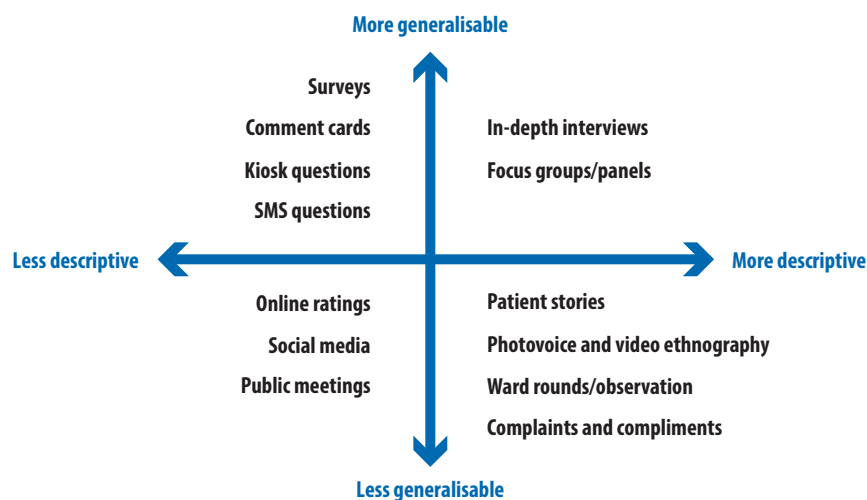
“If clinical teams were honest and brave enough to say what is not possible, and why not then it may be possible to manage high expectations, and people would be more satisfied.”
Expert with lived experience.

“If people stopped and thought, would I be satisfied with this care? It may prevent us from being complacent when satisfaction is high, due to low expectations.”
Analyst in conversation with expert with lived experience.

The approaches used to measure experience

There are two different dimensions to measuring experience: descriptiveness and generalisability (see Figure 2).

Figure 2: Examples of methods used to measure experience of health and care services



Adapted from the Health Foundation (2013) [Measuring Patient Experience](#).

Feedback from staff providing end of life care is that they tend to hear only two views – either care was excellent or was really poor (and anger when things have gone wrong). This highlights the need for a **proactive and systematic approach** to give a balanced (generalisable) view, and also one that goes beyond satisfaction.

More descriptive qualitative methods allow for diversity of views and individualisation. This is helpful, in particular for end of life care due to the individualised nature of care, and is the reason why surveys often include an open ended question or comment box.

“You gain a lot of rich information with descriptive data. You can understand why someone was not satisfied. Every situation is different, and new common threads may come through the narrative that hasn't been counted before.”

Patient and service user's stories often resonate and can be powerful for board level executives as they are engaging. However, over reliance on the same expert patient or service user may reinforce a single perspective, that may or may not represent others' views.

One conclusion from the roundtable discussions is that you often need both qualitative and quantitative methods. In particular frontline staff find more descriptive, qualitative information meaningful, and especially so if provided real time or near real time (see also Fitzpatrick *et al*, 2014).

"I get frustrated by a tick box if my issue isn't covered. Give me the chance, especially if it my last chance, to say what I want to say."

Expert with lived experience

Equality and diversity

There are a number of people whose views/voice may not be well represented in surveys. This can be a concern **if their experience of care differs significantly from others**. There are two groups.

"Hard to find" groups include people who are not aware or accessing services in the first place. For example those who are homeless, black and minority ethnic communities, people who are travellers. The feedback from these groups is usually "please come and talk to us". Starting here, either a meeting or a focus group is a good first step. Another, is checking to see if there is relevant studies or research.

"The main theme coming back from discussion groups was a lack of knowledge of palliative care services."

A Community Development Officer, Marie Curie. 2014

Some people need **"additional help or provision"** to ensure their experiences are represented. Adjustments here include: large print, brail, translations, interpretation, "easy to read" text with supporting visuals, face to face data collection. A tip is to check first and do not make assumptions about why people may or may not engage. Talk, either to the people themselves or those who provide services for them or represent them, to understand what would help.

