Consultation Report: Feedback on the Quality of End of Life Care

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Feedback on the Quality of End of Life Care: Consultation Summary

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- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and

- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

Contents

1 Introduction

1.1 Background to the VOICES-SF survey

The ‘End of Life Care Strategy’ was published in July 2008 - a vision for better care administered to patients in end of life. The document recognised that the “measurement of end of life care provision is a key lever for change and is essential if we are to monitor progress”.[1] With this in mind, the VOICES-SF survey (Views Of Informal Carers’ Evaluation of Services – Short Form) was commissioned. The sample is extracted from the database held by The Office of National Statistics by selecting from adult deaths registered in the months January to April. Due to ethical considerations, 6 months are left before the registrant of the death is posted the survey, and the data is published 15-21 months after the care to which it relates was received. The VOICES-SF survey methodology has remained in this format, largely unchanged, to this day. Commissioning responsibility moved to NHS England in 2013.

1.2 Policy Context

Since the phasing out of the Liverpool Care Pathway (LCP) in 2014 the focus has shifted to the next steps that need to be taken to ensure a thorough and well-rounded end of life care approach is developed from this.[2]

In response to the independent review of the LCP, the Leadership Alliance for the Care of Dying People articulated five priorities for care of the dying person in ‘One Chance to Get it Right’ (published 2014).[3]

More recently the ‘Ambitions for Palliative and End of Life Care’ was published by the National Palliative and End of Life Care Partnership as a system-wide national framework for local action. More closely aligned with the NHS 5 year forward view, this framework sets out 6 ambitions and incorporates the recommendations from preceding reports and reviews on end of life care.[4]

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[1] End of Life Care Strategy, Department of Health (July, 2008) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf [Accessed 03/11/2015]

[2] More Care, Less Pathway: A Review of the Liverpool Care Pathway, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf [Accessed 01/12/2015]

[3] One Chance to Get it Right, The Leadership Alliance for the Care of Dying People (June 2014) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Accessed 22/10/2015]

[4] Ambitions for Palliative and End of Life Care: A National Framework for Local Action, The National Palliative and End of Life Care Partnership, http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf [Accessed 22/10/2015]

1.3 Consultation Overview

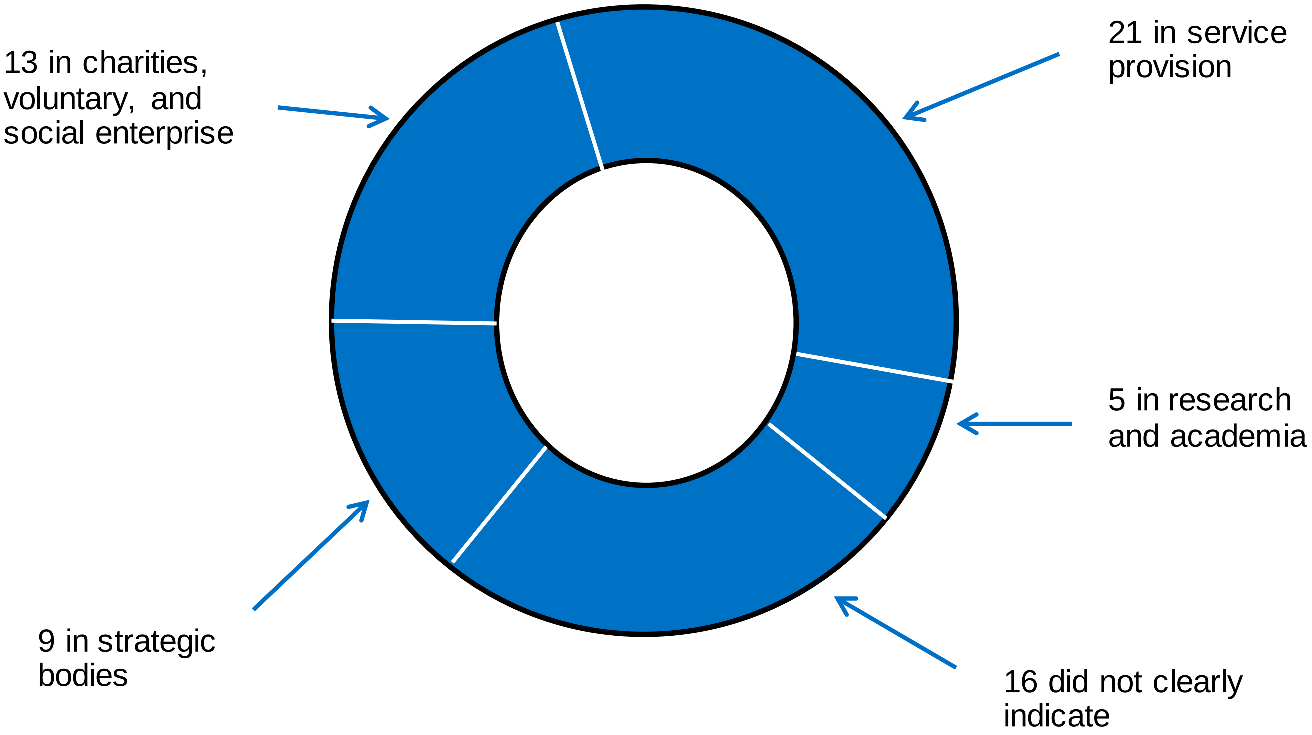
As the VOICES-SF survey has now been carried out for 4 years, NHS England has decided to seek views on the approach and relevance of the survey to ensure that it remains fit for purpose. The resulting consultation was carried out between the 27th March 2015 and the 23rd June 2015 and was open to anyone with an interest in feedback on the quality of end of life care.

