# Additional file 1: Data collection tools

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## 1: WS1.3 data collection tools

### Q Statements for people with dementia

1. My opinions and choices for my care should be respected
2. I should be able to continue with my hobbies and interests in the last year of my life
3. Paid carers and family carers should take account of my spiritual or cultural beliefs in all caring duties
4. Paid carers should be trained to notice if I am in pain
5. I would like to have family/friends with me at the very end of life
6. I would like to have a plan in place for what care I would like to receive at the end of my life when I might not be able to clearly express myself.
7. My care plans for end of life care should be regularly checked by paid and family carers in case I want to make any changes.
8. I should be helped to take my medication even if I forget what it’s for
9. Paid carers and family carers should help me eat only if I want to
10. Important medical decisions about my end of life care should be left to healthcare staff
11. My family should make decisions about my end of life care if I no longer can
12. I would move to a care home if it becomes too much for my family/friends to look after me
13. I would like to be able to receive the majority of the care I need at the same location (e.g. in my own home or care home).
14. I would like my family to be told about how my needs and care will change over time
15. Short stays in respite care should be available to give my family/friends a break from caring
16. Paid carers should be trained how to give me my medication
17. My day to day care should be regularly discussed by family carers, paid carers and me
18. I should have help to put my affairs in order and make preparations
19. Care should be taken to find the cause of any distress which may affect me
20. Hospice care should be more available to me
21. I should be cared for with compassion
22. Support should be available for my family after I pass away.
23. Care homes should allow me to keep personal things in my room to make it homely
24. When I or my family have to make decisions about my care, there should be someone who can provide us with information to help us.

### Q Statements for current and bereaved family carers\*

1. My relative’s opinions and choices for his/her care should be respected
2. My relative should be able to continue with his/her hobbies and interests in the last year of his/her life
3. Paid carers and I should take account of my relative’s spiritual or cultural beliefs in all caring duties
4. Paid carers should be trained to notice if my relative is in pain
5. My relative should be able to have family/friends with him/her at the very end of life
6. My relative should have a plan in place for what care he/she would like to receive at the end of his/her life when he/she might not be able to clearly express himself/herself
7. My relative’s care plans for end of life should be regularly checked by paid carers and I in case he/she wants to make any changes
8. My relative should be helped to take his/her medication even if he/she forgets what it’s for
9. Paid carers and I should help my relative eat only if he/she wants to
10. Important medical decisions about my relative’s end of life care should be left to healthcare staff
11. Family members should make decisions about my relative’s end of life care if he/she no longer can
12. My relative should move to a care home if it becomes too much for me to look after him/her
13. My relative should be able to receive the majority of the care he/she needs at the same location (e.g. in his/her own home or care home)
14. The family should be told about how my relative’s needs and care will change over time
15. Short stays in respite care should be available for my relative to give me a break from caring
16. Paid carers should be trained how to give my relative his/her medication
17. Paid carers, my relative and I should regularly discuss his/her day to day care
18. My relative should have help to put his/her affairs in order and make preparations
19. Care should be taken to find the cause of any distress which may affect my relative
20. Hospice care should be more available to my relative
21. My relative should be cared for with compassion
22. Support should be available for me and other family members after my relative passes away
23. Care homes should allow my relative to keep personal things in his/her room to make it homely
24. When my relative or I have to make decisions about his/her care, there should be someone who can provide us with information to help us

\* Parallel version with appropriate wording for bereaved carers

## 2. WS2 data collection tools

### WS2.1 Topic guide

**WS2.1 Identifying the range of approaches to end of life care in dementia**

**Topic guide**

1. Introduce self and remind the respondent about the project
2. Explain purpose of scoping survey (seeking examples of different models of end of life care – including traditional models for people with dementia of all ages)
3. Ask what models of end of life care for people with dementia are available locally (nationally)?
4. Ask for a description of each model, probing for:
* Setting
* Focus
* Clientele
* Examples of the model
1. Explore respondent’s views on good/best practice in end of life care for people with dementia
	* Key components (for pwd, carers and staff)
	* How it differs from/is similar to end of life care in other conditions
	* Perceived value of existing EOLC frameworks to dementia
2. Check whether respondent can think of anyone else who might be able to help us with the study
3. Thanks and arrangements for sending feedback on the results of WS2

### WS2.2 Topic guide

**WS2.2 Service manager approaches to providing end of life care in dementia**

**Topic guide**

1. Introduce self and remind respondent about the project including the purpose of detailed telephone survey and the potential for further involvement in the study.
2. Seek consent for recording the conversation; confirm consent with the recorder running
3. Confirm the respondent’s role
4. Detailed description of service, including:
	1. Service title
	2. Description of service
	3. Provider (e.g. NHS, Social Services, non-statutory organisation)
	4. Referral routes into the service and any inclusion/exclusion criteria
	5. Documentation available
	6. Strengths of the service
	7. Areas for development
	8. Anything else they would like to add about the service
5. Explore respondent’s views on good/best practice in end of life care for people with dementia
	1. Key components (for pwd, carers and staff)
	2. How it differs from/is similar to end of life care in other conditions
	3. Perceived value of existing EOLC frameworks to dementia
6. Discuss interest in participating in WS2.3 and/or WS2.4.
7. Check whether respondent can think of anyone else or any other services (either locally or nationally) we should contact
8. Thanks and arrangements for sending feedback on the results of the telephone interviews.

### WS2.3 Topic guide

**WS2.3 Frontline staff views and experiences of providing end of life care**

**Topic guide for focus groups/interviews**

1. Introduce self and project
2. Discuss confidentiality and recording; obtain informed consent
3. Introductions, what sorts of end of life care they provide for people with dementia
4. Defining good end of life care for people with dementia
* Explore successful (and less successful examples of end of life care)
* Key components (for pwd, carers and staff)
* How it differs from/is similar to end of life care in other conditions
* Perceived value of existing EOLC frameworks to dementia
1. Thanks, reminder about confidentiality, arrangements for sending feedback on the focus groups.

