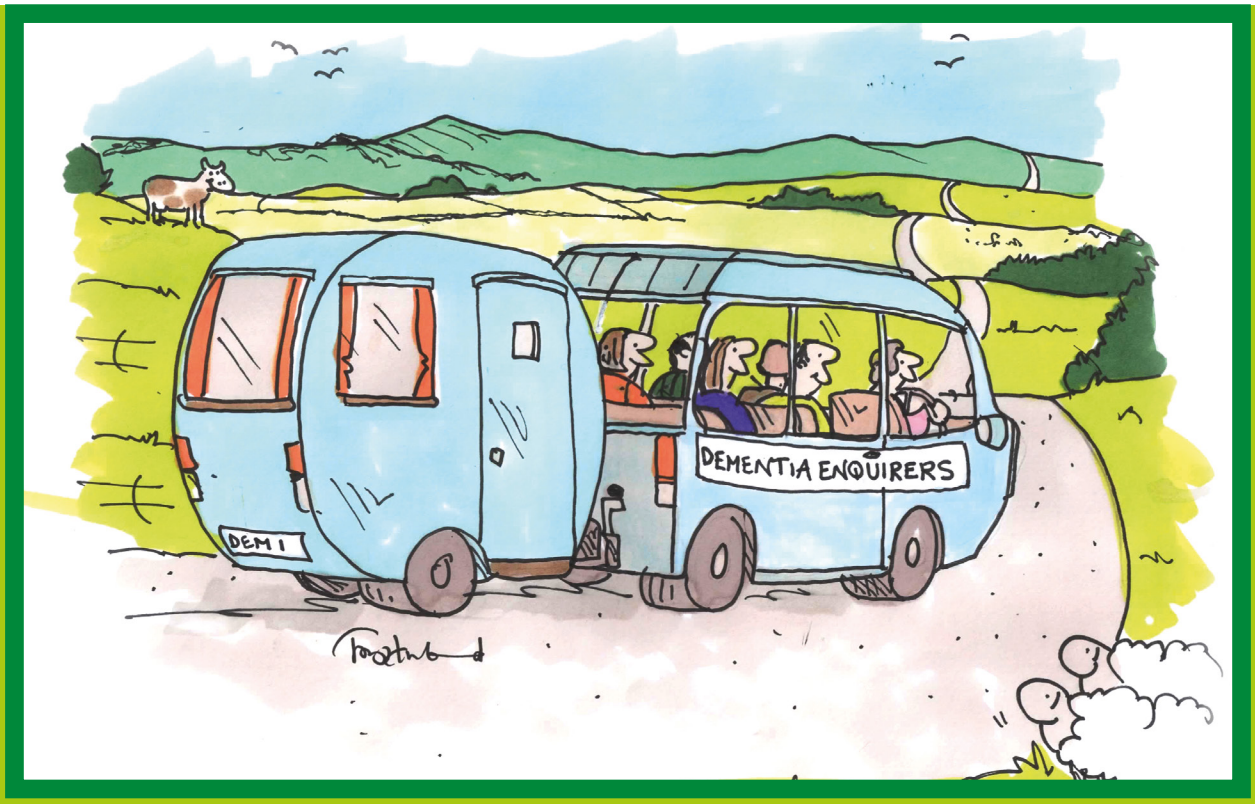
SUNshiners

Dementia Enquirers Report



Dementia as an invisible disability: a consideration of the pros and cons. Is invisibility a super-power or a curse?

November 2022

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication October 2022

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/sunshiners/

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

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Acknowledgments

Thank you to DEEP for setting up the whole Dementia Enquirer project. It was great to get a chance to lead research ourselves.

We would particularly like to thank Rachael Litherland for being so enthusiastic and encouraging and travelling down to Dover to see us in person.

Rosie Ashworth has saved the day when it came to working out how to handle such a large data-set. We could not have done this without you Rosie!

We must not forget the Harbour Inn team, our supportive local pub who kept us warm and well caffeinated.

Who are we

- The SUNshiner group is a friendly, relaxed, all-inclusive, activist group for people in the early stages of dementia.
- We make a difference by reducing stigma and raising public awareness of dementia.
- We support the NHS through guiding recruitment and service development.
- We have a track record of being interested and engaged with research related to dementia and we were therefore very keen to take up the opportunity to lead ourselves on this ground-breaking Dementia Enquirers project through our membership of DEEP