The consultation consisted of 23 questions, split into 7 categories:

1. Use of the survey findings
2. Question specific
3. Local feedback
4. The person giving feedback
5. Reporting the feedback and sample size
6. Survey frequency.
7. The time gap between point of care and data publication.

A full list of the consultation questions can be found in the appendix. Responses were submitted through the NHS England website, with further feedback given via email and over the phone. The following report is a summary of the key findings.

We received 64 responses to the consultation from the range of institutions and individuals who have a stake in end of life care. 21 respondents worked in service provision: in NHS Trusts, GPs, hospices and pharmacies. 13 worked in charities, voluntary, and social enterprise. 9 worked in strategic bodies: in commissioning, regulatory bodies, clinical networks, and public health. 5 worked in research and academia. 16 did not clearly indicate who they were.



2 Executive Summary

2.1 Summary overview

How the survey findings are reported:

- Whilst the consultation showed that the VOICES-SF survey is useful as a national indicator, it also demonstrated that the current sample size limits its use as a stand-alone resource for commissioners and service providers. The majority of respondents, as a result, indicated that the VOICES-SF findings would be more helpful if the sample size were made large enough to report at a local level, and that they would support this change.

How the survey is currently used:

- The consultation showed that the current VOICES-SF survey has a variety of uses, but is most effective when used in combination with local sources of feedback and other data. Respondents indicated that without local data it is difficult to use the VOICES-SF survey for service improvement.

Who is asked to fill out the survey:

- The respondents were clear that asking for the views of a range of people, and not just the bereaved, would provide different perspectives and give richer sources of insight. Respondents were also clear that the survey should make room for the experiences of the carer/relative/friend to be included too, as opposed to focusing exclusively on the treatment and care administered to the patient.

How frequently the survey is conducted:

- Although a more regular survey was called for by some respondents (particularly those from smaller providers) the majority would prioritise a change in the level at which the VOICES-SF findings were reported, and an increase in sample size, over any alterations in frequency.

How quickly the survey data is published:

- Almost all of the respondents identified the time lapse between the point of care and the publication of results as a limiting factor in the utility of the VOICES-SF survey. They would prefer to shorten this gap so as to enable them to confidently make decisions based on up-to-date and relevant data, but appreciate the ethical implications of this.

2.2 Key figures at a glance

Should the bereaved person be asked for feedback on the quality of care OR the person receiving care?
59 answered.

- Both = 30
- The bereaved person = 18
- The person receiving care = 8
- Other = 3

Which of these levels [of reporting] do you think is most important?
59 answered.

- CCG = 36
- Individual provider = 10
- Local office = 2
- SCN = 2
- All levels = 5
- National = 4

How often should a national survey be carried out?
59 answered.

- Annually = 37
- Biannually = 20
- Ongoing = 1
- Biennially = 1.

What would be an acceptable time gap between the collection of feedback and the results being published?
42 answered

