

A commissioners' guide to involvement

About this guide



This guide was co-produced with 20 commissioners across the UK to capture key points and helpful tips, which will support them to co-produce and involve people with lived experience in their work.

Ensuring that people living with a diagnosis of dementia and their carers can share their knowledge and skills can help plan, shape, and influence the work of Integrated Care Systems, and will ensure that services are designed and created to meet local need.

Alzheimer's Society have dedicated teams who can support commissioners to meet their strategic aims and goals for people living with and affected by dementia, which will create transformational change locally.

“Why wait until the last minute to involve people with dementia in a project – you might waste hundreds of hours on something that doesn’t work.”

Person living with dementia

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The images used throughout this guide are of participants in various Alzheimer's Society co-creation workshops and focus groups.

How we involve people

“
People don't always realise what we can give to society through our own life experiences.
Person living with dementia”

Informing

Sharing stories, information or awareness raising activity.

Consulting

Asking people's opinions on a range of options to influence our decisions and plans. Can be seen as tokenistic if there is no opportunity to influence change.

Example: Answering a series of set questions about the layout and content in a publication or designing guidance for research grants.

Engaging

Ongoing conversations to help understand issues, where people with 'lived experiences' express views and discuss ideas for change.

Example: A series of focus groups influencing guidance for a sports venue.

Co-creation

Designing with people with 'lived experience', sharing ideas together and incorporating these into the outcome.

Example: Designing learning resources.

