



Department
of Health

Dementia 2020 Citizens' Engagement Programme

Toolkit for engaging people with dementia and carers

Co-produced by Alzheimer's Society, Alzheimer's Research UK, the Dementia Engagement and Empowerment Project (DEEP), Innovations in Dementia and people with dementia and carers on behalf of the Department of Health's Advisory Group for the Dementia 2020 Citizens' Engagement Programme.



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Contents

Contents.....	4
1. Introduction.....	5
1.1 The Department of Health's Dementia 2020 Challenge and its Citizens' Engagement Programme.....	5
1.2 Who is this toolkit for?	5
1.3 What do we mean by "people with dementia and their carers"?.....	5
2. Engaging people with dementia and carers	7
2.1 Who is in the conversation?	7
2.2 One to one conversations.....	7
2.3 Group discussions	7
2.4 Individual surveys	8
2.5 Recruitment	8
2.6 Consent	8
2.7 Be clear on influence	8
2.8 Submitting your feedback	9
3. Appendix A: Guiding principles	10
4. Appendix B: Facilitation hints and tips	11
4.1 Organising one to one discussions.....	11
4.2 Organising group discussions	12
4.3 Useful links	14
5. Appendix C: Project resources	16
5.1 Group discussion: template for feedback	16
5.2 Consent form	20
5.3 Individual Survey	21

1. Introduction

1.1 The Department of Health's Dementia 2020 Challenge and its Citizens' Engagement Programme

The Department of Health published its implementation plan for the Dementia 2020 Challenge in March 2016¹. The implementation plan sets out a number of key commitments to ensure that dementia care, support, risk reduction, awareness and research are transformed by 2020.

One of the priority actions in the plan is to establish a Dementia Citizens' Engagement Programme in England. The purpose of the programme is to find out first hand from people with dementia and carers if the actions in the plan are making a difference to their day to day lives. This feedback will be used by the Department of Health and its partner organisations to check progress and to ensure that everything that can be done is being done to make improvements. The feedback will also directly inform a full, formal review of the Dementia 2020 Challenge Implementation Plan in 2018. Opportunities to provide views will be publicised at:

<http://consultations.dh.gov.uk/dementia/care-support-and-awareness>.

Guiding principles for the Citizens' Engagement Programme are set out in Appendix A.

1.2 Who is this toolkit for?

We want as many people as possible with experience of dementia to be engaged in the Department of Health's work on dementia, so that we can improve the lives of those living with dementia and their carers today. During the course of the Dementia 2020 Challenge there will be a number of opportunities for people living with dementia and their carers to give their views and influence the work of the Dementia 2020 Challenge.

We have asked people with dementia and their carers how they would like the mechanics of this programme to work. They said that there were three ways in which they would like to participate; via one-to-one conversations, in group meetings, and through online or paper surveys. The first two of these will need a person able to facilitate the session and this toolkit is to provide guidance for them. This toolkit is not intended to be an in depth facilitation training guide although Appendix B contains hints and tips as to how to manage this process effectively and sensitively and is worth reading, even if you are an experienced facilitator.

If you have access to people living with dementia and their carers then please use this toolkit to facilitate discussions with individuals or groups and to feedback to the Department of Health who are collecting the data from the engagement programme.

1.3 What do we mean by "people with dementia and their carers"?

When we talk about "people with dementia and their carers" we mean those involved on a day by day basis – the person with the condition, the person or people living with them (who we tend to simply refer to as "the carer") or the person who probably lives close by who takes on that responsibility. The key is that these people "experience" dementia - what it does to the person with the condition, and the practical and emotional impact it has upon their own lives. They are

¹ Prime Minister's Challenge on Dementia 2020: Implementation Plan, Department of Health, March 2016

Dementia 2020 Citizens' Engagement Programme

the ones who can judge at first hand the impact of medical and social support, the effectiveness of services, the toll the condition has on day to day living and the way that society reacts to and treats a person with dementia.

It is very important to recognise that people with dementia and carers each have their own needs, both physical, emotional, practical and psychological. As the condition progresses and changes occur in the person they are caring for they will often need psychological support. They will need respite to recharge their batteries. They will need education about the condition and its progression and training on how to deal with some of the more difficult emotional and behavioural aspects. They will need help to “get through the system” on behalf of the person they care for. The Dementia 2020 Challenge recognises this and includes actions to support the carer as well as the person with dementia.

