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DEPARTMENT *of*  
MEDICINE



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Experimental Medicine Division

# BRIEFING NOTES ON THE PATIENT EXPERIENCE OF CARE QUESTIONNAIRE PROJECT

Revised February 2018

## Introduction

These briefing notes are aimed at those providing palliative and end of life care services across settings who are interested in registering to take part in the phase two of a project to test the use of a patient experience of care questionnaire.

In phase one of the project the team at Oxford University trialled the questionnaire with a test community including hospital, hospice and community services, and gathered information and learning focussed on how it had been used locally. The results were encouraging, and a second test phase is now taking place with a slightly modified questionnaire. As before we are inviting expressions of interest from organisations to join this community of test sites, and we are looking for providers of both generalist and specialist services across settings. It is not our intention to have access or to use the findings from patients and individuals, as this information will remain with the participating organisation to inform their localised service improvement activities. At the end of this phase we will again ask for feedback from these participating organisations who have registered as part of the community on their use of the questionnaire, take the opportunity to ensure it remains fit for purpose and focus more on how local findings have been used to inform service improvements.

## Background

The National Survey of Bereaved People (VOICES SF - Views of Informal Carers – Evaluation of Services (Short Form)) is an annual survey designed to look at the quality of end of life care and collects information on bereaved people's views on the quality of care provided to a friend or relative in the last 3 months of life, for England. The survey has now been run for 5 years and was commissioned by the Department of Health in 2011 and 2012, and NHS England from 2013. It is administered by the Office for National Statistics (ONS). The questionnaire is sent by post to the person that registered the death of the deceased (usually a relative or friend of the deceased) between 4 and 11 months after the death.

Whilst activities may have been undertaken locally it is fair to say that a consistent approach for seeking feedback from patients and individuals receiving palliative and end of life care themselves has not been developed. Obtaining patients and individuals views on care in the last days of life may be difficult, nor appropriate, but comments from some would indicate that they would like to be asked for feedback earlier in their declining health trajectory.

Many organisations do have satisfaction questionnaires available and in use, however these mainly relate to feedback against expectations and are often used to provide information/data for benchmarking or making judgements. This questionnaire differs and aims to offer a standardised tool that can be used across care settings, and questions have been carefully developed to capture **experiences** of care which should be used only to inform service improvement initiatives. We recognise certain tensions will exist when using the questionnaire, such as anonymity versus being able to quickly follow up if the care experience is reflected as poor for a patient or individual, making sure it is the patient or individual's experience being recorded away from the influence of staff or family/friends etc. We do not have all the answers on how the questionnaires should be used – we have learnt from phase one and a guide based on the learning will be provided to support the test community in phase two. It is our hope that the collective learning that arises from both phases of the project will be able to benefit everybody.