**WS2.3 Topic guide for interviews with people with memory problems**

*Note: The topic guide is developmental. The questions will need to be tailored to the specific answers of each interviewee. The topic guide given here is therefore a general guide for the one-to-one qualitative interviews.*

**1. Introduction**

* Introduce self
* Explain purpose of the study and this interview:
	+ Won’t affect care
	+ We’re interested in the experiences of people who have memory problems, in particular their view on the care they have received.
	+ No right or wrong answers – not a test of your knowledge
* Consent – written, because this is extra to standard care.
* Explain interview recorded but details will be confidential. If the interview raises any issues of concern regarding health and safety these will be raised with service manager.
* Questions or concerns?

**2.** **Building rapport and exploring values**

* Can you tell me about your life at the moment?
* Routines
* Activities
* Relationships
* What is most important to you at the moment?
* Explore why this is the case

**3. Current care**

* What do you think of the care you are receiving from <*name of service*>?
	+ Communication
	+ Eating and drinking
	+ Personal care
	+ Medication
* What do you like most about <*name of service*>?
* What could be improved?
* Can you think of a time when the care you received, really went the extra mile, or provided exactly what you needed at the time?
* Are there any other aspects of care you would like to talk about?

(*If appropriate, use a photograph of an older person to explore what they might think of the service*)

**4. Defining good end of life care**

* What are your hopes and fears for the future?
	+ Is this something you have been able to talk about, either to your spouse/relative/friend or to staff at <*name of service*>?
	+ If yes, explore what happened
	+ If no, explore barriers
* What would an ideal care service for you at this point in time be like? What would happen? How might this change over the next few months?

**5. Thanks, reminder about confidentiality**

**WS2.3 Topic guide for interviews with carers**

*Note: The topic guide is developmental. The questions will need to be tailored to the specific answers of each interviewee. The topic guide given here is therefore a general guide for the one-to-one qualitative interviews.*

**1. Introduction**

* Introduce self
* Explain purpose of the study and this interview:
	+ Won’t affect care
	+ We’re interested in the experiences of carer of people living with dementia, in particular their view on the care their [partner/relative/friend] has received.
	+ No right or wrong answers – not a test of your knowledge
* Consent – written, because this is extra to standard care.
* Explain interview recorded but details will be confidential. If the interview raises any issues of concern regarding health and safety these will be raised with service manager.
* Questions or concerns?

**2. Route to care**

* Can you tell me how your spouse/relative/friend came to be involved with [name of service]?
	+ How were you made aware of the service?
	+ What were your first impressions of the service?
	+ What difference has the service made to you? To your spouse/relative/friend?
* We are interested in how the services used change over time. Can you tell me more about the services you and your spouse/relative/friend have used in the last couple of years?
	+ Transitions (how decisions were made and by whom)
	+ Met and unmet needs at different points on the trajectory

**3. Current care**

* What do you think of the care your[partner/relative/friend] is receiving from <*name of service*>?
	+ Communication
	+ Eating & drinking
	+ Personal care
	+ Medication
* What has been done well?
* What could have been done better?
* What are the key aspects of care that are important to you and/or your spouse/friend/relative?
* Are there any other aspects of care you would like to talk about?

**4. Current needs of the carer and their spouse/relative/friend**

* How are you doing?
	+ Is there anything that you’re finding particularly difficult at the moment?
		- Is that something you’ve tried to get help with?
		- If yes, what happened?
		- If not, why haven’t you tried to get help?
* How is your spouse/relative/friend doing?
	+ Is there anything that they are struggling with at the moment?
		- Is that something you/they have tried to get help with?
		- If yes, what happened?
		- If not, why haven’t you/they tried to get help?

**5. Defining good end of life care**

* What are your hopes and fears for the care of your spouse/relative/friend in the future?
	+ Is this something you have been able to talk about, either to your spouse/relative/friend or to staff at <*name of service*>?
	+ If yes, explore what happened
	+ If no, explore barriers
* We are looking for examples of ‘good’ practice, can you think of a time when the services you or your spouse/relative/friend received, really went the extra mile, or provided exactly what you needed at the time?
* How do you judge the quality of the care your spouse/relative/friend receives? What sorts of things do you consider?
* What would an ideal care service for you and your spouse/relative/friend at this point in time be like? What would happen? How might this change over the next few months?

**WS2.3 Topic guide for interviews with bereaved carers**

*Note: The topic guide is developmental. The questions will need to be tailored to the specific answers of each interviewee. The topic guide given here is therefore a general guide for the one-to-one qualitative interviews.*

**1. Introduction**

* Introduce self
* Explain purpose of the study and this interview:
	+ We’re interested in the experiences of carers of people who lived with dementia, in particular their view on the care their [partner/relative/friend] received towards the end-of life
	+ No right or wrong answers – not a test of your knowledge
* Consent – written, because this is extra to standard care.
* Explain interview recorded but details will be confidential. If the interview raises any issues of concern regarding health and safety these will be raised with service manager.
* Questions or concerns?

**2. Route to care**

* Can you tell me how your spouse/relative/friend came to be involved with [name of service]?
	+ How were you made aware of the service?
	+ What were your first impressions of the service?
	+ What difference has the service made to you? To your spouse/relative/friend?
* We are interested in how the services used change over time. Can you tell me more about the services you and your spouse/relative/friend have used in the last couple of years?
	+ Transitions (how decisions were made and by whom)
	+ Met and unmet needs at different points on the trajectory

**3. End of life care**

* What do you think of the care your[partner/relative/friend] received from <*name of service*>?
	+ Communication
	+ Eating and drinking
	+ Personal care
	+ Medication
* What was done well?
* What could have been done better?
* What are the key aspects of care that were important to you and/or your spouse/friend/relative?
* Are there any other aspects of care you would like to talk about?