- 6 months or less = 30
- 6 months to a year = 6
- A year or more = 6

3 Thematic Analysis

3.1 Survey Sampling and the Spatial Level of Reporting the Findings

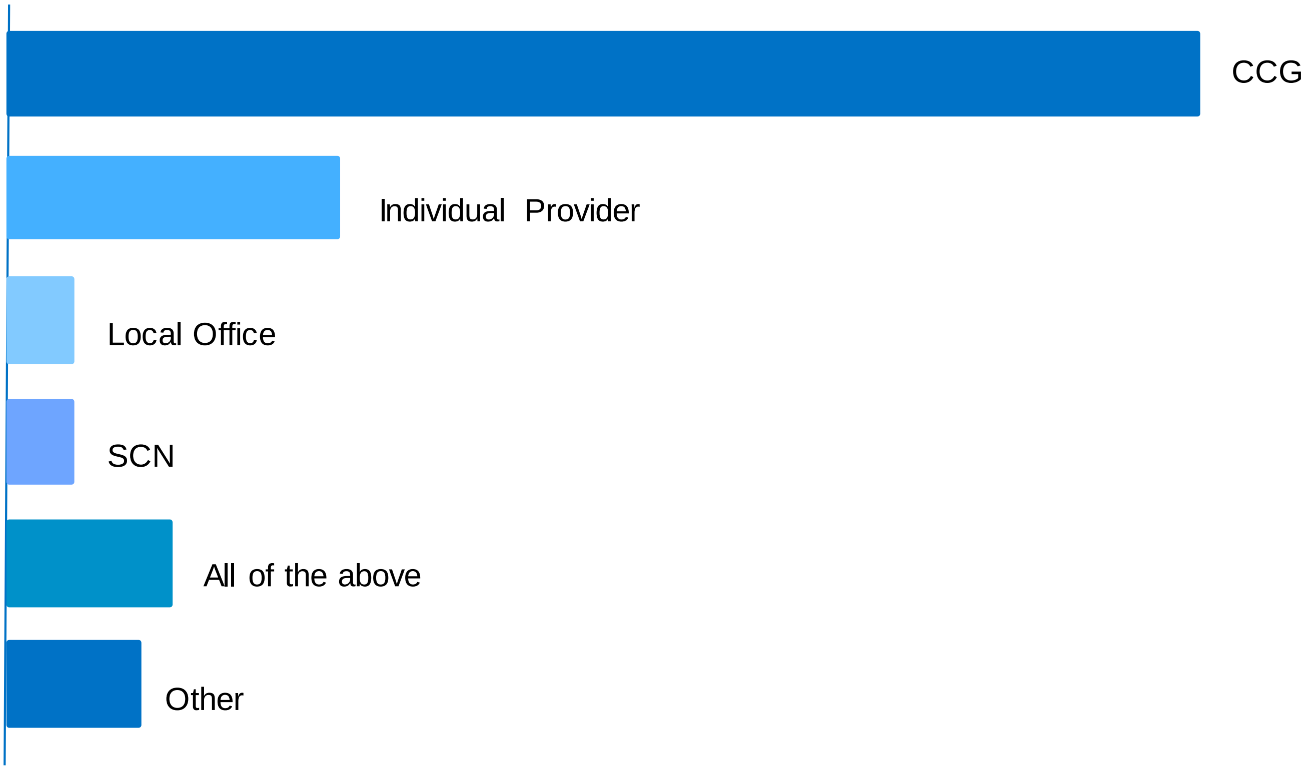
The majority of respondents would find a more local level of VOICES-SF findings better supportive of service improvement.

Although respondents found the VOICES-SF survey a useful resource, the majority of responses demonstrated that, without additional local data, it was difficult to use VOICES-SF data for service improvement. The majority of respondents highlighted the shortcomings of the VOICES-SF survey not reporting data at the level of local services:

> “It is useful to be able to have this as a benchmark, but it would be even more useful to have it at a more local level which would allow more local planning”

> “It covers too large an area to make it really meaningful when trying to look at gaps in service provision”

The level at which the VOICES-SF survey findings are reported can be identified as the most prominent issue of the consultation. Of the 59 responses to the question on reporting levels, 36 wanted CCG level reporting, 10 for reporting at the level of individual provider, with both local office and SCN level reporting identified by 2 respondents apiece. 5 respondents thought that all levels should be made available. 4 answered this with alternatives.



4 of the respondents were opposed to any changes in the way that the VOICES-SF survey is currently reported and would like to see it remain at a national level. These respondents recognised that any future changes may endanger the current data set, for which they have much use, and were conscious that data specific to locality might make it easier for scapegoating in the national press:

> "Often the media pick up individual stories of poor end of life care"

> "[Local level reporting] would lead to finger pointing"

> "Areas performing badly may be those that are badly led and mismanaged with the most limited funds, undermining their already demoralised staff"

The respondents who were cautious of this still displayed an understanding of the benefits of localised data; that which might enable the sharing of ideas to support good practice, for instance. Despite the negative connotations which come with highlighting bad practice, locally relevant data could evidently do much for the positive image of the health service, too.

The overwhelming majority of respondents did identify the need for reporting at a local level, namely for the VOICES-SF survey data to be made available at CCG level. Respondents told us that this would better inform commissioning decisions on what works (and doesn't work) for end of life care and propel service improvement. The pros and cons of CCG level data that our respondents identified are grouped in summary below:

- The respondents thought that CCG level reporting would be an adequate size: not so large as to be vague, but focused enough to highlight gaps in service provision. This would enable an appropriate overview of the many services involved in end of life care: "you need feedback by small enough localities to see what the overall experiences are for patients and be able to see where gaps are."