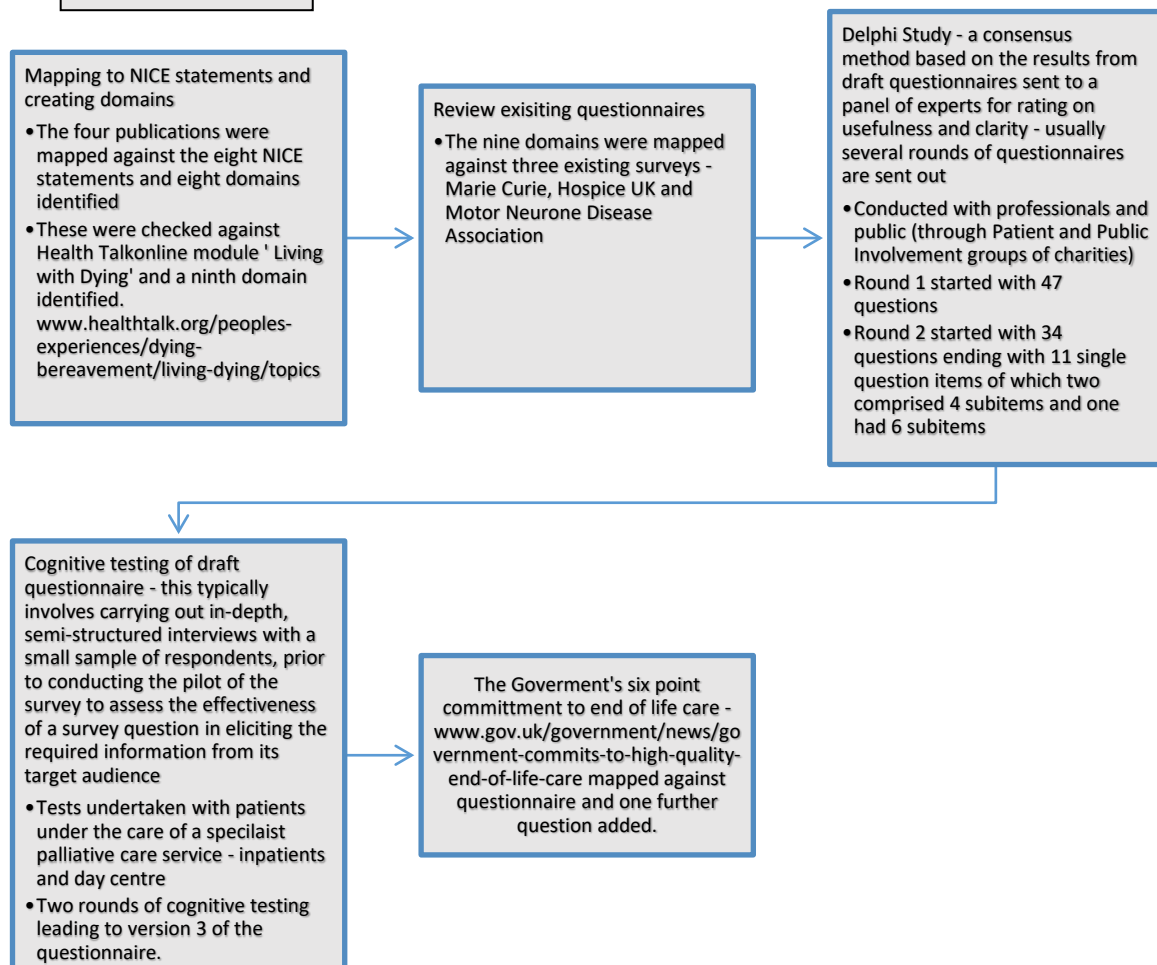
## How the questionnaire was developed

At each stage of its development the questionnaire has been informed by what matters most to people about their experiences of end of life care. Initially key national publications were referenced with at least three having had extensive public and professional engagement. The starting point was the NICE Quality Standard for End of Life Care (2011), which had a number of quality statements that

patients/individuals could usefully comment on, as opposed to those which rely on infrastructure or facilities. These are listed in **Annex 1**. The following formal publications on palliative and end of life were then used to develop the questionnaire by mapping their content and findings against the NICE statements:

- ❖ Every Moment Counts (Feb 2015) - [www.nationalvoices.org.uk/publications/our-publications/every-moment-counts](http://www.nationalvoices.org.uk/publications/our-publications/every-moment-counts)
- ❖ Priorities for Care of the Dying Person (One Chance to Get It Right (2014)) - [www.england.nhs.uk/ourwork/qual-clin-lead/lac/](http://www.england.nhs.uk/ourwork/qual-clin-lead/lac/)
- ❖ What's Important to Me – Review of Choice in End of Life Care (2015) - [www.gov.uk/government/publications/choice-in-end-of-life-care](http://www.gov.uk/government/publications/choice-in-end-of-life-care)
- ❖ Dying without Dignity: Ombudsman Report (2015) - [www.ombudsman.org.uk/publications/dying-without-dignity-0](http://www.ombudsman.org.uk/publications/dying-without-dignity-0)

**Diagram A - Process**



### Domains Identified

1. Communication including offering information appropriate to stated needs and preferences
2. The patient/individual's preferences and involvement in assessment and planning decision making
3. Physical and psychological needs addressed – including access to equipment and medicines
4. Social, practical and emotional needs addressed
5. Spiritual and religious support offered
6. Coordinated care and access to the right service at the right time delivered by competent practitioners who know the patient/individual's condition, care plan and preferences
7. Prompt and effective urgent care appropriate to needs and preferences

8. People important to the patient/individual are involved in their care and decision making (if included in preferences and wishes) and their needs are considered
9. A safe environment supporting needs and preferences

**Annex 2** shows the questionnaire used in phase one and how each of the questions relate to the domains and the six-point Choice Commitment.

### Next Steps

Phase two will be from February 2018 to 31<sup>st</sup> July 2018, when organisations interested in joining the test community will be able to register with the project team at Oxford University. As with phase one we are seeking a range of care settings and services to be able to fully test the questionnaire including hospitals, hospices, care homes, community and care at home services. Those registered will have access to a support coordinator for the duration of the project.

