

healthwatch

How to engage with people who live with dementia

A guide

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Introduction

This guide describes an approach to gathering the views of people who live with dementia, a group often excluded from engagement. The approach is based on partnership working, co-production and engaging through community groups.

You could also use this model with other local organisations and groups of people. The focus is on involving people in the design of a project from an early stage to promote involvement. This can enable you to gather both quantity and quality of information that can be used as a platform to influence considerable change.

This guide has been written by Healthwatch Wiltshire, who draw from their experience of working with people who live with dementia.

What is dementia?

[NHS England](#) explains: Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. There are many different causes of dementia, and many different types. For example, [Alzheimer's disease](#) is a type of dementia and, together with [vascular dementia](#), makes up the majority of cases. Dementia symptoms may include problems with:

- Memory loss
- Thinking speed
- Mental sharpness and quickness
- Language, such as using words incorrectly, or trouble speaking
- Understanding
- Judgement
- Mood
- Movement
- Difficulties doing daily activities

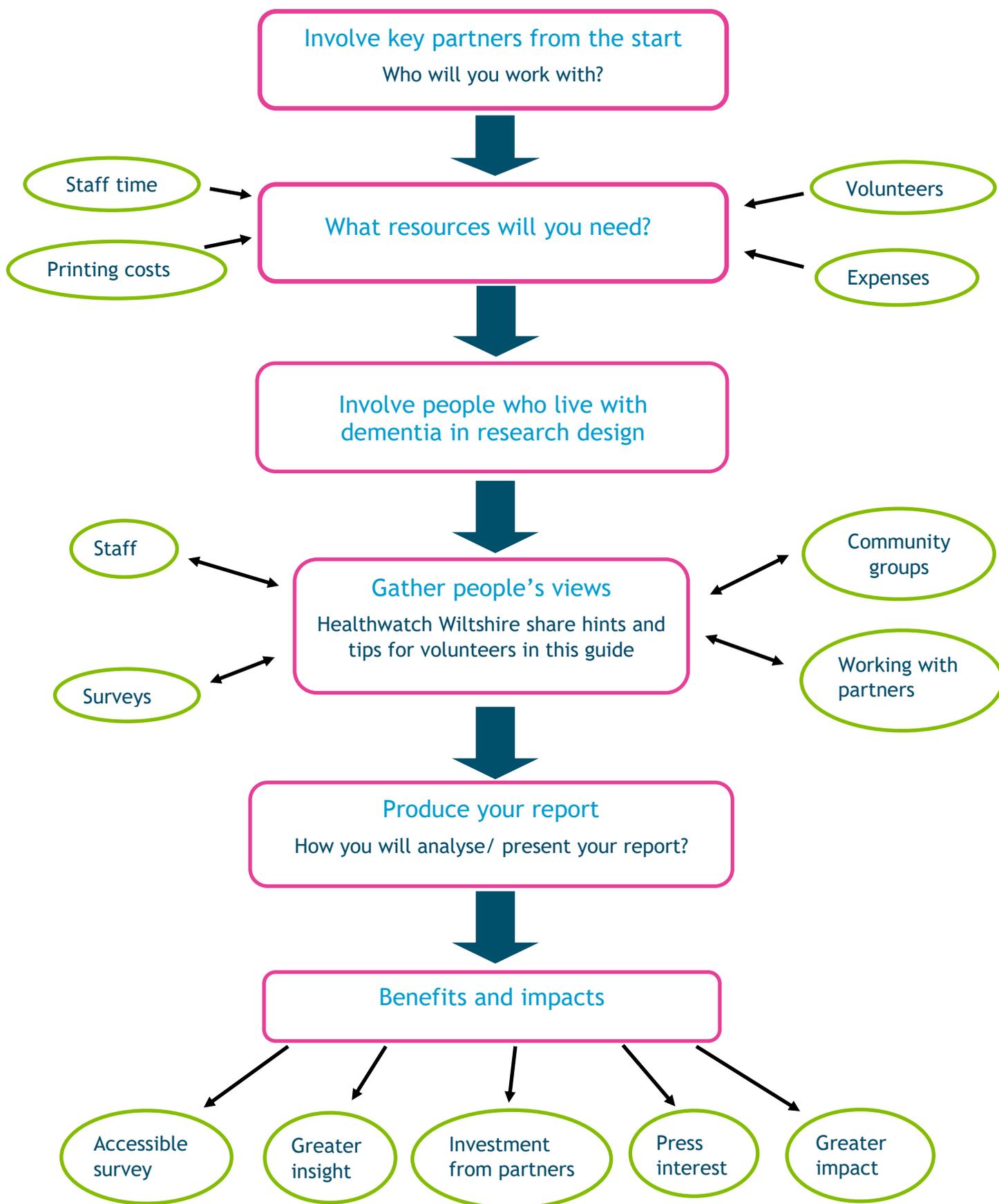
Why use this guide?

