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MEDICINE



Experimental Medicine Division

PATIENT EXPERIENCE OF CARE PROJECT

BACKGROUND AND SUMMARY OF FINDINGS

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SUMMARY OF KEY FINDINGS:

- ❖ Feedback indicates the questionnaire is usable across all settings, and minor changes are required to move to next steps.
- ❖ 18 of the 20 sites within the test community would use it again.
- ❖ No meaningful correlation between the model used locally to implement the questionnaire and completion response rates can be observed. However, six sites received more than 29 completed questionnaires each and achieved response rates above 50%, with five of these sites using a variation on a 'snapshot' approach.
- ❖ Responses remaining anonymous to try to facilitate honest and non-bias feedback was felt to outweigh the need for direct feedback unless requested.
- ❖ There is no full proof way to ensure the patient/individual completed the questionnaire or their responses had not been influenced, especially when taken home, and it is thought to be an unrealistic expectation.
- ❖ Using volunteers and administrative staff to support completion of the questionnaire can reduce influence, but it depends on their availability which can have a significant impact on numbers of individuals approached, distribution and collation processes.
- ❖ All test sites used a basic selection criteria which excluded patients/individuals if they lacked capacity, had cognitive impairment or had a clinical condition which would preclude their ability to complete the survey even with assistance.
- ❖ Analysis showed that differing selection criteria did not appear to influence the results.
- ❖ Overall staff were supportive of the questionnaire. A minority expressed concern about overburdening/approaching patients and individuals in their care, and it was suggested that low numbers being approached and completing the questionnaire could be down to an element of 'gatekeeping'.

SECTION 1 – Introduction and Background

Introduction

The team at Oxford University have developed a patient experience of care questionnaire, which as part of the development phase has already been subject to a Delphi Study, and cognitive testing with patients using an earlier draft. The next phase of the project to test the questionnaire more widely was undertaken between April and mid October 2017, and this report summarises the findings relating to this phase.

In early 2017 the team approached organisations providing palliative and end of life care services across settings to ask whether they would be interested in registering to take part in the next phase. The aim was to gather information and learning focussed on how the questionnaire had been used locally. It was not the intention for the University to have access or to use the findings from patients and individuals, as this information would remain with the participating organisation to inform their localised service improvement activities.

In October 2017 organisations registered as part of the test community were asked to complete a feedback template on the processes used for implementing the questionnaire, and how patients, individuals and staff reacted to its introduction. This has provided an opportunity to modify the questionnaire to ensure it remains fit for purpose across care settings, enable additional guidance to be developed drawn from lessons learnt, and inform the formal validation processes.

Background

A consistent approach for seeking feedback directly from patients and individuals receiving

palliative and end of life care has not been developed, although some localised initiatives may exist. Obtaining views of patients and individuals on their care in the last days of life may be difficult for staff, nor appropriate, but comments from some would indicate that they would like to be asked for feedback earlier in their declining health trajectory.

The questionnaire was developed using the NICE Quality Standard for End of Life Care (2011)¹, which had a number of quality statements that patients/individuals could comment on with validity, as opposed to those which rely on infrastructure or facilities. A number of formal publications on palliative and end of life care were used to identify domains by mapping their content and findings against the NICE statements. The questionnaire was then developed by using the domains identified.

This questionnaire differs from others used and aims to offer a standardised tool that can be utilised across care settings. Questions have been carefully developed to capture **experiences** of care which should be used only to inform service improvement initiatives. It is likely certain tensions will exist when using this 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. The University team do not have the solutions and the feedback template was designed to capture the ideas and learning from those involved who may have resolved some of these tensions.

1

www.nice.org.uk/guidance/qs13/chapter/Introduction-and-overview

SECTION 2 – Process

Over 40 organisations expressed an interest in joining the test community. They were sent:

- ❖ A briefing paper detailing the development of the questionnaire and what was expected of organisations as members of the test community.
- ❖ A sample of the questionnaire – (**Appendix A** - this version also shows how each of the questions relates to the domains that were identified during development and the six-point Choice Commitment²).
- ❖ A commitment form to sign and return, registering the organisation with the project.

