The Smarties guide to co-production
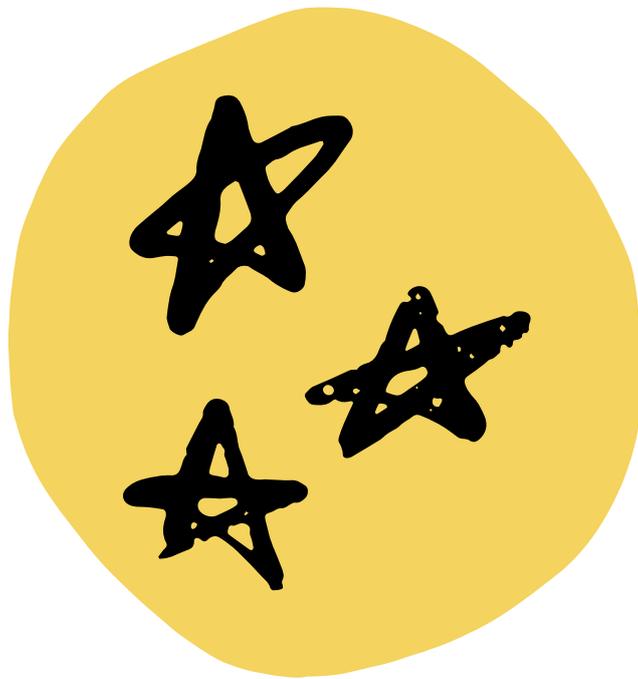
This guide was developed by The Smarties research group and draws on our own experiences co-producing dementia research.

We share our top tips on how to best involve people living with dementia in co-produced research.

What should you do before a research project starts?

- Use your networks to identify people who are keen to take part in the project from the very start.
- Build the cost of remuneration into your budget - so that you can offer a token of appreciation to people for their time and contribution (see https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392 for guidance).

Ground rules need to be set out before we agree to take part:

- Clearly explain what you are asking us to do.
- How much of our time do you want?
- If possible, offer different depths of involvement to suit people's interests and needs.
- Such as, inviting people to choose how much time they want to commit to the project and giving different options of activities they can get involved in.

Remember that we are all at different stages:

"Some researchers you mention dementia and they automatically jump to end-stage dementia and they forget that there's a beginning and there's a middle and that we can still speak, we still have opinions and we've got a lot to give"

Discuss our needs as individuals:

- It is very important to speak with the people living with dementia beforehand and ask them how their dementia affects them.

"We are all different and have varying issues, e.g. sensory issues"

- Some people find background noise distracting.
- Other people can't look at the screen for too long.
- Some people can't read stuff if you put it in the chatbox.

"Find out what matters to us"

If working remotely send us what we will need in advance:

- Stationary, printed resources, folders etc.
- For printed resources don't use too small a font or acronyms, use clear language and avoid jargon.
- Some treats are appreciated such as tea, coffee, biscuits, chocolate etc.

"Little things can go a long way towards helping people feel valued and part of a group – for example, we might all sit together online eating the same chocolate bar"

- Make sure you send resources with plenty of time to spare so we can look through them before we meet.

What should you do during research project sessions?

Consider using the Zoom platform:

"It's easy for people with dementia to access, you basically receive a link, you click on the link and you're in the meeting"

"You can see everybody who's speaking to you"

"Working from home can keep it in our comfort zone"

- It can be a time saver – avoiding time spent travelling.

"Zoom allows people who live in rural areas without any other real peer support groups to join in"

- Great for meeting people and forming connections across the UK and beyond.

"Online has many benefits but we always like to remember that nothing beats face-to-face, you can't beat a good cuddle"

- If you work in person, offer options for joining virtually so people who can't travel can still be involved.

How to use Zoom:

- Offer guidance before sessions if someone is unfamiliar with Zoom.
- Share printed guidelines on how to use Zoom for those who need them.
- Ask everyone to stay on mute when not speaking.
- Use 'I want to speak' cards (or hands up function) to avoid interrupting each other.
- Have a dedicated facilitator to direct the turns for speaking.
- Don't have too big a group, around 6-8 people on a screen works well.
- Stay on screen after the meeting.

"Invite us to stay if we need a bit of a chat or a wee debrief or just to get something off our chest. Zoom calls just end and you're sometimes left thinking did I actually have that conversation or have I just dreamed that"

Structure and process for sessions:

- Let the group negotiate and decide the day, time, length and frequency of sessions.
- Keep these timings regular throughout.
- Have at least the next few meetings scheduled in the diary.
- Each session should have a definite beginning, a middle and an end.

