Submission to the Independent Review of Targets and Indicators for health and social care

Measuring improvement: people's experiences of deteriorating health, death, dying and bereavement.

1 Summary

This paper explores some of the challenges and complexities involved in measuring the quality of patient and carer experiences towards the end of life.

We propose a two-tiered approach to future measurement of this area:

- **The introduction of a single, system-wide national survey of bereaved informal carers.**

This Independent Review represents an opportunity to move on from using process indicators as proxies for quality. We therefore propose the introduction of a Scottish National Survey of Bereaved Informal Carers, using the VOICES (Views of Informal Carers - Evaluation of Services) tool[i].

- **IJBs should be expected to use appropriate approaches at local level**

During the development of this paper we identified many examples of different approaches being used locally to measure the quality of palliative and end of life care, for example data from complaints; Patient Opinion; real time feedback from patients and family; measures developed by the Outcomes Assessment Complexity Collaborative (OACC); local analysis of process and activity data that may be available via the LIST resource, including KIS; case note reviews; significant event reviews.

We recommend that IJBs should be expected and supported to use such approaches locally, and to share learning via SPPC and other mechanisms.

This paper is the product of consultation with the range of stakeholders involved in the SPPC, with particular thanks to the SPPC Council for the considered contribution of expertise and experience from such a wide range of perspectives. (Council Membership is listed at Appendix 1.)

2 Why is it important to measure the quality of people’s experience of deteriorating health, death, dying and bereavement?

2.1 Human Impact

Even the most healthy, active and independent individuals eventually face ill health or frailty as they approach the end of their lives. Deteriorating health, death, dying and bereavement affects everyone deeply and profoundly at some stage in their life.

An individual’s experience of this has an impact not only on them, but also on their family and carers, that can continue into bereavement.

2.2 Scale of the Issue and Resource Use

Around 56,000 people die annually in Scotland. Of these it is estimated that as many as 46,000 people will have needs arising from living with deteriorating health for years, months or weeks before they die. It is measurement of the experiences of this group (who are often described as having “palliative and end of life care needs”) which this paper seeks to address.

Use of health and social care services rises steeply towards the end of life and represents a very significant proportion of total resources available.

Death in hospitals: 29% of all acute bed days are used by patients in their last year of life. Nearly 1 in 10 of patients in hospital will die during their current admission and 54% of deaths take place in hospital.

Death in Care Homes: 33 000 older people live in a care home, their median length of stay is less than 18 months, over 60% have dementia and over 11 000 die each year.

Death in homes: In 2013 63 000 people aged over 65 received care at home services.

The health and social care system is well placed to have a positive impact towards the end of life, but equally well placed to do harm. The care provided towards the end of life can been seen as an indicator of compassionate cultures and behaviours across the wider health and care system.

3. What are we aiming for?

Scotland should be a place where:

- People are able to 'live well' as their health declines
- People die well
- People are supported throughout bereavement.

More detailed exploration of what we mean by this is described in **Appendix 2**.

4 Why isn't it straightforward? Some challenges in measuring quality of care towards the end of life.

It is hard to define when dying 'starts'

Defining the scope of what we measure is complex: Are we looking at care in the last year of life, or the last 6 months, or the last few days and hours? People with cancer, organ failure (including neurological conditions), frailty and/or dementia all follow different trajectories of decline. Even if the scope is narrowed to the very end of life it is hard to define when dying 'starts', or to identify that point for a particular individual.

What constitutes "a good death" is very individual and personal.

Therefore it is a challenge to find one measure that meaningfully reflects this at scale.

Optimised wellbeing may mean very different things for different people.

Whilst "a good death" is important, it is *only part* of what matters - emphasis should always be on optimising wellbeing for as long as someone remains alive, whether that turns out to be years, months or hours – a focus on living well, not on dying.

Care takes place within and across multiple formal and informal settings.

This means that indicators and targets based on specific distinct episodes are problematic.