2. End of life care perspectives and measuring experience

End of life care is a sensitive topic area. Both for the person who receives services and, in particular for those important to them as often we ask the views of people who are bereaved. There are two considerations.

There can be **positive consequences**. Examples include that people find it cathartic to be able to tell their story or someone who is at the end of life feeling they are able to contribute, and that this gives sense of value and worth.

There is a **potential unintended consequence**. For example a bereaved person may feel guilty about something they could have done differently prompted by a survey. Or recalling events prompts distress and significant grief. Ensuring there is always a point of contact to provide additional support should be designed in any data collection.

Measuring experience in end of life care has other attributes needing consideration. These are:

- Individualised nature of care, a person's preferences and goals, and these maybe quite dynamic and change over time
- People may be at an advanced stage of illness and find it difficult to complete surveys, give interviews and contribute their experiences (and with this a potential overdependence on proxy measurement)
- There is a dependence on professionals to facilitate a shared understanding about what someone needs and their personal aspirations i.e. "people do not know what they do not know"

- Family and carers experience alongside the person receiving care is an important consideration
- Staff experiences of providing care is an important dimension to support quality improvement.

The conclusion is that we need to be careful about making assumptions and carefully, sensitively design any data collection about experience.

Box 1: An example of sensitively designed data collection: wards in an acute hospital

The hospital piloted collecting patient experience data for patients recognised to be in the last days of life. Experienced staff, palliative care matrons, who were not ward based so relatively independent from the ward teams, collected information from either family and/or patients. This provided a safety net. They are able to shift their focus from data collection to providing care, if the patient's condition changed. The patients and those important to them benefited, as senior nurses they could deal with concerns or questions there and then, and provide an instant feedback to staff on the ward.

Gatekeeping

“Gatekeeping” occurs when frontline staff assume that patients or service users do not want to give their views or participate in research.

There are many potential reasons ([Stone et al, 2012](#)). Understanding and working with frontline staff and guiding them through their concerns will reduce gatekeeping. For researchers, it may be important to emphasise the offer is “choice” rather than “recruitment”.

“Please don't deny me my right to take part in a study.”

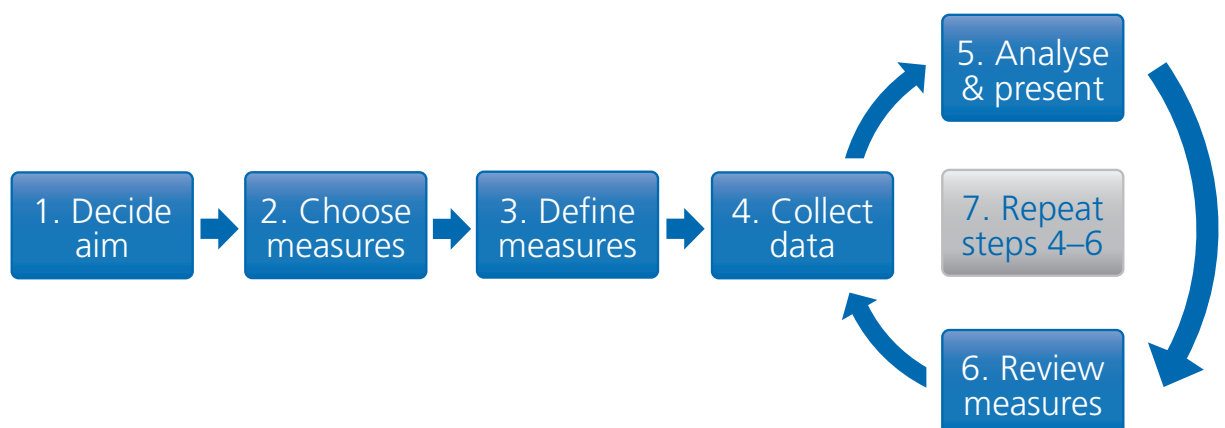
Expert with lived experience

3. Practical aspects in measuring experience in end of life care

The seven steps in the [guide to measurement for improvement](#). (Davidge et al 2015) provide a structured approach to ensure measurement adequately supports improvement activity.