**4. Current needs of the bereaved carer**

* How are you doing?
	+ Is there anything that you’re finding particularly difficult at the moment?
		- Is that something you’ve tried to get help with?
		- If yes, what happened?
		- If not, why haven’t you tried to get help?

**5. Defining good end of life care**

* We are looking for examples of ‘good’ practice, can you think of a time when the services you or your spouse/relative/friend received, really went the extra mile, or provided exactly what was needed at the time?
* How would we know whether end of life services are doing a good job?
	+ What sorts of questions would we ask?
* If we were to design an ideal service that would have met you and your spouse/relative/friend’s needs at the end of life, what would it look like?

**6. Thanks, reminder about confidentiality**

### WS2.4 Topic guides

**WS2.3 Frontline staff views and experiences of providing end of life care**

**Topic guide for focus groups/interviews**

1. Introduce self and project
2. Discuss confidentiality and recording; obtain informed consent
3. Introductions, what sorts of end of life care they provide for people with dementia
4. Defining good end of life care for people with dementia
	1. Explore successful (and less successful examples of end of life care)
	2. Key components (for pwd, carers and staff)
	3. How it differs from/is similar to end of life care in other conditions
	4. Perceived value of existing EOLC frameworks to dementia
5. Thanks, reminder about confidentiality, arrangements for sending feedback on the focus groups.

## 3: WS4 data collection tools

###

### WS4 Activity logs

**Weekly log**

**SEED Nurse Specialist Activity Log – week commencing ………………….**

Nurse Specialist: ………………………

|  |  |  |  |
| --- | --- | --- | --- |
|  | Morning | Afternoon | Evening |
| Monday |  |  |  |
| Tuesday |  |  |  |
| Wednesday |  |  |  |
| Thursday |  |  |  |
| Friday |  |  |  |
| Saturday |  |  |  |
| Sunday |  |  |  |

**Activity codes for weekly log**

|  |  |  |
| --- | --- | --- |
| **Service activities** | **Patient & carer activities** | **Other intervention activities** |
| 1. Mapping local services
 | 11. Screening patients | 21. Familiarisation with SEED intervention |
| 1. Networking
 | 12. Recruitment activities (phone calls; follow up with GPs etc) | 22. Familiarisation with resources |
| 1. Attending practice meetings
 | 13. Review of patient notes | 23. Attending training |
| 1. Exploring service development needs
 | 14. Discussion of individual patients with other professionals | 24. Peer support |
| 1. Developing training
 | 15. Identifying unmet needs & ways of meeting these | 25. Clinical supervision (PR, PP, CM, other) |
| 1. Delivering training
 | 16. Face to face work with individual patients | 26. Research supervision (CB) |
| 1. Mentoring
 | 17. Face to face work with individual family carers | 27. Other meetings with research team |
| 1. Co-working
 |  | 28. Process evaluation (MP) |
| 1. Shadowing, observation
 |  | 29. Developing study materials (e.g. assessment form) |
|   |  |  |

|  |
| --- |
| **Other activities** |
| 31. Travelling |
| 32. Admin |

Log for contacts with care homes and professionals

|  |  |  |  |
| --- | --- | --- | --- |
| Date  | Activity | Outcomes / Comments | Themes |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  | Codes for themes |  |  |
| 1. | Timely planning discussion | 5. | Managing hospitalisation |
| 2. | Recognising EOL and providing supportive care | 6. | Continuing care after death |
| 3. | Co-ordinating care | 7. | Valuing staff and ongoing learning |
| 4. | Working effectively with primary care |  |  |

Log of activities with patients and carers

|  |  |
| --- | --- |
| ID of patient/carer | DNS |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Date of visit**  | **Description & action** | **Duration of visit**  | **Themes** | **Comments** |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |
|  |  |  |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
|  | Codes for themes |  |  |
| 1. | Timely planning discussion | 5. | Managing hospitalisation |
| 2. | Recognising EOL & providing supportive care | 6. | Continuing care after death |
| 3. | Co-ordinating care | 7. | Valuing staff & ongoing learning |
| 4. | Working effectively with primary care |  |  |

### WS4 Topic guides

**Questions for topic guides for process evaluation study**

Rather than produce multiple topic guides with considerable overlap between them, we have instead provided a single list of questions (and related them to the relevant construct within Normalisation Process Theory) and indicated which groups of respondents each question is applicable to. The questions will be framed appropriately for different groups of respondents. The phrasing of the questions will also be modified as appropriate at different time points.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Health & social care professionals** | **Dementia Nurse Specialists** **delivering the intervention** | **PWD** | **Family members** | **Supervisory team** |
| What are your expectations about the Nurse Specialist role | ✓ | ✓ |  |  | ✓ |
| How do you think the study/intervention is going so far? | ✓ | ✓ | ✓ | ✓ | ✓ |