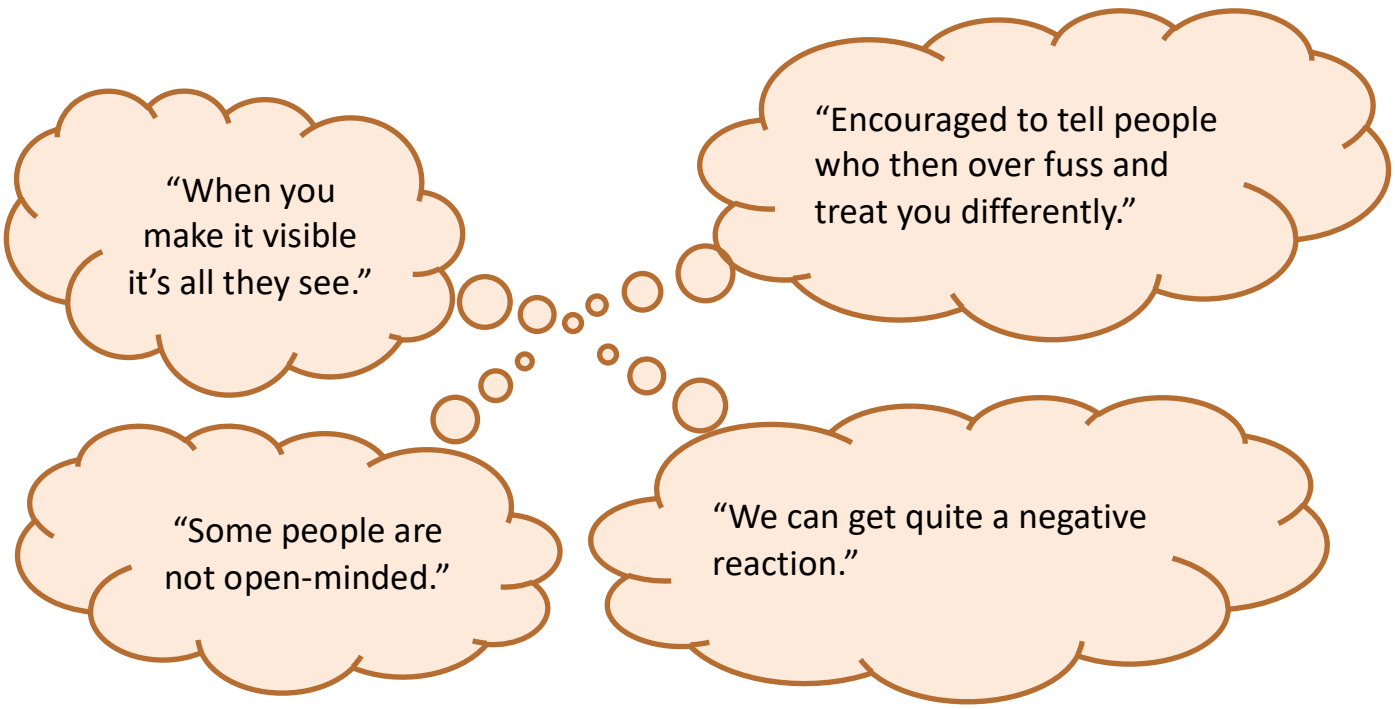
Introduction

How we came up with our topic

Around the time of the start of this project the Hidden Disability lanyard scheme was launched. Although this was not specific to dementia, it helped us to focus on the potential pros and cons of letting others know about our diagnoses.

We had varied experiences interacting with other people, before and after disclosing our dementia diagnoses. Some of us had positive experiences in airports, hospital, shops etc, others were less fortunate.

One of us stated that **"when you make dementia visible, I become invisible".**



After looking through the published literature, we realised that there had been no research in this area. This was the moment that our research question was born and we were very excited to find out what the public thought about the invisibility of dementia.

How we built up our ideas into a research project

We met regularly in a pub to discuss the experiences that we had had. For example, one of us was told by a member of the public that we really needed to have a carer with us at all times, when in fact that group member was able to live independently. Another one of us informed airport staff of our dementia diagnosis and was offered excellent support when she arrived at the airport. When staying in hospital, two of us had very different experiences. One of us was given a separate, quieter room and allowed to have a family member present to support us. The other, was locked in, presumably in case we wandered off?

Our research questions

Having talked through our experiences we wondered:

- What the public knew about dementia
- What they thought about the invisibility of dementia
- Why they might want to know if we have dementia.

How we collected the information

We went back to the pub! We created a questionnaire (Appendix A) and decided that we wanted to have both paper and online versions of this. We used SurveyMonkey for our online version and asked our friends and colleagues to share the link for this on social media accounts. We also put 100 printed copies and stamped addressed envelopes in local

shops, cafes, groups etc so that people who did not have access to computers could still take part.

Our questionnaire included both closed-ended questions (i.e. Yes/No answers) and open-ended questions where people could write a sentence or two to give their views

Our questionnaire was for people over 18 year of age who were living in the UK.

Covid

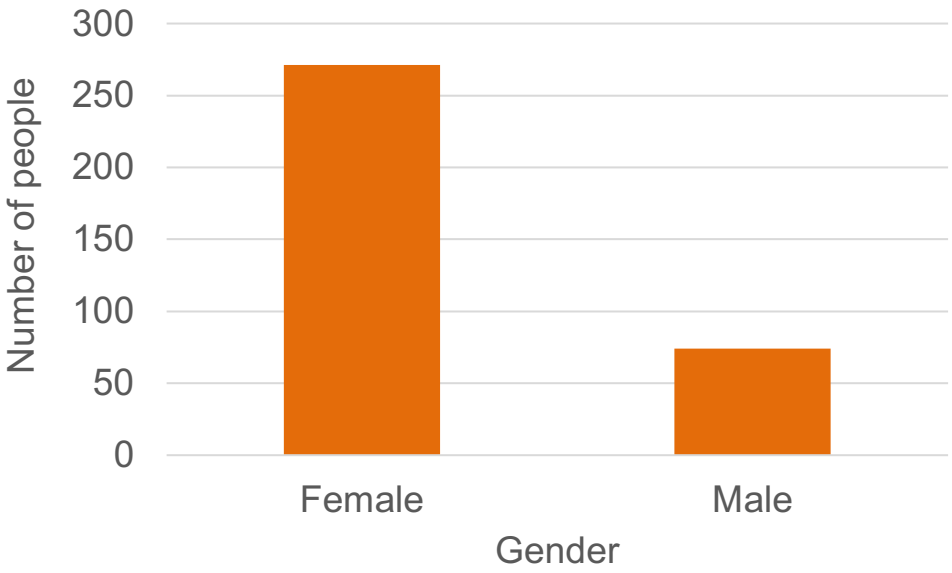
We were just about to launch our survey when Covid and lockdowns struck. We decided to postpone the launch of our survey until the world was less pre-occupied with Covid. We eventually started data collection in November 2021.