- As many sought to underline: CCGs are largely responsible for commissioning end of life services. This level of data would "inform commissioning decisions and planning of services", but would also lead to greater accountability when it comes to instances of bad practice: by allowing services to correlate the quality of care with funding.

- Many respondents thought CCG level reporting would mean commissioning decisions could be made with greater confidence. They suggested that this would in turn have implications for commissioning efficiency and effectiveness.

- As some pointed out, not all providers are commissioned by CCGs and, with CCG boundaries often changing, not all providers in a locality fall under the same CCG.
    - In light of the above – many pointed out that several services fell under Health and Wellbeing Boards, and that this needed to be taken into account.

In particular instances, however, it was demonstrated that CCG level data would not entirely support the planning and delivery of services for individual providers. Some respondents fed back that CCG level reporting is more inclined to identifying quanitity rather than quality and that providers would, as a result, be asked to do more rather than do better.

Some respondents, too, questioned how powerful the feedback would be if it were only relevant to CCGs. With evaluations of end of life care having a strong emotive capacity, respondents suggested that VOICES-SF data should be appropriate to individual providers for its potential to be realised.

Many respondents, however, were aware that the reporting of results at provider level may endanger patient confidentiality:

> "There are clear potential issues with anonymisation"

> "Reporting at GP practice or care home level will certainly be impractical if results are to remain confidential: the numbers of responses available will be far too small for many practices."

Some respondents did identify reporting at the level of Strategic Clinical Networks (SCN) as important. As many or more respondents, however, underlined the potential shortcomings of SCN level reporting:

> "SCN level is too far removed from providers"

> "SCN/local areas are less helpful as they don't commission eolc [end of life care] services".

Overall, the vast majority of end of life care stakeholders who responded to the consultation would prefer VOICES-SF data to be reported at a more local level, with CCG reporting preferred. This supports the recent shift in end of life care away from a 'one size fits all' model. As each individual should be supported in end of life by care that is relevant and specific to them, the majority of respondents have expressed in this consultation that they would also like to be supported by data that is relevant and specific to them.[5]

Whilst all respondents were under the impression that a change to the reporting was feasible, they also recognised the need to increase sample size in order to ensure reliable data:

> “It would be of benefit if there was a larger sample size to enable more detailed analysis at locality level.”

> “Yes [it is feasible to report at local level] but recognise that sample size would need to be increased to ensure sufficient numbers”

One respondent, a commissioner, had attempted to directly replicate the VOICES-SF survey at CCG level only to find that the current methodology and sample size did not allow them to do this. Respondents were also aware of the financial and other implications of this: that a larger sample size would in turn require additional funding, and that the frequency of the survey may well have to change in order to accommodate this:

> “We understand that the most recent VOICES survey had a sample size of just under 50,000 and achieved 22,000 responses. This is relatively low for disaggregation to CCG level because it equates to around 100 responses per CCG: this corresponds with confidence intervals on estimates of up to ±10%. Higher reliability data would obviously be preferable but this will be a trade off against costs. A larger sample would be needed to disaggregate results.”

> “[There would be] issues with sample sizes, and measures to mitigate this would be crucial, whether the outcome was a less frequent survey with a larger sample size, or publishing CCG data only every two years.”

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[5] That each person is seen as an individual is a key ambition of The National Palliative and End of Life Care Partnership (2015).

3.2 Use of the survey findings

The majority of respondents found the current VOICES-SF survey data to be of limited value when considered in isolation, but proved more useful when the findings could be contextualised through additional local data.

In the opening questions respondents identified the current VOICES-SF survey as useful, being the only end of life care resource that is available at national level:

> "Whilst it is not perfect, we consider it to be the best available evidence and an invaluable resource until there is a more detailed and comprehensive resource in place"

> "How else can we know whether the half million people dying each year are getting good care? It will become increasingly more relevant, not less, over time"

The respondents identified a variety of uses for the survey, including that of underlining the importance of end of life care services:

> "[VOICES_SF] is a positive move to both recognising and reporting on the things that help and things that don't work around end of life care [and] a useful approach to opening public discussion around death and dying"

> "It acts as a catalyst, provides motivation for those who want to improve the standards of care"

> "It has been very useful in order to educate population, to get more funding and to sensitizing commissioners and politicians."

Many of the respondents pointed to the application of the VOICES-SF survey as a training and information tool that has helped to stimulate discussion, develop staff communication skills and contextualise first-hand experience. The consultation showed that the VOICES-SF survey has been used in a number of different settings: by researchers and academics; in presentations, public affairs, at board meetings and by lobbying groups.