2. Engaging people with dementia and carers

2.1 Who is in the conversation?

People with dementia and their carers are the experts on what it is like to live with the condition. Their expertise must inform the health and social care services that they use, the development of research that improves diagnosis, treatment and care, as well as the services and amenities that are in their local community. Research has found that 38 per cent of people with dementia do not have a choice about how they live their life (Alzheimer's Society, 2014). We are committed to ensuring that the views of people with dementia across all communities and within all stages of the condition are heard and help shape the Department of Health's work on dementia.

At regular intervals throughout the implementation of the Dementia 2020 Challenge we will be asking people their opinions on progress and how the changes have affected them. The specific subjects will be outlined in detail by the Department of Health at the time and a series of questions produced.

2.2 One to one conversations

One-to-one conversations are useful for exploring the views and attitudes of the person living with dementia and their carer/s in detail and enable greater insight into their lived experience. They are also useful if individuals do not engage well in group settings. As the conversation is conducted privately, it may also be a suitable opportunity for discussing sensitive issues.

Due to the detailed nature of one-to-one conversations, the process can be lengthy and time-consuming. Therefore, always check with the individuals the amount of time that they have available and ensure this is valued and respected.

2.3 Group discussions

Group discussions (or focus groups) should consist of 2 to 8 people with a facilitator helping the group to talk to each other. They can be particularly useful for exploring views and attitudes on broad subject areas. A group will often produce a greater range of opinions as people build on each other's ideas or challenge them.

These discussions can be highly flexible – both in terms of number of participants, groups, costs and duration, but also in that the group discussion format can sometimes uncover related but unanticipated topics. The relatively informal nature places participants on a more even footing with each other and with whoever is leading the session, which can appeal to participants and potential participants.

As focus groups lend themselves to broad discussion, only a limited number of questions can be used during each session for it to generate any useful insight. The facilitator must keep the conversation on track, and must also be mindful of any dominant personalities coming to the fore. It is for this reason that we suggest limiting the number of participants to 8, so that everyone can have a say.

We hope that many existing groups of people living with dementia and carers will choose to discuss the Department of Health's Dementia 2020 Challenge. These groups may have individual ways of working and needs and we are happy for facilitators to find a way which works for the individuals in the group.

2.4 Individual surveys

To ensure that we get the maximum number of people with dementia and carers contributing to this programme, we are also inviting individuals to respond directly to surveys if it is more convenient to them. To support this there is an Individual Survey available in Appendix C. This is available in written format and online at <http://consultations.dh.gov.uk/dementia/care-support-and-awareness>. Please share this with any mailing list or group where you are unable to facilitate individual or group discussions.

2.5 Recruitment

When running a group discussion you should seek to be as inclusive as possible, making sure you involve different people, and try to include people who would not usually access local services.

Advertising the opportunity externally - in local newspapers, at GP surgeries or even the local shop - as well as through local services will encourage people you are not already connected with.

You should be clear from the start on what support (including expenses) can be provided to people to get to the event.

2.6 Consent

You must gain informed consent from all people with dementia and carers who you engage with face-to-face. A consent form is included in Appendix C to support this.

To gain consent you should be clear about what we will ask them to do and what their contributions will be used for. You are responsible for making it clear how their contributions will be anonymised, where their data will be stored and how. Make sure consent forms are signed and saved within your organisation, and that participants understand the implications of providing consent.

Local dementia groups and networks should ensure that their systems and processes for collecting and holding any data or information obtained as a result of engaging with people with dementia and carers are compliant with guidance provided by the Office of the Information Commissioner at: <https://ico.org.uk/for-organisations/guide-to-data-protection/>

2.7 Be clear on influence

It is important to ensure that you manage the expectations of the people you speak to. Be clear from the outset how their engagement will affect the outcome of the work, and how decisions are made.

Here is some text which will help to explain how people affected by dementia are influencing this programme.

