

UCL COHORTS, BIOBANKS & BIG DATA

**Wednesday 22 March 2017
13.15–18.30**



**Research
Domains**

**Populations
& Lifelong
Health**

Programme

13.15-13.45

Registration and networking

13.45-13.55

Welcome and introduction

Professor Michael Arthur,
UCL President and Provost

13.55-15.15

**Past, present and future:
Innovation in cohort studies**

Chair: Professor Aron Hingorani,
Director, UCL Institute of
Cardiovascular Science

Helen Pearson

- *The Life Project: How the British birth cohorts inspired a book*

Professor Alison Park

- *The changing face of cohort studies - from punch cards to PCs*

Professor Nishi Chaturvedi

- *Mind the gap: precision medicine needs precision phenotyping*

Professor Ruth Gilbert

- *Harnessing data about public services*

Professor Caroline Sabin

- *Tapping into the potential of clinic and surveillance databases for HIV research*

15.15-15.40

Networking break

15.40-16.40

'Question Time': Making the case for cohorts, biobanks and big data

Chair: Professor David Lomas,
UCL Vice-Provost (Health)

Professor Alissa Goodman

- *Cohorts*

Professor Sir Rory Collins FRS

- *Biobanks*

Professor Harry Hemingway

- *Big data*

Panel and participant discussion

16.40-17.10

Opportunities and challenges for investment in cohorts, biobanks and big data

Chair: Professor Graham J Hart,
Dean, UCL Faculty of Population
Health Sciences

Dr Joe McNamara

- *Medical Research Council (MRC)*

Rebecca Fairbairn

- *Economic and Social Research Council (ESRC)*

Professor Jeremy Pearson

- *British Heart Foundation*

Dr Erica Pufall

- *Wellcome Trust*

Panel and participant discussion

17.10-17.30

Closing remarks

Professor Dame Anne Johnson,
Chair, UCL Populations & Lifelong
Health Domain

17.30-18.30

Networking drinks reception

Introduction



More than 2.2 million people in the UK are currently participants in population-based cohort studies, and 15 of these cohorts are hosted by or have links to the UCL Faculty of Population Health Sciences and the UCL Institute of Education. This includes the oldest and the newest British birth cohort studies, and the largest tri-ethnic cohort in the UK.

UCL also curates or otherwise takes a leadership role in 24 intensively characterised clinical or electronic health record cohorts (with over 1000 patients/ participants), focused on infectious diseases (particularly HIV and TB), obesity, cardiovascular disease, ovarian cancer, and the health of premature infants. These cohort studies benefit from our expertise in basic bioscience, clinical science, and epidemiology – all the way through to applied public health and policy-related research.

In recognition of an exceptional concentration of investigator-led population and clinical cohort studies and expertise in health informatics research at UCL, together with national pre-eminence in these areas, UCL Faculty of Population Health Sciences has made cohort-based research a central component of its academic strategy.

But the high cost of cohort research in

comparison with other areas of biomedical endeavour means there is a continuing need to justify funder support for such studies. This is particularly so in an era of investments in large national initiatives such as UK Biobank and the Farr Institute which, though perceived as competing, may actually be complementary.

The opportunity of today's meeting is to provide a showcase for cohort studies at UCL, but also to surface a range of issues regarding the future scientific value of these longitudinal studies in an era of biobanks and big data. We are fortunate to have a range of experts, including representatives of funding agencies, to speak to these issues.

May I extend a warm personal welcome to UCL academic and research staff to this symposium, and to our guest speakers who have very generously given their time to join us today in what I know will be an exciting and rewarding meeting.

Professor Graham J Hart
Dean, UCL Faculty of Population Health Sciences

Event Steering Committee

Professor Graham J Hart

Professor Aroon Hingorani

Professor Dame Anne Johnson

Professor Alison Park

Sarah Welsher (Strategic Coordination)

Jessica Grant (Event Management)

UCL Research Domains

The UCL Research Domains are large, cross-disciplinary research communities that span UCL and our partner organisations, with the aim of fostering interaction and collaboration. By bringing together a critical mass of expertise, we believe that we can further encourage and support internationally leading research in our key areas of strength.