On returning the registration form, the test sites were committing to:

- ❖ Sending back a completed feedback template at the end of the project phase.
- ❖ Adopting a quality improvement approach when using the questionnaire to ensure the findings drive service improvement.
- ❖ Taking responsibility to ensure any local governance arrangements needed to use the questionnaire had been agreed and in place.
- ❖ Using the questionnaire provided and not to make any changes other than tailoring the first introductory paragraph. If they wanted to add supplementary questions they were asked to detail what they were on the feedback template.
- ❖ Ensuring the patient/individual should either be able to complete the questionnaire themselves or have their responses recorded ideally by someone who could not influence their responses.
- ❖ If they could not continue as a member of the test community to inform the team as soon as possible.

25 organisations (**Appendix B**) registered between April 2017 and the end of the test phase (13th October 2017) to become part of the test community and were sent a clean Word version of the questionnaire to use. To support the test community a ‘Question and Answer’ (Q&A) was developed and three WebEx were held. All sites had access to project support should they wish to discuss any issues arising. A further workshop was held in December 2017 with representatives from the test sites to discuss the interim findings and next steps.

20 sites completed the feedback template by mid-October, and Table 1 shows the specific service areas where the questionnaire was tested:

Table 1

6 Hospitals	2 Primary or Community Care	12 Hospices
<ul style="list-style-type: none"> • 4 looked at SPC units • 1 looked at medical services for the elderly • 1 looked at the whole service, in particular those receiving SPC/EoLC screening 	<ul style="list-style-type: none"> • Community teams in the area • GP practices (not yet started) 	<ul style="list-style-type: none"> • 1 IPU • 1 IPU/Community • 1 Day Unit • 3 IPU/Day Unit • 3 Community • 3 IPU/Day/Community

The people taking responsibility locally for the questionnaire were mainly staff having a direct involvement in the care of individuals selected to be approached and usually coordinated by a more senior staff member. In many cases the completed questionnaires were sent to another part of the organisation, such as the wider Patient Experience or Quality Improvement teams to analyse.

² www.gov.uk/government/publications/choice-in-end-of-life-care-government-response

No one identified any additional major governance issues as generally the survey was incorporated into existing processes.

16 sites provided a covering letter with the questionnaire highlighting that it was optional, confidential and anonymous, and eight mentioned that either choosing to complete the questionnaire, or not, would not impact on the care they received. The majority had staff or volunteers directly handing out the questionnaire with SAEs used for return.

SECTION 3 – Using the questionnaire

Balancing the need for anonymity

When feedback was positive it was easy to give non-patient specific feedback. In most cases the covering letters used to introduce the survey included the project lead contact details enabling patients/individuals to make contact if they wanted to discuss the questionnaire or their care more fully. A small number also put details directly on the questionnaire of other patient experience groups and links to PALS, as well as the project lead, to enable patients/individuals who felt they were not receiving a good experience of care to make contact more widely to have their concerns directly addressed.

Many sites were keen to provide an optional section directly on the questionnaire for the patient/individual's name and contact details to enable a direct response to concerns raised, similar to the VOICES-SF survey. Around a third of sites wanted to be able to at least identify the care area/setting the responses related to, especially if a negative response had been given, to allow them to address the issue quickly.

Staff reaction to the survey

Support came from all sectors, with only a few expressing lack of interest or general negativity.

It was noted that whilst surveys were often used in inpatient units, they were less familiar in community settings for some staff. A small number of community staff felt it was difficult to select appropriate patients, and explaining the purpose of the questionnaire was uncomfortable. A minority of staff expressed concern about overburdening/approaching patients and individuals in their care, and it was suggested by local project leads that low numbers being approached and completing the questionnaire could be down to an element of 'gatekeeping'.

Analysing the findings, feeding back to staff, and informing service improvements

For many it was too early to provide feedback on the project template, or to staff, as they had not analysed the findings of their local survey. For some it was lack of availability of staff to undertake the analysis, and for others they were later in finishing the test phase.

