



How dementia friendly is Wiltshire?

July 2019



Chippenham Memory Café

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Report summary

What is this report about?

This report is about how dementia friendly initiatives are working in Wiltshire and their effect on people living with dementia and their carers. It details what people living with dementia and their carers told us they value most about dementia friendly initiatives.

What did we do?

We carried out a survey for dementia friendly initiatives to gather information from them. We designed a survey for people living with dementia and their carers with the support of people living with dementia.

We visited community groups and day services across Wiltshire to distribute our survey and talk to people there. Other organisations also supported us to share the surveys.

There were 24 responses from dementia friendly initiatives and 109 responses from people living with dementia and their carers.

What were the key findings?

- Most people living with dementia and their carers feel that their local community is dementia friendly and feel part of it.
- People told us they most valued greater dementia awareness, understanding and assistance from individuals, and community groups.
- The effects of dementia friendly initiatives for people living with dementia and their carers are positive and wide-ranging including improved physical and mental health, wellbeing, independence, activity and community involvement.
- The successes of dementia friendly initiatives closely aligned with what people living with dementia and their carers said they found most useful.
- Dementia friendly initiatives would value support with promotional materials and publicity.
- Volunteers play a key and valuable role in dementia friendly initiatives.

Next steps and recommendations

We have made seven recommendations which will involve key organisations working together. They aim to ensure that dementia friendly initiatives can be sustained and further developed to deliver the positive benefits that people living with dementia and their carers have told us about.



Introduction

Over the last four years dementia has been a priority area for Healthwatch Wiltshire, and we have gathered over 1,600 views and experiences from people affected by dementia. One of the key things that we have been told is that dementia awareness is improving and that this is important. People living with dementia have told us that they want to be active and involved in their local communities.

Between 2015 and 2017 Wiltshire Council funded a Dementia Aware Project which involved them working in partnership with Alzheimer's Society and Alzheimer's Support. This involved a project worker delivering Alzheimer's Society Dementia Friends sessions and supporting Area Boards to make their communities dementia friendly.

By 2017, as a result of this project over 5,600 Dementia Friends were created and 17 of the 18 Area Boards in Wiltshire had been supported to set up Dementia Action Alliances. (Ref: Wiltshire's Dementia Aware Project)

The aim of this Healthwatch Wiltshire engagement project was to get an overall picture of how dementia friendly initiatives are now working across Wiltshire and their effect on people living with dementia and their carers. We wanted to find out what people living with dementia and their carers value most about dementia friendly initiatives.

Healthwatch Wiltshire hosts a dementia engagement steering group where we work in partnership with voluntary organisations to ensure that people living with dementia are heard. This includes Alzheimer's Support, Alzheimer's Society, Rethink, Carers Support and Age UK. Our partners supported us with this work by sharing our surveys and welcoming us to their groups to talk to people there.

Our volunteers

Healthwatch Wiltshire has a team of committed, trained volunteers. Our volunteers supported this engagement by sharing our survey, attending groups and carrying out interviews, entering data and proof reading the draft report. Nine volunteers contributed a total of 50 hours of their time.



Our approach

This project had two elements, the first aimed to gather information from dementia friendly initiatives and the second was to talk to people living with dementia and their carers:

1. Information from dementia friendly initiatives

We designed a survey for people involved in dementia friendly initiatives. We asked questions about how well they thought their initiative was working overall, what they have achieved, what they would like to develop further and if there were areas that may need further support. It aimed to assess how 'linked in' dementia action alliances are with other dementia initiatives and identify any areas where improved communication would be beneficial.

2. Views of people living with dementia and their carers

We wanted to find out from people living with dementia and their carers about their experiences and views of living in their local communities. The aim was to find out how 'dementia friendly' people thought their local communities were, to identify what aspects were most valued and the impact of these, and to see what they would like to see prioritised in the future.

To assist us to design a survey that would do this, we involved the Laverstock Memory Support Group for people living with dementia. We held a group discussion and they shared some initial views with us about what they regarded as being dementia friendly in their local communities. We asked for this group's views on some proposed questions to find out whether they made sense, how they were interpreted, and whether there was anything that was missing.

We used these responses to inform what we asked and how our survey questions were phrased. We would like to acknowledge and thank the Laverstock Memory Support Group for working with us to design this survey. The survey was designed so that it could be completed by people online, on paper, or through a 1-1 interview.

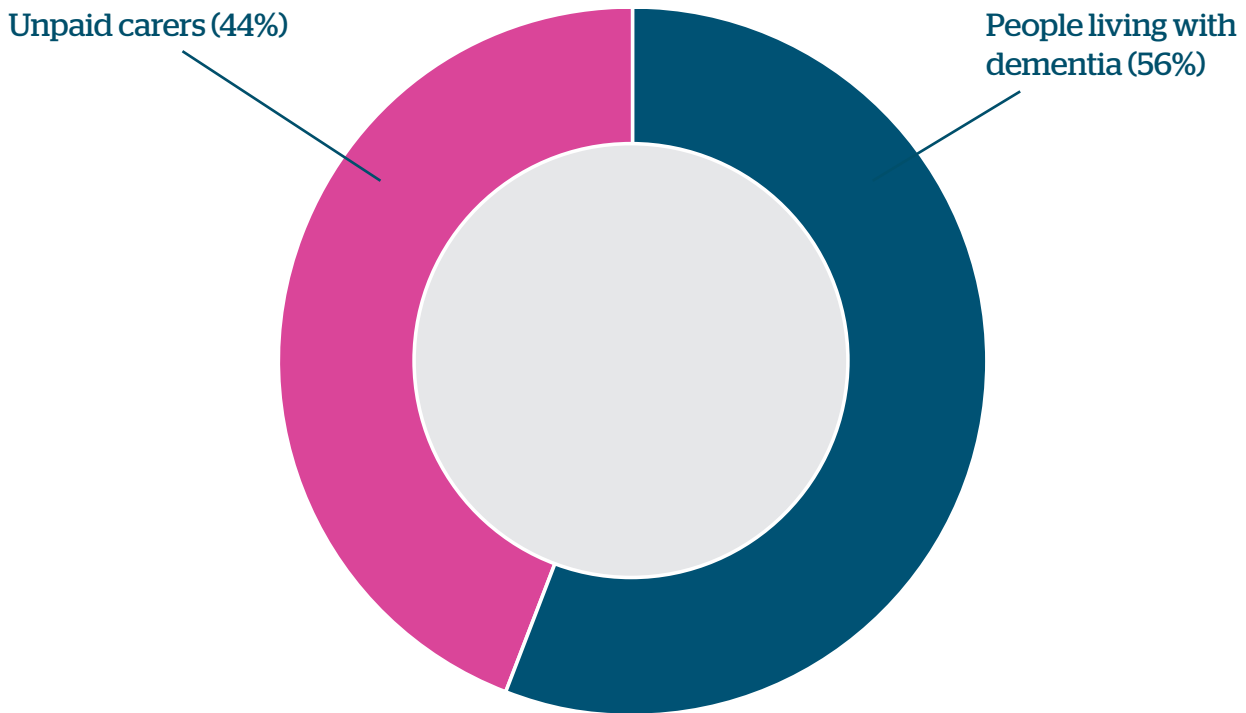
Between January and March 2019, both our surveys were widely shared throughout our dementia engagement steering group partners, other voluntary organisations, the Dementia Action Alliances, Wiltshire Council Community Engagement Managers and through social media. We also visited a number of dementia groups and day clubs to talk to people there.