|  | **Health & social care professionals** | **Dementia Nurse Specialists** **delivering the intervention** | **PWD** | **Family members** | **Supervisory team** |
| --- | --- | --- | --- | --- | --- |
| **Coherence** |  |  |  |  |  |
| How confident are you in the intervention? | ✓ | ✓ | ✓ | ✓ | ✓ |
| What reservations do you have about the intervention? | ✓ | ✓ | ✓ | ✓ | ✓ |
| What kinds of patients do you think would benefit most from this type of intervention? Are there patients for whom it would not be useful? | ✓ | ✓ |  | ✓ | ✓ |
| In what circumstances could you see this potentially benefiting people with dementia and their families at end of life? | ✓ | ✓ |  | ✓ | ✓ |
| Have there been any patients who met the inclusion criteria but you felt were not appropriate for the study? | ✓ | ✓ |  |  | ✓ |
| Based on your experience of the Nurse Specialist sessions, who do you think might benefit from this approach? | ✓ | ✓ | ✓ | ✓ | ✓ |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Cognitive participation** | **Health & social care professionals** | **Dementia Nurse Specialists** **delivering the intervention** | **PWD** | **Family members** | **Supervisory team** |
| How interested do patients seem to be in the intervention? | ✓ | ✓ |  |  | ✓ |
| In this study, the Nurse Specialists have a nursing background. From your perspective what are the advantages and disadvantages of a clinical background? | ✓ | ✓ | ✓ | ✓ | ✓ |
| From your perspective, what are the facilitators and barriers to getting people/patients engaged in the study? | ✓ | ✓ | ✓ | ✓ | ✓ |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Collective action** | **Health & social care professionals** | **Dementia Nurse Specialists** **delivering the intervention** | **PWD** | **Family members** | **Supervisory team** |
| Can you describe the contact you have had with the Nurse Specialist (e.g. training, co-ordinating care etc) | ✓ |  | ✓ | ✓ |  |
| Who takes the lead in explaining the study to patients and how do you go about it? |  | ✓ |  |  |  |
| Which aspects of the Nurse Specialist intervention do you feel most confident with/have been most useful\*? | ✓ | ✓ |  |  | ✓ |
| Which aspects of the Nurse Specialist intervention do you find most challenging/have been least useful\*? | ✓ | ✓ |  |  | ✓ |
| Do you feel you have the support you need to recruit patients to/deliver the study/intervention? | ✓ | ✓ |  |  |  |
| From your perspective, what are the facilitators and barriers to implementing the intervention? | ✓ | ✓ |  |  | ✓ |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Reflexive monitoring** | **Health & social care professionals** | **Dementia Nurse Specialists** **delivering the intervention** | **Patients** | **Family members** | **Supervisory team** |
| What sense do you have of how useful the intervention is? | ✓ | ✓ | ✓ | ✓ | ✓ |
| Have you had any feedback from patients, carers or GPs about the intervention? | ✓ | ✓ |  |  | ✓ |
| What opportunities have you had to discuss the value of the intervention with your colleagues? | ✓ | ✓ |  |  |  |
| How important is it to continue to offer Nurse Specialist sessions to people like yourself? | ✓ |  | ✓ | ✓ |  |
| How helpful were different components of the intervention (e.g. job description, manual, resources)? |  | ✓ |  |  | ✓ |
| To what extent do you feel the sessions were tailored to your individual needs? | ✓ |  | ✓ | ✓ |  |
| From your perspective, what are the facilitators and barriers to evaluating the acceptability/cost effectiveness/efficacy\* of the Care Facilitator intervention? | ✓ | ✓ |  |  | ✓ |

\* Questions asked as appropriate depending on role

## 4: WS5 data collection tools

### Example of contingent valuation survey questionnaire

Note this tool is designed for administration on line. As such the text below also contains some of the programming instructions used to aid in administration.

**SURVEY QUESTIONNAIRE**

This survey is being carried out by researchers at the Institute of Health & Society, Newcastle University. We want to know your views on the care provided to people with dementia at the end of life.

The questionnaire has three sections: **PART-A, PART-B** and **PART-C**. It should take no longer than 15 minutes to complete.

* **PART-A** presents you with background information on dementia care at the end of life and the different options for how care can be provided to people with dementia at the end of their life.
* **PART-B** asks questions about the value you place on the different options for care.
* **PART-C** asks general questions about yourself.

There are no right or wrong answers. We are just interested in your views. The questionnaire is anonymous and we will not be asking any personal identifiable information. Your participation is voluntary and you can withdraw from this survey at any time you wish to without giving any reason whatsoever.

This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This committee contains members who are internal to the Faculty, as well as one external member. This study was reviewed by members of the committee, who must provide impartial advice and avoid significant conflicts of interests.

**[PN - new screen – hold next button for 3 seconds]**

**For this survey our client at the Institute of Health & Society, Newcastle University would like to ask your opinion about a personal or sensitive topic, please be assured that all the answers will be treated as confidential and will be used for research purposes.**

**All data will be processed in adherence to Market Research Society’s Code of Conduct and Data Protection Act 1998.**

1. What is your gender?
	1. Male
	2. Female
2. What is your age? [OENUM OR DROP DOWN]

**[DAGE.1.** **Punch answers from Q2 into age NET]**

1. <18 **[TERMINATE]**
2. 18 – 24
3. 25 - 34
4. 35 - 44
5. 45 - 54
6. 55 - 64
7. 65+
8. In which region do you live?
9. North East
10. North West
11. Yorkshire
12. Scotland
13. Northern Ireland
14. East Midlands
15. West Midlands
16. Wales
17. East
18. London
19. South East
20. South West

**[DREGION. Punch answers from Q3 into regional NET]**

1. North
	1. North East
	2. North West
	3. Yorkshire
	4. Scotland
	5. Northern Ireland
2. Midlands
3. East Midlands
4. West Midlands
5. Wales
6. South
7. East
8. London
9. South East
10. South West

**[PN – show each infox1-4 page on a separate screen. Hold next button for 3 seconds per screen]**

**Infox1**

**Please take your time to read the descriptions below…**

**PART-A**

This part of the survey provides brief description about dementia, the reason for conducting this survey, and a practice question showing what the survey involves.

***What is Dementia? (information from the Alzheimer’s Society website)***

The word ‘dementia’ describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour. Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes. Alzheimer’s disease is the most common cause of dementia, but not the only one. The type of symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

**Infox2**

***What is the problem?***

People with advanced dementia can receive poorer quality end of life care compared to those with conditions such as cancer, because it can be harder to identify when symptoms are getting worse and the individuals affected with advanced dementia may not be able to say when they are in pain. The person with dementia may also suffer from other conditions that are caused by or which are made worse by dementia.