“The Department of Health has worked with some people with dementia and carers to shape the design of this engagement programme. For example looking at what priority themes in the Dementia 2020 Implementation Plan people would like to provide feedback on and what engagement methods people prefer. The Department of Health will use the feedback gained from the engagement programme to report to Ministers and to ensure that everything that can be done is being done to make improvements. The feedback will also directly inform a full, formal review of the Dementia 2020 Challenge Implementation Plan in 2018.”

2.8 Submitting your feedback

Individual survey responses (using the survey found in Appendix C) or comments from a group discussion (using the proforma found in Appendix C) should be sent to the address below by email or post:

All feedback should be sent to dementiasurvey@dh.gsi.gov.uk or by post to:

Dementia Policy Team

Room 2E56

Department of Health

Quarry House

Quarry Hill

Leeds, LS2 7UE

Thank you for supporting this important activity. We welcome any feedback on this toolkit so that it can be constantly improved so please send us any improvements you'd like to see made at: dementiasurvey@dh.gsi.gov.uk

3. Appendix A: Guiding principles

These guiding principles demonstrate this engagement programme is underpinned by a shared commitment to working in equal partnership with people living with dementia and their carers. It is important to understand what living with dementia is like from the perspectives of people living with dementia and their carers and recognise that it impacts on all areas of their lives. Therefore, it is important to view dementia in a much broader context (beyond the focus on symptoms and behaviours) and ensure that people with dementia and their carers have an ongoing right to be fully engaged and involved as set out in the Health and Social Care Act 2012.

Setting out guiding principles will ensure that everyone (including all organisations, networks and professionals) working on this engagement programme, know what they can do to enable people living with dementia and their carers to be actively involved as equal partners.

The following principles will underpin how partners together will work on implementing this engagement programme. The programme will be:

- Informed – It will be based on best practice and what people with dementia and carers have told us works for them – what really matters to them.
- Inclusive – We will reach out to those people living with dementia and their carers whose voices are not often heard.
- Accessible – We will work with people living with dementia and their carers in ways that best meets their needs and wishes and will provide varied opportunities for people's views to be heard and respected.
- Supported – People with dementia and their carers are provided with the necessary support before, during and after involvement / engagement activities.
- Purposeful – We will talk to people with dementia and their carers for a reason and want to hear their views as to whether the work we are all doing is making a positive difference to people's lives.
- Responsible – We will inform people about how we intend to use the information they have given us and we will respect people's anonymity. We will make sure we know what to do if the information given to us raises concerns.

4. Appendix B: Facilitation hints and tips

4.1 Organising one to one discussions

- The conversations should not last more than one hour. This may be too long for some people and it is important to be aware of the on-going capabilities of the person.
- Let the person with dementia and/or carer decide on the venue - the home setting may be best. Ensure that you have an ID badge to ensure authenticity.
- It may help to have a second person to observe and take notes, or to use a voice recorder with permission. Part of an interviewer's task is to make sure that the participant feels listened to throughout the conversation, so try to maintain eye contact and put the participant at ease.
- Do not forget refreshments and a comfortable, preferably light and airy room. You should also ensure there will be no interruptions.
- Some people with dementia may wish for a family member or a friend to join the conversation. This is fine, provided that the person with dementia is able to speak openly for themselves, without the other person speaking for them. This may require tactful facilitation. To help us understand your data please ensure it is clear whose views (the person with dementia or their supporter) are being expressed on which statement.

How to lead the conversation

- Introduce yourself (if required). Explain the purpose of the conversation (that is to find out their views about XYZ in order to help it develop further).
- Emphasize that we need their help and encourage them to speak openly. For example "We want to know what you really think!", "I am here to learn from your experience"
- Reassure them that, although you will be taking notes/ recording, what they say will remain anonymous and confidential, and comments will not be attributed to them.
- If taking notes, you need to record the person's words as far as possible - this kind of qualitative data is much more useful and real. If you do not have another member of staff to assist you, keep writing as you talk and keep as much eye contact as possible.
- At the end thank the person for their time, explain what will happen next, and reaffirm confidentiality
- Write up your notes as soon as possible after the event.

Interview questions: some guidance

- The questions should be taken from the 'Group discussion: template for feedback' provided in Appendix C so that they are consistent with the other discussions taking place. Use these questions as conversation prompts, and be sure to follow up on any questions that lead on from the discussion.