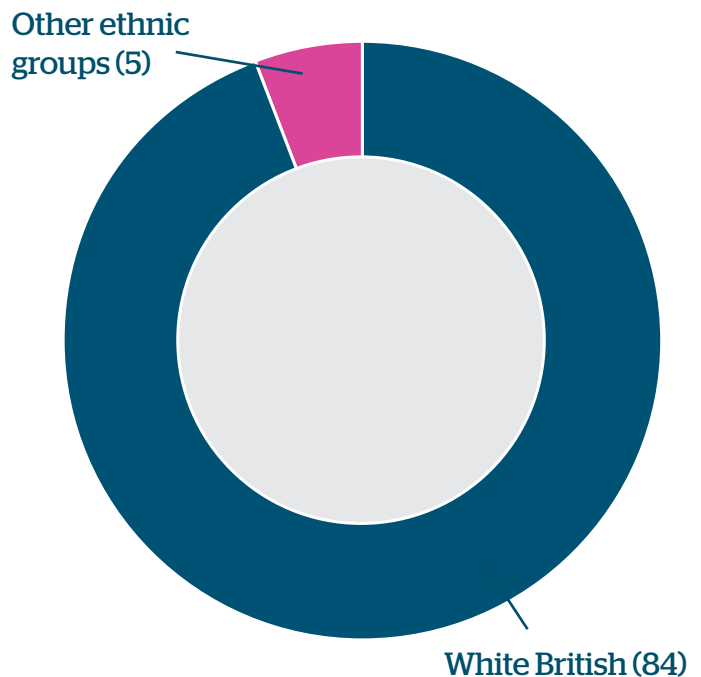
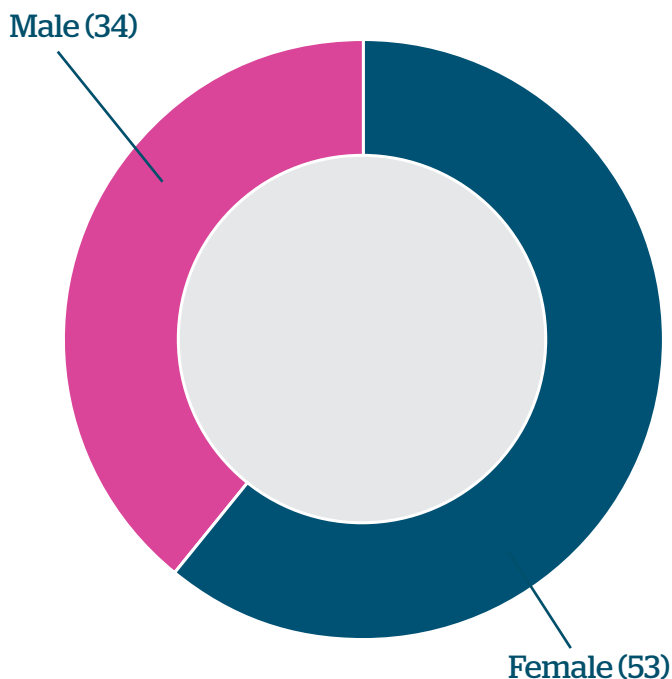
Who we spoke to

There were 23 responses to our survey about dementia friendly initiatives and one person had an informal interview.

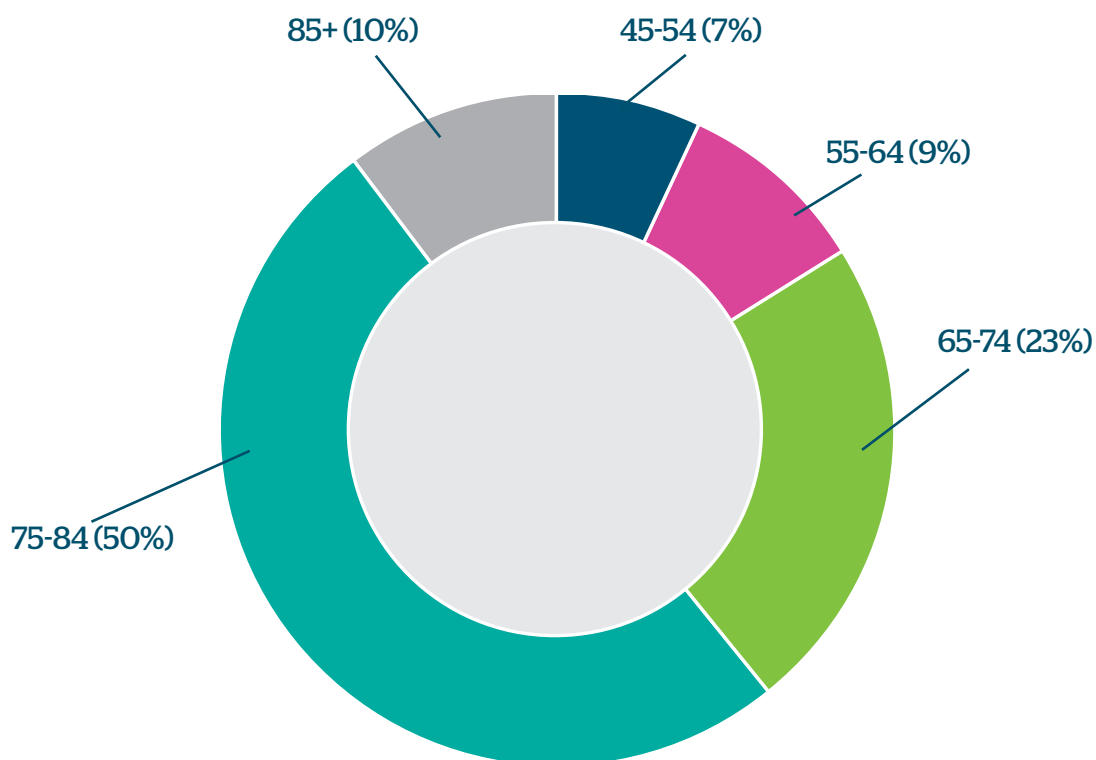
109 people living with dementia and their carers gave us their views. 89 of these completed our survey and 20 people took part in a group discussion. Of these 109 people, 61 (56%) were people living with dementia and 48 (44%) were unpaid carers.



