2017-2018 has been a busy and exciting time for the SABRE study team. In May 2017 we moved into our new office and clinical space in UCL’s Roger Williams Building called the Bloomsbury Center for Clinical Phenotyping. Nearly 1,000 SABRE study participants have undertaken measurements as part of the third wave of follow-up; you have provided us with nearly 1100 sets of questionnaires about your health and lifestyles; 410 new participants have joined in the study during the SABRE V3 visit; 801 participants, who were originally seen between 1988-1991, are still participating. This response is fantastic. We thank you for your dedication to the SABRE study.

We’ve moved!

2017-2018 has been a busy and exciting time for the SABRE study team. In May 2017 we moved into our new office and clinical space in UCL’s Roger Williams Building called the Bloomsbury Center for Clinical Phenotyping.

But first, if you haven’t yet been able to attend a clinic day in the 2014-2018 (visit 3) wave, and you would like to, there is still time to come to our new facility and participate.

SABRE visit 3

2014-2018 Study Progress

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- You have provided us with nearly 1100 sets of questionnaires about your health and lifestyles;
- 410 new participants have joined in the study during the SABRE V3 visit;
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Cognitive function, electrocardiogram (ECG) assessment and image of the heart.
‘Mini’ health check

Until mid-December 2018 we invite you to come in for a ‘mini’, but detailed health check, which will last about 2½ hours and will help us to boost the number of people in the study.

If you live in the Greater London area and you haven’t already attended a clinic day in the 2014-2018 (visit 3) wave you are eligible for the mini-clinic.

We are able to provide taxi transport to and from the clinic, some light refreshments and, as gratitude for you participation, we will offer you a £30 M&S voucher on the day.

None of the clinical tests we carry out are invasive. The mini-clinic includes:

- Ultrasound (echocardiography) of the heart and an ECG
- Tests to assess the health of your blood vessels
- Blood pressure measurements
- Body size and weight measurements
- Tests of memory and problem solving
- Blood and urine tests
- Strength and muscle-function tests

None of the clinical tests we carry out are invasive.

How else can you participate?

New Dizziness Study

Dizziness affects up to 3 in 10 people over the age of 65, and in many people routine tests do not find a cause.

We suspect that age-related wear and tear of small blood vessels within the brain is the cause of unexplained dizziness.

Doctors from Imperial College London have asked us to help in their research by sending questionnaires to find out about experiences of different types of dizziness in people who have had brain MRIs as part of SABRE at visit 3 (2014-2018). They will use the questionnaire responses and data from the brain MRI scans to better understand if unexplained dizziness is related to this wear and tear.

Do please look out for the short questionnaire which we will send to most people who had a brain MRI scan as part of SABRE during the past 4 years. We would be most grateful for your help with this. We will not reveal your name or any other personal details to the Imperial College team (unless you choose to do so yourself).

The more we understand about what causes these problems, the more likely we are to be able to work out how to prevent or to treat them in people of all ethnicities.

Scientific research from the SABRE study

What’s going on behind the scenes with your information?

Quick reminder: The SABRE study started back in the late 1980s in the London boroughs of Brent and Southall with the aims of understanding why some people are more likely than others to suffer from diabetes, coronary heart disease and strokes. At that time very little was known about whether people of different ethnicities might be more or less likely to suffer these disorders.

We now know, partly as a result of the first SABRE study, that there are large differences in the risk of coronary heart disease and strokes between different ethnic groups in the UK, as well as differences in risk factors such as diabetes, blood pressure and levels of ‘good’ and ‘bad’ blood fats. But we still don’t know why these ethnic differences happen. Now, at the 25 year follow-up we are measuring changes in the health of the heart and circulation, with a special focus on the health of the blood vessels of the brain, as well as early signs of diabetes. We also want to look at physical function and how well (or otherwise) people are keeping as they get older.

The more we understand about what causes these problems, the more likely we are to be able to work out how to prevent or to treat them in people of all ethnicities.
We have welcomed Jingyi Wang and Vicky Garfield to the research team as post-doctoral research fellows.

Jingyi is working on understanding the link between depression and function of the heart and circulation.

Vicky is working currently on cognitive function and its associations with type 2 diabetes and markers of glucose control. She is also looking at the associations between sleep quality (from your questionnaires) and risk of cardiovascular disease.

Lorna Smith is close to completing her PhD using information from brain MRI images.