What we found out

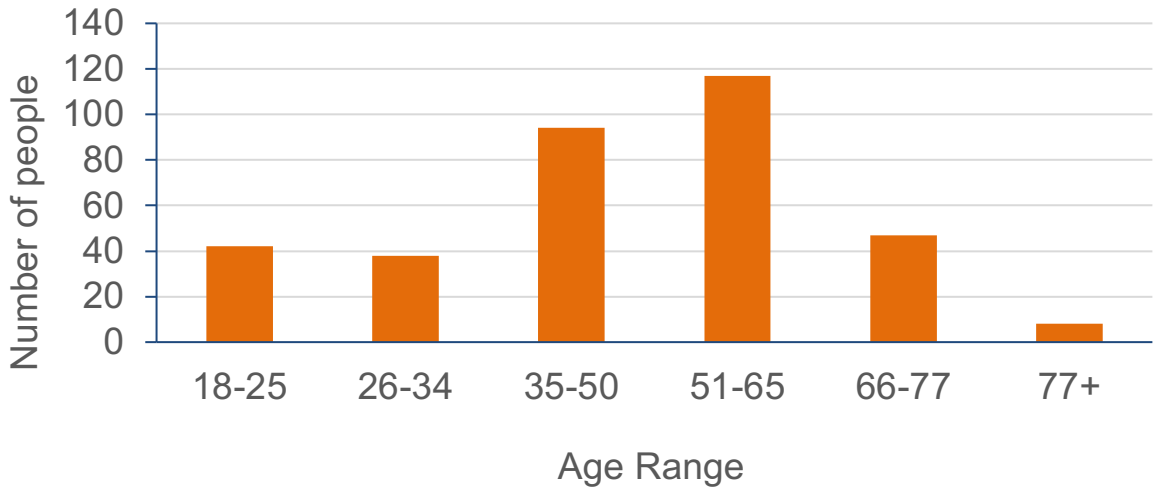
People were very interested in our topic and we had so many responses, 347 in total: 315 online and 32 paper copies. This was an extremely impressive accomplishment but, it was rather overwhelming, particularly the prospect of analysing all those open-ended answers.

Who responded to our questionnaire?

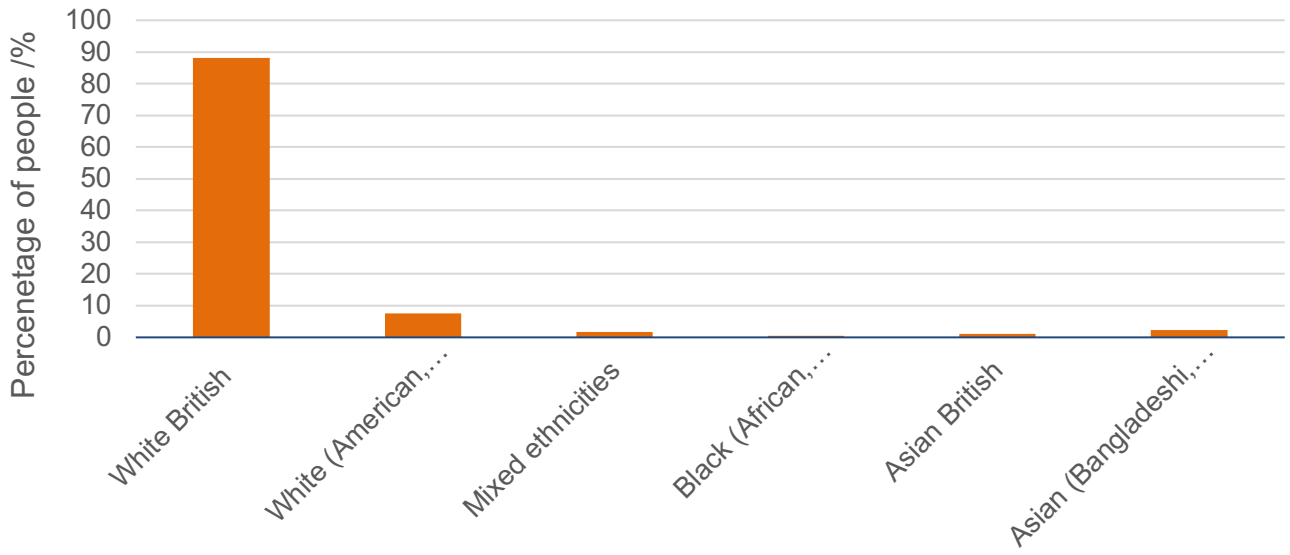
271 Females (78%), 74 Males (21%) and 2 (1%) Others answered our questionnaire.



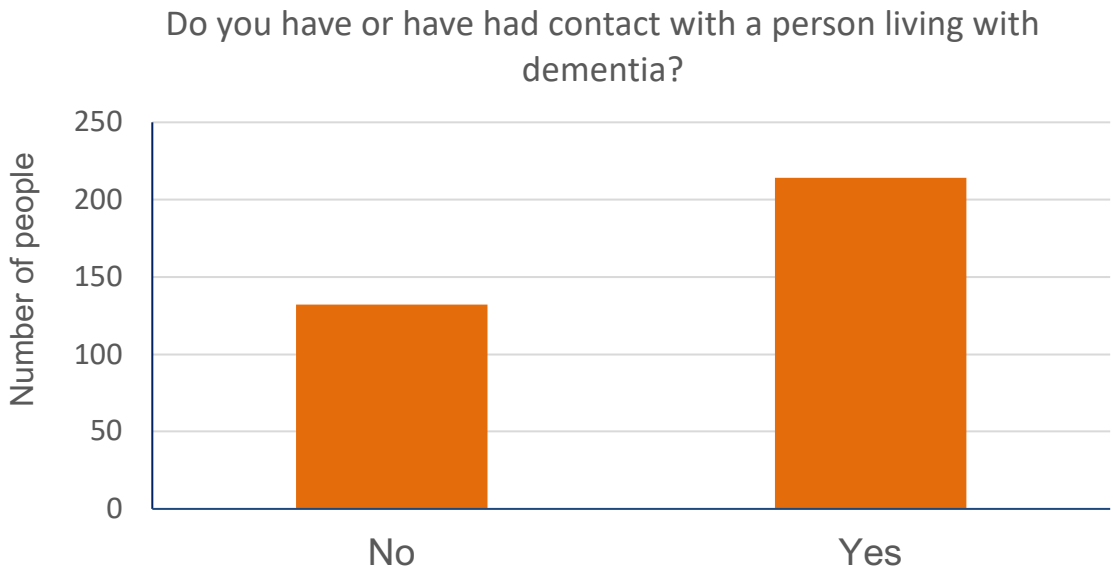
The majority of people (61%) were between 35-65 years old