Here are some of the benefits of using the approach in this guide:

- Working with your target group - people who live with dementia - to co-produce your project promotes equality and gives control to the people whose views you are looking to gather.
- Co-production improves the design of your survey. You can find out if your questions will be understood, and how people may respond to them. Your survey will more accessible to your target group, and you will be able to gain greater insight into people's experiences.
- Engaging with people at community groups is a good way of enabling open discussions as people are in a familiar and safe environment and may feel happier to share their views.

A step-by-step guide

Flow chart for engaging with people who live with dementia



Partnership work

It's important to identify partners you can work with early, so that they can be involved right from the start. This can be the key to reaching people living with dementia. You may want to form a steering or advisory group made up of local organisations who work with people living with dementia.

To identify your partners, you could think about:

- What community groups are there for people who live with dementia in your area and who provides these?
- Does your local authority or CCG have a dementia strategy group?
- Who are the commissioners for dementia services?
- Are there active dementia action alliances in your area?
- Is there a lead GP for dementia?
- Does your area have a dementia adviser service and who provides it?
- Which other organisations are involved in supporting people with dementia in your area?

By involving key partners at the start, they can contribute ideas to your proposal, and tell you what sort of information they would find useful and how they can support the project.

At this stage, you can work with your partners to identify the community groups where you will carry out your engagement. It's a good idea to plan this well in advance as groups often have a schedule of activities or speaker and you may need to book a slot.

Top tip:

Think about what will make your partners want to be involved

- What goals might you share?
- How might your project be of use to them?
- What are the advantages of working with local Healthwatch?

These can be powerful arguments to help you overcome any barriers to partnership working and gaining commitment.

Examples of this, used in the project Healthwatch Wiltshire led engaging with people who live with dementia, include:

- Gaining an impartial view
- Finding out what people value about services
- Having greater insight into people's attitudes
- Generating information that can be used to develop services
- Promoting the involvement of people with dementia.

Approach to equality and diversity

It's important to think about who you want to speak to, and whether there are any demographics you might want to monitor or filter your results by.

For example, it was particularly important to Healthwatch Wiltshire to hear directly from people who live with dementia, and so their approach was tailored to ensure that this group were involved from an early stage and that their voice was heard.

Healthwatch Wiltshire also identified some other relevant demographics, such as age and location, and worked with their dementia support group to design a small number of simple demographic questions which were incorporated into their survey.

Resources and costs

Your resources and costs for this sort of project will vary, according to the availability of volunteers and the location that is being covered.

The location of Healthwatch Wiltshire is in a relatively large county, with a mix of rural and town areas. Their Healthwatch has an active team of volunteers who were able to support them and carried out many of the visits to the groups.

Here is an indication of resources used at each stage of Healthwatch Wiltshire's project:

Task	Who	Hours/ Costs
Preparing proposal and discussing with partners	Manager Engagement Lead	7 hours
Designing survey with dementia support group	Engagement Lead	10 hours
Arranging visits to groups and co-ordinating volunteers	Engagement Lead Volunteer Lead	6 hours
Printing surveys (approx. 250)		£10
Publicising project	Communications Lead	2 hours
Visiting community groups (14 groups)	Engagement Lead Volunteer Lead	39 hours
Visiting community groups	Volunteers	46 hours
Travel expenses	Staff and volunteers	£190 (422 miles)
Inputting surveys	Volunteers	14 hours
Analysing data	Engagement Lead	15 hours
Writing report	Engagement Lead	8 hours
Proofreading	Volunteers	8 hours
Putting report in into template and producing easy read report	Communications Lead	8 hours
Publicising report	Communications Lead	5 hours

Presenting report and following up	Manager Engagement Lead	10 hours
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Working together with people living with dementia

This approach can be valuable in enhancing the quality of your survey or questions, and ensure that they are clear, accessible and easy to understand. This will enable more people who live with dementia to take part, and you will gain greater insight.

Before you conduct research:

- Consider which members from your team should be involved in the project. It could be staff members or volunteers with some experience or interest in dementia.
- Identify the right group of people to conduct the research with - people from an existing group that know each other and enjoy discussion are ideal. You could look for local living well groups, or there may be a local [Dementia Voice](#) group in your area.
- Where possible, visit the group at their usual time and place. This will be an environment that they feel comfortable in.
- Get to know the group first - if you haven't met them before, it's a good idea to visit one of their meetings first as a guest before you have your discussion.
- Talk to the group organiser or facilitator beforehand - let them know what you would like to do, and take their advice of how this would best work with their group. They may want to have a look at your materials and discussion questions beforehand.
- Be flexible and try fit your discussion around the usual pattern of the group.
- Prepare beforehand - think about the themes of what you want to find out about and what information you are looking to gather.