Siana Jones has recently completed her PhD. She has been using the results of the stepper test which you might have undertaken in clinic.

Congratulations to Sophie Eastwood on the birth of Nina and to Chloe Park on the birth of Effie. Chloe is just back from maternity leave and is continuing her work on the structure and function of the heart using data from SABRE as well as from other cohorts such as the 1946 group.

Sophie has also recently returned to resume her fellowship funded by Diabetes UK, studying ethnic differences in prescribing and the effectiveness of anti-diabetes medications, anti-hypertensives and statins using data from electronic databases and from UK Biobank.
We welcome Lamia Al-Saikhan, who is studying for her PhD in heart physiology – some of her work will involve new analyses of echocardiograms taken at SABRE visit 2.

Brian Wong has also joined us and is studying for a PhD using epidemiological data collected in the SABRE and NSHD studies. Brian is interested in the health of blood vessels and how the changes that happen to blood vessels in the brain effect cognitive function.

We also welcome Shikta Das, a post-doctoral statistician. At present she is analysing some of the very detailed information regarding metabolites (‘metabolomics’) in blood samples collected at SABRE visit 1 to see how these relate to insulin resistance (a precursor of type 2 diabetes).

Alicja Rapala has taken on the role of research manager and co-ordinator for SABRE.

Latest Publications

Dr Annebet Leeuwis has published a paper in Frontiers in Aging Neuroscience: ‘Cerebral Blood Flow and Cognitive Functioning in a Community-Based, Multi-Ethnic Cohort: The SABRE Study’ – the main finding was that decreases in blood flow in the brain are associated with lower cognitive functioning. This agrees with other studies that showed older individuals with dementia have low brain blood flow.

Dr Carole Sudre has published a paper in the Journal of the American Heart Association entitled: ‘Cardiovascular risk factors and white matter hyperintensities: Difference in Susceptibility in South Asians compared to Europeans.’ White matter hyperintensities seen on MRI of the brain are indicators of damage to the brain’s small blood vessels. The main finding of this paper was that the amount of lesions increases with age and this rate of increase is greater in South Asians. Also, South Asians with diabetes had more white matter lesions than Europeans who had diabetes implying that this group may be more vulnerable to disease of the small vessels in the brain.

Do get in touch if you have any questions about the SABRE study. We also have a website www.sabrestudy.org
Email: sabre@ucl.ac.uk Telephone: 020 7679 9471
Address: SABRE Study, UCL Institute of Cardiovascular Science, Gower Street, London WC1E 6BT
Recently, members of the SABRE team and one of our participants helped to make a Youtube video on understanding patient data – it lasts just a few minutes and you can view it here: youtu.be/5Lcf6Kj4rQI

Nish Chaturvedi, who leads the SABRE study, also now leads the MRC Unit for Lifelong Health and Ageing at UCL (www.nshd.mrc.ac.uk/news-events/recent-news/mrc-lha-ucl-welcomes-new-director). This research programme includes another cohort study – the 1946 birth cohort. We are pleased to be involved in a new neuroscience follow-up of that study called ‘Insight 46’. Many of the participants of the 1946 birth cohort (National Survey of Health and Development, NSHD) have been followed up more than 20 times since they were born—another example of an amazing cohort of people, like you, who have contributed much to science over a long period of time. The NSHD and SABRE study teams work closely together and there are many opportunities for collaboration and sharing of ideas.

We were very sad to say goodbye to Innocent, Livia and Katherine this year, as the visit 3 clinics near completion. We thank them for their great contributions to SABRE and wish them very well in their new roles.

Photo showing (from left to right) Tara, April, Alicja, Anish, Lorna, Siana, Hannah, Alun, Nish, Brian, Tom, Therese, Vicky, Daniel, Katherine – all have been or currently are part of the SABRE team.
We plan to present some of the results of our work to you and to your GPs and would be interested to hear your ideas as to how we should do this. For example, would you like to hear in a newsletter and/or on the website and/or would you like to come to a meeting? Do you have some other ideas?

Do get in touch if you have any questions about the SABRE study.

We also have a website www.sabrestudy.org

Email: sabre@ucl.ac.uk

Telephone: 020 7679 9471

Address: SABRE Study, UCL Institute of Cardiovascular Science, Gower Street, London WC1E 6BT

And lastly – once again we would like to extend our heartfelt thanks to all of you for your time and help – none of our work would be possible without you.
Transparency statement: Information about how we use your data in the SABRE Study and what we must tell you under the new General Data Protection Regulation (GDPR) which came into force on 25th May 2018.