Of those people who shared information about their demographics:



The age range of those we spoke to was:



Note: Some of those in the younger age ranges were carers who were children of people living with dementia.

We spoke to people at these groups and locations:

Group and location	Supported by
Gardening Group, Malmesbury	Alzheimer's Support
Laverstock Memory Group and Peer Support Group, Salisbury	Laverstock Memory Support Group
Carers Support Group, Melksham	Alzheimer's Society
Memory Café, Chippenham	Alzheimer's Support
3 M's Memory Cafe, Lyneham	Wiltshire Service Users Network
Music for the Mind, Seend	Alzheimer's Support
Hungerford House Day Centre, Corsham	Orders of St John Care Trust
Music for the Mind, Lockeridge	Alzheimer's Support
Movement for the Mind, Devizes	Alzheimer's Support
Tisbury Memory Club	Wiltshire Service Users Network
Memory Café, East Grafton	Alzheimer's Support
Foresters Day Support Service, Salisbury	Alzheimer's Society
Harnham Memory Café, Salisbury	Alzheimer's Support
Art Group, Warminster	Alzheimer's Support
Dementia Carers Group, Royal Wootton Bassett	Alzheimer's Society



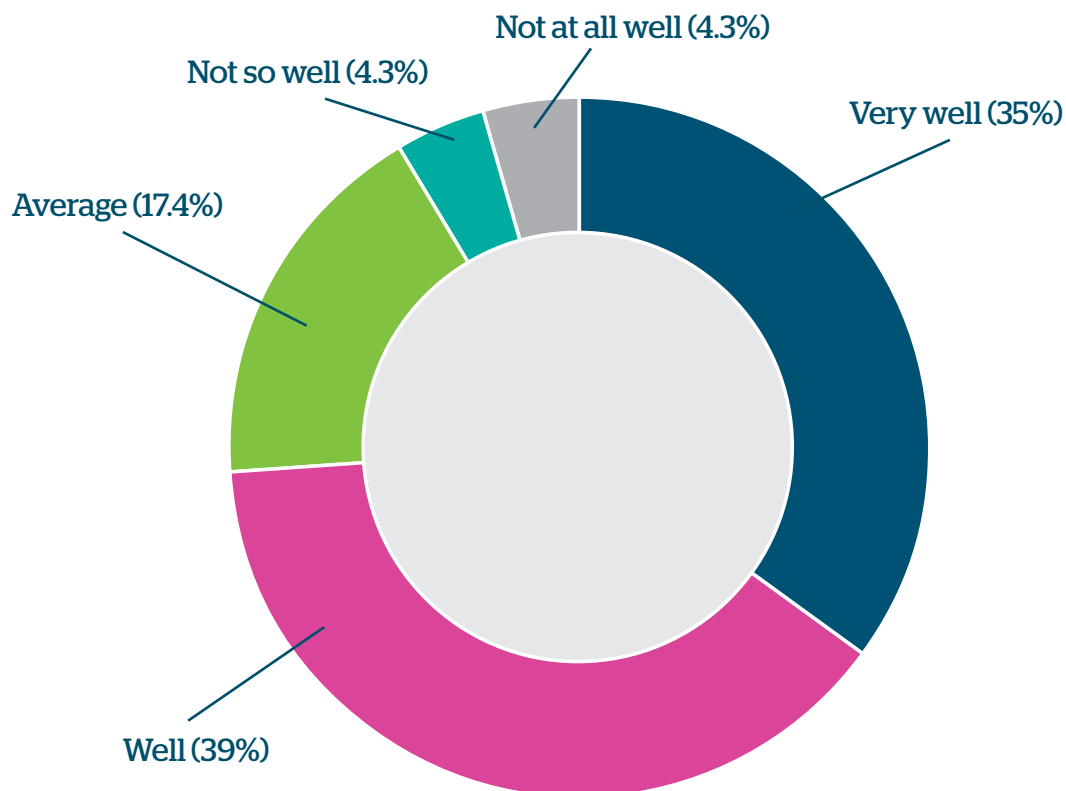
What did people say?

1. Information from dementia friendly initiatives

We had a total of 23 responses to this survey, and one informal interview.

Most dementia friendly initiatives thought that they were working well overall. 17 of the 23 survey responses indicated this compared to two who thought they weren't working well. The breakdown of responses is shown in the graph below.

Of those that thought they were not working well one response came from a group and the other from a member of a Dementia Action Alliance.



What were the successes?

We were given a range of examples of what dementia friendly initiatives thought that their main successes had been. Many of these responses covered several different things that had been successful.

One of the most frequently mentioned concerned increasing dementia awareness. Many initiatives mentioned that they had either organised dementia friends sessions or given people information about them. Other ways of increasing dementia awareness included involving people living with dementia in local initiatives and bringing them together with other members of the local community.

Initiatives talked about their successes providing information about dementia and dementia services. These included providing information guides and holding dementia information stands and a dementia roadshow.

Establishing community groups and arranging social activities were also highlighted as a success of several dementia friendly initiatives. This included both groups that meet regularly such as memory cafés and activity groups and one-off social events for example day trips out, plays and film showings.

