CCACE Notes
Celebrating Participatory Research
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Scotland and the broader UK have a proud tradition of participatory research, which has brought about many significant advances in physical and mental healthcare.

Here at CCACE, participatory research runs to the very core of what we do. Thanks to our generous participants, we have access to highly detailed records about the health and lives of many thousands of people. As researchers we have a responsibility not to forget the exceptional acts of kindness that our participants have undertaken, and the selflessness that they have shown in sharing their information for the benefit of people they will never meet.

To show our appreciation, we are hosting a large celebratory event in the grand surroundings of the Assembly Hall, Edinburgh. At this event, hundreds of members of research cohorts from across Scotland will be invited to hear first-hand about the results and health advances that their participation has made possible.

However, participatory research is about engaging with people as equals, so, we will also be taking time to listen to our guests, to share experiences and stories and to give them an opportunity to make contributions to our ongoing research process.

But most of all, we want to say a big thank you to each and every cohort member. Together we are part of something much bigger than any one of us says Professor Andrew McIntosh, Director of CCACE

What is participatory research?

‘An approach to knowledge discovery in which participants, researchers and funders work collaboratively and reflectively to prioritise and deliver better understanding about health and disease.’
The magic of cohorts

Cohort studies are almost magical in what they offer scientists declares Professor David Batty

‘They are a fantastic resource that allows us to “follow” the same people over many years (sometimes a lifetime), gaining insights into their health and well-being.’

‘As a public health researcher, I am interested in diseases that commonly occur in society, such as cancer, cardiovascular disease and mental health problems such as depression,’ says Professor Batty. ‘By following large groups of people I investigate why some people develop these diseases, while others do not.’

But it is a difficult puzzle to solve: some of the reasons for these differences are environmental (e.g. how much people drink or smoke, how heavy they are) and others are genetic. It is only by studying a large number of people that we can hope to gain insights into these complex interactions – which is why cohort studies are so important.

One example is the Scottish Health Survey which has been conducted repeatedly over a number of years in Scotland in order to monitor the nation’s health. Crucially, because of the excellent infrastructure in Scotland, with their permission, we were able to link people who participated in these studies with records for hospitalisation and death. This enabled us to examine the future health consequences of depression and anxiety – known as psychological distress. By adding data from the Health Survey for England to this project we had high numbers (160,000 men and women). We found that even in people with lower levels of distress there were higher rates of later heart attacks, accidents, and specific cancers. Further research is required to investigate whether treating psychological distress could lower the risk of these diseases.

Yet, these important results and many others like them would not be possible without each and every cohort member: ‘I genuinely cannot thank study participants enough for their generosity and altruism in taking part in our studies. Simply put: without them, these studies would not exist. Our study members have made a considerable contribution to society by helping us understand disease prevention and treatment. It makes me misty-eyed.’


The LBC studies were set up to understand why some people age better than others, especially regarding thinking skills and brain health.

‘Every 3 years our participants come to a research clinic and take over a dozen cognitive tests, undergo lots of mental health checks, fill in many questionnaires, take a brain scan, provide blood samples and much more.’

‘From these data, over 400 scientific reports have been written, including publications in the world’s top scientific journals, Nature and Science.’

The researchers have been careful to keep their members informed. ‘From the start, we’ve held regular reunions, and I’ve made sure that the participants see their basic results before we report them. Of course, they are also happy occasions, at which to have a good blether and swap the pleasures and pains of growing older,’ says Professor Deary.

Participatory research is also about listening: ‘The suggestion to build an LBC Brain Tissue Bank came from a participant during a reunion meeting,’ reports Professor Deary. ‘Since then, many of our LBC members have agreed to have samples of their brain tissue collected and analysed after they die.’

All of this together has made the LBC world-famous.

‘I would love each participant to see the scientists who come across the LBC, their data, and their results for the first time. The combination of admiration and flabbergast on their faces would puff their chests with pride, and quite rightly,’ asserts Professor Deary.

With success comes responsibility. ‘The LBC studies have never had funding that was guaranteed for more than a few years at a time. Like the directors of other cohorts, one wakes up in the morning knowing that this valuable scientific show must be kept on the road,’ asserts Professor Deary. ‘I acutely feel the responsibility I have to the LBC participants and their families, as well as to my staff and collaborators. I also have a duty to society to make the most of these valuable data.’

Since our research started almost 20 years ago, a great esprit de corps has developed, such that our members think of it as their study and not just the researchers’ study.

Whose study is it anyway?

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Why don’t you ask?

What happens when you ask patients for their opinions on your research methods? ‘You get answers you didn’t expect!’ says Professor Stephen Lawrie

‘Before we started our most recent study, we interviewed patients with schizophrenia and asked them for their opinions on our plans. We found (much to our surprise), that patients much preferred brain scans to pen and paper cognition [thinking skills] tests.’