Test sites who had an overall small sample size or poor response rates said it was difficult to identify plans for service improvements in any meaningful way. When responses received from the survey were all positive, it usually resulted in no further planned action other than to report the positive feedback to staff and local relevant groups and governance structures. One test site did identify that staff had not been addressing emotional needs as well as physical needs and were able to introduce improvements to support staff to deliver a change. At another site a group discussing the questionnaire did not consider the questions on some elements of support were relevant to them, however it generated discussion on how their future needs could be met which was useful.

Selection criteria and participation rates

All test sites had used basic criteria to exclude patients/individuals if they lacked capacity, had cognitive impairment or had a clinical condition which would preclude their ability to complete the survey even with assistance. This was usually determined by the direct care clinical staff. Many also mentioned that they would not approach anyone in the last few days of life.

Five test sites selected and approached all patients who met the basic criteria but usually within a set time frame, five undertook a basic sampling methodology and nine added additional selection criteria such as length of stay, number of visits by a community team or having a Treatment Escalation Plan in place. Table 2 shows the numbers approached and completed questionnaires by care settings.

Table 2

Hospital Sites	Community	Hospices
136 approached	29 approached	512 approached
63 completed	12 completed	270 completed
46% completion rate	41% completion rate	53% completion rate

Analysis showed that differing selection criteria did not appear to influence the response rates.

Support for patients/individuals unable to complete the questionnaire

A wide range of support was provided to help patients/individuals complete the questions if required, often with a mix within a test site due to the differing services being accessed. Volunteers and informal carers (taken as family and friends) providing support were mentioned most often, with members of the care team, administrative staff and senior managers/project leads also highlighted. Volunteers were generally viewed as less likely to influence responses

When the questionnaire was taken home to complete it was not possible to know if the patient/individual completed it themselves or had help, what influences may have taken place or the reasons why the questionnaire was not returned.

Suggested changes to the questionnaire

Generally, feedback on using the questionnaire in its current format was positive. A summary of suggested changes includes (Table 3):

Table 3

• The term 'care team' caused some confusion for patients/individuals – needs greater clarity
• The questionnaire was too long/wordy – 15 to 30 minutes seems a long time for an unwell person – most felt this comment came from staff rather than patients/individuals
• More free text boxes for expansion e.g. if a negative response to a question was given, such as how safe someone feels, it would be important to understand more about the reason for the response.
• Put the patient/individuals contact details on the questionnaire as optional
• An electronic version would be very useful
• Be able to identify area/ward/service the response was received from

Only six out of the 20 test sites added additional questions. These were mainly focussed around who completed the questionnaire, was it easy to complete, which care setting the response was from and the option for patient/individual's contact details.

Problems using the questionnaire

Generally, comments were related to resources, including:

- ❖ Lack of availability of volunteers/staff to support patients/individuals

- ❖ Lack of staff engagement with the project /gate keeping reducing numbers
- ❖ Lack of administrative staff
- ❖ Because the questionnaire is anonymous it is not possible to trace back negative comments

SECTION 4 – Correlation between models adopted for implementing the survey and response rates

To develop a 'User Guide' to support the wider implementation of the questionnaire it is useful to see whether any patterns or themes emerged from test sites which could increase numbers of patients/individuals approached and conversion rates to completed questionnaires.

Statistically the feedback from the test sites is not robust enough to draw any meaningful conclusions about any correlation between the response rates and the models adopted by the test community, and at best it can only be indicative. The reasons being:

- ❖ The feedback template was primarily designed to collect qualitative feedback as this was considered more important for moving to the next stage of evaluation and formal validation of the questionnaire, i.e. whether the questions, their wording and format were relevant and useful across care settings to inform future service improvement planning.
- ❖ Whilst some very high percentage response rates were experienced, the numbers approached were often relatively low and may not be representative of the total target population potentially available at some of the test sites. This could be due to staff concerns and elements of 'gate keeping' resulting in a potential bias that those approached would be most able and likely complete the questionnaire. Equally, it could be reflective of the size and limited resources available at some test sites to undertake the survey within the time frame, but it is not reliable enough to draw evidence-based conclusions.

To try to determine any correlation between response rates and models adopted to implement the survey the following factors were considered:

- a) Did the test site use additional criteria to select patients/individuals or did they include all patients/individuals?
- b) Did the test site provide a covering letter or take a personal approach to introduce the questionnaire?
- c) Did the test site undertake the survey within a specified time frame, specifically during a 'snapshot' of one month or less?
- d) Did the test site use a SAE for return of the completed questionnaire or was it collected?