Other successes mentioned include establishing 'Safe Places', and working with care homes, health organisations, businesses, schools, supermarkets and cinemas.

Carrying out Dementia Friends Sessions for businesses and voluntary groups and offering sessions for residents.

Holding a session for children which included rock painting (the current craze) around the dementia theme.

Involving people living with Dementia in our Steering Group and encouraging two of them to be my vice chair.

Hosted Alzheimer's Roadshow bus plus stands for several dementia related local groups to promote their services. Took place in local market place.

Spreading the word about Dementia Friends and setting up Safe Places in a number of businesses in our town.

Lots of varied activities enjoyed by our members at the venue every month including gardening sessions and sing-alongs with local groups and entertainers.

By opening it to the public as well as to people with dementia we have brought the community together and given people a better understanding of what it is like for the person living with dementia and their carers.

Launch event, dementia friendly walking group, cinema showings, intergenerational opportunities awareness raising events during Dementia Action Week and at other times.

What difficulties or barriers have they faced?

Dementia friendly initiatives mentioned a variety of different difficulties or barriers they faced. There was no one aspect that stood out as being common across the initiatives. However, the following things were mentioned:

- Need for someone to lead the initiative
- Recruiting enough volunteers, volunteer availability and getting new people involved
- Publicity for events, poor attendance at some events
- Lack of understanding and reluctance to talk about dementia
- Getting local businesses, GP surgeries and schools involved
- Transport

Those initiatives which gave examples of how they had overcome difficulties said that perseverance, 1-1 conversations, getting good press coverage, holding ‘dementia friends’ awareness sessions, working with key organisations, changing times and locations and providing transport had been effective.



Involvement in Wiltshire's Dementia Strategy and planning

We asked if dementia friendly initiatives knew about Wiltshire's Dementia Strategy and the Dementia Delivery Board. 12 said they did, 9 said they would like more information about it, 1 said that they didn't know much about it but felt it wasn't relevant to their initiative.

At a discussion with people living with dementia some people said that they didn't feel that the term "Dementia Delivery Board" was dementia friendly as it did not accurately describe what took place there.

Information about Dementia Services

We asked whether dementia friendly initiatives could access the information they needed about dementia services in their area:

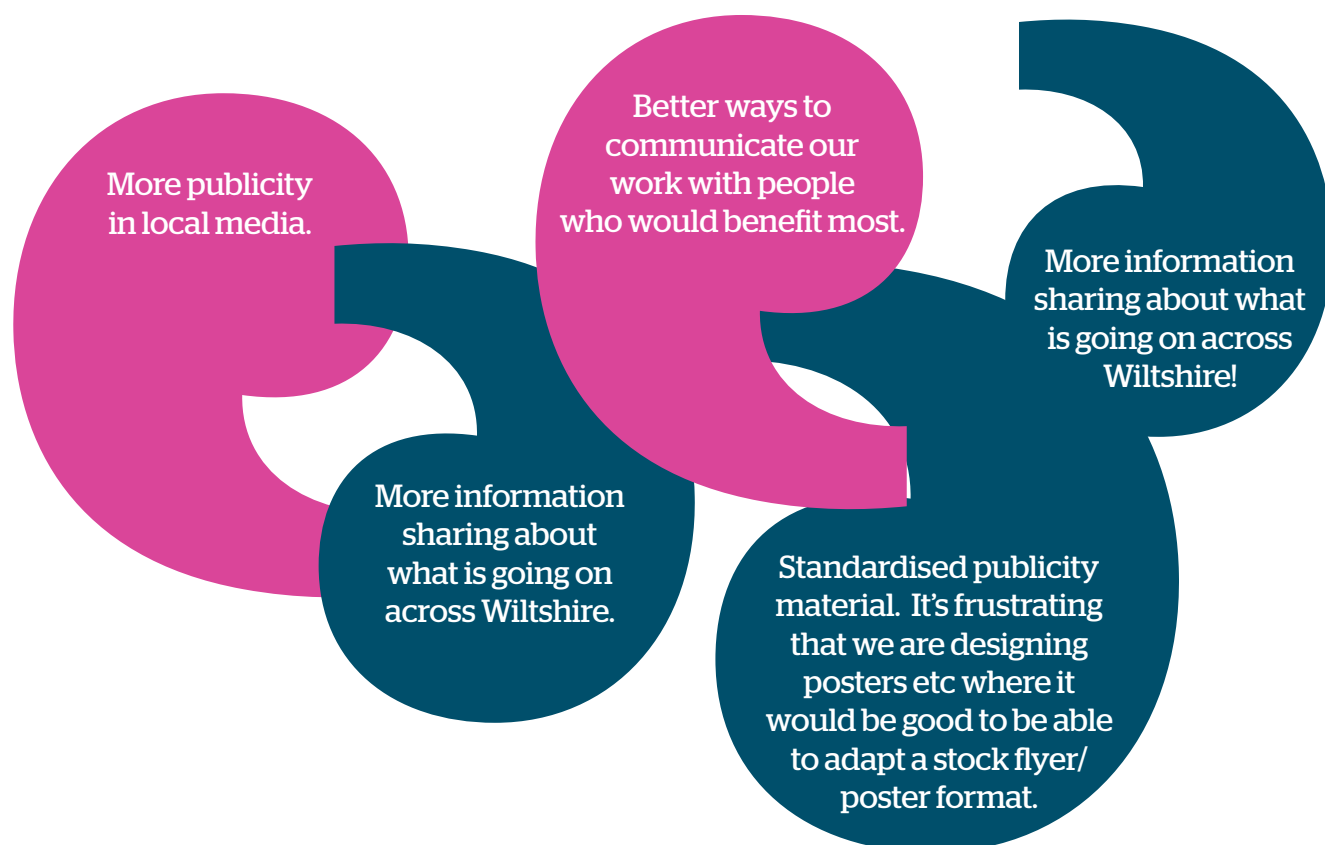
- 10 responses said that they could access all the information they needed,
- 9 said that they could access some information but that there were some things they would like more information about,
- 3 said they were not able to access the information they needed about services
- 2 didn't answer this question.

What would further support initiatives?