UCL Research Domains aim to:

- develop new research collaborations and partnerships, within and beyond UCL
- support academic communities in developing strategic ambitions that further develops UCL's internationally leading research profile
- underpin strategic developments and attract major funding
- provide development opportunities for early career researchers
- exemplify how research communities can become greater than the sum of their parts.

The current UCL Research Domains are: Neuroscience; Personalised Medicine; Populations & Lifelong Health; Environment; eResearch and Collaborative Social Science.

UCL Populations & Lifelong Health Domain

UCL encompasses arguably the greatest concentration of biomedical science and population health expertise in Europe. The Domain brings together over 800 Researchers with an interest in population health from across the university, who conduct world-leading work.

Our researchers generate 10% of the country's contribution to the most highly cited publications in public, occupational and environmental health, and in the last five years the citations of the ten most highly cited researchers exceeded 180,000.

Populations & Lifelong Health is a strategic priority for UCL, with research in this field accounting for almost 20% of UCL's entire research income.

Our vision is to build not just on world-class infrastructure but fundamentally on the people who make up the UCL Populations & Lifelong Health Domain community. We aim to build upon our existing excellence by supporting and investing in cross-disciplinary research teams, and to extend our reach as one of the world's leading institution focused on populations and lifelong health.

In addition to the seven Institutes that form the UCL Faculty of Population Health Sciences, the Domain brings together activity in six research Themes. These Institutes and Themes reflect the strength of research in populations and lifelong health at UCL.

Our work ranges from studies that measure the burden of disease in populations, through to cross-sectional and longitudinal studies which seek to understand the relative influences of environmental, socio-economic, behavioural, biological and genetic factors on disease and lifelong health. We undertake clinical, behaviour change and health service interventions in community, primary and secondary care settings nationally and globally to evaluate their benefits to health in populations.

The health of populations is influenced by a wide range of factors including law, economics, culture and the environment. A key objective of the Domain is to bring together researchers across the UCL School of Life and Medical Sciences (SLMS) and beyond, whose work has a bearing on populations and lifelong health e.g. lawyers, health economists, geographers, philosophers, ethicists, anthropologists, mathematicians and those working on the built environment, alongside epidemiologists, statisticians and clinicians. We aim to build capacity by bringing together researchers working across a broad range of disciplines, and developing strategic initiatives to build the academic community and further developing novel research. We also aim to disseminate UCL's research and support interaction with key opinion formers and practitioners to translate research into policy and practice.

Opening and closing remarks



Professor Michael Arthur
UCL President and Provost

Opening remarks

Professor Michael Arthur is President and Provost of University College London. Prior to this he was Vice-Chancellor of the University of Leeds, and formerly Professor of Medicine (1992), Head of the School of Medicine (1998-2001) and Dean of the Faculty of Medicine, Health and Life Sciences in Southampton (2003-04). He is a hepatologist with research interests in liver cell biology developed initially at the University of California, San Francisco (1986-1988) and more recently as a Fulbright Distinguished Scholar at Mount Sinai School of Medicine in New York (2002). In 2015, Professor Arthur became the first Vice-Chancellor of a Russell Group University to become a Principal Fellow of the Higher Education Academy.

Professor Arthur has a significant national and international profile. He was Chair of the Advisory Group for National Specialised Services (NHS) (2010-2013) and was a long standing member of the Council of the Medical Research Council until recently (2006 - Sept 2014). He has also been a US/UK Fulbright Commissioner and is a former Chair of both the Worldwide Universities Network and the Russell Group of Universities.

Professor Arthur took up his current post on 1 September 2013.



Professor Dame Anne Johnson
Chair, UCL Populations & Lifelong Health Domain

Closing remarks

Anne M. Johnson (MD FMedSci FRCP FFPH FRCGP) is Professor of Infectious Disease Epidemiology at UCL. She is Chair of the UCL Populations & Lifelong Health Domain and Vice-Dean for External and International Relations, UCL Faculty of Population Health Sciences. Her research focuses on the epidemiology and prevention of HIV, sexually transmitted infections and other infectious diseases. She is a member of the DEFRA Adaptation Sub-committee of the Committee on Climate Change and is Chair of the Academy of Medical Sciences Health of the Public 2040 Working Group. She is a Governor of the Wellcome Trust.