Although many of the test sites had a poor sample size on which to draw any meaningful observations, it is likely their findings will still be useful locally.

The analysis showed:

- ❖ There were not any significant differences in completion response rates across IPU, Day or Community services
- ❖ Ten sites had a completion response rate above 50%
 - 6 of the sites achieving a completion response rate above 50% received more than 29 completed questionnaires each and all were hospices
 - 3 of the other sites achieving a response rate above 50% were NHS Hospital Trusts, and one of these sites received 19 completed questionnaires (which was the highest for this group) with a response rate of 76%
- ❖ Eight test sites chose a 'snapshot' approach for undertaking the survey over a period of 1 month or less, and 5 of these achieved more than 29 completed questionnaires each and response rates above 50%

- ❖ A mix of selection criteria were used in addition to the basic selection criteria and no one model highlighted any significant variation in response rates
- ❖ The majority of test sites used a covering letter, and whilst important it did not seem to influence results
- ❖ The majority provided a SAE for completed questionnaires to be returned, but again did not seem to influence results

Observations

The reasons why the results from the feedback are not robust enough to draw meaningful conclusions on what factors can influence response rates were stated at the beginning of this section. It is more likely that those driving and engaging local staff to become involved with the survey had greatest influence. It could be indicative that five (25%) of the test sites achieving high numbers of completed questionnaires used a variation on a 'snap shot' model for undertaking the survey. Within the narrative feedback 'survey fatigue' was highlighted as a risk for staff and patients/individuals, which this approach would alleviate.

SECTION 5 – Summary of lessons learnt reported by the test community (Table 4)

Table 4

- Check the individual hasn't died or they haven't already received the questionnaire from another area of your service.
- Try to ensure it 'fits' with other surveys in the organisation and that the time frame for undertaking the survey doesn't clash with others being undertaken – survey fatigue for all!
- The engagement of staff has an impact on the number of individuals identified to take part as well as the number of completed returns.
- If it is well organised it reduces the potential negativity from busy staff.
- Have clear selection criteria.
- Make sure patients/individuals are given an explanation about the survey and its use.
- There is no indication that it is distressing or inappropriate to approach patients for their experience of care at end of life.
- Using volunteers, students and administrative staff to support individuals completing the questionnaire made them feel more involved in service improvements - having a crib sheet available to them was useful.
- Using volunteers reduced the pressure and obligations on the individuals receiving care to complete the questionnaire.
- Use volunteers from a different area to reduce further influence.
- It was a good reason for staff, students and volunteers to have conversations with individuals.
- Numbering questionnaires for tracking or printing questionnaires on different coloured paper helped identify the area the response was received from.
- Engage User Advisory Groups or similar.
- It takes time!

SECTION 6 – Results of a workshop held in December 2017

Representatives from several test sites met with the project team in December to discuss interim findings from the feedback provided and look at next steps. As a result, the following has been agreed:

- 1) The desire and commitment to remain part of this community of practice was strong.
- 2) A further six-month test phase will start in February 2018 with an updated questionnaire and a user guide developed from the analysis of feedback and lessons learnt.
- 3) Options will be explored in the future to improve the design of the questionnaire to make it more user friendly as well exploring the potential for an electronic version.
- 4) The number of questions would not be reduced as they each map to the domains identified and 6-point Choice Commitment (see Appendix A)
- 5) The feedback template at the end of the next phase will be less onerous but will focus more on how the findings from the questionnaire have been used locally to inform service improvements.
- 6) Changes to the questionnaire include:
 - a. The feedback indicated that there had been significant difficulty with the term 'Care Team'. At the workshop it was decided to keep the term but to suggest flexible options to provided clarification locally:
 - i. Describe exactly what is meant either in the pre-amble and/or the covering letter
 - ii. Provide a tick box of different roles/team members for patients/individuals to tick as their care team
 - iii. Be specific about which role/team member the organisation wishes the patient to refer to
 - b. Comment boxes after questions 1 and 2 have been added to encourage further information if negative responses have been given
 - c. Optional name and contact details have been added if the patient/individual wants direct feedback
 - d. Other minor changes to wording have been made based on suggestions
- 7) The project team felt that some of the additional questions suggested should be locally based decisions e.g. identifying the area the response came from and asking who completed the questionnaire, so will not include them on the standard questionnaire.