‘[She] wouldn’t have been able to co-operate in [thinking skills] tests like that at all. She wouldn’t have had the staying power or the co-ordination to do anything because of the other drugs she had been taking.’ (Carer.)

Professor Lawrie and his team believe that by splitting people into sub-groups (based on their mental and physical test results), they may be able to prescribe treatments that are more closely tailored to the individual’s bodily needs. This is referred to as ‘stratified medicine’.

‘Approximately 20–30% of people with a diagnosis of schizophrenia receive little to no benefit from current medications,’ says Professor Lawrie. ‘Furthermore, they often undergo a lengthy period of trial and error prescribing.’ Stratified medicine could potentially end that guessing game.

‘It sounds sensible because the previous system is a bit like going to the opticians and [them] handing you a box of glasses and saying, “Try them and come back in a week and see if you can see anything,” so I think it’s wonderful.’ (Carer.)

Despite an overall positive attitude towards stratified medicine, the participants did raise some very practical concerns. Many of these matched the researchers’ conclusions (lengthy or invasive procedures and confined spaces). However, others came from a more personal angle, such as the adverse effect on self-esteem of a poor performance in a mental test.

‘I could see that … when she was very big, [she] would’ve felt uncomfortable going in there [the scanner] and if she’d not fitted, it would’ve been something else that would’ve not been good for her, to have not fitted in the tube.’ (Carer.)

Yet, despite these genuine concerns, most participants would still choose to take part in clinical research.

‘Despite the inconvenience […] I would take part, coz I would see it as something—I’d obviously not benefit from it now—it would help other people in the future.’ (Service user.)

But this dream of stratified medicine will only become a reality if researchers and service users continue to work together to design practical, high-quality research studies.

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Schizophrenia is a mental health condition that encompasses a wide range of psychotic symptoms, including hallucinations (mainly hearing things that others don’t) and delusions (mistaken beliefs). These symptoms are often accompanied by more general symptoms, such as a lack of energy or enthusiasm.
'For many years I have been creating “virtual cohorts” to study chronic diseases like kidney disease,’ says Professor Black. ‘I will never meet these people, yet I have much to thank them for.’

Virtual cohorts are based on routine medical data from general practitioner (GP) and hospital appointments, which are anonymised and coded (e.g. 1 = bowel cancer, 2 = breast cancer) before being released to researchers for analysis. All data are held within a secure facility to protect it carefully, and all potential research studies are examined by an ethics board before they can proceed.

However, it is not an either/or situation. Virtual and traditional cohorts can work hand-in-hand.

‘Recently, we have been working to gain access to the electronic health records of the Aberdeen Children of the 1950s,’ says Professor Black. ‘Every piece of information, every sample and every image are vital.’

Research results from virtual cohorts

Cancer

Using data from a local cancer database, a virtual cohort of cancer cases in Grampian, Orkney and the Shetland Isles was created. This information was combined with several other national databases (e.g. postcode and death registry data) to see how travel times affected cancer survival rates.

Professor Black and her colleagues found that patients who had to travel farther (across the mainland or from the islands) were actually treated more quickly than those who lived closer to their cancer treatment centre. However, they still had a survival disadvantage compared to those living nearer to their treatment centre. Cancer services in rural areas may therefore need to be adjusted.

Kidney disease

Professor Black’s team have also created virtual cohorts to study diseases such as kidney disease.

To do this, they created the first UK virtual kidney function laboratory cohort from routine laboratory data and linked this to hospital data to study outcomes. Using the data, they were able to show that a diagnosis of acute kidney injury (AKI) had ongoing health implications for as long as 10 years after the event.

As AKI occurs in 1 in 7 of hospital admissions, they recommend careful long-term follow-up even when kidney function tests have returned to the normal range.


From the beginning

How does being ‘born too soon’ or ‘too small’ affect your health in later life?

This is what Professor James Boardman and his team at Theirworld Edinburgh Birth Cohort would like to find out.

“We are trying to identify the key factors (which may be medical, educational or family circumstances) that can affect a child’s growing brain. Our aim is to discover new ways of protecting the brain after pre-term birth, so that children can grow to reach their full potential, despite early life adversity.”

Professor Boardman’s team have begun to follow hundreds of babies who were born pre-term, and are collecting information about their health, wellbeing and development in unprecedented detail.

“So far over 100 families have agreed to take part, and some are returning to visit us with their 9-month-olds and 5-year-olds,” says Professor Boardman.

The team aim to recruit 400 mothers and infants (300 pre-term babies and 100 full-term babies) and follow them as they grow, tracking their health and development and collecting biological samples and brain scans.

“We are so grateful to our participants who share their information and time to help develop knowledge that will shape improvement for others.”