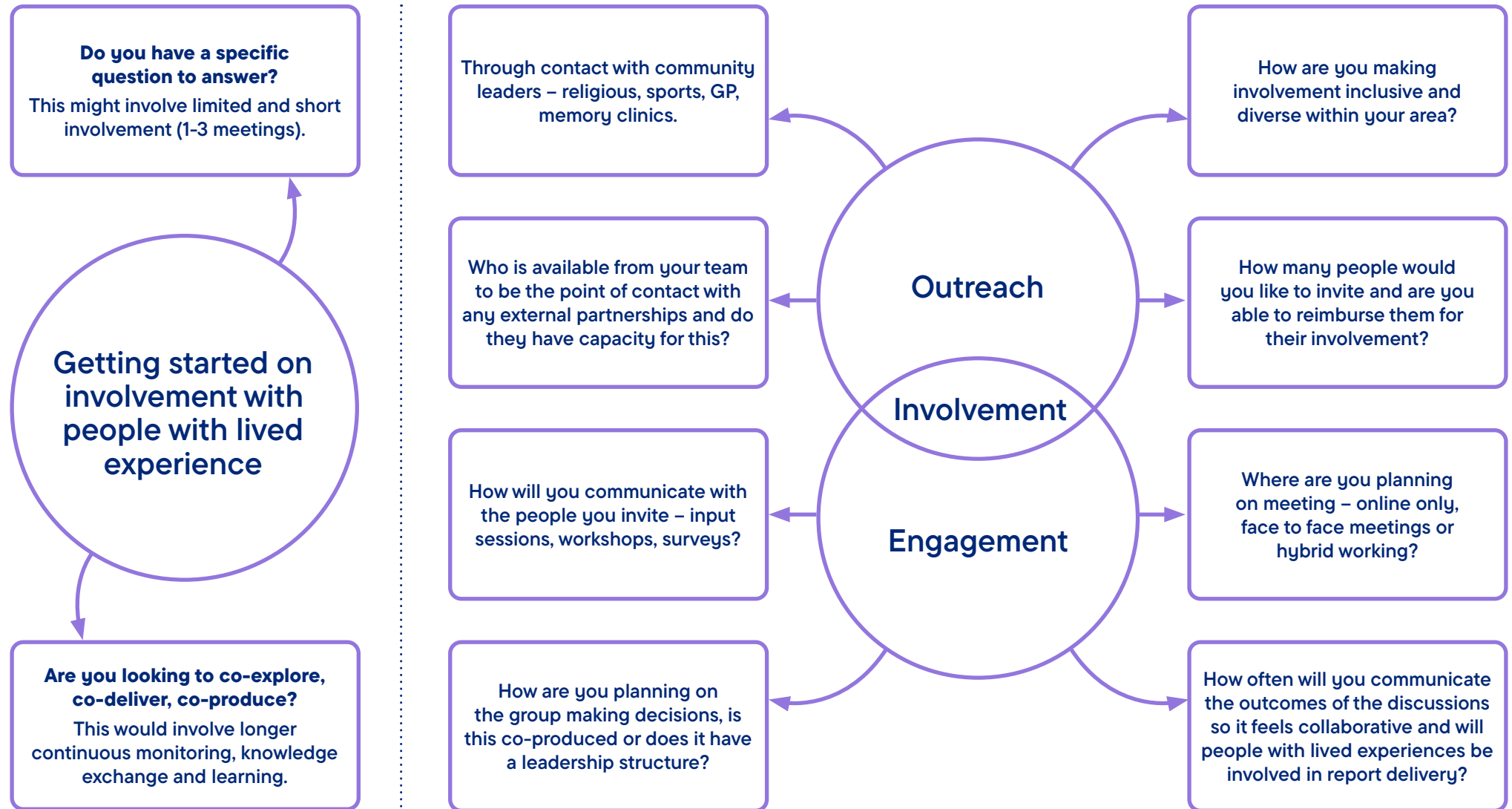
Co-production

An equal partnership where people with lived and learnt experience work together from start to finish.

Example: Creating and developing a service together and influencing how it is commissioned and delivered.



What involvement looks like



Involvement guidance

Things to consider before you start your project

If you have chosen Co-production as your involvement type. Please follow the guidance on page 8.

For all other types of involvement continue with this guidance.

Consider the length of time that you need to complete the initial project as this will determine the timeframe for involvement.

Where are you planning on meeting – online only, face to face or hybrid working?

Is this dementia friendly and accessible to everyone?

Which type of involvement have you chosen:

- Informing
- Engaging
- Consulting
- Co-creation
- Co-production

How will you communicate with the people you invite?

How are you planning on making decisions?

Who will lead on this project and be the dedicated point of contact with stakeholders and do they have capacity for this?

How are you making involvement inclusive and diverse?

Are you clear about what you want to achieve from this involvement?

Identify where you will reach people with lived experience. Consider community groups, other organisations, GPs, religious groups, memory clinics.

How many people would you like to be involved at each stage of involvement?

How are you reporting back what has been discussed/decided to the group.



Involvement guidance

How to involve people



Create a project plan with specific milestones to ensure that you have a focus.

Check that everyone is still willing to be involved and can commit their time to achieve the outcomes of the project.

Thank them for their time and explain next steps.

Invite people with lived experience and stakeholders ensuring that your communication method is accessible to all. Ensure this is captured on a spreadsheet or database, so that you can refer back and update.

Discuss the best way for the group to have their say – hands up, have 'I'd like to speak cards' etc.

Send out follow up communication detailing agreed actions and next steps within a week. Consider easy read, depending on your audience.

Provide individuals with a brief overview of the project i.e., what the project is, why you are involving people, what people would be doing, what time commitments there are.

Hold your first meeting to explain what you are hoping to achieve, give timescales, expectations, terms of reference.

Explain your expense policy to the stakeholders and what you would like to offer them for their involvement. They may be happy with just coming together for a cuppa and cake as long as they are able to fully participate.

Please refer to our useful links on page 17 to find out more about paying expenses

Re-imburse expenses after each session. Be timely with this to keep people engaged and explain timeframes for any payments.

Allow at least one month for individuals to consider their involvement before planning your first meeting.

Regular communication is key to ensure that people stay engaged and involved.

Involvement guidance

Reaching your outcome and next steps

Ask if they would like to continue to work with your organisation on future opportunities.

Continue to communicate opportunities on a regular basis or consider forming a steering/reference group to meet on a regular basis to discuss opportunities and future planning.

Meet with the group to discuss lessons learned. What went well and not so well. What can be done to improve things for the future.

Thank everyone for their involvement and explain how working together has impacted on the outcome.

Have you evaluated your project? If not, consider doing so and the methods of doing this.

Showcase what you have achieved together. Consider a launch event, media opportunity etc.

Involving people with lived experience can only improve local services. Continue to invest your time to involve people to make transformational change.



Co-production guidance

Things to consider before you start your project

Consider the length of time that you need to complete the initial project as this will determine the timeframe for involvement.

How are you planning on making decisions? Co-production is an equal decision-making process, and this should be discussed with your project group.

