Guidance for supporting volunteers to complete paper Join Dementia Research application forms

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Document purpose

This document is designed to help staff answer questions about registering with the Join Dementia Research service and help people to complete a form. It may be useful for all staff who could be asked to hand out forms, including reception staff, doctors, nurses, support workers and volunteers.

Signing up to Join Dementia Research offers huge benefits to dementia research, and offers real hope to people living with dementia and their carers, for a future with better information on how to prevent, treat or care for people with dementia.

However, we recognise that the registration form asks for a lot of information, which can be daunting, particularly for someone with a cognitive impairment. With this document and the support of our helplines, we hope we can make the process a little more straightforward. We really appreciate the support and help you can offer in inviting people to sign up to Join Dementia Research, and offering them some guidance in completing the form and answering any questions they may have.

Who can complete the Join Dementia Research registration form?

Registration forms should be completed by the volunteer or representative of the volunteer.

As a nurse, doctor or memory clinic staff member, you can support a person to complete the form or to answer any questions they may have. Only the volunteer, or their representative (if they hold a lasting power of attorney for the volunteer) can sign the form.
Who can be a representative?

- A representative is someone who knows the volunteer well, sees them often and would be willing and able to attend research studies with the volunteer - ideally a partner, relative or close friend.
- A representative cannot be a nurse, doctor or memory clinic staff member
- If the volunteer is unable to give consent, the representative can give consent on their behalf if they hold Power of Attorney for Health and Welfare.

What are the benefits of having a representative?

Volunteers with a diagnosis of dementia often benefit from signing up with a representative. The benefits of having a representative are listed below. These should be fully explained to the volunteer and those attending the appointment with them.

It is possible for someone with dementia to sign up and match to studies themselves, however having a representative can help.

- The volunteer has the option for the representative to receive all communications from Join Dementia Research and from researchers. These communications can be sent to both representative and volunteers, or registrants can choose for just one person to receive communications. Dementia is a progressive condition and while someone may be able to communicate well now, this may not always be the case and so a representative can offer support here.
- Researchers often need to know that the person with a diagnosis has a suitable ‘study buddy’ to attend research studies with. If researchers can identify that a volunteer has a representative it increases the likelihood of the volunteer being matched and being able to get involved in a study.
- Join Dementia Research encourages researchers to make sure their communications are not only lay-friendly but also understandable by people with varying levels of disability due to dementia. Despite this, communication from researchers could be overwhelming or hard to understand for a person with dementia, especially where someone matches to multiple studies at the same time. Having a representative ensures that the volunteer can speak to someone they trust, and who knows them well, about each different study, what the research might involve and whether or not they would like to take part.

The Volunteer Information Sheet

Where possible, please provide all potential volunteers and/or representatives with a copy of the volunteer information sheet or tell them where they can find it.

It explains what the service is, how their data will be used and what to expect, so volunteers and their representatives can make a fully informed and reasoned decision about registering to the service.

Volunteers and/or representatives will be asked to confirm that they have read a copy of the volunteer information sheet as part of the registration process. This point is clearly stated on Declaration A and B on the registration form.

A web and downloadable copy of the Volunteer Information Sheet is available online at [bit.ly/volunteer-info](http://bit.ly/volunteer-info). Please provide a printed copy for anyone you are supporting to register.
What are the different sections on the registration form?

**Section 1: Information about the volunteer (pink text on form, pages 3-6)**

These are the details of the person who will be taking part in research studies.

All questions on the form are mandatory and so must be answered.

Declaration A must be signed and dated by the volunteer themselves, unless they are signing up with a representative who has Lasting Power of Attorney for Health and Welfare.

**Section 2: Information about the representative (blue-green border, pages 7-8)**

These are the details of the partner, relative or close friend who will act as the volunteer's representative and support that person in getting involved in research studies.

This should only be completed if the volunteer is signing up with a representative, otherwise leave these pages blank. If the person does not have a suitable representative they can still register with the service, in this case only pages 3-6 should be completed, including the date and signatory box at the bottom of Declaration A.

If the volunteer does have a representative, all questions in this section must be answered.

Declaration B should be signed by the representative.

If the volunteer is unable to give consent in Declaration A, the representative must have Lasting Power of Attorney for Health and Welfare and to indicate this on the form before signing.
Other key messages to tell potential volunteers or their representatives

Contact preferences and willingness to travel for research

Try to explain to the potential volunteer about how preferred contact methods and willingness to travel to take part in research could affect how they keep up to date with the service or influence the number of studies they match to and can take part in:

- If an email address is provided on the form, an online account registration will be made. The volunteer or their representative will be able to set up a password allowing them to access an online profile via the Join Dementia Research website. This allows them to keep information up to date and to view any study matches themselves. Instructions will be sent via email once the registration form has been processed.
- Telephone and/or email contact are preferential and advised. If a volunteer chooses post as a contact method, there’s a possibility that researchers won’t make contact with them if they are matched to a study.
- If a volunteer chooses the option to only travel within 5 miles of their home address, they may be limiting potential research matches, especially in more rural locations. By choosing regionally or nationally they stand more chance of matching to research studies, especially those based at hospitals or clinics. They still have the right to turn down any research opportunity that is not convenient for them.

Processing the form

It could take up to three weeks for a form to be processed once received from a memory service. When registered, the volunteer and/or representative will be sent a welcome email or booklet (this will depend on what they request on their form). This will provide the information and contact details they need to find out more about Join Dementia Research, the studies and how to get in touch.

Important note: Any form that is missing information or not filled in properly requires Alzheimer’s Research UK to make follow up contact. Due to limited resources only three attempts at contact will be made, if no contact is possible the person will not be registered to the service.

Changes to volunteer or representative information

A registered person should be encouraged to call one of the charity partners to keep their information up to date (e.g. changes to contact details or medical history). Contact details to do this will be sent in the welcome email or booklet once the form has been processed.

A volunteer can add a representative at a later date if they want to.