88% were White British ethnicity



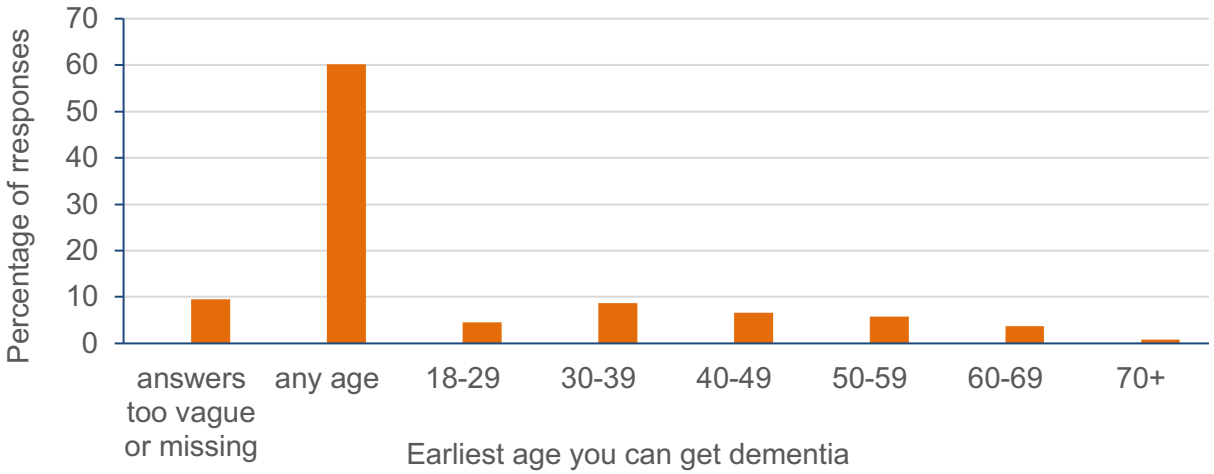
62% of people who responded felt that they had had some contact with a person living with a dementia.



45% of people rated their knowledge of dementia as 8 or higher (out of 10).

83% of people rated their knowledge as 50% or above.

The majority of people noted that dementia could happen at any age (209 responses/ 60%), with the next most likely age it can start being between 30 and 39. Of note, 15% of the answers included some awareness that age was a risk factor, with it being more common in older adults.



The questionnaire had four questions that included a yes/no answer as well as space to expand on why.

- Do you think it is a positive or negative that dementia is an invisible disability?
- Should people with dementia maintain the right to vote?
- Do you think you would benefit from knowing if someone has dementia on initial meeting?
- Do you think a person diagnosed with dementia automatically requires a consistent regular carer?

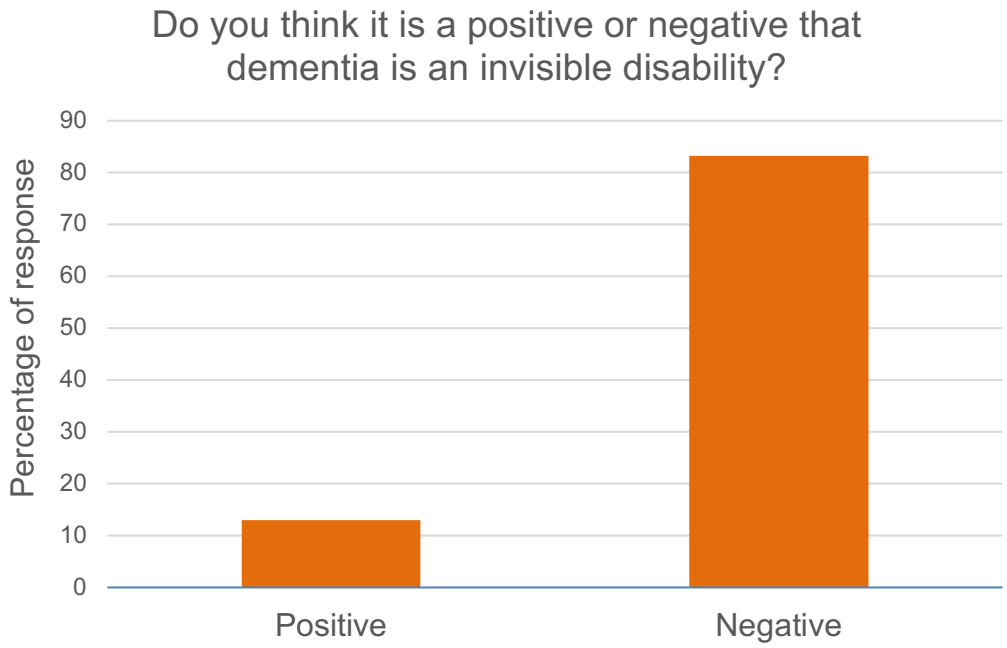
For the first question: Do you think it is a positive or negative that dementia is an invisible disability? We had planned for people to go through the answers and start grouping by possible categories. The group found this particularly overwhelming. So, we came up with a different approach:

- SUNShiners thought about what reasons people may give for their answers.
- These made categories for Rosie to start sorting answers into.
- When Rosie had gone through several responses, she added in categories that had come up
- A set of criteria for what was put in each category was then given back to SUNShiners so that they could go through some more answers
- Finally, Rosie grouped the rest of the answers following the same criteria

A more detailed example of this can be found in the appendix (B).

Do you think it is a positive or negative that dementia is an invisible disability?

- 289 people (83%) felt that the invisibility of dementia is negative.
- 45 people (13%) felt that the invisibility of dementia is positive
- 13 people (4%) were unsure or answered both positive and negative



29 people (8%) did not expand on why they answered positive or negative.

Key findings for invisibility of dementia

- The majority of people thought that it was a negative that you can't always see dementia, because then others won't recognise symptoms and understand experience

"Although things are improving, people tend to be less compassionate about invisible disabilities"

- The invisibility leads to lack of understanding

“Contributes to the general lack of understanding. If people can't see a disability they often don't accept the person is disabled”

- Stigma was mentioned by people who answered positive and negative. The fact dementia is stigmatised means that it could be positive for people not to know someone has dementia.

“Because there is a stigma against dementia and not understood by public”

- But equally, people can experience stigma because they experience symptoms that are not explained or misunderstood.