We asked dementia friendly initiatives if there was anything that they would like more support with. The most commonly mentioned issue was support with communications and publicity. This was mentioned by 5 of the initiatives and we were told that support with both publicity materials, and publicising events would be appreciated, as well as support to ensure that information reached those whom it would be of benefit to.

More information about dementia services and information sharing about the work of dementia friendly initiatives was mentioned twice. One dementia action alliance said that they thought they needed a paid person to lead their initiative and one said that they thought a paid dementia awareness worker across Wiltshire would be beneficial.

Other things that were mentioned included more volunteers, finances, more referrals, greater involvement of people affected by dementia, advice about running a memory café, advice about engaging businesses and the local community and assistance with registering as a charity.



Involvement of organisations

19 of the 24 initiatives said that their initiative involved representatives from other organisations with the numbers of representatives ranging from 1 to 17.

When we distributed our survey Wiltshire Council had recently reorganised its Community Engagement Managers. Some of them who had moved location told us that they were unfamiliar with who was involved in the Dementia Action Alliance in their new area.

Volunteer involvement

Volunteers were involved in all except one of the dementia friendly initiatives who completed our survey. The number of volunteers involved in each initiative varied from 1 to 11, with the average being 5.

We were given many examples of the role of volunteers in dementia friendly initiatives, and it was clear from the responses that they make a very significant contribution to the initiatives in Wiltshire.

Our responses highlighted the large range of ways that volunteers contribute to dementia friendly initiatives. Several responses said that their initiatives were volunteer led, and 3 initiatives only involved volunteers.

We were told that volunteers organised and ran community events and Dementia Friends' sessions that increase dementia awareness. It was also mentioned that they also contribute to dementia awareness by informally talking to people in their local communities. Providing emotional support and understanding was also highlighted as an important role of volunteers, including welcoming people, befriending, and including people who may be isolated. We were told that people living with dementia and their carers volunteer by meeting with others and sharing their experiences and that this is greatly valued.

A huge range of practical ways that volunteers support dementia friendly communities was mentioned. This including giving talks, providing activities, collating information, making teas and coffees, leading walks, knitting 'tweedle muffs', and providing transport.

By giving up their time and spreading the word about becoming a Dementia Friend.

They help with the catering (free tea, coffee and homemade cakes) and chat to people who look alone and isolated to bring them into the conversation.

Our volunteers who are living with dementia giving us their experiences and offering to meet with others.

They do it all – love their community.

They are marvellous! They are collating information and supporting the day.



Chippenham Memory Café



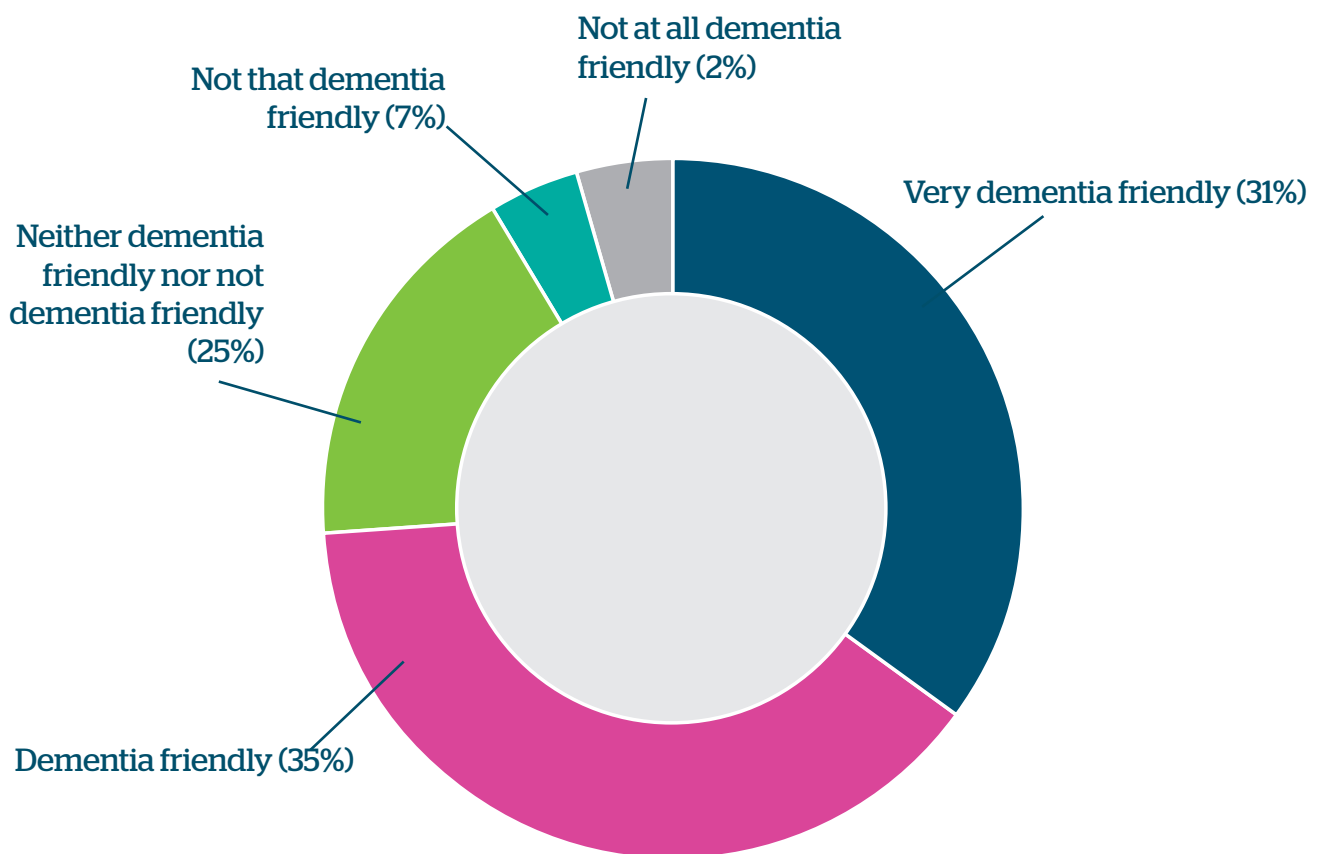
2. Views from people living with dementia and their carers about dementia friendly initiatives

What did people think about their local communities?