Measuring peoples’ experience is no different from any other measurement in this regards.

Figure 3: The seven steps in measurement for improvement



We do not attempt to replicate the guide, instead provide some practical pointers that are specific for measuring experience in end of life care, or are critical to getting measures right.

Step 1: Decide aims and objectives

a) Your current focus: Is your aim to understand if care needs to be improved, or select/prioritise an area for improvement? **Or** is it to support improvement activity, and with this assess if the changes you make are improving experience of care?

b) Who primarily needs the measures?: Is it for frontline clinicians or staff, frontline managers, or those working across a health care provider or commissioning services? Is it to adjust an individual's care or support? Or is it to support quality assurance or improvement activities? Or is it to support strategic decision making?

Developing objectives at the same time as deciding measures helps to make sure there is a fit.

Box 2: Illustration of survey fatigue

"Staff and patients felt saturated with questionnaires. This was because it was the second patient reported experience measure that was delivered by the district nursing teams this year."

Report feeding back semi-structured interviews on experience of end of life care.

Step 2 and 3: Choose and define measures

Experience measures should form part of a suite of measures.

Experiences of patients and people who receive our services may reflect structure, process, outcome and balancing measures.

Experience is important, as it provides a different perspective. For example: a process measure may be about how long a patient waits for pain relief and a measure of experience of this is how long it felt to wait.

Understanding both, may offer different ideas on how to improve outcomes and experience.

Using existing validated tools

There is substantial benefit to using existing validated tools.

It is still important to check it meets your requirements and resolve practical issues. For example try the tool out with one to two people before embarking on a large scale survey (Fitzpatrick *et al*, 2014).

"The value of clear and concise wording, free from professional jargon, ... and can make a significant difference to the level of uptake of a survey." Hospice UK *et al* (2014).

It is a common experience that a two minute wait can feel like nothing at all, or can feel like 'forever'.

[David Masters: the Psychology of Waiting Lines](#). A business focused article.

Prompts staff use include:

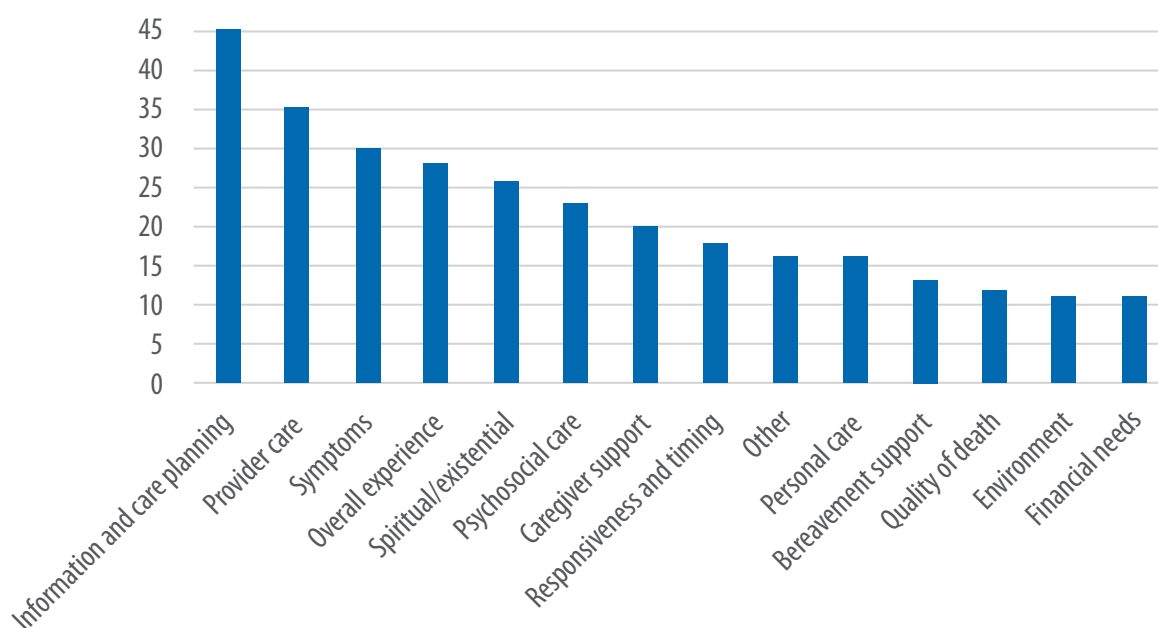
"What could have made you more comfortable today?"

