



MRC
Prion
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Research Database Name:

Database of UK patients with iatrogenic cerebral amyloid angiopathy (iCAA)



What is cerebral amyloid angiopathy?

Cerebral amyloid angiopathy occurs when a protein, called amyloid-beta protein, builds up in the blood vessels of the brain and covering tissues (the meninges). Cerebral amyloid angiopathy can cause strokes due to bleeding in the brain (“intracerebral haemorrhage”). It can also be associated with memory problems, and also occurs in the brains of people with Alzheimer’s disease. Cerebral amyloid angiopathy is usually seen as a consequence of ageing, and, rarely, it can be inherited (passed through a family).

What is iatrogenic cerebral amyloid angiopathy (iCAA)?

Iatrogenic cerebral amyloid angiopathy (iCAA) is a rare and newly described form of cerebral amyloid angiopathy. “Iatrogenic” means relating to, or caused by, medical procedures or treatments. People with iCAA are younger than people with age-related cerebral amyloid angiopathy, and nearly all of them had previous medical or surgical procedures (often three or four decades before they developed the condition). We believe that the amyloid-beta protein which causes iCAA was transferred during these earlier procedures, causing iCAA to develop three or four decades later.

Why are we contacting you?

We are contacting you because we understand that you might have iatrogenic cerebral amyloid angiopathy (iCAA). We would like to ask permission to include your details in a new research database of people with iCAA.

If you believe that we have contacted you in error, please let us know using the email address or phone number at the end of this information sheet.

Who are we and what do we do?

The MRC (Medical Research Council) Prion Unit at UCL (University College London) is a research unit which studies diseases caused by misshapen proteins. The human body contains many proteins, each of which has a different role in the body. Each protein has a unique shape, which allows it to perform its function. When these shapes go wrong, this can cause proteins to build up where they shouldn’t, causing disease. The best known of these is Creutzfeldt-Jakob Disease (CJD), but there is new evidence that misshapen proteins are important for other diseases, including those caused by the amyloid-beta protein (cerebral amyloid angiopathy and Alzheimer’s disease).



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On rare occasions, diseases caused by misshapen proteins can be passed between people via medical or surgical procedures. Our Unit has previously been involved in work on this form of disease transmission, and has experience of informing people of their risk of developing diseases in this way. Our Unit also provides clinical help and advice to people who have developed or are at risk of developing these conditions, including that relating to clinical care and access to appropriate organisations for additional support. We also work closely with the UCL Stroke Research Centre, which has extensive expertise in the diagnosis and treatment of brain haemorrhages (bleeding), including those related to iCAA.

What will this new research database be used for?

We are interested in finding out more about iCAA, and plan is to use this database to contact people with iCAA about future research studies that might be of interest to you. Being part of the database does not commit you to taking part in any future studies.

What will I have to do if I wish to take part and give consent?

If you are happy to give your permission to include your details in this new research database, please complete, sign, date and return the attached consent form using the pre-paid addressed envelope or by email to uclh.iatrogeniccaa@nhs.net. You do not need to do anything else.

What if I do not want to give consent?

If you choose not to consent to your personal data being included in our research database, your usual clinical care will not be affected in any way. Additionally, if you consent but later change your mind, you can ask for your information to be removed from this database at any time. Again, this will have no impact on any NHS care you receive now or in the future.

What are the potential benefits and risks of being involved?

Being included in this database will not have any specific benefits or risks for you. However, should we identify any relevant management or treatment strategies that might be beneficial for your health, we would be able to share these with you.

Who will have access to my personal data?

Your personal data will only be accessible to a limited number of authorised research staff at the MRC Prion Unit at UCL and the UCL Stroke Research Centre, all of whom have training on how to confidentially handle personal data. Dr Banerjee, the Chief Investigator for the research database, and Professor Collinge, the Institute Director,



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will be responsible for granting or rejecting access. Relevant data collected in the creation of this database and its subsequent use for research may be looked at by individuals from regulatory authorities, or from any NHS Trusts involved in your care, for example to check that your personal data is being managed correctly and that any relevant research is being conducted properly. However, access can only be provided if you give permission.

How will my information be kept confidential?

All personal identifiable information (like your name, address, and date of birth) and medical information that can identify you will be held securely in an encrypted online depository (the UCL Data Safe Haven) to prevent external unauthorised access. This will be kept separately from information which will be used for research purposes. Information which will be used for research analysis will not contain any identifiable details, so nobody using this data for research purposes will be able to identify you from the information they have access to. Any non-electronic (physical) completed consent forms will be kept securely in locked cabinets within a locked room; the room is accessible to authorised research staff at the MRC Prion Unit at UCL only. Electronic consent forms will be stored securely in an encrypted online depository (the UCL Data Safe Haven). The creation and ongoing management of this research database will be carried out in accordance with the requirements of UK Data Protection legislation and the General Data Protection Regulation, and UCL policies and procedures covering data and information protection and security.

The Health Research Authority has issued supplementary information about how researchers use information from patients, which can be found here:

https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/My_data_and_research.pdf.

If you would like a paper copy of this document, please contact Dr Banerjee or her research team.

What will you do with my information?

If you agree, we might use your information to contact you directly to ask if you are interested in future research studies which might be of relevance to you, and to update you on any new research that might have implications for your health.

What will happen to my personal data?

Once the project using the research database is completed, your personal data will be securely destroyed. We anticipate the projects using this database will be completed in four years. If we do need to hold your data for longer than this, we will contact you again to ask for your permission to do this.



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Who is organising and funding this research database?

This research database is being organised by Dr Gargi Banerjee, University College London (UCL). It is funded by the Stroke Association UK and Alzheimer's Research UK.

Who has reviewed this research database?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research database has been reviewed and given a favorable opinion by South West - Central Bristol Research Ethics Committee (REC reference 21/SW/0052).

Where can I find out more about this research database?

You can find out more about this research database here:

<https://www.ucl.ac.uk/national-prion-clinic/iatrogenic-cerebral-amyloid-angiopathy-cao>

Further information on how UCL processes and stores personal data can be found in the attached Privacy Notice.

Thank you for taking the time to read this information sheet.

If you have any questions please feel free to contact the Research Team:

020 7679 5142

uclh.iatrogenicca@nhs.net