Death can happen at any age

Anyone from neonates, children and young people to centenarians may be nearing the end of life.

Many traditional outcome measures don't apply

Often, the impact of a service is measured by looking at how it has improved the health or longevity of the population it serves. However, the population being considered here are experiencing a decline in their physical health, so traditional outcome measures such as ‘survival’ are not applicable.

Patient and family-reported outcomes may not always be possible

People who are very ill, and families who are in distress may not be in a position to provide feedback on their experiences of care. (However, there is evidence that people want to provide feedback and that formal services can be overly protective in this regard.)

Death can be traumatic even when optimal care is provided

Even with the best possible care, the last weeks and days of someone’s life can be complicated, difficult and upsetting. A bad experience may not be indicative of bad care.

5 What data could be made available at a national level, and what does it tell us?

With recent investment in data analysis in support of IJBs there is an increasing amount of data which could potentially also be made available at national level. However, none of this routinely collected cost and activity data provides information on quality of care.

Two of the current Integration Indicators (proportion of last 6 months of life spent in a home or homely setting; expenditure on end of life care) are examples:

5.1 Integration Indicators

Proportion of last 6 months of life spent in a home or homely setting: Statistics relating to place of care do not provide information about whether the place of care is aligned with the patient/family preference, whether it is an appropriate place of care, or about the quality of care experienced.

Expenditure on end of life care:

Expenditure on end of life tells us nothing about quality of care – expenditure will probably be highest when most care is provided in hospital (which may be desired and appropriate for some patients but not others).

5.2 Key Information Summary (KIS)

The Key Information Summary (KIS) is another potential source of information. It is important to consider its potential as a proxy indicator for:

a) the number of people identified as having palliative care needs
b) the number of people for whom anticipatory care planning has taken place.

However, as a proxy indicator 'number of people with a KIS' has several weaknesses:

- KIS is designed for use with people who have a range of complex circumstances – **it is not just for people with palliative care needs**. This means that numbers of people with a KIS is not the same as the numbers of people identified as having palliative care needs.

- The KIS is a very crude proxy for anticipatory care planning – **it can't provide any indication of the quality of conversations** and shared decision-making which has led to the population of the record.

- We might know that someone had a KIS, but that on its own **doesn't tell us what care was actually received**, how that related to the preferences of the patient, or what the quality of that care was.

The electronic palliative care summary (which was the predecessor of the KIS) provided the data source for two of the four Palliative and End of Life Care Quality Indicators published by HIS in 2013. The limitations inherent in the use of a process measure as a proxy for quality were widely recognised at that time.

A recent local study has demonstrated the potential for utilising KIS data to better understand service responses to people with palliative needs[ii] using sub-analysis of specific fields and dates of completion. This data, together with data about when the KIS is accessed in different settings can help to characterise what is going on within the system and should prompt further inquiry. There is potential for data linkage to increase understanding of different pathways and place of death.

To summarise:

- The strength of KIS data lies in the contribution it can make to describing, and informing an understanding of how the local system is operating.
- KIS does not provide adequate information about quality of care experienced and is not the basis for assessing outcomes, quality of care or as an indicator of performance.
- There is a risk of unintended consequences when using process measures as proxy indicators of the quality of care, particularly when allied to measures of cost and expenditure within resource-scarce systems.

6 Recommendations

6.1 Introduce a Scottish National Survey of Bereaved Informal Carers

It is important that indicators relating to resource use are balanced by measures which reflect the quality of care delivered. We therefore propose the introduction of a Scottish National Survey of Bereaved Informal Carers, using the VOICES (Views of Informal Carers - Evaluation of Services) tool[iii].

VOICES is a postal questionnaire about experiences of end of life care in the 3 last months of life, focusing on quality of care and services received, domains for which patient and proxy agreement are good. The survey generates a wide range of data about the quality of care across all health and social care settings, including items on respect, dignity, pain relief and involvement in decision making. A discrete section explores experiences in the last 2 days of life. The survey provides some data on carer as well as patient experiences.