“I've seen some people get annoyed with someone who has dementia, and we've had to explain to them that they aren't doing things on purpose”

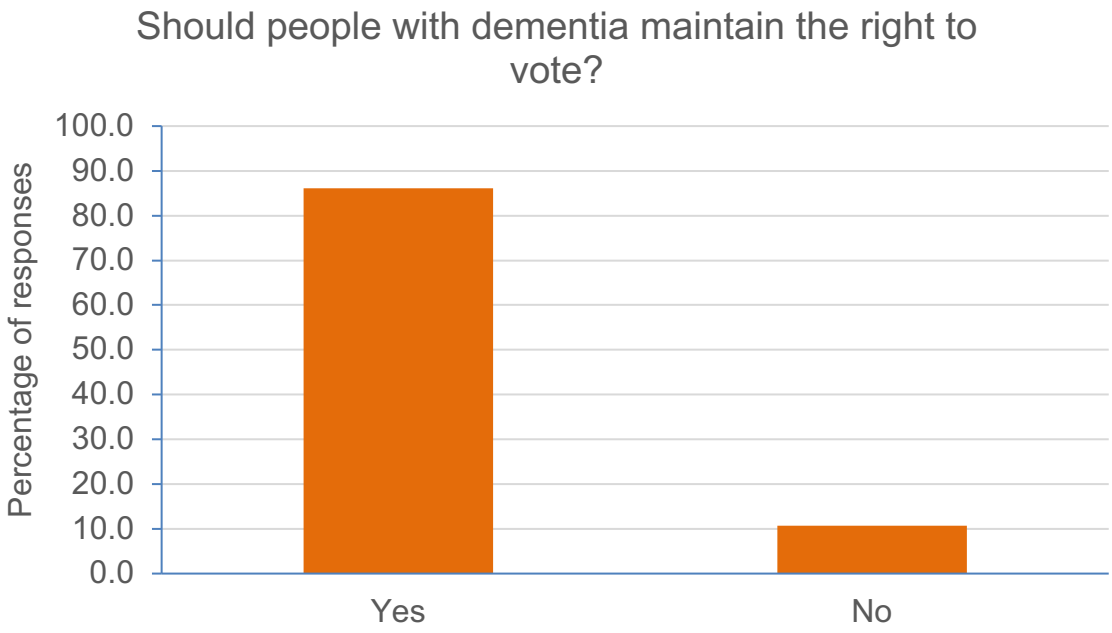
- Not visibly having dementia can mean that the public are less aware of the condition and the need to learn more about it

“Because by definition being unseen, not immediately apparent then this can be a barrier to understanding.”

However, focusing on people showing symptoms of dementia to help educate others, puts a lot of the responsibility on the person with dementia. There is a sense that they should lose their privacy in order to help others understand what they are going through. Whereas, the other answers put more of the responsibility on people without dementia.

Should people with dementia maintain the right to vote?

Most people (86%) agreed that people with dementia should maintain the right to vote.

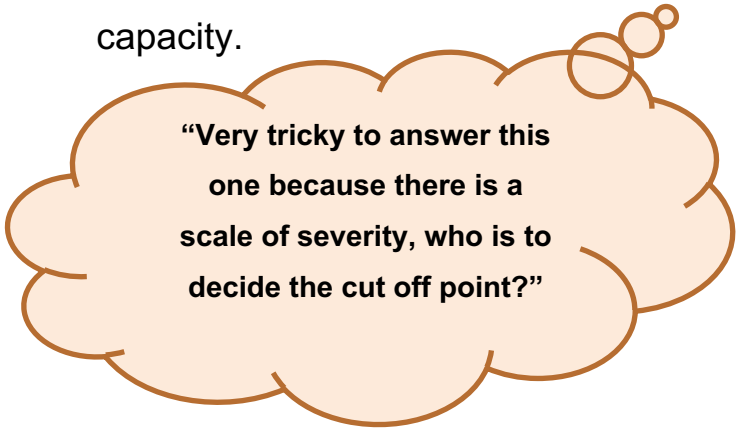


- **86%** of people said that people with dementia should maintain the right to vote
- **11**% of people said that people with dementia should not maintain the right to vote
- **3%** did not answer yes or no
- Of the 336 answers, 51 people (15%) did not expand on their answer

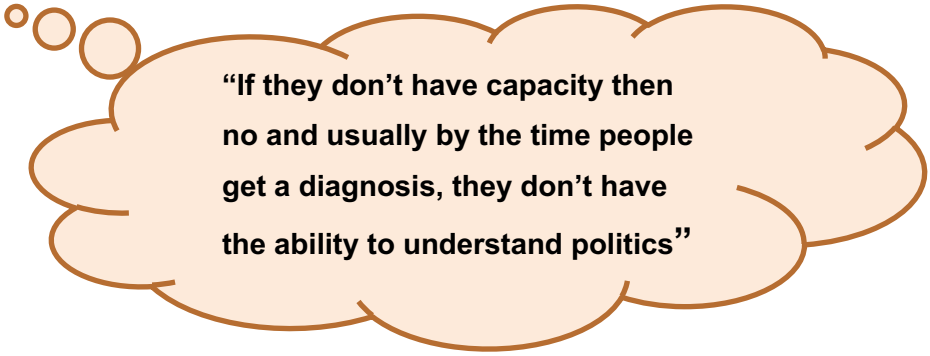
SUNshiners predicted reasons people might say:	
Should maintain right to vote	**Should not maintain right to vote**
○ Diagnosis does not equal capacity ○ As long as able and understanding ○ Human right to vote	○ Lack of capacity or severity of dementia ○ Won't know what they are doing ○ Risk of being manipulated to vote a certain way

Key findings for maintaining the right to vote

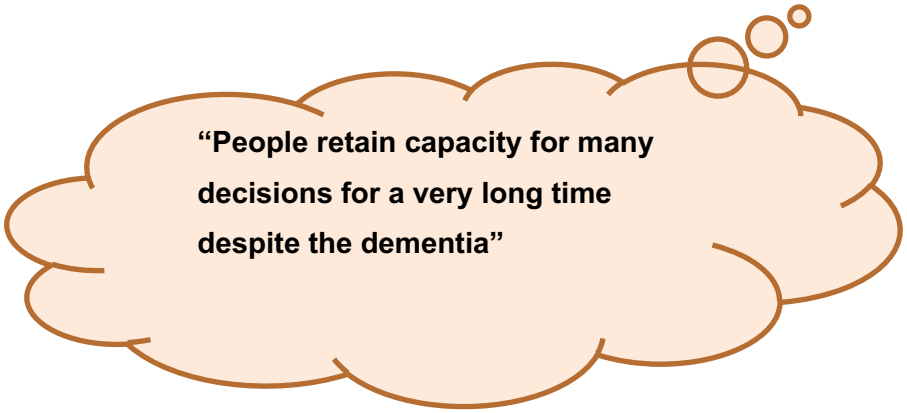
- The majority of answers focused on whether a person had capacity.