Past, present and future: Innovation in cohort studies



Professor Aroon Hingorani

Director, UCL Institute of Cardiovascular Science, and Professor of Genetic Epidemiology

Chair

Aroon obtained a degree in Physiological Sciences at University of Oxford and qualified in Medicine from Guy's Hospital, London before undertaking specialist training in Internal Medicine and Clinical Pharmacology in London and Cambridge. After a PhD at Cambridge University, he was awarded a British Heart Foundation Intermediate and then Senior Fellowship at UCL. His research interests are in the use of human genomics to identify and validate drug targets for common disease.



Helen Pearson

Chief Magazine Editor, Nature

The Life Project: How the British birth cohorts inspired a book

Helen is a science journalist, editor and author. As Chief Magazine Editor for the world's leading science journal, Nature, she oversees all its journalism and opinion content. Her own stories have won accolades including the 2010 Wistar Institute Science Journalism Award and two best feature awards from the Association of British Science Writers. Helen's popular science book, *The Life Project*, was published in 2016 to wide critical acclaim. It was named best science book of the year by The Observer and was a book of the year for The Economist. The book tells the story of five major British birth cohort studies, the scientists who fought for them, and their remarkable scientific legacy. "Eye opening, extraordinary insights into ordinary lives," wrote the Financial Times. Helen has a degree in natural sciences from the University of Cambridge, and a PhD in genetics.

Past, present and future: Innovation in cohort studies



Professor Alison Park

Director, CLOSER (Cohort and Longitudinal Studies Enhancement Resources), UCL Institute of Education

The changing face of cohort studies - from punch cards to PCs

Alison Park is Director of CLOSER (Cohort and Longitudinal Studies Enhancement Resources) at the UCL Institute of Education. CLOSER brings together eight leading longitudinal studies, the British Library and the UK Data Service to share resources and expertise, provide training and stimulate longitudinal research. Its research activity has focused particularly on data harmonisation and data linkage. CLOSER is funded by the Economic and Social Research Council (ESRC) and Medical Research Council (MRC).

Before joining UCL Institute of Education, Alison led a research team at NatCen Social Research where she designed, resourced and implemented a range of commissioned and grant-funded research studies.

Her research interests include research methods and social and political attitudes and behaviour.

Alison is a Fellow of the Academy of Social Sciences.



Professor Nishi Chaturvedi

Professor of Clinical Epidemiology, UCL Institute of Cardiovascular Science

Mind the gap: precision medicine needs precision phenotyping

Nishi Chaturvedi qualified in Medicine at the University of London in 1985 and has subsequently specialised in clinical epidemiology, obtaining first an MSc and subsequently an MD in epidemiology. Professor Chaturvedi began her epidemiological career at UCL, moving to Imperial College as a Professor in 2000, and then returning to UCL in 2013.

Professor Chaturvedi leads one of the largest tri-ethnic older age cohorts, (SABRE, Southall And Brent REvisited), and was appointed to lead the oldest national UK birth cohort (National Survey for Health and Development) in 2017. Her work highlights the marked ethnic contrasts in risks of cardiometabolic disease. This was used to inform lower obesity thresholds for diabetes screening in the UK. Previously, she led the largest cohort of type 1 diabetes (the EURODIAB cohort), which informed two trials of interventions to reduce the burden of diabetes complications, the EUCLID trial and the DIRECT programme, all of which were published in the *Lancet*. She has also worked on the aetiology of and interventions for cardiometabolic in low to middle income countries such as the Caribbean, Egypt and Pakistan. Her current key interest is the exploitation of detailed, non-invasive precision phenotyping to understand disease aetiology and mechanisms for the identification of novel interventions. Additional current roles include Vice Dean for Research for the UCL Faculty of Population Health Sciences, Associate Editor of *Diabetologia* and Chair of the British Heart Foundation Fellowships Committee.