Dementia 2020 Citizens' Engagement Programme

- Start with easy general questions to try and get their interest - leave specific and sensitive questions to the end.
- Often the conversation will take off in a different direction from the one you had planned, but try to steer it so that all of the things you would like to discover are discussed in one way or another!
- Try to check as you go along what you think you are hearing them saying - especially if you are finishing off a long discussion on a single topic, for example ask 'Am I hearing what you are saying correctly?'
- Probe if they give you vague answers.

Remember: *The main aim is to obtain information, not to offer your own views, though sometimes people will ask.*

- *Be as encouraging/neutral as possible, even if you do not agree.*
- *Do not let your tone betray your views. You can share your views at the end of the conversation, if you wish. It is always acceptable to offer information.*
- *Be sensitive to communication problems or fear of expressing views.*
- *Do not forget posture - gesture, facial expressions - you need to communicate warmth, interest, encouragement and caring.*

4.2 Organising group discussions

- Provide clear, straightforward information about the purpose of the meeting beforehand. Try to keep the information short and to the point. One or two A4 sheets is enough. The 'Dementia Engagement and Empowerment Project' (DEEP) Guide 'Collecting the views of people with dementia' provides useful guidance.
- Think about providing a photograph of yourself so the group know who you are, where you work, and what your job is.
- Think about the location of the session – is it accessible by public transport? Is there parking? Is the room easily accessible to a person with dementia? Will someone be available to greet them, show the way and escort out at the end?
- Think about any other adjustments that you need to make for your participants to participate, including differing languages, signing or culturally appropriate refreshments.
- Do not forget refreshments and ensuring that the room is comfortable and accessible.
- Think ahead of how you would support someone who may feel upset or distressed during the conversation - is there a quiet space available for someone to go?
- The discussion should not last more than two hours. This may be too long for some people and it is important to be aware of the on-going capabilities of the group. We recommend having a comfort break in the middle of the discussion.

Appendix B: Facilitation hints and tips

- It helps to have more than one facilitator at each session
- We recommend a maximum of 8 participants per session to ensure that everyone can participate.
- Facilitating group discussions
- Introduce yourself. Explain the purpose of the group meeting.
- Ask the others to introduce themselves. Ask for names and how they heard about the session. Name badges or cards may be useful.
- Emphasize that we need their help and encourage them to speak openly, for example: "we want to know what you really think!", "I am here to learn from your experience - you are the experts here." "I want to hear as many different experiences and views as possible."
- Reassure that, although you will be taking notes/ recording, what they say will remain anonymous and confidential, and comments will not be attributed to them.
- When taking notes, record people's exact words as far as possible - this kind of qualitative data is much more useful and real. Keep writing as you talk and keep as much eye contact as possible – this is where it helps to have a second facilitator, even in smaller group sessions.
- Have pictorial cues available to help facilitate the discussion if needed.
- It is useful to have a set of cards for participants to raise if they want to speak; for the facilitator to slow down; or if they need help.
- Try not to offer your own views, though sometimes people will ask. You need to be as encouraging/neutral as possible, even if their views are not what you would wish.
- Be sensitive to communication problems or fear of expressing views. Do not forget posture, gesture and facial expressions. You need to communicate warmth, interest, encouragement and caring.
- Given the potential emotive nature of the experiences of people living with dementia and their family carers, it is important to ensure that there is an appropriate supervision/debriefing process available after the event should the facilitator or volunteer require this.
- At the end thank the participants for their time, explain what will happen next, and affirm confidentiality.

DEEP recommendations on facilitating focus groups for people with dementia

- Have a clear timetable for your session, with refreshments available at set times
- Take your lead from the group. Be prepared to join in other group discussions or activities before it is time for your discussion
- Take it slowly, don't overwhelm people with too much information at the beginning
- Use visual aids where possible to help people connect with the discussion topics
- Think about different ways that people can be supported to express their views. For example:
 - Small group discussions: very helpful for people who are quieter or who struggle to speak in a large group
 - Questions to help people begin to talk about a particular issue
 - Visual aids to help people recall discussions
- Let people know about these beforehand

Group discussion questions: some guidance

- Start with easy general questions to try and get their interest - leave specific and sensitive questions to the end. Often the discussion will take off and your well prepared topic guide is not used!
- Feel free to use supplementary questions to elicit ideas or explanations -if people do not use the internet to access services then find out what are the reasons for this and what might support them to do so.
- 'Am I hearing what you are saying correctly?' - check as you go along what you think you are hearing them saying - especially if you are finishing off a long discussion
- If a lot of people are silent, break the groups into 2s or 3s and get them to feed back - or ask people direct questions.