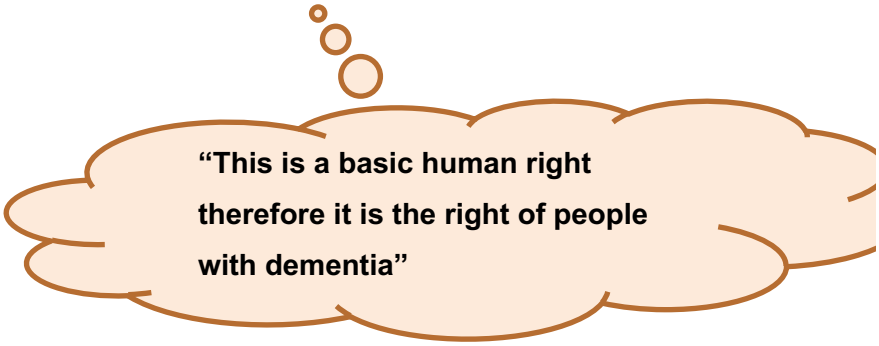
For people who said no, there was a bigger emphasis on assumed lack of capacity



For people who said yes, there was a bigger emphasis on recognising that a diagnosis did not equal lack of capacity.



It was also good to see that the second most common answers for people maintaining the right to vote, were explained as a person's human right to vote and be an equal member of society



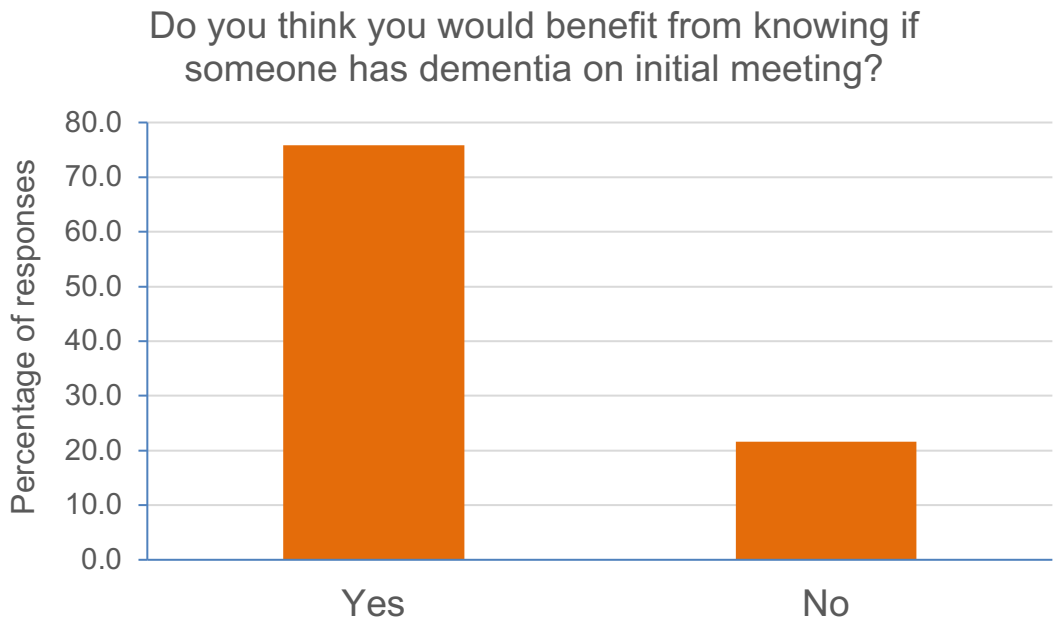
- People who answered no, also raised concerns around whether a person with dementia would know what they were voting for and whether that could put them at risk of being manipulated.
- People who answered yes were more likely to focus on how people should be able to vote if they understand what they are doing. The answers are very similar but the difference comes from whether people are assumed to have an ability or not.

Do you think you would benefit from knowing if someone has dementia on initial meeting?

22% of people felt that they would not benefit from knowing if someone had dementia on initial meeting

76% of people felt that it would be helpful to know if someone had dementia on initial meeting

2% of people did not answer yes or no but specified that it depends on the situation.



17% of people did not expand on their yes/no response.

SUNshiners predicted reasons people might say:	
Would benefit from knowing	**Would not benefit from knowing**
○ To help others/ assisting them ○ Avoiding situations getting out of hand ○ To know how to adjust to the person	○ Should be kind and thoughtful to everyone ○ Need to know basis ○ To not be seen as vulnerable to others

Key findings for whether it would help to know someone had dementia

- The majority of answers centred on people wanting to know so that they could tailor their behaviour where needed to support someone better.

"I'd be a bit more attentive and a bit more aware of the potential need for me to adjust my communication style"

- It was very positive to see that people were keen to know so that they could take responsibility for supporting a person with dementia and their needs. As opposed to expecting people with dementia to do anything differently.

"There would be understanding of someone's behaviour if aggressive or emotional. That way you could be supportive and help them with their needs."

- There was also understanding that although it may be helpful to know, it was also a personal choice, with a right to privacy

"Because you could be more understanding if they repeat questions or don't understand something. It should be personal choice though as they may not want people to know their medical history."