### The conditions of taking part in this trial phase are:

- ❖ At the end of July 2018, a completed feedback template should be returned to us.
- ❖ Assurances that a quality improvement approach is adopted when using the questionnaire to ensure the findings drive service improvement.
- ❖ During this test phase, the questionnaire must not be changed other than the preamble as indicated on the questionnaire. If you want to add questions we would like to know what they are on the feedback template.
- ❖ The patient/individual should either be able to complete the questionnaire themselves or have their responses recorded ideally by someone who will not influence their response.

For patients/individuals to feel comfortable to be involved, be able to give honest responses and not risk the perceived 'consequences' of upsetting or annoying those caring for them, ideally the questionnaire and the processes for undertaking it, and collecting on completion, should provide anonymity. However, this must be carefully considered as it limits the ability for the service to respond, and real time or near real time feedback can be valuable for the well-being of the patient/individual who has completed the questionnaire highlighting they have concerns about their experience of care. We do not wish to be prescriptive about this, but it is important that at the time of being invited to respond to the questionnaire it is made clear to the patient/individual whether or not their responses will be anonymous and what will happen with the findings. We will be seeking examples of how this is managed locally in our feedback template.

### What we are seeking to understand

The feedback template covers a number of areas where we are seeking information on how you have used the questionnaire and the processes/governance you put in place as well as how you have used the findings to drive service improvement. Detailing problems and issues you may have faced and how you were able to address these will help us to continue to provide guidance to others. The template for phase two will be provided to those registered. Areas it will cover include:

#### a) Interaction with patients/individuals:

- ❖ What criteria, if any, did you use to select patients/individuals to ask if they would be willing to answer the questions?
- ❖ How many did you approach in the period you decided to undertake the survey in, how many agreed to take part, and how many completed questionnaires did you have returned?
- ❖ If they did not agree, do you know their reasons?
- ❖ If the patient/individual was not able to physically complete the questions how did you manage to record their responses e.g. use of local patient group representatives, volunteers?
- ❖ How were you able to limit the influence of staff and family/other carers on the responses made?

#### **b) Governance/Processes:**

- ❖ Did you provide a covering letter explaining the purpose of the questionnaire and were you clear on how you would be using the information gathered?
- ❖ How did you select the person responsible/managing the process for approaching patients/individuals to undertake the questionnaire?
- ❖ How did you distribute/collect the questionnaires? Was the exercise undertaken across a whole unit at one time, and how many times did you run it, did you use a sampling or 'snap shot' approach, or was it undertaken on consecutive admissions/referrals/visits over a period of time?
- ❖ How did staff react to the questionnaire being undertaken?
- ❖ How are you analysing the findings?
- ❖ How did you balance the need for anonymity versus being able to respond if it became clear that a patient/individual was not having a good experience of care?
- ❖ Any additional governance arrangement required locally?

#### **c) Using the findings:**

This will be the main focus of feedback required from phase two:

- ❖ How and when did you feed back the findings to staff?
- ❖ How have you used the findings to improve care?

#### **d) The questionnaire:**

Although we have slightly modified the questionnaire following phase one feedback we will still want to know:

- ❖ Are there any questions or parts of the questionnaire that are more/less useful than others?
- ❖ If you could make future changes to the questionnaire what would these be and why?
- ❖ If you added questions to the current questionnaire what were they and your reasons?
- ❖ If you had problems with any aspect managing the questionnaire process what were they and were you able to find solutions, if so what?
- ❖ Will you continue to use the questionnaire, or modified version, after the trial phase? Please give reasons for your response.
- ❖ Any other tips?

A report on the summary findings and learning from phase one is now available.

If you are interested in participating in the project over the next six months please contact me at [Bee.Wee@ouh.nhs.uk](mailto:Bee.Wee@ouh.nhs.uk) or Glenis Freeman at [gjfreeman@btinternet.com](mailto:gjfreeman@btinternet.com) who will be supporting the project and be the main contact point.

Once you have registered the project team at Oxford University will send you a clean version of the questionnaire, a guide for using it in phase two, and a copy of the feedback template so that you are aware of our requirements at the end of the test phase.