4.3 Useful links

Alzheimer's Society Factsheet on communicating with someone with dementia and on how to encourage the person to communicate in whichever way works best for them:

https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1128

DEEP guides available at: <http://dementivoices.org.uk/resources/deep-guides/>

DEEP guide: Involving people with dementia as members of steering or advisory groups

[http://dementivoices.org.uk/wp-](http://dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)

[content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf](http://dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)

DEEP guide: Tips for organisations wanting to consult people with dementia about written

documents <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf>

DEEP guide: Choosing a dementia-friendly meeting space <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf>

Appendix B: Facilitation hints and tips

DEEP guide: Dementia words matter: Guidelines on language about dementia
<http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

DEEP guide: Collecting the views of people with dementia <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf>

5. Appendix C: Project resources

5.1 Group discussion: template for feedback

This template can be used for recording feedback from a group discussion with people who have received a diagnosis of dementia in the last two years (between November 2014 and November 2016) and from their unpaid carers.

This template can be downloaded from:

<http://consultations.dh.gov.uk/dementia/care-support-and-awareness>

(Please note the boxes in the word version will expand as you type in to them.) Please indicate whether the responses you are recording are from people with dementia or carers of people with dementia or a mix of both.

Number of participants with dementia:

Number of carers of people with dementia:

GETTING A DIAGNOSIS OF DEMENTIA

How well was the diagnosis communicated to you as a person with dementia or as a carer?

Could anything be improved about the way the diagnosis was made? For example what you were told or the process you had to go through.

THE HELP YOU HAD AFTER A DIAGNOSIS

What kind of support did you get as a person with dementia or as a carer in the 12 months after your diagnosis? Please provide the prompts below:

Support to help you manage the symptoms of dementia.

Review of your medication

Support for stress, anxiety or depression

Help for your family or carer

Support to help improve and maintain your memory (e.g cognitive stimulation therapy)

Support to improve and/ or maintain your quality of life (e.g. information and advice, art, music or reminiscence activities, living well with dementia groups)

Support for your physical health (e.g. occupational therapy, falls prevention support or physiotherapy)