During the discussions:

Build relationships:

- When attending a session to conduct your research, it can help to join in with the group and any other activities or discussions that they are doing that day. This helps them to feel comfortable around you and builds trust.
- Take your lead from the group organiser or facilitator, and work with them in the discussion. Make it clear from the start that they can interrupt you. They will know the group best and will be able to assess how things are going and intervene.

Keep it short:

- Keep the introduction of who you are and where you are from, short. It's tempting to want to explain the background of Healthwatch, the purpose of the work, and your role in detail. However, a lot of detailed information at the start is likely to be difficult for people to follow and may put them off joining in the discussion. You can always pick up any questions people have during the discussion.
- Keep the number of themes or questions you want to discuss short.

Watch your language:

- Be aware of the language and terminology you use, particularly using words that have been used in different contexts over time. For example, for some of the groups Healthwatch Wiltshire visited, the term 'Engagement Officer' had associations with someone who organises weddings.

Check understanding and adapt:

- It's good to check out the group understanding of the key theme or terms of your work. This might help you define them in your survey. For example, in the group Healthwatch Wiltshire worked with, they talked about the term 'dementia friendly'. The group felt that it was a good term and that it meant 'understanding and happy to help people living with dementia'.
- Ask people how they might ask a question about a theme. Be open-minded about the wording of questions and listen to the group's suggestions about wording. For example, one group Healthwatch Wiltshire worked with associated the word 'impact' with a crash. So, in their survey questions, they asked what effect something had, rather than the impact of it, because that made more sense to people there.

Gather feedback:

- It may be useful to take some draft questions you have written, as these may help the group understand the idea of what you want to get at. However, try to use just a few of these as examples, and try not to ask the group leading questions. This can be a balancing act, but the aim should be that the group has as much influence as possible on the eventual wording of the questions.
- As well as asking about the wording of questions, also ask people how they would answer that question. This will give you an idea of whether your question is going to give you the information you are looking for. If it doesn't, you can work with the group to rephrase it.
- Remember to ask the group if there is anything about the topic that they don't think has been covered by the questions - there may be things that are important to people that you hadn't thought about.

Before you leave:

- Take some written information with you to leave with people. This can cover more of the information about Healthwatch, background to the work and should have contact details should people wish to get in touch.
- Remember to say thank you to the group and show appreciation for their input. Make sure you let them know how this will be used.

Following discussions:

- Make sure the group see the final product - the survey or interview questions.
- Encourage them to participate in sharing their views, by completing the survey.
- Acknowledge their contribution in the final report and presentations of it.
- Keep the group informed of any developments and what is happening as a result of their input.

Healthwatch Wiltshire's experience:

Healthwatch Wiltshire worked with a dementia support group in designing their survey, following the steps above to co-produce their research. Healthwatch Wiltshire then used this to inform what survey questions were asked and how they were phrased.

The result of this was a survey with a mix of quantitative and qualitative questions that aimed 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 find out what people would like to see prioritised in the future.

The full survey used is shown in Appendix 1.

Carrying out your engagement through community groups

Visiting dementia community groups to carry out your engagement is an effective way to reach people with dementia. An advantage of this is that the people you will be talking to are in a space where they feel comfortable and at ease, meaning that they are more likely to take part and feel they can be honest. Being in a familiar place with those they know can support people with dementia with concentration and focus, enabling you to gather better quality information.

Things to consider when planning your visits:

- Where are the groups, are they evenly spread across your area?
- Do they cover a range of activities that might attract different people?
- What about age range - are there any groups for younger people with dementia?
- Can you visit groups that are run by a range of organisations?
- How is each group run and what opportunities will there be to talk to people?

Carrying out the visits

How? Be flexible!

Community groups for people living with dementia can run very differently to each other.

People living with dementia are likely to have individual preferences and abilities that affect how they can best engage with you.

Think about the range of options you can offer:

- A one-to-one interview during the group to complete the survey
- Complete the survey on paper during the group
- Take the survey away to complete and post back
- Arrange a one-to-one interview another time
- Complete the survey online

Who?

Visits can be carried out by staff members or volunteers. They can be time consuming, so it will be more cost effective if you can involve volunteers. You could consider if there is anyone who already has experience and understanding of dementia.

There are also a range of free resources that can support you and your volunteers to learn more about dementia. Examples include:

- [Dementia Friends](#)
- [Dementia e-learning](#)

Once you have organised your schedule and who is visiting where, you will want to give your volunteers some hints and tips. This can help them to know what to expect and also means that volunteers can get in touch in advance with any questions or concerns. This could be covered in a volunteer meeting or training session.