Past, present and future: Innovation in cohort studies



Professor Ruth Gilbert

Professor of Clinical Epidemiology, UCL Great Ormond Street Institute of Child Health, and Deputy Director, Administrative Data Research Centre England

Harnessing data about public services

Ruth Gilbert leads programmes of maternal and child health research using electronic health records with the UK Farr Institute, within the Children's Policy Research Unit, funded by the Department of Health. She is Deputy Director for the Administrative Data Research Centre for England where she leads longitudinal studies based on linked administrative data involving children's health, education and family courts and methodology research focused on record linkage. She has conducted studies comparing UK countries and has established productive international collaborations with the Karolinska Institute, Ontario and Australia using standardised, whole-country electronic birth cohorts linking mothers and their children.



Professor Caroline Sabin

Professor of Medical Statistics and Epidemiology, UCL Institute for Global Health, and Director, NIHR Health Protection Research Unit (HPRU) in Blood Borne and Sexually Transmitted Infections

Tapping into the potential of clinic and surveillance databases for HIV research

Caroline has worked on many large observational HIV databases, with particular interests in undertaking studies of the natural history of HIV infection, responses to and adverse events of antiretroviral therapy and, the effects of ageing in the HIV population. She established, and is the PI of, the UK Collaborative HIV Cohort (UK CHIC) Study, a multicentre study of >50,000 HIV-positive individuals which is one of the largest clinical cohorts of HIV-positive individuals worldwide. She is the principal statistician for the D:A:D Study, an international multi-cohort study of >54,000 HIV-infected individuals which has described the relationships between antiretroviral drugs and serious non-AIDS outcomes, including cardiovascular disease, cancer, liver and renal disease. She is the co-PI on the POPPY Study, a cohort study of the effects of ageing in people living with HIV in the UK. She has been closely involved with many other large national and international HIV cohort studies.

'Question Time': Making the case for cohorts, biobanks and big data



Professor David Lomas
UCL Vice-Provost (Health)

Chair

Professor David Lomas PhD, ScD, FHEA, FRCP, FMedSci is Vice-Provost (Health), Head of UCL School of Life and Medical Sciences and Head of UCL Medical School. He is the Academic Director of the UCLPartners Academic Health Sciences Centre. David is an NIHR Senior Investigator and works as a respiratory physician at UCLH and the Royal Free Hospital. He was Chair of the Population and Systems Medicines Board at the Medical Research Council and previously chaired the Respiratory Therapy Area Unit Board at GlaxoSmithKline. David chaired the Scientific Priorities Committee for the 100,000 genomes project and serves as Deputy Chair of the Scientific Advisory Committee for Genomics England. He was a member of the Expert Advisory Group for the UK Minister of Life Sciences Innovative Medicines and MedTech Review.



Professor Alissa Goodman
Professor of Economics, Principal Investigator of 1958 National Child Development Study and Director, Centre for Longitudinal Studies, UCL Institute of Education

Cohorts

Alissa's main research interests relate to inequality, poverty, education, and the intergenerational transmission of health and well-being. Alissa is Director of the Centre for Longitudinal Studies, which is responsible for the scientific development and management of four major national cohort studies, and Alissa is Principal Investigator of the 1958 National Child Development Study, leading the team responsible for developing its content, and design. Alissa's previous roles include having served as deputy Director of the Institute for Fiscal Studies in London (2006-2012).

'Question Time': Making the case for cohorts, biobanks and big data



Professor Sir Rory Collins FRS

Head of Nuffield Department of Population Health and BHF Professor of Medicine and Epidemiology, University of Oxford

Biobanks

Rory Collins studied Medicine at St Thomas's Hospital Medical School, London University (1974-1980), and Statistics at George Washington University (1976-7) and at Oxford University (1982-3).

In 1985 he became co-director, with Professor Sir Richard Peto, of the University of Oxford's Clinical Trial Service Unit & Epidemiological Studies Unit (CTSU). In 1996, he was appointed Professor of Medicine and Epidemiology at Oxford, supported by the British Heart Foundation.

He became Principal Investigator and Chief Executive of the UK Biobank prospective study of 500,000 people in September 2005. From July 2013, he became the Head of the Nuffield Department of Population Health at University of Oxford.

His work has been in the establishment of large-scale epidemiological studies of the causes, prevention and treatment of heart attacks, other vascular disease, and cancer. He was knighted in 2011 for his services to science.