Support to remain at home i.e Home Care, meals on wheels etc

Peer support such as Dementia Café's

Support for your relationships

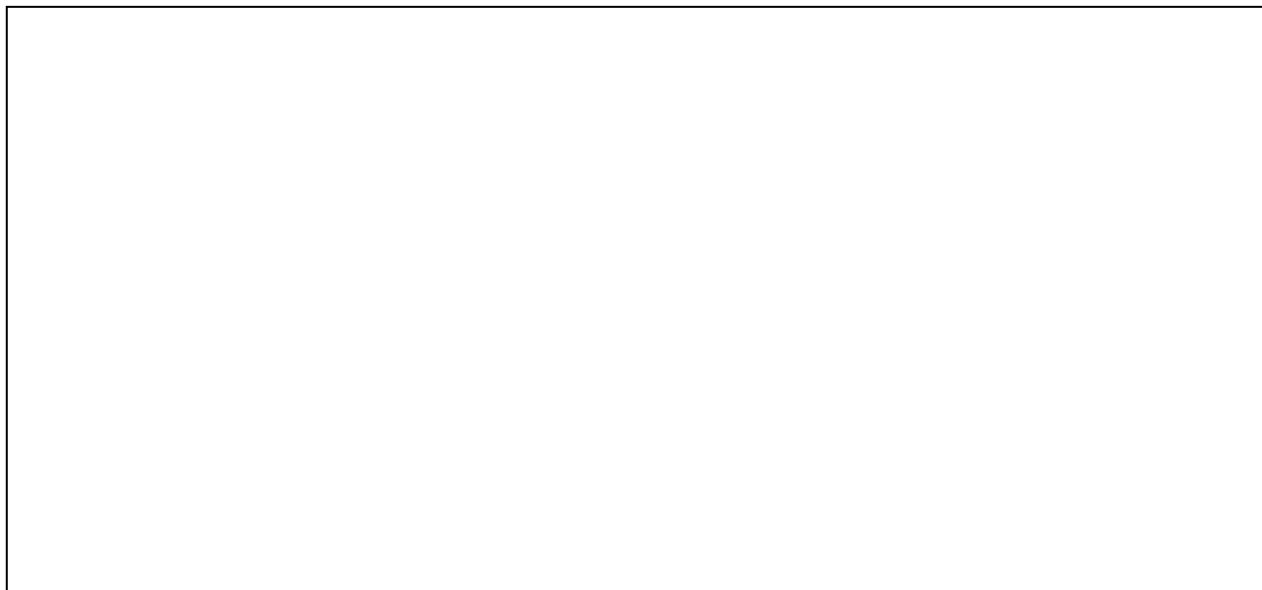
Support with communication

Support with your finances

I did not feel I needed any support at this stage.

No support was given

Could the support you received have been improved. If yes, please provide more information.
(This question is aimed at both people with dementia and carers)



HOW WELL PEOPLE UNDERSTAND DEMENTIA

In your experience, what is your overall impression of how well people understand dementia?
(This question is aimed at both people with dementia and carers)



Appendix C: Project resources

What are the 3 most effective ways of helping people to understand more about dementia?
(This question is aimed at both people with dementia and carers)

Please offer the below prompts and ask participants to identify the top 3:

Dementia Friends

Education in schools

Training for all staff groups

Promoting research findings

Online information (e.g on the website)

Information on the TV and Radio

Information in newspapers and magazines

Information and advice available in the community (for example leaflets etc)

Community events



Please send your completed template to dementiasurvey@dh.gsi.gov.uk by 31st January 2017
or via post to:

Dementia Policy Team

Room 2E56

Department of Health

Quarry House

Quarry Hill, LS2 7UE

5.2 Consent form

The Dementia 2020 Challenge

I understand why I am being asked about the Dementia 2020 Challenge and what will happen next.

I know I can ask questions about this.

I know that if I become uncomfortable, or don't want to keep going I can stop.

I know that my name won't be used, but that things I say might be used.

I agree to participate in the Programme as outlined to me.

Name of participant:

Signature:

Date:

This consent form will be kept and stored by the person who you return this form to. This will be according to guidance provided by the Office of the Information Commissioner.

5.3 Individual Survey

Survey on Dementia Care, Support and Awareness

Introduction

Over recent years great progress has been made to improve dementia care and support. More people than ever before are receiving a diagnosis of dementia. Improvements have also been made in raising awareness in local communities with over 1 million people becoming Dementia Friends. The health and care workforce are also receiving dementia training to better support you.

But there is still more to do. The Government's aim is for England to be the best place in the world for people with dementia, their families and carers to live and the best place to undertake research into dementia.

This is your opportunity to tell us how we are doing. We want to hear first-hand from people with dementia, their families and carers if we are making a difference to your day to day lives.

Your views will be used by the Department of Health and the partner organisations we work with to check our progress. We want to continue to work harder than ever to improve dementia care, support and awareness.

Who should complete the survey?

The survey is for:

- any person in England who has received a diagnosis of dementia in the last two years (between November 2014 and November 2016) and;
- any person in England who currently provides unpaid care or support to a family member, friend or neighbour who has been diagnosed with dementia in the last two years (between November 2014 and November 2016)

When is the closing date?

The survey will close on 31st January 2017. After this we will be looking at what you have told us.

Confidentiality

Any information you provide will be confidential and is anonymous. The results will be used by the Department of Health:

- to help us to see if policies on improving dementia care and support are making a positive difference;
- to see where further improvements may be needed and;
- to influence and improve the delivery of services and support at a local level.

Your information will be used for this purpose and no other.

Accessibility

We have made the survey as accessible as possible. The questions have been informed by work we did over the summer of 2016 with groups of people with dementia and carers. We do appreciate that some people may need help to complete the survey and suggest that you ask someone in a support role such as – a carer, friend, family member, or personal assistant. Please click [here](#) to complete the survey online or if you wish to reply by post please click [here](#) to print a PDF version of the survey.