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**National Clinical Director for End of Life Care, NHS England**

**Consultant in Palliative Medicine, Sir Michael Sobell House, Oxford University Hospitals NHS Foundation Trust**

**Associate Professor and Fellow of Harris Manchester College, Oxford University**

**Visiting Professor, Oxford Brookes University and University of Worcester**

## ANNEX 1 – Related NICE Quality Standard Statements

### Quality Statement 2: Communication and Information

People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

### Quality statement 3: Assessment, care planning and review

People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

### Quality statement 4: Holistic support – physical and psychological

People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

### Quality statement 5: Holistic support – social, practical and emotional

People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

### Quality statement 6: Holistic support – spiritual and religious

People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

### Quality statement 7: Holistic support – families and carers

Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

### Quality statement 8: Coordinated care

People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

### Quality statement 9: Urgent care

People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

## ANNEX 2 - Experience of Care Questionnaire used in Phase One with Domains and Choice Commitments mapped

Please answer the following questions about what your experience of care [*at home*] has been like over the last month. [*Your 'care team' may refer to your GP, nurses and other health and care staff who look after you, including specialist doctors and nurses*]

**Note:** text in brackets can be locally tailored to the care setting and care team involved.

Please write in the box below here whom you will keep in mind as your 'care team' as you answer the questions. There is no right or wrong answer – it's just helpful for us to know who you are referring to:

In this context, my 'care team' means:

**Please answer the questions by ticking the box that most applies to you.**

In the last month, how often have you felt ....

		Always	Most of the time	Some times	Almost never	Never	Not required
a.	...that you have had enough opportunity to ask questions?	<b>D1: Communicated with / information offered</b> [Choice commitment: 2 <sup>nd</sup> point]					
b.	...that you have been able to talk with members of your care team as openly as you would wish?	<b>D1: Communicated with / information offered</b> [Choice commitment: 1 <sup>st</sup> point]					
c.	...that you have been as involved as you would like in decisions about your care and treatment?	<b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b> [Choice commitment: 2 <sup>nd</sup> point]					
d.	....that things that are important to you are considered in planning your care?	<b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b> [Choice commitment: 3 <sup>rd</sup> and 4 <sup>th</sup> points]					
e.	...that your care team works well together?	<b>D6: Coordinated care, and access to right service at right time / Practitioners aware of person's condition, care plan and preferences, and know what (and how) to do</b> [Choice commitment: 4 <sup>th</sup> point]					

**(1). In the last month, how often have you felt.....**

		Always	Most of the time	Some times	Almost never	Never	Not required
f.	...that your care team treats you with respect and dignity?	<b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b>					
g.	....that the care and support provided by your care team meets your physical needs (e.g. pain, breathlessness, nausea, mobility)?	<b>D3: Physical and psychological needs addressed, including access to medicines and equipment</b>					
h.	...that the care and support provided by your care team meets your emotional needs (e.g. feeling low, feeling worried, feeling anxious)?	<b>D4: Social, practical and emotional needs addressed</b>					
i.	...that your care team treats you as a whole person (e.g. takes into account your beliefs, hopes, traditions, customs, spirituality)?	<b>D5: Spiritual and religious support offered</b>  <b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b>  [Choice commitment: 4 <sup>th</sup> point]					
j.	...that your care team helps you to have as much privacy as you want?	<b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b>					
k.	....safe in your place of care?	<b>D9: Safety and environment</b>					
l.	...that when you need advice or help urgently, your care team responds quickly?	<b>D7: Urgent care received</b>					



In the last month, has your care team given you ...

		Yes, as much as I need	Yes, to a great extent	Yes, to some extent	No	Not required
a.	...information that you can understand about your condition?	<b>D1: Communicated with / information offered</b> [Choice commitment: 1 <sup>st</sup> point]				
b.	...information that you can understand about your prescribed medicines?	<b>D1: Communicated with / information offered</b> <b>D3: Physical and psychological needs addressed, including access to medicines and equipment</b>				
c.	...support to get help with your personal care (e.g. dressing, washing, eating)?	<b>D3: Physical and psychological needs addressed, including access to medicines and equipment</b>				
d.	...support to get help with practical matters (e.g. social benefits, wills, finances, legal matters)?	<b>D4: Social, practical and emotional needs addressed</b>				
e.	...support to get any equipment or aids that you need (e.g. oxygen, hospital bed, wheelchair)?	<b>D4: Social, practical and emotional needs addressed</b>				
f.	...support to do things that you enjoy (e.g. spending time with family and friends, reading, going outdoors)?	<b>D4: Social, practical and emotional needs addressed</b> <b>D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment</b>				
g.	...support to involve your family and those close to you, as much as you wish, in decisions about your care?	<b>D8: Centrality of people important to the person</b> [Choice commitment: 5 <sup>th</sup> point]				

In the last month, how often has your care team offered help and support to the people important to you (e.g. your family, friends, carers)?

**D8: Centrality of people important to the person**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Always	Most of the time	Sometimes	Almost never	Never	Not sure	Not required

Do you know whom to contact if you have any concerns or problem?

**[Choice Commitment: final point]**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yes	No	Not sure

If there is anything else you would like to tell us about your experience, including how to improve it, please use the box below to write this down.