Respondents found the survey most valuable when it was used specifically for local service improvement by comparing its data with the findings from other local data collections. This was particularly the case for larger organisations such as NHS Trusts, which have access to supplementary data about local end of life care from bereavement services, local patient experience surveys and other sources:

> “Many of the providers are undertaking local post-bereavement surveys, but without the national VOICES, it is hard to contextualise findings.”

> “The 2010 survey provided evidence about the quality and experience of care in hospitals in terms of the varying quality of care found in different settings which, with hindsight, taken alongside other evidence about staff training and confidence levels, amounted to a warning about the way the LCP was being used”

Using VOICES-SF data against local feedback, providers were able to identify areas for improvement by comparing local findings with the national averages for satisfaction with service availability, access, and experience.

However, respondents indicated that, without local data to hand, the VOICES-SF survey was of limited use:

> “[VOICES-SF is] Interesting. Not specific enough to each area or organisation”

> “The current format does not allow us to extract our own local data.”

> “The lack of data available at local level… limits the usefulness of the information from the perspective of regulation and quality improvement.”

> “It shows some of the trends but it has been difficult to access very localised data to find out the real areas for improvement locally.”

In conclusion, respondents generally indicated that the VOICES-SF survey was useful, particularly as an educational tool or introduction to end of life care in general. Although there was evidence that VOICES-SF survey data could be used to drive service improvement, this was often difficult without information about local services to compare it to.

3.3 Local Feedback

Many local organisations have systems in place for collecting information about end of life care.

Two questions in the consultation asked respondents to provide us with information about local sources of feedback: what examples of local feedback tools are there, and how they are used alongside the VOICES-SF data.[6]

Although some respondents indicated that the VOICES-SF survey was the only feedback resource available to them about end of life care, the majority used the VOICES-SF survey alongside locally-collected feedback and other service information:

> “[We] cross reference our local survey responses against the regional/national data”

> “These together can give indicators of good or bad services. From there, we can further refine models of care.”

Many, too, were in the process of commissioning local feedback:

> “We have just commissioned care of the dying evaluation survey which 18 organisations are participating in so will use as a supplement”

> “We have commissioned a local community needs assessment to supplement data and encourage patient stories. Commissioned University to research appropriate feedback tool to measure the impact of hospice services and ascertain optimum feedback tool and timing”

While the value of local data collections to supplement the VOICES-SF survey was clear to local service providers, many respondents were aware of ethical issues around surveying bereaved people at multiple touchpoints and hence were cautious about collecting too much data:

> “[As] the data isn't available locally providers are having to do their own surveys which I don't think is good given a bereaved person may receive more than one survey.”

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[6] Please see appendix for full list of local feedback methods that our respondents highlighted.

3.4 The Person Giving Feedback

The respondents thought that other perspectives should be explored.

The respondents generally agreed that the feedback obtained from the registrant of the death does not provide a rounded enough perspective of the quality of care in the last 3 months of life. It was this section of the consultation where the complexity of this broader issue – the personalisation of dying, of who it effects and when – was at its most pronounced. Whilst many respondents thought that the views of the bereaved should remain the central measure of end of life care, many were also critical that capturing this perspective alone did not address the far-reaching effects of death.

The issue centred on the feasibility of including feedback from the person in receipt of care. When asked about the advantages and disadvantages of asking the bereaved in comparison to asking the person receiving end of life care, respondents provided a wide variety of answers:

	Asking the bereaved	**Asking the person in receipt of care**
Pros	Has a valid contribution regardless – all data is useful data.	It is the best way of understanding patient experience directly.
	The bereaved person wants what's best for the patient.	The patient best understands their wishes.
	Is a vital source of information in cases where the dying person lacks capacity.	Would have a much better recall of information. (dependent on advancement of illness/condition)
	Is particularly necessary for the way that we comprehend the last few days of care – when the person in receipt of care is not fully aware of what is occurring to them.	It would eliminate much of the current time gap between the point of care and the publication of results – as the timing is due to the need to give the bereaved person time post-death.
	Is likely to have a better idea of the co-ordination of care.	Would form part of the process whereby the family understands the needs of the dying person.
	Asking the bereaved, too, will help break the taboo of not talking about dying.	Would provide a critical counterweight to the bias of the bereaved (and vice versa).
Cons	Their opinion may well be clouded by grief.	The opinions of the dying person as much as the bereaved may be coloured by a sense of loss.
	It is not certain that the registrant of the death will be the closest person or have the best idea of the care administered.	There are numerous ethical considerations that need to be navigated with the utmost caution and sensitivity.
	With a significant time lapse from the point of care, their views may well engender memory bias.	There are issues of prognostication – how do you know that someone is dying? How do they know that they are? How will they react to being asked about care in such a situation?
		The dying person may not want to compromise the standards of care they are receiving by offering up either criticism or praise.
		They may be in denial of their condition.
		They may lack capacity.

