

## Participant Information Sheet



# CHARIOT: Cognitive Health in Ageing Register: Investigational, Observational and Trial studies in dementia research

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## We invite you to take part in dementia research

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In view of the growing numbers of dementia sufferers world-wide, there is now an urgent need to discover and develop new methods and effective treatments that can prevent, arrest and/or slow this disease. Clinical research, based on healthy individuals is therefore now required to better understand risk factors leading to memory problems and dementia, how they impact, and how we might better predict and diagnose dementia in the earliest stages.

A research team from Imperial College London has created a register of volunteers who are interested in research looking at the prevention of dementia and other age-related diseases.

You are being invited to join this register because you are between the ages of 50 and 85 years old and have no known diagnosis of memory problems. In the future we will ask individuals from this register if they wish to participate in research projects.

Before you decide whether you want to take part or not, it is important for you to understand what this research register is, why it is being developed and what it will involve. Please take time to read the information carefully. Talk to others about the research register if you wish.

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## How to contact us

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If you have any questions about this register, please talk to the study team on **0207 594 8886**

### **1. Why are you contacting me?**

We are building a register of individuals who may be interested in receiving information about studies that aim to better understand healthy ageing, memory problems, dementia and Alzheimer's disease and work towards possible disease prevention in future. You have been invited to take part as you are between the ages of 50 and 85 and have no known diagnosis of memory problems.

### **2. What is the research register and what is it for?**

The number of sufferers of age-related dementia in the UK exceeds 800,000 people. In the years ahead this number is expected to rise considerably because ageing is the main risk factor for developing dementia and people are generally living longer.

There are other risk factors for developing dementia (for example: high blood pressure) which can be controlled and others that currently cannot be controlled (for example: family history). Research into better treatments and ways of preventing dementia is a global healthcare priority, and over recent years the prospect of preventing dementia has become a reality.

We are asking individuals to sign a consent form which will allow us to obtain the following details: your address, landline/mobile contact number, email address, date of birth, gender, ethnicity and NHS number. We also ask that you complete the back page in case of any updates to your details, as well as let us know how you heard about the register.

We will keep a record of this information and update it periodically. We will contact you in the future if a study aimed at investigating healthy ageing and ways to prevent memory problems and dementia becomes available.

### **3. How do I take part?**

If you are happy to join this research register please sign, date and enter your date of birth and contact details on the enclosed consent form (last page attached, please complete both sides). We are unable to accept consent forms signed by someone else on your behalf. Please hand it back to a member of our study team, or return it in the enclosed pre-paid envelope – no stamp is required. You do not need to visit your GP or Imperial College London.

Upon receipt of your form, we will counter-sign it and we will confirm once we have added you to the register. Please take a copy of the consent form before returning it to us if you wish to keep a copy for reference. Alternatively, you can email us at any time for a copy of our current information sheets (see page 3 for our contact details).

### **4. What do I do if I don't want to take part?**

If you do not wish to join the research register, you do not need to do anything. You may disregard this invitation pack, and please be assured that your details have not been shared with Imperial College London.

Once received by the CHARIOT office, we will wait for 24 hours before adding your details to the register. If you decide that you do not wish to take part, please contact us within those 24 hours and we will not update the register with your details and your consent form will be destroyed.

### **5. What will I have to do if I agree to join the register?**

At this stage we are only asking for your permission to collect the aforementioned information and check periodically if these details are up-to-date. Apart from completing the consent form enclosed

you do not have to do anything at this stage and there is no need for you to visit your GP or Imperial College London.

## **6. What will happen next?**

As studies investigating dementia and healthy ageing are developed, we will contact potentially suitable participants to ask whether they would be interested in taking part. Studies may vary from a simple questionnaire which can be completed in your own home to clinical trials investigating a new preventative treatment. If we contact you, it is entirely up to you whether you wish to take part. You will be given full details of the proposed specific research project, time to consider your involvement and opportunities to ask questions. The register will only be used for research that is considered of highest quality. All research plans will be independently reviewed and be subject to ethical approval. You are under no obligation to take part in any future research.

## **7. If I join the register will I have to travel somewhere? How much time will it take up?**

At this stage we are only asking permission to contact you about research studies. Your participation will involve returning the consent form enclosed in the pre-paid reply envelope.

## **8. What are the possible benefits of taking part?**

If you decide to take part, you may be contacted about opportunities to participate in research studies. We hope that some of these may lead to preventative measures, such as the development of life-style advice, medicines or therapies that reduce the risk of developing age-related illnesses and/or dementia for potential sufferers. As a result, participation, primarily may benefit future patients. You may also be among the first to receive these interventions, which may be subsequently found to have a positive impact on the risk of developing dementia symptoms.

## **9. What are the possible disadvantages and risks of taking part?**

We do not anticipate any disadvantages or risks in being a member of the research register.

