

Taking Part opportunities – things to think about before you become involved in a project.

Key messages

- Know who you are working with.
- Does the project fit with your interests and values.
- Make sure all costs will be covered.
- Practicalities – will you be supported to contribute in a meaningful way?
- Your personal information is kept safe.

Taking part opportunities

There are many requests from organisations and researchers who want to ask you about what you think as a DEEP group and/or as a person living with dementia. They may want to find out your views on a particular topic or to ask you to get involved in research or to support a new project.

There are real benefits to taking part in opportunities to have your say. Being valued, listened to, and getting your views considered can feel really rewarding and worthwhile under the right conditions. You may even get the opportunity to travel and be part of new and exciting experiences.

It is important to make sure that the people you would be working with are ethical and straightforward. If you have any concerns/questions, make sure the organisation or researcher answers them before you agree to be involved. These are some of the things you might want to think about before agreeing to take part.

The organisation and contact for the project.

- The name of the person/people you will be in touch and working with.
- Their contact details: email, telephone, and address if necessary.
- The organisation: find out a bit about the organisation. For example:
 - Is it big?
 - Is it local?
 - Does it make a profit?
 - Who funds it?
 - Does it fit with your values?
- Think about what you would be comfortable with.

The project/research.

- What is the project? Find out a bit more about the project. How does this link with other things you are interested in?
- Are they looking for a particular type of person to be involved? E.g., people in Manchester; people who have a pet, or people who ride a bike. How do you feel about who they want and why?
- Why do they want to involve people with dementia? Be sure that your agenda matches theirs – Do you think they are involving people for the right reasons, and it is not just a ‘tick box’ exercise? You should expect that they provide a short, clear description of why you should contribute their project.
- You might need to think about ‘conflict of interest’. This can be quite a complicated thing to understand. So, declaring what other things you are involved with and also expecting the same from the people you are working with is a good rule of thumb.
- How will they let you know what has happened because of your involvement?
- What, if anything will come out of the project/research – will it make a difference to you and other people with dementia?

- Check that the researchers have got ethical approval for research projects.

Practicalities for you to think about

- How will your involvement happen? You may have a preference.

It is important you understand how you will be involved for example:

- face-to-face
- on the phone
- online Zoom/Teams/Skype

- How long you will be involved for - e.g., one hour, every week, one-off or one year or even longer.
- How many people will be involved? You might want to know if other people and/or groups are involved so you can connect with them.
- What support they can offer you? It is important that you are clear about what support - practical and financial - you need to take part. It is important that you ask because they may not offer.
- If you need to travel, ask if they will book the type of transport, you feel most comfortable with.
- If you need to stay, overnight ask if they will book the kind of accommodation, you feel most comfortable with.
- Will they pay for your meals and refreshments on your journey?
- Will they pay expenses for somebody to support you?
- Will they pay for the time of a professional supporter/carer if needed?
- Will they pay you or thank you for your contribution?

Some people don't want to be paid but, some people feel if they have budgeted for your involvement, it shows that your voice is valued. Be aware of any impact on your benefits or taxes if paid to you as an individual. Sometimes payment/thank you is offered in the form of a gift card rather than money.

- As an individual you may choose to use your payment to donate to your group or the organisation which hosts your group. Make sure that money can be 'ring-fenced' for the group and not get sucked up in to general funds.
- You should never be out of pocket for your contribution. Some organisations take a long time to reimburse expenses. Ask them if they are able to pay your expenses in advance.
- Will they give you clear information about meetings? Will they send you reminders, notes, and questions before and after the meeting?
- This experience should be enjoyable for you.

Your personal information

- How will they keep your information safe or anonymous? It is important to be clear if you are happy, or not, for them to use your name, direct quotes or stories or photographs.
- Make sure you sign a consent form and clearly state if you are not happy to be named, quoted, photographed, or filmed.
- You may need to sign a confidentiality agreement which can sometimes be quite challenging as sometimes they can be complicated. Ask for help in completing it if it is required. Is there some kind of understanding/provision within the agreement about your dementia as a disclaimer (you might forget it is confidential!).
- Will you be given the opportunity to be credited and named in research and /or a publication if you would like to be?

A quick checklist of the information to expect

- Their name
- Their Email address
- Details of the organisation
- Information about the project
- Who they specifically need to take part

- When will the project take place
- How long will you be involved for
- How many people with dementia will be involved
- What kind of support is available
- Is there a budget for refreshments, venue hire, accommodation and transport
- Will you be offered a payment/thank you for your input
- How they will keep your personal information safe or anonymous
- If they have ethical approval
- Are they going to profit financially or otherwise
- How will they let you know what has happened because of your involvement
- When will they be able to let you know what has happened

Further guides about involving people with dementia:

- DEEP travel, accommodation, and event planner information. Don't be afraid to ask for support to enable you to take part.
- Valuing the contributions of people with dementia.
- Involving people with dementia as advisors.
- Collecting the views of people with dementia.
- Involving people with dementia in conferences and events.
- Guidance for film-makers working with people with dementia.
- Involving people with dementia in recruitment and selection.
- Dementia words matter: Guidelines on language about dementia.
- Tips for consulting people with dementia.

All guides can be found at:

www.dementiavoices.org.uk/deep-resources/involving-people-with-dementia/

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