When asked whether the bereaved person or the person in receipt of care should be asked for feedback, the majority of respondents suggested that both should be asked. They understood the ethical and practical implications of such a change, but believed that cross referencing the two perspectives would provide a more reliable and better detailed volume of feedback.

Several respondents, however, pointed out that asking the person in receipt of care would have to be handled sensitively and thought that asking the bereaved was the safest option. Some respondents also identified the issue of prognostication when asking the person in receipt of care for feedback – namely that it is easier to determine that a cancer patient is nearing the end of life than it is for most other types of patient. As one of the respondents put it:

> “We are also concerned that asking people in the last three months of life would skew the survey towards the experiences of people with cancer, since this is the only condition where prognostication is even remotely accurate… so we would miss out on hearing about the experiences of people without specialist palliative care support.”

Nonetheless, most respondents felt that feedback should be sought from both the patient and the carer. In some instances respondents thought that this should not stop at simply asking the bereaved person or the person receiving care. Respondents also thought that others should be asked to provide feedback: under 18s, the official next of kin, a close friend, and a relevant clinician (GP, district nurse, main carer or consultant). Moving to include under-18s was passionately called for by a significant number of respondents, particularly from those delivering services for children and young people.

Linked to this, the majority of respondents thought that the VOICES-SF survey should include the possibility of providing feedback that captures personal experience, as opposed to focusing only on the treatment and care administered to the patient. 52 out of the 57 who answered thought that the person supplying feedback “should also be asked to give feedback on their own experiences as a relative, friend or carer”. Symptomatic of this, a significant volume of responses asked for more free text boxes to be made available:

> “It is important to understand some of the stories behind the tick boxes”

> “The current survey will be helpful for data collection and analysis, but doesn’t provide much space for more substantive interpretation of these statistical results”

Widening the perspective on the quality of end of life care - by adding to the source of feedback and better capturing personal experience – is evidently something that respondents thought would help them to better understand who end of life care affects, and how.

3.5 Survey Frequency

Whilst there was a range of views on the frequency at which the survey is carried out, respondents thought that the level at which the survey findings are reported is more important.

When asked about the frequency with which the VOICES-SF survey should be carried out there was a broad spectrum of responses. As above, a lot of responses recognised the relationship between survey frequency and sample size.

It is important to stress, however, that the majority of respondents (37 of the 59 who answered) believed that the VOICES-SF survey should be carried out annually (as it currently is). Those who tended to hold this opinion often belonged to larger institutions - NHS trusts, large research bodies and prominent.

A significant proportion of respondents (20 of the 59 who answered) on the other hand, believed that the annual reporting of results was not sufficient and that the survey should collect data biannually. Those who sought a more frequent reporting of the VOICES-SF survey tended to be smaller institutions – hospices, small charities and think tanks.

It is evident from this that the VOICES-SF survey does not do enough to support the smaller end of life care institution. When questioned about the importance of survey frequency in relation to the level at which the survey findings are reported at, the respondents overwhelmingly prioritised the level at which the findings were reported – indicative that more local data would go some way to correcting this imbalance.

3.6 Time Gap Between the Point of Care and the Publication of Results

Respondents thought that the time between the point of care and the publication was too long, and should be shortened.

All of the respondents bar one thought that the current time gap has a detrimental effect on the usefulness of VOICES-SF data. On the one hand, the delay was acknowledged by the respondents as appropriately mindful of best practice/ethical considerations:

> “The risk of upsetting bereaved relatives is much, much lower if they receive a letter addressed directly to them some months after the death”

> “The survey is very sensitive and compassionate”

Yet on the other hand respondents were aware of the effect this time gap has on being able to apply the VOICES-SF data for service improvement:

> “Delayed data means delayed progress”

> “The lengthy delay in reporting would carry a risk the remedial actions are not instigated where they are needed. It would also be a missed opportunity to spread good practice where it exists”