We asked people overall how dementia friendly they felt their local community was. Most people we spoke to thought that their local community was dementia friendly with 66% saying they thought their community was either dementia friendly or very dementia friendly, compared with 9% who thought that their community was either not that or not at all dementia friendly. The majority of those we spoke to during our focus groups discussions also told us that they thought their communities were dementia friendly.

We compared the responses of people living with dementia and carers of people living with dementia. We found that more people living with dementia (69% of those who answered the question) thought that their local community was dementia friendly compared with 60% of carers.

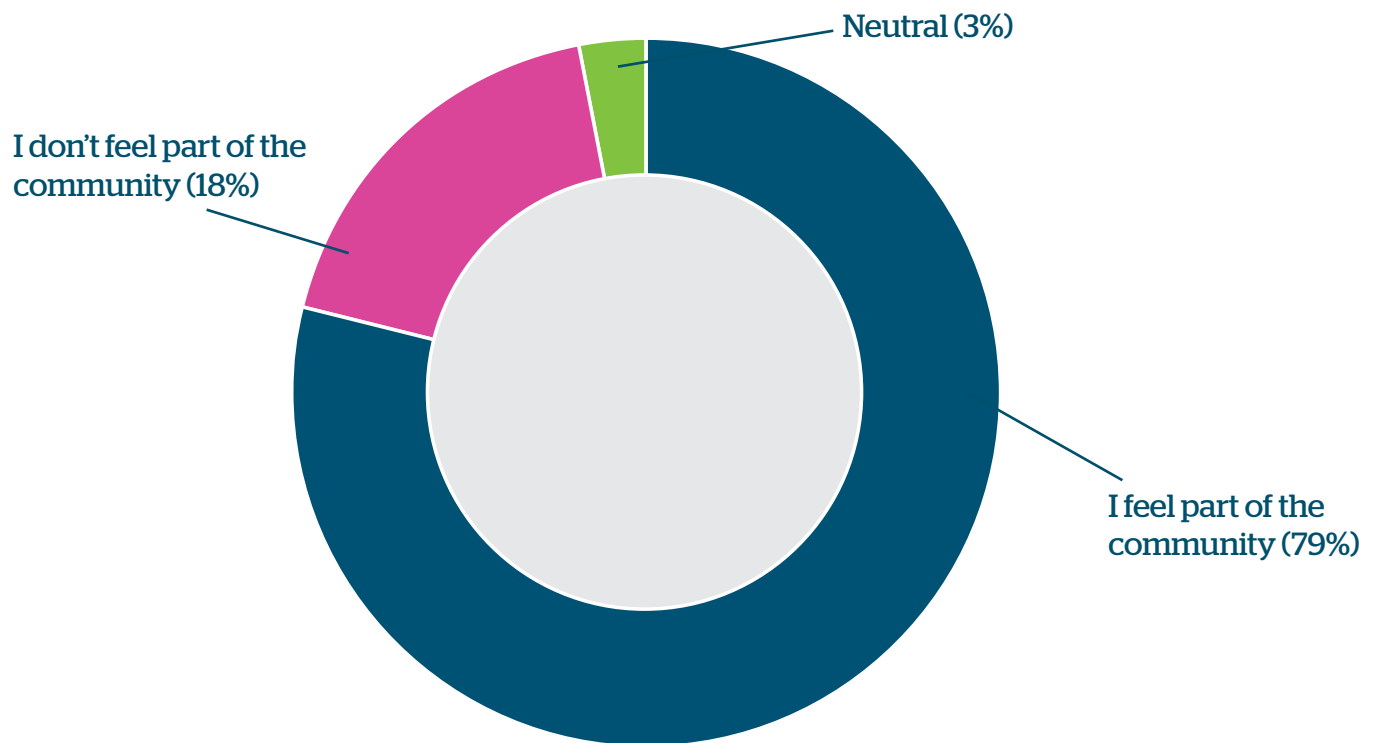
The below chart shows the full breakdown of results:



We asked whether people felt part of their local communities. Of those who answered this question 79% (61) said that they did, 18% (14) said they didn't and 3% (2) responses were neutral.

Of those who said they didn't feel part of their local community, two people said that was down to personal choice. The others said that they felt isolated, lonely and could not find much to do in their local communities. Some carers also mentioned that the demand of caring meant that they were restricted in terms of getting out.

Those who said that they did feel part of their local communities gave us lots of examples of how people were involved. The majority of these included being involved in things that were going on in the local area including church and local clubs. Many responses also mentioned having good social relationships with neighbours as the reason why people felt part of their community.



We don't find much to do here, family isolated, most people around are employed.

By being treated well by neighbours and the community as a whole,

Local lunch club, gardening club, cricket club, neighbours who look after each other. Buses every 20 mins.

I've got good neighbours. They know me in my local supermarket and I go there for fish and chip lunch on a Saturday and then go back and watch football. I am a great football fan.

I feel part of the local area. At Christmas staff at GP surgery put on a do at the village hall. We went to this and it was brilliant they made me feel very welcome. We still go to the chapel but we are restricted with transport.

I feel quite lonely. Can't leave partner alone at all. I would need someone to look after partner whilst away from home.

What did people find most valuable?

We asked people what things in their local community had helped them.

Many people told us that they found community groups helpful with 64% talking about groups. This included a wide variation of groups which were both dementia specific and general. Examples included singing groups, exercise groups, discussion and support groups, church groups, memory cafés, men's sheds and range of local clubs and associations.

Also frequently mentioned by people living with dementia was the attitude of others in their local community. People gave examples of how they were included, felt understood and offered help when they needed it. These comments related to both the general public and to people working in businesses and services.

We were told about a wide range of people in Wiltshire who demonstrated an understanding of dementia and how to offer support to people. People living with dementia told us how this approach had a positive impact on their lives and supported them to remain independent. Carers who felt that their community was 'dementia friendly' told us that this helped to reassure them and could enhance their day to day experience as a carer.

Another thing that was mentioned as having been helpful was local organisations and services. The most common ones mentioned were Alzheimer's Support, Alzheimer's Society, Carers Support and GP surgeries.

Relatively few people mentioned 'dementia friendly' changes to physical environments, compared to those who talked about the 'dementia friendly' approach of people which was seen as much more important. However clear signage was mentioned, and people with dementia told us that it was important that signage in buildings also included directions for the way back to communal areas.