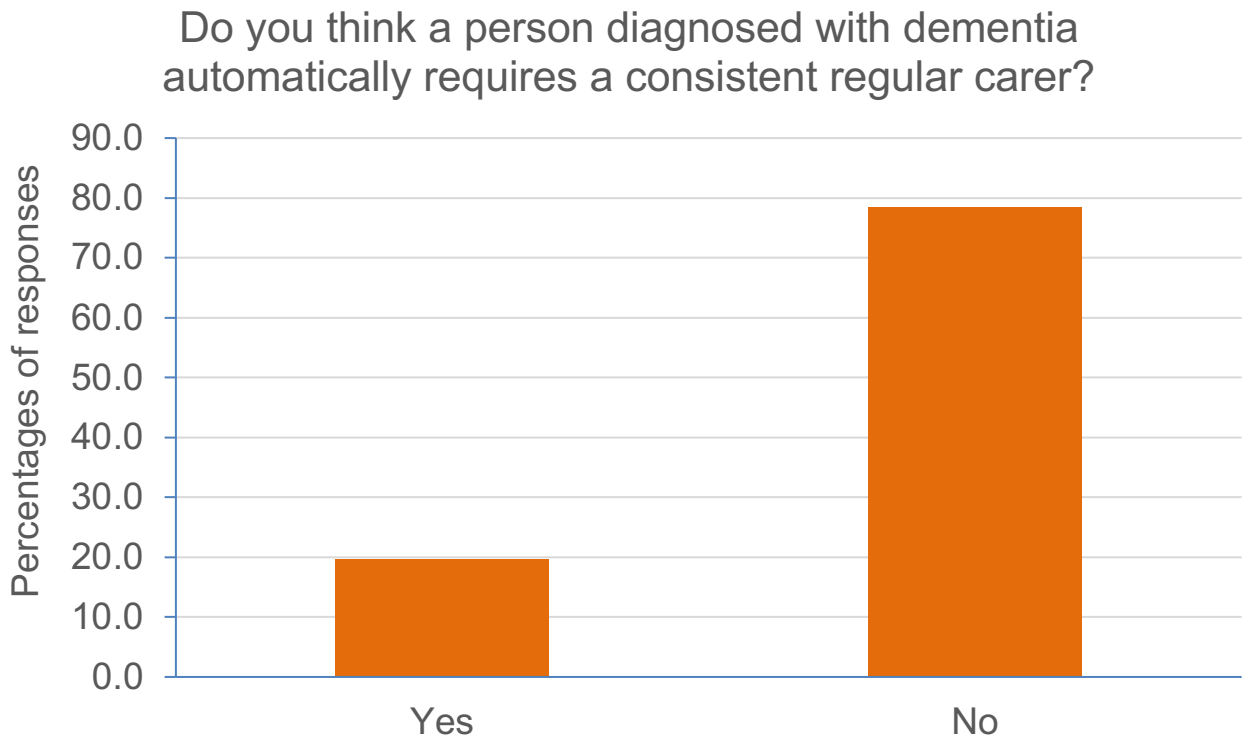
- For people who thought it would not be helpful to know, privacy was the most common reason, with the second most common reason a tie between 'should be kind and thoughtful to everyone regardless of diagnosis' …
- …and 'may alter perceptions of behaviour' which links back to concern about stigma.

Do you think a person diagnosed with dementia automatically requires a consistent regular carer?

78% of people did not think that a person diagnosed with dementia automatically require a consistent regular carer.

20% of people thought that a person diagnosed with dementia automatically require a consistent regular carer

2% (people did not answer yes or no)



63 of the 347 people (or 18%) did not specify why they picked yes or no.

SUNshiners predicted reasons people might say:	
Should have a regular carer	**Should not have a regular carer**
○ Only seen later stages of dementia ○ Stigma ○ Safety and guidance/ supporting ○ Deserving help/ Support	○ Dementia does not define need/ everyone is different ○ Dementia is not always visible ○ Still the same person that they were

Key findings for automatic, regular carer

- Most people said that it would depend on the severity of a person's dementia. This was the case for people who answered yes and no

"In the early stages, little help is needed but later the person will need help and understanding."

"They have good days, times. Only as time goes on is more support needed"

- The next most popular category for people who answered no- people with dementia do not automatically require a regular consistent carer was "dementia does not define need/everyone is different"

"That may be totally unnecessary for many years. Access to support, resources and community which promotes and enables independence, even within structured care plans, would be preferable"

"Lots of people living with dementia are able to remain independent"

- The next most popular category for people who answered yes- people with dementia do automatically require a regular consistent carer was “people deserve access to help”

“I think they should have access to this and the person/next of kin should decide if they would like to access this service”

“Automatically requires is a stronger term than I am agreeing with, but I think it would be very helpful and I think it should be an automatic right they/their family could take advantage of.”

- For people who thought that someone would require a carer, the answers were largely positive in that they thought it would be useful to have someone consistent and familiar involved in providing support.

“To help maintain and support them in their daily routine should the time come that they are unable to do so themselves”

“To help build confidence and provide stability and security”

- As we can see from the other answers, the people answering the questionnaire seemed aware of the individual differences and variation in capacity. The differences in whether people answered yes or no seemed to be linked to the assumed need for help i.e. people answered yes if they thought people **would** need help vs. answering no if they thought people **might** need help.

Key findings across the open-ended questions

- Across the answers, people recognised that their answers were dependent on things such as the individual with dementia, the symptoms they are experiencing, and the access they have to support.
- Most peoples' answers seem to come from a position of wanting to help or being cautious about doing the 'wrong thing'.
- Answers focused on how to support people with dementia to feel part of society, rather than put the responsibility on them to stay involved.
- Some of the difference in answers were from people who assumed somebody with dementia will need help compared to might need help.
- The positive focus on answers may come from that the majority of people (83%) rating their knowledge of dementia as 5 or higher on a scale from 1-10.

Our Conclusions

As people with dementia, here are some of our thoughts about leading this research project from start to finish:

"It made me feel like I was able to contribute to something positive by challenging members of the public to think about how it might feel to live with Dementia."

"It was important to get involved in a research project for a few reasons, 1 to have a voice and 2 to prove to people that we can still do things. Just because we have a dementia doesn't mean we are unable to get involved. Our brains still work to a degree just in a different way. I have enjoyed being part of the project and working as part of a team."

"It has enlightened me positively to read the answers people gave. On the whole the answers were very caring in their responses. It also made me feel useful being part of the working group. I felt I had a purpose and enjoyed it very much."