"The beginning being the more informal chat, humour, social catch up with the group, those times are crucially important to then enable us to move from that into the more formal middle bulk of the meeting and then there's always an ending, looking forward to the next time we come together"

- Schedule regular breaks.
- 2 hours max works well.
- Make sure there are no surprises – consider sending an agenda before to make sure people know what will happen. Let people know in advance if you are inviting a new person to join a session.
- Pace **"not too fast and not too slow"**. Allow space for digesting things and give opportunities for questions.
- Try to limit screen sharing.

"It's difficult for us to concentrate on the screen and what we are saying, also not being able to see the other people"

Focus on relationships:
- A good co-production group is built on trust, respect and clear communication.
- Allow space and time for the group to build friendships.

"A sense of camaraderie is so important"

- Allow time for humour and going "off-topic".

> "It enables us to then focus on the more serious aspects as well, to all work better together as a team and be more committed to the actual project"

> "The laughs and the jokes are important because they put you in a good mood and it helps you to concentrate a bit better"

- Actually listen to and respect each other.

> "Often you don't get that on research and Zoom meetings. People don't listen, they switch off or you'll see them reading something in the background"

- Create a safe space.

> "It's important that we feel we are in a safe place because when we're talking about how dementia affects us and how things crop up in our lives, we don't know what sort of emotional reaction we're going to have"

- If someone shares something personal, listen, be respectful, and be non-judgemental. Offer supportive comments and do not share beyond the group.

Facilitators:

- Regular, prompt communication is essential.
- Respect and value the group members.

"Very often people living with dementia are not respected and people don't think that we do have anything to offer, always remember to remind the group that we do have a lot to offer"

- During your video call smile and be kind.

"This costs nothing but means a lot to us"

- Consider your use of language/words.

"It's best not to use words like dementia sufferer, senile dementia etc."

- If unsure, ask people what language they prefer.
- Create an environment where there are no wrong answers.

"Enforce the positive and totally reject the negative"

- Concentrate on the things we can do and not the things we can no longer do.

"When faced with a problem we work to find a solution"

- Reject tokenism.

- Make sure everyone has a chance to speak at every session and for every topic covered in a session.

- Be a good listener and try not to interrupt the group member speaking as they may lose their train of thought.
- Be wary of allowing one person to dominate the conversation.

- Always make time for group discussion.

> "We bounce off each other as we talk, somebody might say something and it might trigger something in another person's head"

- Allow for differences in abilities and difficult patches that individuals may go through.

> "When living with dementia we face daily challenges, we don't know when we wake up what the day ahead holds for us. It may be a good day or a bad day when you don't feel able to do anything"

> "Allow time for us to process what is being said before moving on to the next thing. Don't ask multiple questions at once"

- Give feedback throughout.

> "We so often doubt our abilities and doubt what we can do and doubt whether we're coming across well or whether we're saying things well"

What should you do after sessions and when the project ends?

Offer a token of appreciation for people's time and contribution:

- Some people may not want to be paid to take part.
- But a voucher can be a lovely bonus and enable members to use it for something for their own benefit.
- Offer a variety of options for different shops and ask if the group member would like an e-voucher or a physical card.

Offer feedback to the group:

- After sessions send a thank you email and include a brief summary of what you did together.
- Pay attention to the group – if someone seems a little quieter, seems anxious or upset, or mentions anything is up then check in with them by email or phone.
- Let the group know that you can be contacted if they have any issues after the video call.

"We may have shared something very personal which may evoke unhappy memories and just need assurance"

Listen and act on feedback from the group:
- If someone offers some feedback or criticism, then listen carefully to what they are saying and demonstrate how you will meet that feedback and adapt things for the next session.

Offer follow-up sessions if someone can't attend the session:
- Contact the people who couldn't attend and update them on what happened and offer a 1-1 to catch up on everything at a time of their convenience.
- Allow them time to give their input on what was discussed.

"This can help people feel like a valued member of the group and project"

Ending a project:
- Give regular reminders on how far through you are and the ending date that you are working towards.
- Take time to discuss how you all feel about ending.
- Have a celebration of the work together and send the group thank you gifts and letters.
- Do not just disappear, keep in contact and give updates if appropriate.
- Share all outputs with the group.
- Acknowledge the group's contribution on all outputs.

- Offer opportunities for collaborating on dissemination or future work.
- Give information on other projects the group could get involved in if they are interested.

Remember good practice can have a ripple effect:
- Group members will take from a good experience and pass the word on.
- Other research projects can then benefit from the good practice you show when conducting yours.
- Then people living with dementia are more likely to want to take part in future research and share their important skills, experiences, and perspectives.

Thank you for taking the time to read our guide.

We hope you found it helpful.

This guide was co-produced by The Smarties research group (Irene Donaldson, Julie Hayden, Gerald King, Chris Maddocks, Keith Oliver, Martin Robertson, Rosie Ashworth and Rose Vincent).