As a consequence, people with dementia are less likely to die in their preferred place of care and may experience unnecessary hospital admissions in the last year of life. An increasing number of people with dementia are taken to hospital as an emergency admission. A large proportion of those admissions are avoidable.

**Infox3**

***Why this survey is being carried out?***

There are a number of ways the health and social care systems can help people with dementia and their family, and friends at the end of life. We are interested in your views about how we might provide care to people with dementia. The views of the public are important as it is the general public who fund the NHS and are potential users of the services provided.

In this study what the researchers are looking at is one particular way of assessing how important the public think the different options for providing care to people with dementia are compared to each other and how valuable each option is to them.

The NHS is paid for by taxation therefore we would like to know how much people would be willing to pay for each of the different options of care in the form of extra taxation which would be earmarked to provide this care.

We want you to think about how much you would be willing to contribute (not how much you think it would cost), for the NHS to provide each option described. The amount you are willing to pay tells us how important the different care options are to you.

The information is not and will not be used to think about introducing payments for health care but it will help the NHS decide how best to spend the funds available to it.

**Infox4 x**

**To start, we will work through a practice question.**

Imagine you are on holiday abroad in quite a remote place and you get a bad sore throat – bad enough that it is painful every time you swallow food. If you don’t take anything for it, suppose it will last for 3 days. However, someone can arrange to have medicine delivered to you that will cure your sore throat within 24 hours, thereby saving you 2 of the 3 days of painful sore throat. Think about what would be the MOST you would be willing to pay from your household budget to get the medicine delivered.

4. Would you be willing to contribute something, extra from your available household budget, to get this medicine delivered which will reduce your sore throat from 3 days to 1 day? (Please select your answer)

Yes

No

**[Ask if Q4=1]**

5. You said you would be willing to contribute for the medicine to be delivered.

What is the maximum you would be willing to contribute for the medicine to be delivered?

When you are thinking about this, please bear in mind what you really think you would or would not be prepared to pay, given your actual income and savings.

To help you decide the amount you would be willing to contribute, you are going to see different amounts of money. For each amount decide if you ‘Definitely Would Pay’, ‘Definitely Would Not Pay’ or ‘Maybe’.

Would you be willing to pay **[pipe in amount from a list below]** for the scenario described earlier?

|  |  |  |
| --- | --- | --- |
| **Definitely Would Pay** | **Maybe** | **Definitely Would Not Pay** |
|  |  |  |

**[PN - Randomly select. drag and drop buckets. Keep amount visible once in bucket. Respondents should be able to change their answer and drag into another bucket once placed.**

**Validate (and show error) so there shouldn’t be an amount in ‘Definitely would not pay’ that is lower than an amount in ‘Definitely would pay’]**

**[Amount to pipe into question text] [Programming Instruction: The money amounts must appear one at a time in a random order. Participants not to see all of the values at the beginning]**

£0.50

£1

£1.50

£2

£5

£7.50

£10

£15

£20

£30

£50

£100

6. The highest amount you said you WOULDbe willing topay was **[insert highest amount from ‘definitely would pay’ at Q5]**

The lowest amount you said you WOULD NOT be willing topay was **[insert lowest amount from ‘definitely would not pay’ at Q5].**

What is the **maximum** amount you would be willing to pay, it could be one of these two amounts or something in between.

Maximum willingness to pay: £ **[OENUM text box]**

**[PN - If a respondent has no payment cards in the ‘Definitely Would Not Pay’ column then they should see the following text instead of that above].**

The highest amount you said you WOULD be willing topay was **[insert highest amount from ‘definitely would pay’ at Q5]**.

What is the MAXIMUM amount you would be willing to pay? It could be this amount or something higher than this.

Maximum willingness to pay: £ **[OENUM text box]**

**[Ask if Q4=2. SC]**

7.You said you would not be willing to pay anything to get the medicine delivered. Why are you not willing to pay anything for this new medicine? Please select **one reason** below:

1. The illness only lasts for 3 days so it is not worth paying for the treatment
2. The symptoms of the illness are not too bad, I could live with it
3. I cannot afford to spend money on medical treatments
4. I don’t think I should have to pay for healthcare
5. Other (please specify) **[OE text box] [Programming Instructions: system to read what people enter. Minimum character limit (10) and maximum character limit (500).**

**Infox5**

**We will now move onto our questions about dementia care in PART B.**

**PART B**

To help people with dementia at the end of life a new service provided by a Dementia Nurse Specialist is being considered by your NHS. You will be shown three different options the Dementia Nurse Specialist service could provide. We would like to know how valuable each of these options would be to you.

**Infox6 [Add a time stamp and hold next button for 3 seconds]**

**Scenario A**

The Dementia Nurse Specialist provides tailored support to enable the provision of high quality end of life care to people with dementia. The support from the Dementia Nurse Specialist is expected to result in the following:

* Develop confidence in people with dementia, their family and carers, doctors (General Practitioner/GP) to make timely and early decisions about end of life care and the arrangements after death.
* Document the wishes of the person with dementia to help everyone involved in their care to quickly access and understand their preferences and needs.
* Timely coordination of care with multiple services to reduce the burden on carers.
* Regular involvement of and visits from the same doctor (General Practitioner /GP), nurse or care workers meaning the values, medical need and history of the person with dementia is well understood.
* Early recognition of the person nearing the end of life well in advance to help care providers recognise changes indicating the person with dementia is nearing end of life so that pain and discomfort are easily detected and managed responsively with the appropriate medication.
* Avoidance of unnecessary hospitalisations, but if admission to the hospital is needed, helps to assist discharge and prevent excessive length of stay.
* Ensure healthcare workers possess the right skills to provide compassionate care to people with dementia.

8. Would you be willing to pay something to have a dementia care service in the NHS as described in the Scenario A? (*Please select your answer below*).

Yes

No

**[Ask if Q8=1]**

9. You said you would be willing to contribute through increased taxation which will be earmarked for the dementia care service as described in Scenario A.