References

Hidden Disabilities website https://hiddendisabilitiesstore.com/

Appendices Appendix A

Information sheet:

The purpose of this nationwide study is to investigate the public's perception regarding the invisibility of dementia. The study contains a short survey which will take no longer than 5-10 minutes to complete. The data collected will not identify individuals and it will only be used for the purpose of this study. Your responses will be very much appreciated. There will be links at the end of the survey if you require any further information.

We do ask that you only complete the survey is you are over the age of 18 and are a UK resident – thank you.

Consent form

By filling out this survey you are consenting to the following:

I confirm I have read the information sheet for the above study

I understand that the data collected will be anonymised

I understand that the data collected will be used for research purposes only

I agree to take part in the study

Demographic questionnaire:

What gender are you?

☐ Male
☐ Female
☐ Other

How old are you?

☐ 18-25
☐ 26-34
☐ 35-50
☐ 51-65
☐ 66-75
☐ 76+

What is your Ethnicity?

☐ Asian (Bangladeshi, Chinese, Indian, Pakistani, Other)
☐ Asian British
☐ Black (African, Caribbean, Other)
☐ Black British
☐ Mixed ethnicities
☐ White (American, European, Irish, Other)
☐ White British

What county do you live in?

Do you have or have contact with a person living with dementia?

☐ Yes
☐ No

How would you rate your understanding of dementia? (add circle)

1	2	3	4	5	6	7	8	9	10
Little understanding									Good understanding

Main questionnaire

How old do you have to be to have dementia?

Do you think it is a positive or negative that dementia is an invisible disability?

☐ Positive
☐ Negative

Please explain why:

Should people with dementia maintain the right to vote?

☐ Yes
☐ No

Please explain why:

Do you think you would benefit from knowing if someone has dementia on initial meeting?

☐ Yes
☐ No

Please explain why:

_____

_____

_____

Do you think a person diagnosed with dementia automatically requires a consistent regular carer?

☐ Yes
☐ No

Please explain why:

_____

_____

_____

Appendix B: Example criteria document:

Do you think a person diagnosed with dementia automatically requires a consistent regular carer?

80% or 252 people did not think that a person diagnosed with dementia automatically require a consistent regular carer.

19.4% or 61 people thought that a person diagnosed with dementia automatically require a consistent regular carer

0.6% (2 people did not answer)

SUNShiners reasons for why people may say no

- Dementia is not always visible
- Still the same person that they were
- Dementia does not define need/ everyone is different

Criteria- Dementia does not define need/everyone is different

I have kept this label as you have worded it, it fits neatly into responses around different needs and how people with dementia are all different

e.g. “not all dementias are the same” or “Most people newly diagnosed are perfectly capable of living without needing care”

- Key words: need, different types of dementia, different symptoms, different experiences

Criteria- Progressive/Severity/stage dependent

I have added this category in, although it has a lot of overlap with the category above, answers are more focused on the progression of the condition and how stage or length of time with dementia is important

e.g." it depends what stage of dementia people have. Some people live with it for years before officially knowing they have it" or "Depends on the severity of the illness"

- Key words: early stages, severe, progressive, changes over time

Criteria- Personal/Family Choice

A new possible category is around the individual choice people should have over whether they have a carer or not

E.g. "I know people with dementia who live well without a carer. It needs to be about what works for the individual."

- Personal choice, individual, family decision, discussion, informed decision/choice

Of the answers I have been through so far-

I have not come across answers that fit neatly into 'dementia is not always visible' and 'still the same person that they were' but may fit within 'severity' and 'dementia doesn't define need'.

Other answers that could become a category if come across it more:

- Worry that having a carer could make it worse/progress
- Concern about loss of independence
- Regular review but not necc. Consistent

SUNShiners reasons for why people may say **yes**

- Only seen later stages of dementia
- Stigma
- Safety and guidance/ supporting
- Deserving help/ Support (this might link nicely to the one before)

In some ways, a lot of the ‘yes’ answers can be seen as stigma-led based on whether a person is assumed to need help versus potentially needing. It is where the ‘depends on how things are for the individual’ comes in

Criteria- only seen later stages of dementia and stigma

I have combined the ‘only seen later stages’ and ‘stigma’ as these answers focus on a stereotypical view of dementia

e.g. “Dementia sufferers don't like change” or “Because of the insidious way in which the illness affects their performance at work or their ability to maintain social contacts”

Its hard to define key words for this one, but covers stereotypes around ‘demented’ ‘sufferer’ ‘no capacity’ etc. and used as a reason to need a regularly consistent carer.

Criteria- Safety and support

I have focused more of safety-specific comments for this category and have included possible support within the ‘deserving help/support’ category.

e.g. “Consistency is key, someone to make sure they are living safely” or “Ensure they’re eating and doing all the things they may forget they have or haven’t done”

Key words: risk, safety, aid, danger, concern

Criteria- deserving help/support/may be helpful

It was great to see this being included, as answers tended to have a focus on the fact people are deserving of help and support, and have the right to support that may be helpful

E.g. “I think they should have access to this and the person/next of kin should decide if they would like to access this service” or “Automatically requires is a stronger term than I am agreeing with, but I think it would be very helpful and I think it should be an automatic right they/their family could take advantage of.”

Key words: rights, potential, choice, helpful, deserve, compassion

Criteria- Need help

In contrast to the focus on potentially wanting help, these answers carry an assumed need for that help (which links back to stigma too)

e.g. “As they may not be in a sane state of mind all the type as should be regularly checked up on to see if the progression is getting worse” or “Does not need to be 24/7 but need someone to support and help with daily challenges”

- Key words: need, unable, help, care, support, supervision etc

Criteria- Consistency and familiarity

People who answered No tended to push against the consistency and felt like it should be more flexible/not needed. Whereas people who have said yes tend to focus on the importance of familiarity.

e.g. “Consistency is a big help. Only needs a carer at certain stages but familiar faces are very important to ease confusion” or “Continuous support from one person must be more beneficial than continuous changes”

- Key words: get to know you, consistent, familiar, comforting, less disruptive, ease change or transitions etc.

Additional potential categories include the focus on psychological support and depending on severity, which links back to some of the reasons people answered no.

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

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