

cromis-2

Clinical Relevance Of Microbleeds In Stroke

PARTICIPANT NEWSLETTER 2016

Welcome to our participant's newsletter. We aim to update patients and their relatives, friends and carers on the progress of the CROMIS-2 study.

Study Recruitment

We recruited over 2700 participants from 80 hospitals from August 2011 to July 2015. Originally we were going to recruit participants for 3 years, but we extended this with the help of our funders for another year due to the success of the study. By recruiting more participants, we will be better able to answer our research questions.

Follow up

If you were recruited to Study I (AF), after your discharge from the hospital, you will or have been followed up with a short postal questionnaire at 6 months, 12 months and finally at 24 months. If you were recruited to Study I (ICH), we followed all patients up at 6 months by postal questionnaire.



Our postal questionnaires ask you a few straightforward questions about your health, assess your current level of independence and quality of life. If you prefer, a Research Practitioner can telephone you and complete this information over the phone together.

We also ask your GP and/or your anticoagulant clinic for this information and to ask them to inform us of any changes in your health status.

If you have changed your home address, or GP, please do contact Clare Shakeshaft, our Study Co-ordinator, by phone on 020 3108 7495 or email c.shakeshaft@ucl.ac.uk to update your details with us.

Thank you!

Your confidential information

We have registered your inclusion in the study with NHS Digital to provide ongoing information on your health status to the study team and to keep in touch with you.

We would like to clarify our statements about the sharing and processing of your confidential information provided in the consent material for CROMIS-2 and the role of NHS Digital.

We provided your identifiable data (name, address, date of birth and NHS number) to NHS Digital. NHS Digital are able to provide us with information about people who may have passed away in order that we do

not make contact and cause any distress to relatives. This information includes date and cause of death information supplied by NHS Digital on behalf of the Office for National Statistics and is sourced from civil registration data.

In addition, NHS Digital has a record of all hospital admissions and outcomes data from the Hospital Episode Statistics (HES) dataset and will link this information to individual participants in the study.

The NHS Digital then provides the study with your date of birth, sex, postcode, and NHS number together with your study identifier and cause and date of death.

How long will we store your data for?

The CROMIS-2 study will store your data for the duration of the study, and then archive your data for a further five years in accordance with University College London data storage guidelines.

Your participation in the study is entirely voluntary. It is up to you to decide whether or not to take part. Even though you decided to take part when you were in hospital, you are still free to stop taking part at any time and without giving a reason. This will not affect the standard of care you receive.



Thank you to everyone who has contributed to the study so far!

Your input is vital to its success.

From all at the CROMIS-2 Stroke Research Team

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