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### DECLARATION B

#### I am registering someone else as a volunteer

- I have lasting power of attorney formally in place for the registered person on health and welfare grounds, and it is my opinion that registration is in their best interests. (If I do not have this, I understand the registered person needs to sign the form themselves or provide contact details so that helpline staff can speak to them to confirm their wish to be registered.)
- I confirm that I have read and understand the information within this form and can access a copy of the Volunteer Information Sheet on the Join Dementia Research website or via the charity helplines.
- I understand that registration is voluntary, and that my details and the personal details of the registered person will be stored securely.
- Only approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research can look at the registered person's information on Join Dementia Research. I give permission to these individuals to view the registered person's information and use this information for the purposes of delivering Join Dementia Research.
- I understand that only approved researchers and NHS staff will be allowed to access the registered person's medical records held by their hospital consultant and/or GP. I give permission for these individuals to look at the registered person's medical records to help check their suitability for research studies.
- I understand that the volunteer can withdraw at any time, or I can do so on their behalf, without giving any reason. If the registered person withdraws from Join Dementia Research then their medical care will not be affected.
- I understand that if the registered person withdraws, or after their death, then all their personal identifiable information, and mine as their representative, will be removed from Join Dementia Research.

#### I, THE REPRESENTATIVE, UNDERSTAND AND AGREE TO DECLARATION B

Signature

Today's Date  
DD / MM / YYYY

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FOLD AND SEAL TO PAGE 4

FOLD AND SEAL TO PAGE 3

### PLEASE ONLY COMPLETE THIS PAGE IF YOU ARE REGISTERING SOMEBODY ELSE FOR THE SERVICE

If you are signing up yourself as a volunteer, you do not need to complete this page.

Although you are registering someone else, we also need some information about **you**. You can write the details of the person you are registering on pages 3, 4 and 5. You **MUST** answer ALL questions. **Before completing this section, please read Declaration B on page 7 carefully.**

**Important note: We can only register a volunteer with their consent, or the consent of someone who holds lasting power of attorney (LPA) for the volunteer on health and welfare grounds.**

**If you do not hold this LPA, we will only complete the volunteer's registration if the volunteer has signed the form themselves or if one of our charity helpdesks is able to confirm over the phone that the volunteer agrees to be registered.**

#### YOUR RELATIONSHIP TO THE VOLUNTEER

What is your relationship to the volunteer?

\_\_\_\_\_

Do you hold lasting power of attorney (LPA) for the volunteer on health and welfare grounds?

YES  NO

Should communications to the volunteer be sent through you?

YES  NO

Should communications be sent directly to the volunteer?

YES  NO

*If you tick 'yes' to both of the above, both you and the volunteer will receive a welcome booklet.*

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#### YOUR INFORMATION AS A REPRESENTATIVE

TITLE (Dr, Mr, Mrs etc.) \_\_\_\_\_

FIRST NAME  
\_\_\_\_\_

SURNAME  
\_\_\_\_\_

DOB (DD/MM/YYYY) \_\_\_\_\_

GENDER

Male  Female  Not Specified

EMAIL (Please leave blank if you do not have one)

\_\_\_\_\_  
\_\_\_\_\_

Do you have the same postal address as the volunteer?

YES  NO

If no, please add **your** address below

HOME ADDRESS \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

TOWN / CITY \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

COUNTY \_\_\_\_\_

POSTCODE \_\_\_\_\_

PHONE \_\_\_\_\_

## WHY SIGN UP?

Everybody should have the chance to find and take part in dementia research.

Join Dementia Research provides that chance, and can connect you to suitable studies taking place across the country.

By registering, you can play an important part in finding new ways to diagnose, treat, manage and care for people affected by dementia.

HELPING FUTURE GENERATIONS

"FIGHTING BACK" AGAINST THE DISEASE

ACCESSING NEW TREATMENTS

FEELING PART OF SOMETHING VALUABLE

WHY PEOPLE LIKE TAKING PART IN RESEARCH

Follow us: @beatdementia /joindementiaresearch

To request a large print version of this form, please email [comms.jdr@nih.ac.uk](mailto:comms.jdr@nih.ac.uk) or call one of the charity helpdesks.

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CRN155



Join dementia research



National Institute for Health Research

HELP BEAT DEMENTIA

REGISTER YOUR INTEREST IN DEMENTIA RESEARCH TODAY

### REGISTRATION FORM

Join Dementia Research is a national service which enables you to be told about research studies that you may be able to take part in.

