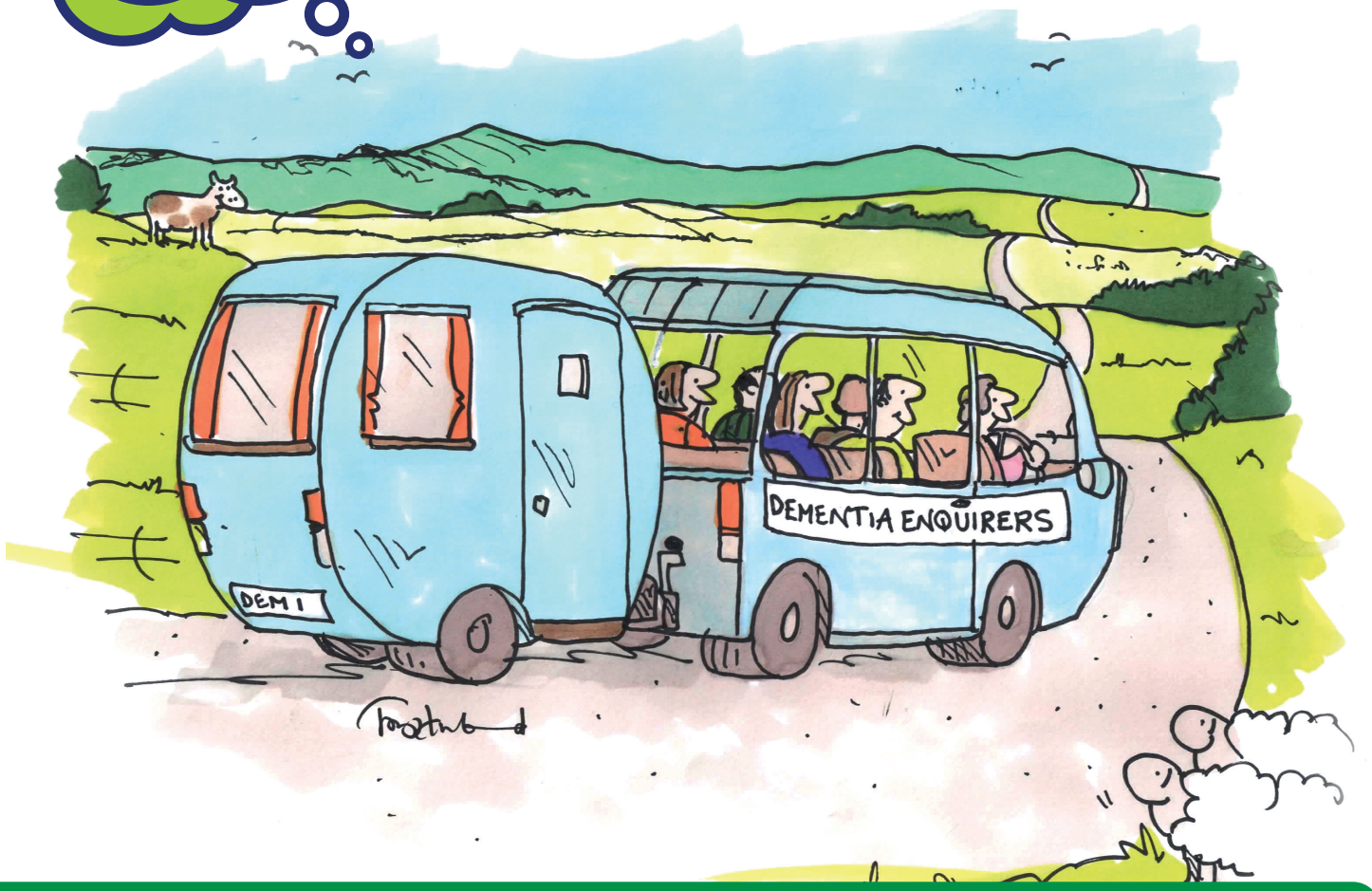
Dementia Enquirers

Bringing people with dementia into the heart of research



Our learning on communication and accessibility

This resource has been produced as part of the Dementia Enquirers programme. Dementia Enquirers puts people in the driving seat of research – planning and leading their own research enquiries. Dementia Enquirers has produced a range of resources to support the involvement of people with dementia in research.

We have learnt so much in this programme about what is different about research led by people with dementia themselves. Here are some ways we can all help with communication and accessibility:

Explaining your project

Take time to find out each person's preferred ways of communication.

Give enough information (but not too much) to enable people to make an informed decision about whether to take part.

Keep everything as simple as possible – tailor your information so it is fit for purpose, for the audience, and for the level of risk.

Use photos and other images if this helps to convey information.

Avoid overloading people with other (less accessible) information where it's not absolutely necessary.

Give people enough time to ask questions and make decisions.

Consent

Offer extra help to give informed consent. Visual props, Talking Mats, easy-read information etc. can help people to understand and decide whether to be involved.

If people cannot sign a form, allow them to record their agreement on video or audio, or you could write a 'field note'.

Accept that consent is an ongoing and flexible process. Provide routine reminders and recaps (verbal, written or pictorial), that prompt people to reconsider and reflect on their involvement.

Making participation easier

Remind participants the day before that they will be meeting with you, using the communication method that they indicate is best for them.

Offer to help with travel plans, remote access, meeting people at stations etc. if they need/want this to keep them safe.

Make the schedule flexible to people's preferred time of day, and avoid days where other support might be limited e.g. Friday evenings.

Ensure that the research is conducted in a quiet, safe, private space and in keeping with the participant's wishes (if at all possible).

For group discussions, think carefully about the venue – it needs to be peaceful, welcoming, fully accessible, well-signed, with easy parking and transport links.

Present all information clearly and accessibly, making reasonable adjustments as needed (including translation/interpretation). You can read about writing accessible information for people with dementia here **https://bit.ly/3DJVTC0**

Speak at a steady pace and in simple (non-academic) language.

Adapt to the person's own pace and preferred communication type and style.

Explain research terms each time they are used (or use simpler alternatives) and avoid using abbreviations and acronyms.

Avoid inappropriate exclusion of people, for example because of a diagnosis, deafness or language barrier. And take reasonable steps to be inclusive. For example, offer translators, remote video conferencing or telephone where transport is not available or easily accessible. Avoid limiting your study to an upper age limit without good reason.

Avoid over-taxing people's memory or communication skills. Always re-cap on previous conversations or interviews each time.

Include enough breaks – e.g. for refreshments, quiet time, toilet and re-focusing – because research involves a lot of concentration.

Feedback

Ask participants (and if agreed, their families or a trusted person who they nominate) how they want feedback: at what points, and in what ways. This may need to be re-checked.

Provide a summary of the final report in simple, understandable language. Offer individuals a choice of what type of report they want (e.g. a summary, two sides of key points, or the full report). Re-confirm this at the end of their involvement.

Thank you payments and expenses

Ensure these are prompt and require minimal or no form-filling.

For more ideas from Dementia Enquirers visit **www.dementiaenquirers.org.uk**

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Phase 1 of Dementia Enquirers (2018-2023) was supported by The National Lottery Community Fund.

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Dementia Enquirers

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