As a group with equal hierarchy discuss together what you want to see as an output and what the challenge is that the group feels is the most important from their lived experience.

Identify where you will reach people with lived experience. Consider community groups, other organisations, GPs, religious groups, memory clinics.

Is this dementia friendly and accessible to everyone?



Co-production is about ensuring that everyone has an equal voice and therefore the numbers in the group should reflect this with an equal amount of key stakeholders.

Where are you planning on meeting – online only, face to face or hybrid working?

“**Co-production starts at the birth of a project or strategy and informs and guides it throughout its lifetime. It’s not an add-on, and nice to have. It’s a vital requirement for an efficient, cost effective solution.**”

Person living with dementia

How are you making involvement inclusive and diverse?

How will you communicate with the people you invite?

Co-production guidance

Getting involved

Invite people with lived experience and stakeholders ensuring that your communication method is accessible to all. Provide individuals with a brief overview of the project i.e., what the project is, why you are involving people, what people would be doing, what time commitments there are.

Best practice is to evaluate regularly; this may involve external facilitators as agreed or people with specific knowledge can be invited by the group.

Discuss the best way for the group to have their say – hands up, have ‘I’d like to speak cards’ etc.

The group will decide equally what the project will look at, any priorities from their lived experience and who would like to be involved where.

Discuss preferred ways of working with the group and establish terms of reference. How frequently do they want to meet and time commitments? Group to agree when they will meet again or if any small working groups need to work together before the next meeting and then report back.

Check that everyone is still willing to be involved and can commit their time to achieve the outcomes of the project.

Create a project plan together with specific milestones and agree individual roles. Ensuring that you include regular reflective sessions; recognising that this may alter the direction of the project plan.

Hold your first meeting. There may be a facilitator for group discussions or there may not be, the group collectively will write together their agreed ways of working.

Regular communication is key to ensure that people stay engaged and involved.

Be timely in re-imbursing expenses and explain timeframes for any payments

Explain your expense policy to the stakeholders and what you can offer them.

Designated person should send out follow up communication detailing agreed actions and next steps within a week. Consider easy read, depending on your audience.

Allow at least one month for individuals to consider their involvement before planning your first meeting.

“**Making a difference is so important, getting a diagnosis isn’t like someone has flicked a switch and you are suddenly a different person.**”
Person living with dementia

Co-production guidance

Reaching your outcome and next steps

Meet with the group to discuss lessons learned. What went well and not so well. What can be done to improve things for the future.

Continue to communicate opportunities on a regular basis or consider forming a steering/reference group to meet on a regular basis to discuss opportunities and future planning.

Involving people with lived experience can only improve local services. Continue to invest your time to involve people to make transformational change.

Showcase what you have achieved together. Consider a launch event, media opportunity etc.

Can this work be expanded on or do you have further opportunities to work with these individuals?

Thank everyone for their involvement and explain how beneficial it has been to work together.

“Inclusion is a byword where skilled facilitators make sure everyone has their say. Regular feedback and progress updates are given and no matter how small, I hope that I am making a difference.”

Person living with dementia



Top tips

Planning your involvement

- Identify the type of involvement you are planning.
- Prepare a brief of your project which can be shared with people you approach to be involved.
- Involvement should be part of your initial planning process. The earlier you consider involving people, the more time you have to get it right.
- You should never pressure someone to be involved. Factor in time for them to consider the opportunity and respond.
- Consider what you will do if someone's needs or capacity changes over the course of the project.
- Always consider if you can increase the level of involvement with a few simple tweaks. For example, you can move from consultation to engagement by having people with lived experience set the questions with you and analyse the results. Or you can move to co-production by ensuring people with lived experience are brought in right now as you begin planning. Just remember, for it to be co-production, those with lived experience must have an equal say.
- Consider your communication methods for those who find it difficult to communicate, such as those who have, learning difficulties, sight loss or are hard of hearing.



Top tips

Finding the right people

- Look beyond dementia. What other skills and experience do people have?
- What knowledge and experience is required for your project?
- Look for people who have not been involved previously. Your work will benefit from fresh perspectives.
- What additional needs does the person have? All efforts should be made to meet those needs. However, it is important to be clear about what is not possible (due to budget, resources, timeframe etc).
- Connect widely across the community, reaching out to local community groups and service providers to include a diverse group of participants in your project.