**Signing up could take us a step closer to beating dementia.**

Register today. Complete the form inside, call one of our helplines or visit:

[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)

Join Dementia Research is funded by the Department of Health and Social Care, and delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.





## VOLUNTEERS ARE VITAL IN THE FIGHT AGAINST DEMENTIA

### Please read the following information carefully.

On this registration form, you will find the basic information needed to register either yourself **or** someone else for the service.

### You can only complete one form for one volunteer.

Completing this form creates an account for you on Join Dementia Research. Once your account has been set up, you can improve your chances of matching to a suitable study by answering more questions and by keeping your details up to date.

If you have provided us with an email address you will be able to do this online yourself, or alternatively you can call one of the charity helplines below.

If you do not wish to register by post, you can sign up over the phone by calling one of our charity helplines below or register online at: [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)

Alzheimer Scotland  
**0808 808 3000**

Open 24 hours a day,  
7 days a week.  
(Scotland)

Alzheimer's Research UK  
**0300 111 5 111**

Mon - Fri: 9am - 5pm  
(UK wide)

Alzheimer's Society  
**0300 222 1122**

Mon - Wed: 9am - 8pm  
Thurs - Fri: 9am - 5pm  
Sat - Sun: 10am - 4pm  
(England, Wales & Northern Ireland)

Calls to Alzheimer Scotland are free. Calls to Alzheimer's Research UK and Alzheimer's Society cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.

You should hear from us within 21 days to confirm we have received this form and created an account. We will send you a welcome email or booklet which will include guidance on how you can update your or the volunteer's information.

The welcome booklet and the website both contain more information about what happens once you have registered with Join Dementia Research. You can also find out more about how we look after and use your data.

Once registered, we hope you will enjoy being part of Join Dementia Research, but if you wish to be removed from the service, please email: [manager.jdr@nihr.ac.uk](mailto:manager.jdr@nihr.ac.uk) or contact one of the helplines.

MOISTEN HERE AND STICK PAGE 8 TO THIS PAGE

### INFORMATION ABOUT THE VOLUNTEER

On these pages, please write either:

- Your details (if you are signing yourself up as a volunteer) OR
- The volunteer's details (if you are signing up someone else).

You must complete a form for each person who wishes to volunteer.

Before completing this section, please read the relevant declaration text on pages 6 or 7 carefully. You **MUST** answer **ALL** the questions on pages 3, 4 and 5.

### THE VOLUNTEER'S DETAILS

Is the volunteer registering as someone who has a diagnosis or concerns about symptoms of a dementia or memory-related disorder?  
YES  NO

If yes, what is the volunteer's diagnosis?

- ALZHEIMER'S DISEASE
- VASCULAR DEMENTIA
- MILD COGNITIVE IMPAIRMENT (MCI)
- MIXED DEMENTIA
- DEMENTIA WITH LEWY BODIES
- FRONTOTEMPORAL DEMENTIA (FTD)
- ALCOHOL-RELATED DEMENTIA (including Wernicke-Korsakoff syndrome (WKS))
- DEMENTIA IN PARKINSON'S DISEASE
- DEMENTIA IN HUNTINGTON'S DISEASE
- OTHER DEMENTIAS
- NOT AWARE OF SPECIFIC DIAGNOSIS

If no, does the volunteer currently help, support or care for a person with dementia or memory problems?  
YES  NO

Does the volunteer have any disabilities?

- DEAFNESS
- BLINDNESS
- MOBILITY
- LEARNING OR INTELLECTUAL DISABILITY
- COMMUNICATION DIFFICULTIES
- NONE OF THE ABOVE
- ANY OTHER DISABILITIES (please specify)

TITLE (Dr, Mr, Mrs etc.)

VOLUNTEER'S FIRST NAME

VOLUNTEER'S SURNAME

DOB (DD/MM/YYYY)

GENDER

Male  Female  Not Specified

HOME ADDRESS

TOWN / CITY

COUNTY

POSTCODE

PHONE

EMAIL (Please leave blank if you do not have one)

TEAR ALONG PERFORATION AND KEEP PAGES 1 AND 2

MOISTEN HERE AND STICK PAGE 8 TO THIS PAGE

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MOISTEN HERE AND STICK PAGE 8 TO THIS PAGE

MOISTEN HERE

Does the volunteer have any other medical conditions?

- DOWN'S SYNDROME
- SLEEP DISORDERS
- CANCER
- SIGNIFICANT CARDIAC PROBLEMS
- STROKE
- HIGH BLOOD PRESSURE
- DIABETES
- DEPRESSION
- OTHER MENTAL HEALTH ISSUES
- NONE OF THE ABOVE
- OTHER MEDICAL CONDITION (please specify)

Is the volunteer currently taking any of these memory medications?