What is the maximum you would be willing to contribute each month for the next 10 years for the dementia care service described in Scenario A?

When you are thinking about this, please bear in mind what you really think you would or would not be prepared to pay, given your actual income and savings.

To help you decide the amount you would be willing to contribute for, you are going to see different amounts of money. For each amount decide if you ‘Definitely Would Pay’, ‘Definitely Would Not Pay’ or ‘Maybe’.

Would you be willing to pay **[pipe in amount from a list below]** in taxation per month for the next 10 years for the dementia care service as described in Scenario A? [Programming Instructions: Could you please place this question like this, it is not done this way in the latest link]

|  |  |  |
| --- | --- | --- |
| **Definitely Would Pay** | **Maybe** | **Definitely Would Not Pay** |
|  |  |  |

**[PN - Randomly select. drag and drop buckets. Keep amount visible once in bucket. Respondents should be able to change their answer and drag into another bucket once placed.**

**Validate (and show error) so there shouldn’t be an amount in ‘Definitely would not pay’ that is lower than an amount in ‘Definitely would pay’]**

**[Amount to pipe into question text]** **[Programming Instruction: The money amounts must appear one at a time in a random order. Participants not to see all of the values at the beginning]**

£0.50

£1

£1.50

£2

£5

£7.50

£10

£15

£20

£30

£50

£100

**[Programming Instructions: If the respondent does not place a figure in the box, a message prompting them to do so should appear]**

10. The highest amount you said you WOULD be willing to pay was **[insert highest amount from ‘definitely would pay’ at Q9]**

The lowest amount you said you WOULD NOT be willing to pay was **[insert lowest amount from ‘definitely would not pay’ at Q9].**

What is the MAXIMUM amount you would be willing to pay from your household budget? It could be one of these amounts or something in between.

Maximum willingness to pay: £ **[OENUM text box]**

**[PN - If a respondent has no payment cards in the ‘Definitely Would Not Pay’ column then they should see the following text instead of that above].**

The highest amount you said you WOULD be willing to pay was **[insert highest amount from ‘definitely would pay’ at Q9]**.

What is the MAXIMUM amount you would be willing to pay? It could be this amount or something higher than this.

Maximum willingness to pay: £ **[OENUM text box]**

**[Ask if Q8=2. SC]**

11.You said you would not be willing to pay anything for the dementia care service described in Scenario A. Why are you not willing to pay anything? Please select **one reason** below:

1. I think the dementia care without the nurse involvement would be satisfactory
2. I do value the improvement in dementia care, but I cannot afford to pay anything for it
3. Other (please specify) [Programming Instructions: Can the system read what people enter? Currently if they just write a single alphabet they can move on, but we want this to have a minimum character limit (say 10) and maximum character limit (say 500).]

**Scenario B**

**[Assign one scenario on a least-full rule from the below or alternatives 3-4 at end of questionnaire [***note these are removed from this document as they are the same as alternatives 3 and 4 in Appendix 26 above***]. Hold next button for 3 seconds. Add a respondent time stamp at each alternative]**

**Alternative.1**

The Dementia Nurse Specialist provides tailored support to enable the provision of high quality end of life care to people with dementia. The support from Dementia Nurse Specialist is expected to result in the following:

* Timely coordination of care with multiple services to reduce burden on carers.

12. Would you be willing to contribute something through increased taxation which will be earmarked for the dementia care service described in the Scenario B (Please select your answer below).

Yes

No

**[Ask if Q12=1]**

13. You said you would be willing to contribute something through increased taxation which will be earmarked for the dementia care service described in Scenario B.

What is the maximum you would be willing to contribute each month for the next 10 years for the dementia care service described in Scenario B?

When you are thinking about this, please bear in mind what you really think you would or would not be prepared to pay, given your actual income and savings.

To help you decide the amount you would be willing to contribute, you are going to see different amounts of money. For each amount decide if you ‘Definitely Would Pay’, ‘Definitely Would Not Pay’ or ‘Maybe’.

Would you be willing to pay **[pipe in amount from a list below]** in taxation per month for the next 10 years for the dementia care service as described in Scenario B? [Programming Instructions: Could you please this question like this, it is not done this way in the latest link]

|  |  |  |
| --- | --- | --- |
| **Definitely Would Pay** | **Maybe** | **Definitely Would Not Pay** |
|  |  |  |

**[PN - Randomly select. drag and drop buckets. Keep amount visible once in bucket. Respondents should be able to change their answer and drag into another bucket once placed.**

**Validate (and show error) so there shouldn’t be an amount in ‘Definitely would not pay’ that is lower than an amount in ‘Definitely would pay’]**

**[Amount to pipe into question text]** **[Programming Instruction: The money amounts must appear one at a time in a random order. Participants not to see all of the values at the beginning]**

£0.50

£1

£1.50

£2

£5

£7.50

£10

£15

£20

£30

£50

£100

**[Programming Instructions: If the respondent does not place a figure in the box, a message prompting them to do so should appear]**

14. The highest amount you said you WOULD be willing to pay was **[insert highest amount from ‘definitely would pay’ at Q13]**

The lowest amount you said you WOULD NOT be willing to pay was **[insert lowest amount from ‘definitely would not pay’ at Q13].**

What is the **MAXIMUM** amount you would be willing to pay? It could be one of these amounts or something in between.

Maximum willingness to pay: £ **[OENUM text box]**

**[PN - If a respondent has no payment cards in the ‘Definitely Would Not Pay’ column then they should see the following text instead of that above].**

The highest amount you said you WOULD be willing topay was **[insert highest amount from ‘definitely would pay’ at Q13]**.

What is the **MAXIMUM** amount you would be willing to pay? It could be this amount or something higher than this.