“
I learnt from being involved that I mattered, what I stand for matters, my opinion matters and how crucial the involvement of lived experience matters.”

Person living with dementia



Top tips

Practical matters



- Gaining consent will differ depending on the ask. There are processes for gaining consent to share someone's information publicly.
- Taking some quick photos to demonstrate your fantastic involvement work? What consents do you need before you post?
- A person's capacity, or just how they feel, can fluctuate. If they cannot consent to something, return to it another time.
- Do some preparation before contacting people. See if they have preferences for how to be contacted and if they have better days or times to get in touch.
- If meeting someone in person for the first time, consider including an image of yourself in your email correspondence, to create a bit more familiarity before you meet.
- Discuss travel arrangements with the person. Many will benefit from you taking on booking and putting together a travel itinerary for them.
- Want some tips on setting up a venue? Refer to links on page 17.
- Will you be meeting people online? Refer to links on page 17.
- Whether your meeting is online or face to face, consider the length of your meeting and how much there is to discuss. Give each topic time and allow for breaks.
- Prioritise agenda items. Most important or more complex topics are best brought forward, as people may struggle towards the end of a session.
- Conflict can be good, but sometimes things can get heated. Breaking into smaller groups can help, both to break up unhealthy interactions and to make it easier for a facilitator to resolve conflict.
- Consider having a break out room in case someone needs to leave or be supported as they may need to rest or the subject matter could be upsetting for them.
- Have a facilitator who has a great rapport with the group or who has a keen interest in the subject being discussed as well as a notetaker.

Top tips

Thanking and feedback



- Find out what makes someone feel appreciated. You can talk to them and perhaps ask others who have worked with them before what they have done.
- What makes people feel most valued is knowing their work made a difference. Timely updates on what has changed directly from their work are key. Equally, if you do not take forward a suggestion, feedback clearly why.
- Plan your feedback process. What are the milestones and check in points? Don't miss these, even if things get moved back. It is important to let people know that timelines have shifted, so they know the work is still happening.
- Highlight their work. This can be done internally through our communication channels, in any documents or reports and more publicly if they consent.
- Be open and honest with the person. Feedback isn't just about the difference they have made, it is about how they engaged. If there is something they could improve on, set some

time to go through this with them. The person can only develop if you give them constructive feedback. It will help with their next piece of work. In extreme cases people stop being offered opportunities because something went wrong, and it was not addressed. This is damaging to the person and prevents growth within an organisation.

“You might go quicker by yourself, but you go further with other people.”

Person living with dementia ”

What does good involvement look like?

Case study: Essex Peer Support Service

How we involve people?

- **Co-production**

What did we do?

The Essex Peer Support service is a new service for younger people diagnosed with dementia. The service provides dementia support from paid staff and peer support from volunteer peer support buddies living with dementia. A project team made up of 3 members of staff and 3 people living with early onset dementia was created and together we:

- Designed the service model and worked with clinical teams to redesign the clinical pathway
- Developed the staff and volunteer structure
- Recruited staff for the new service
- Created a new volunteer role
- Developed a referral pathway

We met regularly on-line and face to face, the project took 8 months from start to finish. There were times when different people in the project team worked on different aspects of the project. We also found that we needed to use some Alzheimer's Society templates so not everything was co-produced from start to finish.

What difference did involvement make?

As the service was designed together with people with lived

experience there was the opportunity to get the service and delivery model right from the start. This included creating a new volunteer role who would provide support to the peer buddy. We ensured that the volunteer role description included specific skills and experience to support the buddy role as it evolved..

The group were also able to affect changes to the clinical pathway, influencing how the pathway could better support people and what support is needed from clinical teams.

What did we learn?

At the start you need a clear brief about how the organisation works, where are the boundaries and barriers likely to be for the project team. A dedicated project manager would have been useful.

You need clear expectations and check everyone's understanding from the beginning.

You need to understand everyone's starting point, how you keep all participants engaged when the project is fast moving.

Communication is important - keeping everyone in the loop at all times with regular meetings and touch points regularly in the diary.

Face to face meetings were more productive & enabled more engagement.

What does good involvement look like?

Case study: Wakefield Services review

How we involve people?