The VOICES questionnaire uses the post-bereavement method to gather information from bereaved relatives, friends or carers, acting as proxies for the person who has died. Response rates are typically around 45%. The Office for National Statistics (ONS) has published an assessment of the quality of VOICES against the 5 European Statistics System quality dimensions including a summary of strengths and limitations of the approach.[iv]

Development of the original VOICES survey was informed by a population based face-to-face interview survey with 3000 bereaved relatives in the UK. The survey has been validated and there is extensive documented learning about its use in England. It is about to be piloted locally at an NHS Board in Scotland and learning from that pilot could inform a national approach.

We suggest that it would be most efficient and effective to fund and administer the survey centrally at national level. In England this is done by ONS.

Why Use this Approach?

The advantages of this approach include:-

- The survey generates findings on the quality of patient and carer experiences and outcomes, rather than measuring processes which are not adequate proxies for quality.
- The survey covers a good range of issues which patients, carers and the public say are important to them.
- Findings from the survey can support a specific focus at national level on end of life care, providing public assurance and encouraging professional and public engagement on end of life issues.
- The survey was developed in collaboration with bereaved relatives and patients.

- The survey is validated and largely ready for use in Scotland.
- The survey allows a consistent nationwide approach with zero measurement burden for frontline staff.
- The survey is capable of repetition at different time points.
- With appropriate sample sizes the survey can also be used at local level to provide data specific to local services. It would be possible to explore local variants to provide more rapid feedback and shorter forms of the questionnaire.

6.2 IJBs should be expected to use appropriate local approaches

During the development of this paper we identified many examples of different approaches being used locally to measure the quality of palliative and end of life care and we briefly describe some of these below. We recommend that IJBs should be expected and supported to use such approaches locally, and to share learning via SPPC and other mechanisms.

Data from complaints – review of individual complaints and thematic review are both useful approaches (both locally and nationally). A sudden change in the number or type of complaints may prompt focussed attention. There is a need to adopt a national approach to coding of complaints so that instances relating to palliative and end of life care are readily accessible. A regular thematic review by the Ombudsman would also be useful. **Patient Opinion** is another source of feedback.

The **Outcomes Assessment Complexity Collaborative (OACC)**[v] has collated a suite of fit-for-purpose measures of both outcomes and quality of care designed to capture and demonstrate the difference that palliative care services make to patients and families receiving their care. It is in use in at least 2 services in Scotland.

Systems for **real time patient and family feedback** are in use in some specialist palliative care settings.

Case note reviews and **significant event reviews** are in use and can be a rich source of learning for improvement.

The Integration Indicator data we discussed in Section 5 is available locally, and some KIS analyses also. A wide range of other **local data analyses** may be available via the LIST resource available at each Health and Social Care Partnership. These can be useful for describing and understanding pathways and patterns of service use, but not for measuring outcomes or as performance or quality indicators.

APPENDIX 1: About SPPC and this Paper

SPPC is a collaboration of over 50 organisations involved in providing care towards the end of life. SPPC’s membership includes all the territorial NHS Boards, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

This paper was developed in discussions with SPPC members between November 2016 and February 2017. Perspectives engaged include public health, general practice, specialist nursing, social care, palliative medicine, Scottish hospices CEOs, service management and policy/advocacy. The production of the paper has been overseen and informed by the Council of SPPC whose membership is shown below.