"Do you have any worries or concerns?"

Topic selection

Figure 4 highlights the topics that are frequently included in quantitative surveys that focus on experience of end of life care.

Figure 4: The most frequently occurring topics in measuring experience in end of life care



From [Lendon et al's](#) (2014) systematic review of 51 unique surveys.

[Co-ordination of care](#) is another important area of focus.

A systematic review of family carers for people with dementia living in the care home identified the following themes of experience:

- 'Unfamiliar territory'
- Making decisions
- The grieving carer².

This ties with taking a holistic approach to total experience of care across services, and opportunities for partnership working and taking a population or public health perspective. An example of this is the VOICES-SF survey of bereaved relatives, where relatives give their views on all services received.

² Hennings, J. et al (2010) 'Approaching the end of life and dying with dementia in care homes: the accounts of family carers', *Reviews in Clinical Gerontology*, vol 20, Issue 2 pp 114–127.

Step 4: Collect data

Use existing data/data collection systems where possible

This section is of particular relevance where there is existing routine data available but has not been collected specifically for end of life care.

If there is **open text data** and/or the **opportunity to identify** relevant patients, service users, or those important to them it is possible to extract learning and measurement for end of life care. For example:

- Complaints, concerns or compliments³
- Friends and Family Test (the wording in the Friends and Family Test has been demonstrated to be acceptable for those with end of life care needs, Hospice UK *et al*, 2014)
- Annual Social Services Survey.

Any feedback that is not anonymous, provides opportunities to identify relevant information. For example in the complaints study, some organisations identified complaints where the complaint was for someone who had died.

Any free text provides opportunities to identify relevant information from the content itself. The latter can be resource intensive.

“Text mining”⁴ is an approach to automatically identify potentially relevant comments. For example we used MS Excel to check if relevant phrases such as “end of life care” and “died” existed in open text data, using formulas. Using this approach, means that any response with these phrases can be automatically highlighted for further review.

To develop this in practice, our experience suggests that is essential for people who are responsible for the information and those with expertise in end of life care to work together.

Supporting people to provide information on their experience

Practically supporting people to give their views is one consideration for data collection in end of life care. Work out the best approach for your requirements. See also Box 3.

Box 3: Examples of different approaches to collect the same data

- Care homes used a mixture of volunteers and a designated senior member of staff
- Community staff invited people to self-complete the survey while visiting their patients at home
- Hospices used designated staff members caring for the person and volunteers
- Hospitals used volunteers trained by the hospice

[Hospice UK et al 2014](#)

³ NHS IQ (2013) [Snapshot Review of Complaints in End of Life Care: Key findings](#)

⁴ Information submitted to the round table: “Text-mining assisted qualitative analysis of free-text comments relating to quality of patient experiences of care within the National Cancer Experience Survey.”

Reducing the administrative burden of data collection

There have been successful pilots using handheld devices ([Hospice UK et al 2014](#)). Some organisations have specialist scanning equipment to avoid the need for manual data entry.

Co-ordinate data collection

Co-ordination locally, and with national and other studies is important. Firstly, to prevent people being either asked the same or similar questions twice and avoid survey fatigue (see box 3).

Design and attention to detail

If you are collecting experience data by a postal survey, consider the design and the cover letter carefully. First impressions really do count.