Read more about the project at www.tebc.ed.ac.uk

A recording of Professor Boardman’s talk, ‘Born too soon: Consequences for brain development’, can be found on the CCACE YouTube channel, ccacevideo.
Thank you, 24,000 times!

To the 24,000 people who have signed up for our study, thank you

says Professor David Porteous of Generation Scotland

'Thank you for the time you have given us and the trust you have placed in us to keep your data safe and secure and to use it well for research. With your help, we have made important advances in understanding how genes, lifestyle and health interact.'

'Thank you to the family members who were recruited alongside you. This family connection is unique to Generation Scotland and allows researchers to study how genes and medical conditions are inherited.'

'A huge thank you for granting us access to your NHS data. This means that extra information becomes available each time a cohort member visits the doctor, is prescribed medication or receives a diagnosis (cancer, diabetes, etc.). Our database will therefore become more detailed (and more useful to researchers) over time.'

'And, finally, thank you for the permission to contact you again. This means additional surveys and follow-up tests can be done, if you agree.'

'For example, researchers may soon ask members for permission to access their “blood spot” (Guthrie card)—a heel prick blood test that is routinely done at birth. This could reveal clues about how pregnancy and the very earliest stages of life influence long-term physical and mental health.'

And if people are thinking of signing up for SHARE or a similar stand-alone research study

Give it careful thought. Read the patient information leaflet. Ask the study team any remaining questions. If you are happy and reassured, sign up! Your participation will be valuable and appreciated,' affirms Professor Porteous.

Generation Scotland

Over 30,000 people from across Scotland are part of Generation Scotland—a vast database of medical histories, blood test results, DNA data and much more.

Generation Scotland has 3 sections:

- The Scottish Family Health Study: ~24,000 people
- The Donor DNA Databank: ~5000 people.

Researchers have used the data to study a wide range of conditions, including heart disease, diabetes, chronic pain and mental health.

From Laboratory to Patient

Thanks to 140 patients who took part in a clinical trial, we now have proof-of-concept that gene therapy can make a measurable difference to the lung function of patients with cystic fibrosis. Although further studies will be needed, this was a major step forward.
Half of the difference in intelligence between people can be traced to their genes

CCACE researchers found that around 50% of the differences in intelligence between people can be explained by an accumulation of small genetic changes (each one changing just one ‘letter’ in the DNA sequence). Furthermore, they were able to replicate this finding in both related and unrelated individuals who are part of Generation Scotland, the linkage being slightly stronger within members of the same family.

Reference: W. David Hill et al (2018) Genomic analysis of family data reveals additional genetic effects on intelligence and personality. Molecular Psychiatry. Published online: 10 January 2018

A unique aspect of Generation Scotland is that participants sign up to the study alongside at least one other member of their family. This gives researchers the opportunity to compare related and unrelated individuals, which improves the strength of their conclusions.

Humanities and social sciences go beyond disease

Health care is not just about science and the body. It is about ourselves, our culture, our values and our expectations. It is also about the health system – how it is set-up, and the financial and political constraints that it works within.

Humanities and social science research investigates these factors and how they affect our health and wellbeing. Such work has had many positive influences on healthcare for example on the Scottish Government’s stroke guidelines and the response to the Ebola outbreak in west Africa.

The Wellcome Trust – a major medical research funder – puts considerable importance on these subjects (as do many other biomedical funders and organisations). For instance, funding that The Wellcome Trust gave to social science researchers influenced how biobanks were set-up and shaped the rules around how data can be shared and linked.

Furthermore, The Wellcome Trust has just invested £1 million in The Centre for Biomedicine, Self and Society, at the University of Edinburgh. This centre will draw together researchers from many different subject areas to tackle the challenges of health and wellbeing.

The humanities and social sciences not only provide answers to questions those working in biomedicine and health care are already asking, they also help to frame new questions. These demand urgent attention and engagement with scientists and the wider public, in critical, creative and collaborative ways.

Read more about this topic in a commentary by Martyn Pickersgill et al, The social sciences, humanities, and health, The Lancet, Vol 391 April 14, 2018
Knowledge Exchange

CCACE at Edinburgh International Science Festival

‘How old are you really?’

CCACE researchers spent a busy 3 days in April interacting with over 1500 people at National Museums Scotland.

‘Our group is from age 7 to 65, and we were all able to take part here.’ [Visitor]

Visitors tried out some of the physical tests that we use in the Lothian Birth Cohort studies, and explored how the body, brain and DNA can age at different rates.

‘How Old Are You Really? was informative and fun!’ [Visitor]

Using the power of machine learning, visitors taught a computer to tell apart the brain scans from our 20, 40 and 80 year olds (and had fun teaching the ‘machine’ to recognise funny faces!). In another activity, Lego and lollipops became a metaphor for DNA ‘methylation’ [switching genes off].

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