People are friendly, patient. Lots of social things – good. People open to any sort of idea. For a village it's got a lot of things going for it.

Chippenham memory café very good. A good community attitude, Easy paced and lots of humour.

The Alzheimer's Group in Trowbridge (Mill Street) has made a big difference. It helps me discuss issues and enjoy singing. I have noticed my epilepsy fits have not been more frequent, and I feel more confident.

Dementia groups, other community activities, my husband attends day care. Good support from local community.

My bank cannot be faulted absolutely wonderful. Taxi men are also very helpful. Rowden Surgery very good, I always see my own GP.

Everybody in Salisbury local community helped me physically and mentally. I think people are friendly and they understand things I need a bit more help with.

People don't think I'm barmy, they help me find places. I take people's deliveries in return.

Relieved some of the worry living with someone with severe dementia.

Local Dementia Coordinator has proved very helpful with what is available and pointing us in the right area for help.



Chippenham Memory Café

What did people think could be improved?

We asked people what things about their local community that they would like to see improved. There were fewer answers to this question than other questions in our survey. Of those who completed our survey 35 either said that they were happy with everything or did not suggest anything that they thought should be improved.

Some people said that they felt there was still a need for more dementia awareness. We were told about incidents where a lack of awareness had led to distress or embarrassment on public transport and in shops. It was also suggested that it would be good if there were more opportunities for further learning that could follow on from Dementia Friends awareness sessions.

Of those who did suggest things that could be improved, transport was the most commonly suggested reply. This included transport for people in more isolated rural areas and transport to enable people to attend groups. People referred to being no longer able to drive due to their dementia.

Other things that were mentioned was more companionship, particularly for people who lived alone, more accessible information about services and for groups to be more frequent.

I discreetly handed over card that explained my husband had dementia. The shop assistant then loudly stated 'Oh, I know all about dementia' – me and my husband were both upset and embarrassed by this.

Help for people on their own and for people who are isolated geographically or lack support from family members.

Transport could be better for people who don't drive.

Extra support groups. A memory group. Extend exercise classes for elderly people.

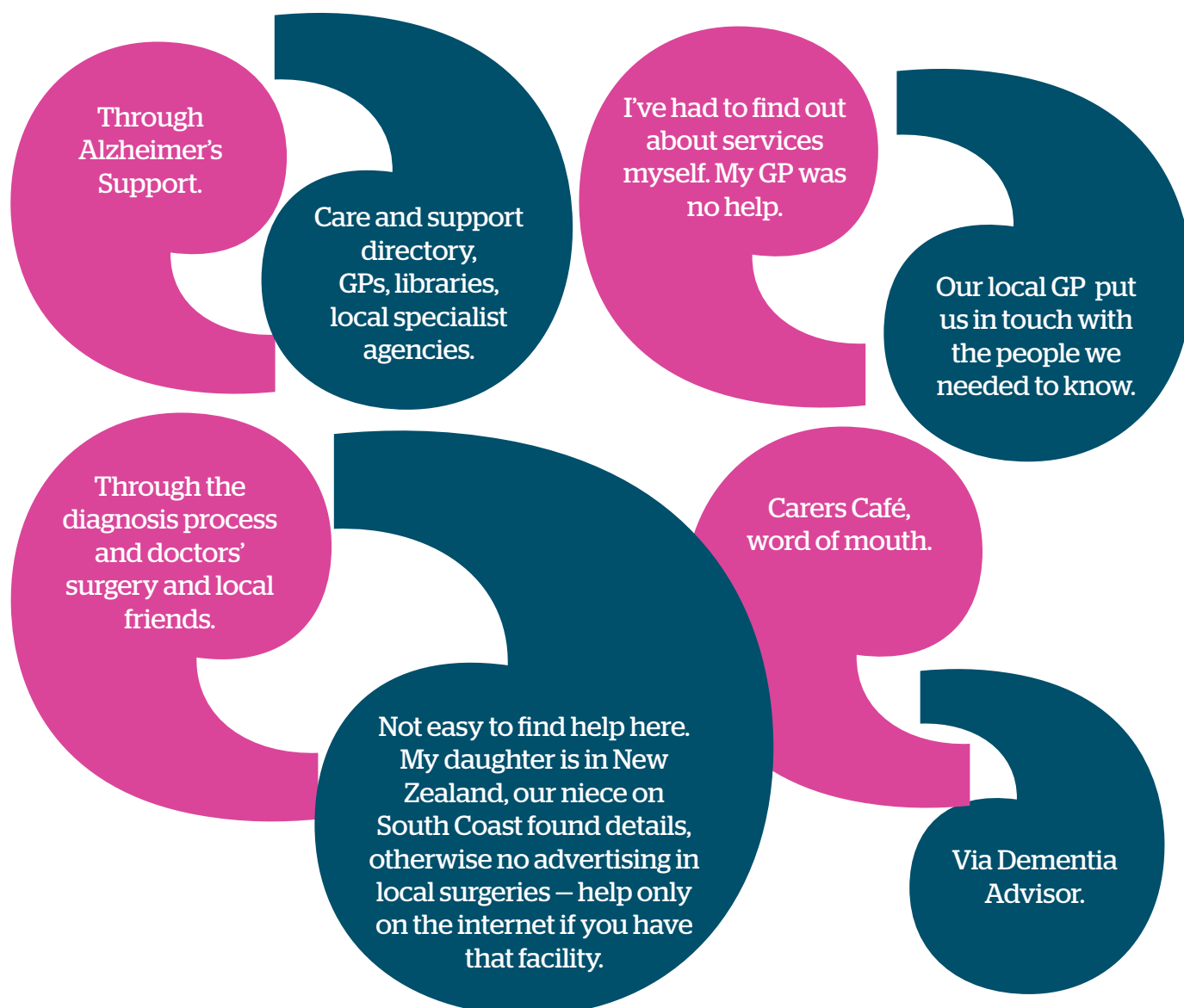
How did people find out about services?

We asked people how they had found out about services for people living with dementia and their carers. There were a wide variety of responses to this question. Alzheimer's Support, Dementia Advisers and Alzheimer's Society were most frequently mentioned.