Maximum willingness to pay: £ **[OENUM text box]**

**[Ask if Q12=2. SC]**

**15.** You said you would not be willing to pay anything for the dementia care service described in Scenario B. Why are you not willing to pay anything? Please select one reason below**:**

1. I think the dementia care without the nurse involvement would be satisfactory
2. I do value the improvement in dementia care, but I cannot afford to pay anything for it
3. Other (please specify) [Programming Instructions: Can the system read what people enter? Currently if they just write a single alphabet they can move on, but we want this to have a minimum character limit (say 10) and maximum character limit (say 500).]

**[Alternative 2]**

**Scenario C**

**[Assign one scenario on a least-full from the below or alternatives 3-4 in at end of questionnaire. Hold next button for 3 seconds. Add a respondent time stamp at each alternative]**

**Alternative.1**

The Dementia Nurse Specialist provides tailored support to enable the provision of high quality end of life care to people with dementia. The support from Dementia Nurse Specialist is expected to result in the following:

The Dementia Nurse Specialist provides tailored support to enable the provision of high quality end of life care to people with dementia. The support from Dementia Nurse Specialist is expected to result in the following:

* Develop confidence in people with dementia, their family and carers and doctors (General Practitioner/GP) to make timely and early decisions about end of life care and the arrangements after death.
* Document the wishes of the person with dementia to help everyone involved in their care to quickly access and understand their preferences and needs.

12. Would you be willing to contribute something through increased taxation which will be earmarked for the dementia care service described in the Scenario C (Please select your answer below).

Yes

No

**[Ask if Q12=1]**

13. You said you would be willing to ~~pay~~ contribute something through increased taxation which will be earmarked for the dementia care service described in Scenario B.

What is the maximum you would be willing to contribute each month for the next 10 years for the dementia care service described in Scenario B?

When you are thinking about this, please bear in mind what you really think you would or would not be prepared to pay, given your actual income and savings.

To help you decide the amount you would be willing to contribute, you are going to see different amounts of money. For each amount decide if you ‘Definitely Would Pay’, ‘Definitely Would Not Pay’ or ‘Maybe’.

Would you be willing to pay **[pipe in amount from a list below]** in taxation per month for the next 10 years for the dementia care service as described in Scenario B?

|  |  |  |
| --- | --- | --- |
| **Definitely Would Pay** | **Maybe** | **Definitely Would Not Pay** |
|  |  |  |

**[PN - Randomly select. drag and drop buckets. Keep amount visible once in bucket. Respondents should be able to change their answer and drag into another bucket once placed.**

**Validate (and show error) so there shouldn’t be an amount in ‘Definitely would not pay’ that is lower than an amount in ‘Definitely would pay’]**

**[Amount to pipe into question text]** **[Programming Instruction: The money amounts must appear one at a time in a random order. Participants not to see all of the values at the beginning]**

 £0.50

£1

£1.50

£2

£5

£7.50

£10

£15

£20

£30

£50

£100

**[Programming Instructions: If the respondent does not place a figure in the box, a message prompting them to do so should appear]**

14. The highest amount you said you WOULD be willing to pay was **[insert highest amount from ‘definitely would pay’ at Q13]**

The lowest amount you said you WOULD NOT be willing to pay was **[insert lowest amount from ‘definitely would not pay’ at Q13].**

What is the **MAXIMUM** amount you would be willing to pay? It could be one of these amounts or something in between.

Maximum willingness to pay: £ **[OENUM text box]**

**[PN - If a respondent has no payment cards in the ‘Definitely Would Not Pay’ column then they should see the following text instead of that above].**

The highest amount you said you WOULD be willing topay was **[insert highest amount from ‘definitely would pay’ at Q13]**.

What is the **MAXIMUM** amount you would be willing to pay? It could be this amount or something higher than this.

Maximum willingness to pay: £ **[OENUM text box]**

**[Ask if Q12=2. SC]**

**15.** You said you would not be willing to pay anything for the dementia care service described in Scenario C. Why are you not willing to pay anything? Please select one reason below**:**

1. I think the dementia care without the nurse involvement would be satisfactory
2. I do value the improvement in dementia care, but I cannot afford to pay anything for it
3. Other (please specify) [Programming Instructions: Can the system read what people enter? Currently if they just write a single alphabet they can move on, but we want this to have a minimum character limit (say 10) and maximum character limit (say 500).]

**Thank you for completing this section of the survey.**

**Infox7**

**PART- C**

In this final section we would like to collect some general information about you. These questions allow us to ensure we survey a wide range of people with different characteristics. This information will not be connected with your identifiable details.

**16.** What is your current marital status?(*Please select one that applies to you*)

1. Single
2. Married/living with partner
3. Divorced/separated
4. Widowed
5. Do not want to disclose

17. What is your employment status? (*Please select one that applies to you*)

1. Full-time (30 or more hours per week)
2. Part-time
3. Contract, Freelance or Temporary Employee
4. Self-employed
5. Semi-retired
6. Retired
7. Homemaker
8. Stay-at-Home Parent
9. Full-time Student
10. Part-time Student (working MORE than 30 hours per week)
11. Part-time Student (working LESS than 30 hours per week)
12. Unemployed
13. Other (please specify)
14. Do not want to disclose

18. What is your highest educational qualification? (*Please select one that applies to you***)**

1. Postgraduate Education Completed (e.g. Masters)
2. Incomplete Secondary Education (Below GC SE / O Level)
3. Secondary Education Completed (A Level or equivalent)
4. Secondary Education Completed (GCSE / O Level / CSE or equivalent)
5. Vocational or Technical Qualifications Completed (e.g. HND, NVQ)
6. Doctorate, Post-doctorate or equivalent (Higher Degree)
7. Prefer not to answer
8. University Education Completed (First Degree e.g. BA, BSc)
9. Some Vocational or Technical Qualifications
10. Do not want to disclose

19. Could you please estimate the annual income of your household before deducting tax and national insurance (if you receive any benefits include them as income)? (Please select one that applies to you)