Hints and tips for volunteers attending community groups

- Talk to the group leader when you arrive and take guidance from them about how and when it may be best to talk to people.
- Be flexible in your approach, some people may want to take a survey home to complete, some may want to complete it themselves at the group and some people may wish you to go through it with them.
- Make sure that there is just one person asking the questions. If there are two of you, the other person can take notes.
- Some people may find it helpful to have a copy of the survey questions in front of them to follow.
- Allow the person time to think about the question and their answer. Don't be concerned if there are quiet periods.
- Don't worry if the person goes 'off topic' for a while, it's fine to spend some time talking to them about something else.
- Be prepared to skip over any questions that the person doesn't want to or can't answer.

Focus on the person who lives with dementia

If you are talking to a person who lives with dementia and they have a carer or supporter with them, make it clear that it is the person who lives with dementia's views you are asking for. Look at the person and address them directly. If their carer or support worker wants to give their views, do this in a separate interview or give them a survey to complete themselves.

Healthwatch Wiltshire's experience

The volunteers in Healthwatch Wiltshire's project were a key part of the success, visiting many of the groups and carrying out one-to-one interviews with people there. Hear from one of our volunteer's reflections on their involvement, in this blog they wrote about their experience - ['People with dementia need to be given the opportunity to speak out'](#).

Analysis and reporting

Your survey results are likely to be handwritten, either completed by people who live with dementia or from one-to-one interviews carried out by volunteers. It is likely that you will have a mix of quantitative and qualitative data.

Inputting your results into a survey tool will help your analysis. These survey tools can be useful for producing charts and statistics from quantitative data and analysing qualitative data using text analysis such as word clouds. These can be very useful to help you discover the key themes.

Here are some you could use:

- [SmartSurvey](#)
- [Survey Monkey](#)

It is important that you share the results of your engagement with your partners and the groups you visited.

Healthwatch Wiltshire's experience

Healthwatch Wiltshire's report aimed to present their findings using some statistics of how 'dementia friendly' people thought their local community was, with insight into what things people thought were of most value and why. Lots of pictures and quotes were used to emphasise the importance of this aspect. You can read Healthwatch Wiltshire's [full dementia report here](#).

An [easy read report](#) was also put together, which was shared with all the groups and individuals that took part. This adopted a simple layout and used photos from the engagement discussions and some images from a [photo symbols website](#).

What outcomes might you expect from this approach?

- An approach that is 'dementia friendly' enables more people with dementia to participate. A person living with dementia added this comment to the Healthwatch Wiltshire survey:

"I have completed this form without help, but my husband is in the room with me. We have discussed each question, and this has been very helpful. It has made me see things differently from before."

- Meaningful information can be gathered about the experiences of people who live with dementia, and what they value most. These comments were gathered from the Healthwatch Wiltshire survey:

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

“The Alzheimer’s group in Trowbridge has made a big difference. It helps me discuss issues and enjoy singing. I have noticed my epilepsy fits have been more infrequent, and I feel more confident.”

“People don’t think I’m barmy, they help me find places. I take peoples deliveries in return.”

- It can lead to participation in services. One of the group members Healthwatch Wiltshire worked with went on to form part of the tender evaluation panel for commissioning of community services.
- A platform for further partnership working and powerful impact. Healthwatch Wiltshire’s project led to a piece of work showcasing the impact of their engagement, and how organisations have worked together to improve services.
- The project also led to the introduction of more support groups and specialist training for care home staff, thanks to the views of 1,600 people living with dementia and Healthwatch working with other organisations. You can find out more about how the feedback was used to improved dementia services [here](#).

COVID-19 update:

Where face-to-face engagement is not possible, there are ways that you could adapt this model so that it could be used virtually. This might include:

- Creating a virtual group where you can involve people in designing a project.
- Attending virtual groups that are taking place in your area to tell people about your project and carry out engagement. This might involve asking people’s views during the group or telling people about the project and the ways that they can get involved.
- For projects involving people living with dementia, it would be a good idea to offer a variety of ways people can take part. For example, a choice of a virtual group discussion, a phone call, or a virtual one-to-one.
- Online surveys and phone calls.
- Where some groups are now starting to reopen but are not open to visitors, you may be able to attend these virtually, or send a video that can be played to tell people about the project you are carrying out and how people can get involved.
- There will be some people who may find virtual engagement very difficult. To ensure that their views are still heard you could consider a virtual meeting with frontline staff who work with them, who can then feed in their views and experiences to you with their permission.

Appendix

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.

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

What things in your local community have helped you?

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

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

What things in your local community would you liked to see improved?

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

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

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)

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:

Please tell us the town or village you live in?

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

What is your age?

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

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 +

Are you?

- Male
- Female
- Other
- Prefer not to say

If applicable, is the person you are completing this with:

- Male
- Female
- Other
- Prefer not to say

What is your ethnic origin?

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:

All data will be help 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.