## **10. Will my taking part in the research register be kept confidential?**

Yes. All the information you give us will remain strictly confidential. Your details are stored in a password-protected encrypted database and stored in a secure server room with highly restricted access in Imperial College London. Access to your personal details would be restricted to named members of the register research team, and only from specified computers within Imperial College London. We will not pass on your details to anyone else, other than carefully-selected and approved providers of secure mailing systems who facilitate our processes. All information about your involvement with the research register will be kept confidential. Our procedures for handling, processing, storage and destruction of participants' data are compliant with the Data Protection Act 1998.

Imperial College London would have a duty of confidentiality to you as a register participant. Nothing that could reveal your identity will be disclosed outside the register team without your consent. You would have the right to check the accuracy of data held about you and to correct any errors. Your details would be held on the register until such a time that you ask for them to be removed, or we may remove them if we have made reasonable attempts to contact you but have been unable to reach you.

## **11. What if I don't want to carry on being involved with the research register?**

You can withdraw from the register at any point and do not have to give a reason. This will have no impact on the usual care or treatment you receive.

## **12. What if there is a problem?**

It is very unlikely that something will go wrong. However, if you are harmed during your involvement and this is due to someone's negligence, you may have grounds for a legal action for compensation against Imperial College London, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate). If you have a concern about any aspect of the research register, please do not hesitate to call the CHARIOT team on **0207 594 8886** who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Imperial College London.

**13. Will anybody else be informed of my involvement in the register?**

No one else will be informed.

**14. Who is organising and funding the register? Has it been reviewed independently?**

The School of Public Health, Imperial College London, will organise and manage the research register. Some of the costs of this register have been secured through various commercial grants from Pharmaceuticals who support the development of such registers internationally. This research register was given a favourable ethical opinion by the East Midlands - Derby Research Ethics Committee, REC Reference 16/EM/0213.

**15. Can I speak to someone if I still have any questions?**

If you have any further questions please give us a call on **0207 594 8886** or send an email to: [dementia.prevention@imperial.ac.uk](mailto:dementia.prevention@imperial.ac.uk) we are happy to answer any questions you have.

**16. I haven't received a pre-paid envelope?**

Firstly, please accept our apologies. You can return your consent form to this address without having to attach a stamp:

*Business Reply Plus RTTK-KHSZ-HLBH  
CHARIOT Registry – NEA Research Unit  
Stadium House  
Imperial College London  
68 Wood Lane  
London  
W12 7RH.*

***If you choose to take part in this research register we ask that you sign and return the enclosed consent form. Upon receipt, we will counter-sign it and keep the original copy for our records.***

***Thank you for considering your involvement in this research register and for taking the time to read this information sheet.***

**PLEASE RETURN THIS PAGE IN THE PRE-PAID ENVELOPE, OR TO (NO STAMP REQUIRED):**

*Business Reply Plus RTTK-KHSZ-HLBH, CHARIOT Registry – NEA Research Unit, Stadium House, Imperial College London, 68 Wood Lane, London, W12 7RH.*



## Participant Consent Form

**CHARIOT: Cognitive Health in Ageing Register: Investigational, Observational and Trial studies in dementia research**

**Thank you for your interest in the CHARIOT Register. If you are satisfied that you fully understand all the information provided and you would like to join the register, please print your name, sign and date the form below.**

We also ask you to complete your contact details on the back – this will allow us to contact you more quickly.

1. I confirm that I have read and understood this information sheet (dated 7<sup>th</sup> February version 5) for the above register and have had the opportunity to ask questions and have had these answered satisfactorily. (As a reminder, you can contact CHARIOT Register Study Team on 0207 594 8886 or email [dementia.prevention@imperial.ac.uk](mailto:dementia.prevention@imperial.ac.uk) with any questions you have about the register.)
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected.
3. I understand that my name, address, landline contact number, mobile phone number, email address, date of birth, gender, ethnicity and NHS number will be recorded on this register and may be looked at by study leads or those to whom they have delegated the right under strict rules, or regulatory authorities, where it is relevant to my taking part in this research register. I give permission for these individuals to have access to these details and to update them.

I agree to take part in this register.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

PRINT  
NAME: \_\_\_\_\_

Date of birth: \_\_\_\_\_

**Please turn over and complete your details on the other side of this form**

**OFFICE USE ONLY** Name of researcher: \_\_\_\_\_

Signature: _____	Date: _____
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## Information about you

Please tick your title:

Mr                       Mrs                       Ms                       Other: \_\_\_\_\_

Forenames: \_\_\_\_\_

Surname: \_\_\_\_\_

Full Address: \_\_\_\_\_

\_\_\_\_\_ Post code: \_\_\_\_\_

Email address: \_\_\_\_\_

Telephone number: \_\_\_\_\_ Mobile number: \_\_\_\_\_

Please tick your preferred method of contact for written correspondence:

Email                       Mail

Date of birth: \_\_\_\_\_

How did you hear about the CHARIOT register? \_\_\_\_\_