1. Less than £10000

2. £10000-19,999

3. £20,000-29,999

4. £30,000-39,999

5. £40,000-49,999

6. £50,000-59,999

7. £60,000-69,999

8. £70,000-79,999

9. £80,000-89,999

10. £90,000-99,999

11. £100,000-149,999

12. £150,000-199,999

13. £200,000-499,999

14. 500,000 or more

96. Prefer not to answer

20. Are you the main income earner in your household? (*Please select one that applies to you*)

Yes

No

Don’t Know

21. How many people (including yourself) live in the household? Please only include people you share budget with. **[Programming instructions: 0 should not be allowed to enter in the box, numbers should be 1 or more to be valid]**

**[OENUM text box]**

22. Have you ever had experience of dementia? (Please select those that applies to you) **[Programming Instructions: Respondents should be allowed to choose multiple answers]**

One of your family member has/had dementia

One of your friend has/had dementia

One of your colleague has/had dementia

One of your relative has/had dementia

Others (please specify)

No

23. Are you a carer or care worker?

1. Yes

2. No

24. Please click the ONE box that best describes your health TODAY **[Programming Instructions: Please show this sentence for each block below]**

**[Programming Instructions: This section should be only in the way EUROQOL suggests. Follow the link to see what exactly is needed –**

**[Programming Instructions: Present each block in individual screens with the current format]**

**1. Mobility**

1. I have no problems in walking about
2. I have slight problems in walking about
3. I have moderate problems in walking about
4. I have severe problems in walking about
5. I am unable to walk about

**2. Self-care**

1. I have no problems in washing or dressing myself
2. I have slight problems in washing or dressing myself
3. I have moderate problems in washing or dressing myself
4. I have severe problems in washing or dressing myself
5. I am unable to wash or dress myself

**3. Usual Activities (**e.g. work, study, house work, family or leisure activities**)**

1. I have no problems doing my usual activities
2. I have slight problems doing my usual activities
3. I have moderate problems doing my usual activities
4. I have severe problems doing my usual activities
5. I am unable to do my usual activities

**4. Pain/Discomfort**

1. I have no pain or discomfort
2. I have slight pain or discomfort
3. I have moderate pain or discomfort
4. I have severe pain or discomfort
5. I have extreme pain or discomfort

**5. Anxiety/Depression**

1. I am not anxious or depressed
2. I am slightly anxious or depressed
3. I am moderately anxious or depressed
4. I am severely anxious or depressed
5. I am extremely anxious or depressed

25.

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

100 means the best health you can imagine.

0 means the worst health you can imagine.

Please click on the scale to indicate how your health is TODAY.

Your health today = **[OENUM text box]**

**[Programming Instructions: Please check the demo in the following EQ-5D-5L link to see what is expected]**

[**http://eq-5d-demo.euroqol.org/demo**/](http://eq-5d-demo.euroqol.org/demo/) -

****

Should you have any questions related to this survey, please contact Research Now quoting your member ID and survey number.

Thank you for your participation.

## 5: WS6 data collection tools

### WS6.1 Topic guide

**WS6.1 Commissioning end of life care in dementia: your experiences and views**

**Topic guide**

*(The topic guide is developmental and will be informed by a review of literature and the analysis of interviews)*

1. Introduce self and remind the respondent about the project
2. Explain purpose of the interviews: to better understand how services are commissioned and to consider how this should be done in the future
3. Ask interviewee to describe their current role and their involvement in the commissioning of end of life care and dementia services
	1. What are the key things they look for when commissioning services?
	2. Who do they involve in the decision-making process?
	3. What guidelines do they use when commissioning services?
	4. Is commissioning end of life care different for dementia?
	5. Ideally, how should commissioning of these services be organised and conducted in the future?
4. Explore respondent’s views on good/best practice in end of life care for people with dementia
	1. Key components (for PWD, carers and staff)
	2. How it differs from/is similar to end of life care in other conditions
	3. Perceived value of existing EOLC frameworks to dementia.
5. Check whether respondent can think of anyone else involved in commissioning who might be able to help us with the study
6. Thanks and arrangements for sending feedback on the results of WS6.

**WS6.1 Commissioning end of life care in dementia: follow up interviews**

**Topic guide**

(The topic guide is developmental and will be informed by a review of literature and the analysis of interviews)

**Introduction**

* Introduce self and remind the respondent about the project
* Explain purpose of **the follow up interviews**: to understand how the commissioning of services *may have changed since the previous interview* and to consider how this should be done in the future. Go through the consent form and obtain verbal or signed consent as appropriate
* Check whether interviewee has same role and their involvement in the commissioning of end of life care and dementia services. [This may have changed in ways that lead onto a discussion of changes in commissioning].

**Part I – Organisation of commissioning: developments since last interview**

* Have you experienced any changes to commissioning since you started?
	+ If so, what were these changes?
* Have you established new relationships with providers you haven’t worked with before?
* Have there been any changes to the training you provide or expect your service providers to offer?
	+ If so, what are these changes and what triggered their implementation?
* Do you have contact with commissioning support units or other organisation to help with commissioning?

**Part II – Information use in commissioning**

* What information or data do you currently use when commissioning?
	+ How useful is it? What could be improved?
* Do you make use of NICE guidance on commissioning end of life care for people with dementia? Are there any other published forms of guidance or information you use?
* What information or data do you need which is hard to access or is unavailable?

**Part III: Example MODEM: we asked you to do a search for ‘End of life’ in the Evidence Database**

* How did you find using the MODEM system?
	+ Had you been aware of this site / project before we asked you to use it?
	+ Are you aware of similar search engines?
* Did you find the information you received helpful in terms of its content?
* Was the information presented in an accessible way?
* What else would commissioners need in terms of content or design?
	+ Would you recommend / use the site as a training / information tool?
	+ Was there anything missing?