Local information such as posters and leaflets, information shared at local groups and word of mouth were also talked about as being useful sources. We were also told that people's friends and families often helped them find information.

A smaller number of people mentioned that they had been given information by the council, found information in the local press, or gone online often with help from family members.

From the responses to this question it seems that most our respondents were able to find information about dementia services, through a wide range of different sources. However there remains a small number of people who said that they had difficulty finding information.





Conclusions & recommendations

The information that people have shared with us would seem to indicate that Wiltshire has made significant progress towards being 'dementia friendly'. People with dementia and their carers have clearly described the benefits that this can bring to them. It is important that this work is sustained and built upon in the future.

With this in mind, we recommend that key organisations work together towards the following recommendations:

1. The findings of this report to be shared with dementia friendly initiatives, providing them with opportunities to share successes and to hear what people with dementia and their carers told us.
2. Information about dementia delivery board to be periodically shared with key people involved in dementia friendly initiatives.
3. Follow up with dementia friendly initiatives who said they weren't working well and Dementia Action Alliances who didn't respond to see how they can be supported.
4. Sources of information about dementia services to be shared with dementia friendly initiatives.
5. Community groups for people living with dementia and their carers to continue to be supported and developed.
6. The contribution of volunteers should be encouraged and supported.
7. Consideration of how dementia friendly initiatives can be supported with communications and publicity.

Thank you

Thank you to all the individuals that stopped to share their honest thoughts, to the Laverstock Memory Support Group for helping us design our survey, to our dementia engagement steering group partners, and to the community groups and organisations that supported this project. Thanks also to our volunteers who gave their time to take part.



Appendices

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Appendix 1



Survey for people who are involved in all dementia friendly initiatives across Wiltshire

This includes Dementia Action Alliances, Dementia Friendly Communities and any other Dementia friendly initiatives. The survey can be completed either individually or as a group.

Healthwatch Wiltshire has made dementia one of its priority areas. People living with dementia and their carers have told us that they think dementia awareness in Wiltshire has improved in recent years. We want to find out more about this:

Our aims are to:

- get an overall picture of dementia friendly initiatives across Wiltshire
- identify any opportunities to further support this work
- find out what people with dementia and their carers value most and what they would like improved
- find out how volunteers have contributed
- highlight successes so that they can be shared
- give people a chance to share experiences of health and care services

We are also asking people living with dementia and their carers for their views in a separate survey

First some questions about the dementia action alliance or initiative you are involved in:

1. Which Dementia Friendly Initiative you are involved in? Please include the location in your answer.
2. On average how many people are regularly involved in your initiative?
3. Approximately, how many of these people are volunteers?
4. Approximately, how many are representatives from organisations?

5. What have your main successes have been?

6. What difficulties or barriers have you faced? How have you been able to overcome these?

7. Can you tell us how volunteers have contributed to your initiative?

8. Is there anything that you would like more support with? If so, please say what kind of support would be helpful.

9. Overall how do you think your initiative is working?
 - Very well
 - Well
 - Average
 - Not so well
 - Not at all well

10. What impact has your initiative had for people living with dementia and their carers?

Now some questions about services for people living with dementia and their carers in Wiltshire

11. Which of these statements describes your thoughts about Wiltshire's dementia strategy and planning?

- I know about the Wiltshire Dementia Strategy and the Dementia Delivery Board
- I'd like more information on the Wiltshire Dementia Strategy and Dementia Delivery Board
- I don't know much about this but feel that it's not relevant for our initiative

12. Can you tell us about any work you do with dementia services in your area?

13. Do you have information the information you need about dementia and dementia services in your area? If not, what information would you like?

14. Is there anything you would like to tell us about health and care services for people living with dementia? (This could include hospitals, doctors, care homes, home carers or support services, please give the names of services)

The results will be collated and put into a report. All responses will be anonymised, and no individuals will be named in the report.

15. If you would like to be added to our mailing list, please provide your email or postal address:

All data will be held securely and in compliance with data protection laws. It will only be used for the purposes of carrying out Healthwatch Wiltshire activity. Your details will not be shared with any other organisation.

About Healthwatch Wiltshire

Healthwatch Wiltshire are the independent champion for people using health and care services in Wiltshire. We listen to what people like about services and what they think could be improved and share their views with those who have the power to make change happen.

Thank you for completing this survey.



Appendix 2

Dementia Survey

Healthwatch Wiltshire has made dementia one of its priority areas. We are asking people affected by dementia for their views about living in their communities.

We'd appreciate it if you could take a few minutes to complete this survey.

First, some questions about the community

that you live in

1. Overall how 'dementia friendly' do you think your local community is?

(By 'dementia friendly' we mean understanding and happy to help people living with dementia)

- Very dementia friendly
- Dementia friendly
- Neither dementia friendly or not dementia friendly
- Not that dementia friendly
- Not at all dementia friendly

2. What things in your local community have helped you?

(This may include things to do with people and places in your local community)

3. What effect has this had on your day to day life?

4. What things in your local community would you like to see improved?

5. Do you feel part of the community where you live? Please give us any examples of how you are involved?

6. Do you attend any general community or dementia groups? If so, what do you think about these groups?

7. How have you found out about services for people with dementia and their carers?

Now, a question about health and care services for people living with dementia and their carers.

(This could include hospitals, doctors, care homes, home carers or support services)

8. Is there anything about your experiences of using health and care services that you would like to tell us? (Please include the name of the service you have used?)

About you:

9. Please tell us the town or village you live in?

10. Are you completing this survey as?

- A person living with dementia
- An unpaid carer of a person with dementia
- A couple including a person with dementia

11. What is your age?

- Under 44
- 45 - 54
- 55 - 64
- 65 -74

- 75 - 84
- 85 +

12. If applicable what is the age of the person you are completing this with

- Under 44
- 45 - 54
- 55 - 64
- 65 -74
- 75 - 84
- 85 +

13. Are you?

- Male
- Female
- Other
- Prefer not to say

14. If applicable is the person you are completing this with:

- Male
- Female
- Other
- Prefer not to say

15. What is your ethnic origin?

16. What is the ethnic origin of the person you are completing this with.

The results will be collated and put into a report. All responses will be anonymised, and no individuals will be named in the report.

17. If you would like to be added to our mailing list, please provide your email or postal address:

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Thank you for completing this survey.



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