- DONEPEZIL HYDROCHLORIDE (ARICEPT)
- RIVASTIGMINE (EXELON)
- MEMANTINE HYDROCHLORIDE (EBIXA)
- GALANTAMINE (REMINYL)
- NONE OF THE ABOVE

Does the volunteer have a carer / someone that knows them well, and who helps support them with their dementia or memory difficulties?  
YES  NO

If the volunteer has dementia, how would you describe the symptoms?  
MILD  MODERATE  SEVERE  UNKNOWN

Is there a history of dementia within the volunteer's family?  
YES  NO  DON'T KNOW

Office use only:

MOISTEN HERE AND STICK PAGE 7 TO THIS PAGE

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MOISTEN HERE

MOISTEN HERE FIRST AND STICK PAGE 6 TO THIS PAGE

The questions below are used to match volunteers to certain studies and for staff working on Join Dementia Research to understand how well we are reaching different communities.

Please choose one option that best describes the volunteer's ethnic group.

- BRITISH (WHITE)
- IRISH (WHITE)
- ANY OTHER WHITE BACKGROUND
- WHITE AND BLACK CARIBBEAN (MIXED)
- WHITE AND BLACK AFRICAN (MIXED)
- WHITE AND ASIAN (MIXED)
- ANY OTHER MIXED BACKGROUND
- INDIAN (ASIAN OR ASIAN BRITISH)
- PAKISTANI (ASIAN OR ASIAN BRITISH)
- BANGLADESHI (ASIAN OR ASIAN BRITISH)
- ANY OTHER ASIAN OR ASIAN BRITISH BACKGROUND
- CARIBBEAN (BLACK OR BLACK BRITISH)
- AFRICAN (BLACK OR BLACK BRITISH)
- ANY OTHER BLACK OR BLACK BRITISH BACKGROUND
- CHINESE OR SOUTH EAST ASIAN
- ANY OTHER ETHNIC GROUP
- PREFER NOT TO SAY

Is English the volunteer's preferred language?  
YES  NO

If no, what is the volunteer's preferred language?

**IF YOU ARE REGISTERING SOMEONE ELSE AS A VOLUNTEER, PLEASE ALSO COMPLETE THE FORM OVERLEAF WITH YOUR OWN DETAILS.**

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MOISTEN HERE FIRST AND STICK PAGE 6 TO THIS PAGE

### IMPORTANT INFORMATION

Please read and sign the declaration text that applies to you.

- Declaration A (page 6) is for volunteers registering themselves;
- Declaration B (page 7) is for people acting as a representative for someone else.

If you do not sign the relevant declaration to confirm you agree to the statements, you/the volunteer will not be registered and will not be considered for studies.

Once signed and completed, please follow the instructions in pink to moisten and seal this form before dropping it in a post box.

If you prefer, you can seal the form and put it in an envelope addressed to:

Freepost RTCX-BRAG-YSUH  
Alzheimers Research UK  
Unit 3  
3 Riverside  
Granta Park  
Great Abington  
CAMBRIDGE  
CB21 6AD

MOISTEN PAGE 5, THEN FOLD THIS PAGE AND SEAL TO PAGE 5

### DECLARATION A

I am registering myself as a volunteer

- I confirm that I have read and understand the information within this form and can access a copy of the Volunteer Information Sheet on the Join Dementia Research website or via the charity helplines.
- I understand that registration of my details on Join Dementia Research is voluntary, and that my personal details will be stored securely.
- Only approved researchers, NHS staff, staff working at partner organisations or agencies working on behalf of Join Dementia Research can look at my information on Join Dementia Research. I give permission to these individuals to view my information and use this information for the purposes of delivering Join Dementia Research.
- I understand that only approved researchers and NHS research staff will be allowed to access my medical records held by my hospital consultant and/or GP. I give my permission for these individuals to look at my medical records to help check my suitability for research studies.
- I understand that I am free to withdraw at any time without giving a reason. If I withdraw, my medical care will not be affected.
- I understand that if I withdraw, or in the event of my death, all my personal identifiable information will be removed from Join Dementia Research.

### I, THE VOLUNTEER, UNDERSTAND AND AGREE TO DECLARATION A

Signature

Today's Date

DD / MM / YYYY

FOLD AND SEAL THIS PAGE TO PAGE 5

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MOISTEN PAGE 5, THEN FOLD THIS PAGE AND SEAL TO PAGE 5