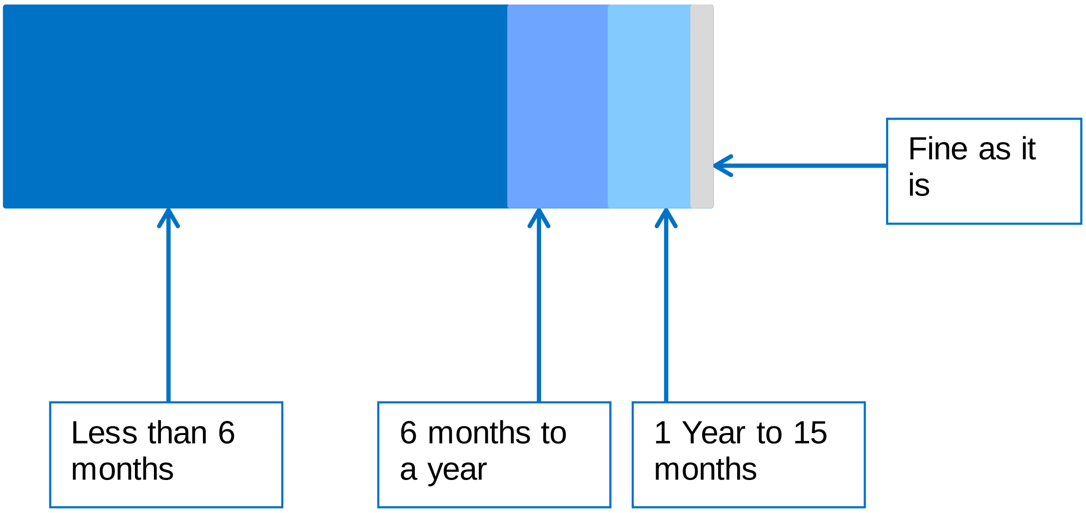
There are several key reasons for this that the consultation responses indicate:

- **The perceived pace of change in the NHS at the current time.** With the VOICES-SF survey data published 15-21 months after the care to which it relates is received, coupled with the potential for rapid change in services within that period, respondents felt that the VOICES-SF reporting was too often out of date and of limited use as a result. Respondents wanted something closer to real-time feedback.

- **It weakens the accountability of the CCGs.** Many respondents expressed their frustration that the time gap was used as a reason to disregard VOICES-SF findings: “commissioner’s main excuse for not developing services is that the data is out of date”. These respondents often went on to point out that the indicators do not move much year on year and, with baseline data to hand, the VOICES-SF survey was the best way of capturing what incremental changes had occurred or needed to be applied.

- **It is not consistent with local feedback that is closer to real time.** The time lapse often means that the ability to benchmark this data – its strongest asset - is hampered as it does not align with the faster and more convenient local feedback tools. This lack of synchronisation further damages the use of the VOICES-SF survey data.

As a result, the majority of respondents would like to see the VOICES-SF survey published sooner after the care it relates to. The majority of responses (30) indicated that they would like to see publication shortened to 6 months or less after care. Those who requested that publication occur 6 months to a year after care or a year or more after care were equal in number (6 each). Almost all of the respondents were happy for any changes in the survey methodology to accommodate this.



4 Conclusion and Recommendations

Since the VOICES-SF survey was commissioned in 2008, the landscape of end of life care has shifted. The 2015 National Palliative and End of Life Care Partnership states in their Ambitions:

> “[The 2008 End of Life Care] Strategy was developed in a different world and a different NHS to the one that exists now".[7]

The responses to this consultation not only represent the broad spectrum of individuals and institutions who are interested in feedback on the quality of end of life care, but also indicate where consensus lies for updating the survey.

- **The VOICES-SF survey is a valuable data source that provides useful information to those involved in the commissioning or delivery of end of life care.** Despite this, it is of limited use locally, and many providers are having to use existing local data or undertake local feedback collection in order to supplement the national survey data.

- **There is a need to change the level at which the VOICES-SF findings are reported.** This was where the greatest consensus lay, with the majority of respondents highlighting the shortcomings of exclusively national level reporting and how more locally relevant data would help drive service improvement.

- **Changing the level of reporting should take priority over any changes to the frequency of the survey.** Although there was some evidence that a more frequent survey would better support smaller end of life care providers, respondents recognised that changes to the level of reporting (and the costings of an increased sample size to support this) were of a greater need.

- **The VOICES-SF survey should seek feedback from additional sources.** The majority of respondents thought that the VOICES-SF survey should explore the possibility of asking the person in receipt of care. They also thought that feedback on personal experience as opposed to just treatment and care should be included. Calls for more free text comments reflect this.

- **The time gap between the point of care and the publication of results should be shortened.** The majority of respondents thought that the current time gap stood in the way of service improvement efforts. Respondents did recognise, however, the ethical implications of soliciting feedback closer to the point of death.

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[7] Ambitions, The National Palliative and End of Life Care Partnership (2015).

NHS England would like to thank all of the respondents for their submissions to this consultation. It has been invaluable in helping us to understand the merits of the current approach and the changes desired to make the survey more effective. We will consider the opinions expressed in the consultation in line with any future work that is undertaken in the measurement of end of life care.

If you would like to further discuss the consultation please contact the Insight Team at NHS England: england.insight-queries@nhs.net.