- **Kenny Steele,** Chief Executive, Highland Hospice
- **Dr Deans Buchanan,** Consultant in Palliative Medicine, NHS Tayside
- **Jackie Husband,** Chief Executive, St Columba's Hospice
- **Mandy Yule,** Chief Executive, Ayrshire Hospice
- **Dr Pat Carragher,** Medical Director and Consultant in Palliative Medicine, Children's Hospice Association Scotland
- **Dr Euan Paterson**, GP, NHS GGC (until Jan 2017)
- **Shirley Fife** Nurse Consultant Cancer & Palliative Care, NHS Lothian
- **Gordon McLaren** Consultant in Public Health (until Dec 2016)
- **Dr Annabel Howell,** Associate Medical Director Primary & Community Services, NHS Borders
- **Dr Libby Ferguson,** Consultant in Palliative Medicine, Marie Curie Hospice, Glasgow
- **Dr Scott Davidson**, Consultant in Respiratory Medicine, NHS Greater Glasgow & Clyde
- **Prof Bridget Johnston,** Florence Nightingale Foundation Chair in Clinical Nursing Practice Research, NHS Greater Glasgow & Clyde
- **Dr Paul Baughan,** GP, NHS Forth Valley
- **Trisha Hatt,** Senior Development Manager (Scotland), Macmillan Cancer Support
- **Dr Donald Macaskill**, Chief Executive, Scottish Care (from Jan 2017)
- **Tanith Muller,** Parliamentary & Campaigns Officer, Scotland, Parkinson's UK
- **Amy Dalrymple**, Head of Policy, Alzheimer Scotland.

APPENDIX 2

What would better death, dying and bereavement look like?

The following vision can only be achieved through co-production by formal services, individuals and communities. Work to promote more openness about death, dying and bereavement will underpin progress.

Scotland should be a place where:

- People are able to 'live well' as their health declines
- People die well
- People are supported throughout bereavement.

Scotland should be a place where communities and individuals are able to help each other through the hard times which can come with decline, dying, death and bereavement. People with advanced disease should experience safe, effective, person-centred care from health and social care services which understand that they can continue to make a significant difference to a person's wellbeing even in the last months, weeks, days and hours of that person's life.

In terms of formal services Scotland should be a place where:

- People's end of life care wishes are elicited and respected.
- People live, decline and die with good control of pain and other symptoms.
- Health and social care staff respond quickly and appropriately to people's physical, psychosocial and spiritual needs relating to decline, death and bereavement.
- Systems, processes and resources are in place within health and social care to give staff the time and support they need to exercise their humanity and skills in providing good palliative care for people and families.
- People die in a place of their choosing, where feasible, remembering that people's preferences may change as death approaches, and that achieving a preferred place of death may involve tradeoffs with other preferences.
- People's dignity is maintained as they approach death.

To build on the assets of individuals and communities Scotland should also be a place where:

- Information is readily available on planning for decline, dying, death and bereavement.

- People have access to legal, financial and spiritual support for end of life planning (including wills, Power of Attorney, funeral arrangements).
- Families, communities and professions support and encourage each other to plan ahead for decline, death, dying and bereavement.
- People have the opportunity to discuss and plan for their decline and death with health and social care professionals.
- Health and social care professionals feel able to engage and initiate end of life care planning discussions with older people and their families.
- People have anticipatory care plans.
- As a result of planning and preparation people have fewer concerns about the practical, legal, financial and emotional aspects of decline, dying and death.
- People are in contact with the people who matter to them as they live, decline and die.
- Families and communities are better equipped to help and support people at times of increased health need and in bereavement.

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[i] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215505/dh_130569.pdf *Hunt & Addington-Hall 2011* A toolkit for the design and planning of locally-led VOICES end of life care surveys. The survey questionnaire features from page 23 of pdf

[ii] *Murray et al 2016* Many people in Scotland now benefit from anticipatory care before they die: an after death analysis and interviews with general practitioners http://spcare.bmj.com/content/early/2016/04/13/bmjspcare-2015-001014

[iii] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215505/dh_130569.pdf *Hunt & Addington-Hall 2011* A toolkit for the design and planning of locally-led VOICES end of life care surveys. The survey questionnaire features from page 39

[iv] ONS Information Paper (2016) https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/qmis/nationalbereavementsurveyvoicesqmi/qmivoicesapr16finalforpub.pdf

[v] Witt, Murtagh et al Introducing the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures https://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/attachments/Studies-OACC-Brief-Introduction-Booklet.pdf