The University will also undertake the formal validation process of the questionnaire during 2018 and some of the current test community may be asked to contribute.

For further information please contact:

Professor Bee Wee - Bee.Wee@ouh.nhs.uk or Glenis Freeman at gjfreeman@btinternet.com who is the main contact point for this work.

APPENDIX A - 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?	D1: Communicated with / information offered [Choice commitment: 2 nd point]					
b.	...that you have been able to talk with members of your care team as openly as you would wish?	D1: Communicated with / information offered [Choice commitment: 1 st point]					
c.	...that you have been as involved as you would like in decisions about your care and treatment?	D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment [Choice commitment: 2 nd point]					
d.	...that things that are important to you are considered in planning your care?	D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment [Choice commitment: 3 rd and 4 th points]					
e.	...that your care team works well together?	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 [Choice commitment: 4 th 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?	D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment					
g.that the care and support provided by your care team meets your physical needs (e.g. pain, breathlessness, nausea, mobility)?	D3: Physical and psychological needs addressed, including access to medicines and equipment					
h.	...that the care and support provided by your care team meets your emotional needs (e.g. feeling low, feeling worried, feeling anxious)?	D4: Social, practical and emotional needs addressed					
i.	...that your care team treats you as a whole person (e.g. takes into account your beliefs, hopes, traditions, customs, spirituality)?	D5: Spiritual and religious support offered D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment [Choice commitment: 4 th point]					
j.	...that your care team helps you to have as much privacy as you want?	D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment					
k.safe in your place of care?	D9: Safety and environment					
l.	...that when you need advice or help urgently, your care team responds quickly?	D7: Urgent care received					

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?	D1: Communicated with / information offered [Choice commitment: 1 st point]				
b.	...information that you can understand about your prescribed medicines?	D1: Communicated with / information offered D3: Physical and psychological needs addressed, including access to medicines and equipment				
c.	...support to get help with your personal care (e.g. dressing, washing, eating)?	D3: Physical and psychological needs addressed, including access to medicines and equipment				
d.	...support to get help with practical matters (e.g. social benefits, wills, finances, legal matters)?	D4: Social, practical and emotional needs addressed				
e.	...support to get any equipment or aids that you need (e.g. oxygen, hospital bed, wheelchair)?	D4: Social, practical and emotional needs addressed				
f.	...support to do things that you enjoy (e.g. spending time with family and friends, reading, going outdoors)?	D4: Social, practical and emotional needs addressed D2: Assessment in response to changing needs / Centrality of person's preferences and involvement in planning own care and treatment				
g.	...support to involve your family and those close to you, as much as you wish, in decisions about your care?	D8: Centrality of people important to the person [Choice commitment: 5 th 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.

APPENDIX B – Organisations in the test community

We would like to thank all the lead contacts and staff in the following organisations for their time and commitment given to this project, and the valuable feedback we received from them. We look forward to working with those joining us in phase two.

Hospitals

Nottingham University Hospitals NHS Trust
Royal Marson NHS Foundation Trust
Poole Hospital NHS Foundation Trust
Lister Hospital, E&N Herts NHS Trust
Derby Teaching Hospitals NHS Foundation Trust
Northampton General Hospital
NHS Forth Valley Scotland
Royal Devon & Exeter NHS Foundation Trust

Primary and Community Care

Bath and North East Somerset Community Health and Care Services
The Freemantle Trust
Somerset Care Ltd
NEW Devon CCG EoL Group - Northern Locality

Hospices

Farleigh Hospice
Martlets Hospice
Isabel Hospice
St Nicholas Hospice Care
St Cuthbert's Hospice
St Richard's Hospice
Katherine House Hospice (Banbury)
Willowbrook Hospice
Nightingale House Hospice
Queenscourt Hospice
Dorothy House Hospice Care
Sobell House Hospice
Earl Mountbatten Hospice