“It is of interest that by far the highest response rate was observed in a primary care setting where the survey was sent out with a personalised letter, with signatures of practice GP and nursing staff in addition to information posters displayed in the practice highlighting the survey.”

Fitzpatrick et al (2014)

Step 5. Analyse and present

Patient experience measurement in end of life care is no different from other data in terms of analysis and presentation. See the [Measurement for Improvement Guide](#).

Steps 6 and 7: Review measures and repeat steps 4 to 6

Your original objectives and aims should define feedback loops.

“Those planning and reviewing care at board level must buy into the process, seek and reflect on the data generated and drive service improvements accordingly. Frontline staff must want to hear about user experience, encourage feedback, embrace the data that is generated and be enabled to find timely solutions to individual patient concerns and dissatisfaction.”

Hospice UK et al (2014)

An expert with lived experience highlighted:

“Be clear about how you will use the data at the start, and give feedback on its impact to patients and the public.”

This highlights a need to plan your feedback to patients and the public, frontline staff, teams, boards, commissioners. Remember to feedback positive aspects of care that needs to be replicated as well as areas for improvement. Each group have different requirements.

A challenge is “use the measure or lose it” for collecting any measure. Measures that are not being reviewed, or if they are being reviewed but not acted on, reflects a huge waste of time and resource.

“Knowledge is knowing that a tomato is a fruit; wisdom is not putting one in a fruit salad.”

Miles Kingston

Box 4: Practical tips for collecting measures of patient or service user's experience

1. Consider how patient experience is being defined to inform exactly what needs to be measured.
2. Think about why patient experience is being measured and how the information will be used.
3. Assess whether it would be useful to combine approaches so that both qualitative and more quantitative material is collected.
4. Consider whether to ask everyone using the services or only a sample to provide feedback.
5. Think about whether the best time to collect feedback is immediately after using the services, when experiences are fresh in people's minds.
6. Allocate enough time at the outset to plan and test measurement methods, particularly if these will be used for many years to monitor change over time.
7. Think about how the end-result needs to be presented for various audiences as this may shape how data are collected. Potential outputs include statistical averages, in-depth quotes or graphs.
8. Make sure that there is appropriate infrastructure at an organisational level to analyse and use patient experience information.
9. Make sure that patients, carers, managers and health professionals are all comfortable with why feedback is being collected and how it will be used. Staff need to be on board as well as patients.
10. Ensure that patient experience measures are seen as one component of a broader framework of measurement and that all of the approaches work well together, without excessive burden for either staff or patients.

From: The Health Foundation (2013) *Measuring Patient Experience*. London

3. Resources

This section does not attempt to review all approaches and tools. It aims instead to illustrate the range of what is available, and highlight useful resources outside of end of life care.

Patient experience and measurement in general

The Health Foundation (2013) [Measuring Patient Experience](#). London.

King's Fund (2013) [Experience Based Co-Design toolkit](#) [website] developed by the King's Fund for approaches to observe in practice that are not specific to end of life care. It includes a number of practical resources.

NICE (2012) [NICE quality statement for experience of care](#) (all adult services) Standards for patient experience in adult NHS services. Ensuring people have a positive experience of care is part of **NHS outcomes framework** and **adult social care outcomes framework**.

[NHS England Patient Experience](#) [website]. Gives an overview of programmes of work that have a particular emphasis on patient experience.

Peninsula Community Health [Kinda Magic](#). Patient experience toolkit

National Quality Board (2015) [Improving experiences of care: our shared understanding and ambition](#).

[Wolf, et al \(2014\)](#) "Defining Patient Experience", *Patient Experience Journal*: Vol. 1: Iss. 1, Article 3.

[Beryl Institute](#) (2015) A global community of practice on improving the patient experience in healthcare website (accessed 02.03.15)

[HSCIC \(2014\)](#) Adult Social Care Survey feedback report. Includes some useful learning and lessons on how social services have increased response rates for different groups.

[National Voices](#) is the national coalition of health and social care charities in England. [Recent research](#) includes a new measure of care co-ordination designed for older adults.