- Engaging
- Consulting

What did we do?

We were asked by Wakefield CCG to help them develop their local dementia strategy by conducting a listening exercise. We used a whole range of methods to engage lots of people and to hear their thoughts on how the dementia pathway in Wakefield could be improved. This included consulting people and engaging people.

People affected by dementia worked with us to design the questions for the survey which formed the main part of the consultation process. We engaged with people in a number of ways, which ensured that we maximised our reach and captured as many voices as possible. Responses were collated and key themes were drawn from them which helped shape the project direction.

We tailored our approach to ensure we took steps to engage people affected by dementia across Wakefield, across communities and in settings where we traditionally do not deliver services. For example, the team introduced Talking Mats as a method to engage with care home residents. The mats benefit people who communicate in a visual way rather than through speech or writing. We also offered drop-in sessions at the hospital and Memory Assessment Service which allowed us to maximise our reach and support more people.

What difference did involvement make?

This work has had a significant impact in Wakefield. Having people affected by dementia involved in the project, and hearing their experiences as part of the consultation led to some significant outcomes:

- Admiral Nurses & Alzheimer's Society starting monthly drop-in sessions for post diagnostic support.
- Local commissioning leads requested additional funding for developing dementia services.
- Discussions taking place about creating training for staff at Primary Care with the aim to raise awareness of dementia and compassionate approach based on the feedbacks from patients. The training will involve people affected by dementia as well as professionals.

What did we learn?

A longer lead in time is needed to help plan for such a wide-ranging consultation.

That consultation needs to be flexible and adapt to people's needs.

Many teams were involved in this project, more clearly defined roles at the start would have been helpful.

Working with us



Michele Richardson
Health and Social Care
Partnerships Manager
Alzheimer's Society

Alzheimer's Society's Health and Social Care Partnerships Team work with integrated care systems across England, Wales and Northern Ireland to identify service needs through co-production.

We will help to design value for money services that provide strategic solutions, deliver quality, and meet the needs of people living with and affected by dementia.

Through our Local Systems Influencing Team we can also support systems to implement recommendations from our policy reports.

The team has resources to help with the development and review of dementia strategies, working with commissioners to address particular challenges or areas of focus within local populations. In addition, we can support with the collection of local views via our campaigners, share good practice with local Councilors and MPs.

If you would like to hear more or have an idea that you would like our support to design and deliver. Please get in touch with the team **HSCPartnerships@alzheimers.org.uk**



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Additional resources

For more information and guidance please see links at right

1. Alzheimer's Society Dementia Experience Toolkit

www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/contents-list

2. Alzheimer's Society Practical Guide To Designing Products And Services For People Affected By Dementia

www.alzheimers.org.uk/research/our-research/practical-guide-designing-products-services-people-affected-dementia

3. Co-production resources from The Co-production Collaborative

<https://resources.coproductioncollective.co.uk>

4. Co-production resources from Think Local Act Personal (TLAP)

www.thinklocalactpersonal.org.uk/Browse/Co-production

5. DEEP

www.dementiavoices.org.uk

6. Co-production Collective Expenses Policy

www.coalitionforpersonalisedcare.org.uk/resources/our-co-produced-payment-policy-is-finally-here

7. Alzheimer's Society Using Video Technology To Connect People With Dementia

www.alzheimers.org.uk/dementia-professionals/dementia-experience-toolkit/real-life-examples/supporting-inclusion/using-video-technology-connect-people-dementia

8. Alzheimer's Society Dementia-friendly Environment Checklist

www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-environment-checklist

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Heather Potter

Alzheimer's Society's
Involvement Team

Emma Lacey

Kate Evans

Rebecca Ballard

Lucile Blight



About Alzheimer's Society

To tackle the UK's biggest killer, we need a Society of people who understand all aspects of dementia and the realities of a disease faced by 900,000 people in the UK. As the UK's leading dementia charity, we're pioneering the way for those experiencing dementia right now, and for all those yet to develop the disease in the future.

As well as being a vital source of support to help people navigate the most frightening time of their lives, we're a powerful force for change by funding groundbreaking research and campaigning to make dementia the priority it should be.



**Alzheimer's
Society**

Alzheimer's Society operates in England, Wales, Isle of Man and Northern Ireland
Registered charity number 296645 and Isle of Man (1128)