University College London (UCL) is the sponsor for this study based in the United Kingdom. We will be using information from you and/or your medical records in order to undertake this study and UCL will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Participants may withdraw from the study and, if you do so, you may decide to allow us to keep information which we already hold about you or you may ask us to remove identifiable data or samples held for long-term storage. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The SABRE Study will keep your name, NHS number and contact details confidential and will not pass this information to UCL. The SABRE Study will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UCL and regulatory organisations may look at your medical and research records to check the accuracy of the research study. UCL will only receive information without any identifiable information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

The SABRE Study at UCL will keep identifiable information about you from this study for 25 years after the study has finished.

Use of your data in future research

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this or other organisations. They may be universities, NHS institutions or companies involved in health and care research in this country or abroad. Your information will only be used to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. It will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

You can find out more about how we use your information in the SABRE study below.

Do get in touch if you have any questions about the SABRE study. We also have a website www.sabrestudy.org
Email: sabre@ucl.ac.uk
Telephone: 020 7679 9471
Address: SABRE Study, UCL Institute of Cardiovascular Science, Gower Street, London WC1E 6BT
Some frequently asked questions and answers about SABRE and how we use your data

Q. Who is the data controller for the study?
This is UCL, which acts as the study’s sponsor. The data controller can be contacted by emailing data-protection@ucl.ac.uk. You can also visit www.ucl.ac.uk/legal-services/privacy for more information.

Q. What is the legal basis for data processing?
The legal basis is processing for public task (this means in the public interest) and the purpose of processing is research. See also https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-be-informed/and www.ucl.ac.uk/legal-services/privacy for more information.

Q. What sort of personal information do you collect and/or process about study participants?
Firstly, we collect your contact details so that we may get in touch with you about the study (name, address, telephone number, email address and NHS number if you have chosen to give these to us).

If you have attended our study clinics then you will know that we record many measurements about your health and wellbeing. We collect information that you give us when you complete our health and lifestyle questionnaires. We also access information provided by NHS Digital regarding your hospital usage (if you have not opted out of this aspect of the study) – more about this in the next question and answer:

Q. The information leaflets says ‘We would like to access information from your medical and health-related records’. What does this mean, why do you need this information, where do you get it from and what do you do with it?
We would like to receive details about your hospital usage. The organisation providing this information is now called ‘NHS Digital’, but it used to be called the ‘Health and Social Care Information Centre’ (HSCIC). The information we will obtain, for people who take part in SABRE, relates to hospitalisations for any reason and includes the number of hospital visits or admissions, reason for admissions, length of stays and treatments received. NHS Digital will also provide us with information about study participants who develop cancer or who may have passed away since the start of our study, including dates, type of cancer or cause of death. The data we obtain will be stored securely at UCL, and used only for the purposes of the study by researchers here.

We can access all of this by securely sharing some of your personal details, specifically your name, sex, date of birth, address and NHS number (if we know this) with NHS Digital who then provide us with the information described above. Importantly, no other information that might identify participants will be shared with the SABRE team and no identifiable patient data will be used in any publication or presentation. If you would like to discuss this or have any questions, please contact us.

If you prefer us not to access your information in this way, please let us know either by e-mail, letter or telephone using the contact details on this newsletter. We will not share your information if you have already opted out of this aspect of the study.

We use the information to help us understand how many people have developed certain types of disorders during the course of the study, for example heart attacks, strokes or cancer. We can analyse the measurements that we have made in our clinics and the information that you have given us when you fill in our questionnaires to see which measurements or lifestyle factors are associated with the hospital events – this is part of the research and may help towards understanding not only the causes of certain types of ill-health in different groups of people, but also why some people enjoy good health into older age.

When we receive linked data, we remove all identifiers except for year of birth, year of death and your 5 or 6 digit study ID number. All subsequent analyses use only subsets of the de-identified data. The data will be held only at the Institute of Cardiovascular Science at UCL. No data is released or shared in any form that would enable individual participants to be identified.

Q. What can I do if I have any concerns about the data held about me by the SABRE Study?
You can contact the data controller or data protection officer at UCL on data-protection@ucl.ac.uk or you can contact the Information Commissioner’s Office (ICO) and you may lodge a complaint with the ICO https://ico.org.uk/make-a-complaint/. In addition, you can always contact the SABRE study team (details below).