[Patient Opinion](#) and [NHS Choices](#) offer the opportunity for patients to feedback their experience of care.

Reviews and overview of measurement of experience in end of life care

Hospice UK (2014) [Listening differently to users](#). An important pilot study on real time data collection of patient experience measures in four different settings in care services.

Lendon, J *et al* "Measuring Experience With End-Of-Life Care: A Systematic Literature Review" (2014) Journal of Pain and Symptom Management DOI <http://dx.doi.org/10.1016/j.jpainsymman.2014.10.018>

National surveys of bereaved relatives

[National Survey of Bereaved People \(VOICES-SF\)](#). Only national survey of experience of care for end of life care.

[Care Of the Dying Evaluation \(CODE\)](#). An optional survey focused on care in the last days of life that was part of the 2014 National Care of the Dying Audit in acute hospitals.

VOICES-Learning Disabilities. Version and method developed for people with a learning disability living in a care facility (completed by the person's carer).

A selection of instruments

The Specialist Palliative Care Minimum dataset will pilot patient experience measures.

Family Perceptions of Care Scale (FPCS) is a Canadian developed 26-item self-completion post-bereavement questionnaire developed for family members perceptions of end-of-life care in long-term care facilities. Vohra JU (2004). Family Perceptions of End-of-Life Care in long-term care facilities. *J Palliat Care*. 2004 Winter;20(4):297-302.

Others: [FAMCARE](#), [Views on Care](#) section of IPOS.

van Soest-Poortvliet MC (2011) *et al* Measuring the quality of dying and quality of care when dying in long-term settings: a qualitative content analysis of available instruments. *Journal of Pain and Symptom Management*. 2011 12//:42(6):852-63 includes review of the SWC-EOLD Experience with care at the end of life in dementia instrument.

The [Hospice UK](#) patient survey is a standard instrument used by many hospices. There is an inpatient and outpatient version.

National surveys not specific to end of life care but with open ended questions

National NHS inpatient survey run by the Picker Institute - includes items that may allow identification of patients more likely to have end of life care needs than not (long-standing illness, and if this affects their daily living, age).

[Friends and Family Test](#) [external link]. See [Frequently Asked Questions](#) [pdf] for guidance on end of life care – includes the ability to select wards in hospitals who provide the most end of life care. This is part of [NHS England's Insight](#) team's work.

Carers needs and end of life care

Ewing G, Grande G. (2013) Carers needs support tool. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. *Palliative Medicine*; 27(3) 244–256.

Children who are carers

The impact of caring on young people ([MACA and PANOC](#)) exist but not been validated for children of people who have end of life care needs.

Hospice approaches

“Tell us what you think”: anonymous patient and carer comment card scheme reviewed on a monthly bases LORUS.

‘Small things make a big difference’ post card.

‘Tell us your concern’ used by Marie Curie as people do not always want to complain.

Patient story group: focus groups to bring clinicians and patients receiving care together.

Loros Hospice ‘Five Senses Survey’ observational tool for trained volunteers visit a care facility and feedback their experiences.

Measurement for improvement and quality assurance

Davidge *et al* (2015) [Guide to measurement for improvement](#). NHS Elect. Interactive PDF guide on measurement for improvement.

Fitzpatrick *et al* (2014) [Development of new model for collection and use of patient experience information in the NHS](#). Briefing. Picker Institute Europe. Research study that looked at the practicalities of data collection in different settings. Includes some practical recommendations.

Monitoring the impact of measuring patient experience

[Involve me](#) is a free resource available to support evidencing the impact of user involvement on service design and delivery for end of life care.

Other resources on measurement for end of life care

NHS IQ (2014) [Considerations on Quality Assurance in End of Life care](#)

NHS IQ (2014) [Factsheet 1: Sources of data and resources](#)

NHS IQ (2014) [Factsheet 2: Clinical audit](#)

NHS IQ (2015) Factsheet 3: Maximising the use of locally available information from your hospital Trust's patient administration system

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