5 Appendices

5.1 Appendix 1: The Consultation Questions

1. Use of the survey findings:
    a. Who is using the information received through the national survey of bereaved people? Please state the organisation or job role if applicable.
    b. How is the information used?
    c. How useful is the information from the survey?
    d. What do you think the key purpose of the survey is?
        i. Comparable data?
        ii. National level results?
        iii. Data for service improvement?
        iv. Other? If selected other please specify.
    e. What should the key purpose be?

2. Survey questions/sections:
    a. Which questions or sections of the survey are particularly useful or important?
    b. Which questions or sections of the survey are less useful or important?

3. Are there any ways in which the national survey could be improved to support further use? For example, areas which the national survey does not cover but that would be useful.

4. Local feedback:
    a. How is the national survey data used alongside local sources of feedback?
    b. Do you have any examples of local feedback methods being used to supplement the national survey findings, such as local surveys or patient stories?

5. The person giving feedback:
    a. Should the bereaved person be asked for feedback on the quality of care provided to a friend or relative in the last three months of life OR should the person receiving care within the last three months of life be asked to give feedback?
    b. What are the pros and cons of asking the bereaved person versus asking the person receiving care within the last three months of life?
    c. Are there any other stakeholders which you think should be asked to provide feedback other than the bereaved person or the person receiving care within the last three months of life? For example someone who knew the deceased, other than the registrant.

   d. If you think that the bereaved person should be asked to provide feedback, do you think that they should also be asked to give feedback on their own experiences as a relative, friend or carer of the person in the last three months of life and into the bereavement?

6. Reporting the national survey findings – we are inviting views on the level at which the findings should be reported at. This could be at:
   a. CCG level (there are 209 CCGs). CCG level results would provide survey results for the population served by each CCG in England.
   b. Strategic Clinical Network (SCN) level. SCN level results would provide survey results for the population served by each SCN.
   c. Local office level (new NHS England structure). There are 12 NHS England local offices.
   d. Individual provider level – at hospice, hospital, GP or community site. Data would need to be collected here and then passed onto a national level.
   e. Any other level which you feel would be useful.

7. It is important to note that, at each of these levels (CCG, SCN, Local office, Individual provider or otherwise) the cost of altering the sample size would need to be considered.
   a. Which of these levels do you think is most important?
   b. What benefits and/or potential negative consequences might there be for providing results at this level?
   c. Do you think it is feasible to report at that level?

8. Survey frequency:
   a. How often should a national survey be carried out?
   b. What is more important, the frequency of the survey or the level at which it is undertaken?

9. The time gap between collection of the data and the issuance of the results:
   a. What impact does the delay between the information being collected and the results being published have on their usefulness for monitoring, evaluation, decision making and service improvement?
   b. What would be an acceptable time gap between the collection of feedback and the results being published?
   c. If you feel that there should be a reduction in the time gap, would you be content for the survey methodology to be changed to achieve this?

10. If there is anything else you would like to tell us about the national survey of bereaved people (VOICES) please include this with your consultation response.

5.2 Appendix 2: Examples of Local Feedback

- FAMCARE and FAMCARE II – used to measure family satisfaction with advanced cancer care. The tool was originally developed for use on inpatient units, measuring different areas such as availability of care, physical patient care, psychosocial care and information giving. It can be given to family members while a patient is receiving palliative care or at some point after a patient's death, and can be completed in interview format or alone. Validity evidence for the tool has been gathered in a number of different settings, including inpatient units, outpatient cancer clinics and home care.[8]

- CODE – Care of the Dying Evaluation, a 40-item self-completion post-bereavement questionnaire, focused on the last days of life and based on key components of best practice for care of the dying.

- Feedback collected from the TRANSFORM team - The TRANSFORM Programme was developed by the National End of Life Care Programme, in partnership with the NHS Institute for Innovation and Improvement and health and social care professionals across a wide range of organisations. It was established in response to the challenges identified in the Department of Health's 2008 End of Life Care Strategy. It is specifically designed to equip hospitals with a comprehensive service improvement framework to ensure consistency, reliability, safety and effectiveness in end of life care.[9]

- Independent suppliers – permit individual providers to collect, manage and analyse data on patient experience via an independent private body.

- Data from local bereavement services.

- Data from complaints and compliments.

- Data from on-site or site-specific surveys (inpatient, ward-orientated etc.)

- Local listening events and feedback forums.

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[8] *What is Famcare/ Famcare-2?*, http://www.palliative.org/NewPC/professionals/tools/famcare.html [Accessed 27/10/2015]

[9] *Transforming End of Life Care in Acute Hospitals*, http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/acute-hospital-care.aspx [Accessed 27/10/2015]