Professor Harry Hemingway

Professor of Clinical Epidemiology, Director of the UCL Institute of Health Informatics, and Director of Farr Institute of Health Informatics Research, London

Big data

Harry is a clinical academic having trained in medicine and public health in Cambridge and London. He Directs the Farr Institute of Health Informatics Research in London, part of a wider national Research Institute innovating improvements in health and healthcare using rapidly emerging data opportunities from electronic health records, imaging, omics and wearables. He is principal investigator of the CALIBER programme which is exploiting linked rich, lifelong patient records in primary care and hospital care to better understand health and disease from cradle to grave. Harry leads the UK Biobank Cardiac Outcomes working group, was a Member of the NICE Guidelines committee on chest pain whose recommendations transformed the investigation of suspected stable angina. He has contributed to the governance and sharing of national registries for research which has directly informed clinical policy.

Opportunities and challenges for investment in cohorts, biobanks and big data



Professor Graham J Hart
Dean, UCL Faculty of Population Health Sciences

Chair

Professor Graham J Hart is Professor of Sexual Health & HIV Research in the Research Department of Infection & Population Health. A medical sociologist, his research interests include sexual risk behaviour and the prevention of HIV and STIs, combining structural, behavioural and biomedical approaches to prevention. He has worked with a wide range of populations at risk of HIV and STIs. This includes men who have sex with men, young people, sex workers, and vulnerable groups in developed and developing countries. His major contributions are to health policies nationally and internationally. Graham is currently Chair of the MRC/DfID African Research Leader Scheme Panel, the MRC Public Health Intervention Development (PHIND) panel and the Academy of Medical Sciences Health of the Public Springboard scheme. He was elected a Fellow of the Academy of Medical Sciences in 2010 and voted by the Fellowship onto its Council in 2013.



Dr Joe McNamara
Head of Population Health, Medical Research Council (MRC)

Joe McNamara is responsible for developing MRC strategy and policy for population health research and oversight of our major investments in population cohorts, including UK Biobank, and aspects of global health and prevention research. He is currently working to develop a new multi-funder partnership in prevention research. Prior to taking on his current role in December 2015, Joe was head of theme for population and systems medicine and he served as MRC's Clinical Trials Manager for four years.

Opportunities and challenges for investment in cohorts, biobanks and big data



Rebecca Fairbairn

Head of Longitudinal Studies, Economic and Social Research Council (ESRC)

Rebecca Fairbairn is Senior Reporting Officer for the ESRC's longstanding, world class, portfolio of longitudinal studies and the shape and sustainability of that portfolio into the future. She moved to this role in 2016 following three years as Head of Knowledge Exchange, where she led the re-development of policy for knowledge exchange and impact, transforming the ESRC's approach to one in which this activity is embedded across the whole of the ESRC's remit.

Rebecca's career has focused on the Research Councils and Foreign and Commonwealth Office (FCO). In 2008 she went to New Delhi to develop the strategy and operations of the Research Councils UK (RCUK) Office in India, with its first Director. She then moved to Bangalore with the FCO as Deputy Head of Mission of that post. She has also advised the UK government on strategic opportunities for the UK knowledge base in Latin America.



Professor Jeremy Pearson

Associate Medical Director (Research), British Heart Foundation

Jeremy's research career focused on the responses of vascular endothelial cells to vasoactive and inflammatory mediators. He led research teams at the Babraham Institute (1970-1983), and at the Medical Research Council (MRC) Clinical Research Centre in Harrow (1983-1991). In 1991 he was appointed Professor of Vascular Biology (the first in the UK) at King's College London (KCL). In 2002 he became Associate Medical Director (Research) at the British Heart Foundation, initially part-time, now full time, though he retains an emeritus Chair at KCL. He was vice chairman of the HEFC RAE 2008 subpanel A1 (Cardiovascular), and a member of the REF 2014 subpanel A1 (Clinical Medicine). He was elected as a Fellow of the Academy of Medical Sciences in 2004 and an Honorary Fellow of the Royal College of Physicians in 2006.

Opportunities and challenges for investment in cohorts, biobanks and big data



Dr Erica Pufall

Science Portfolio Adviser, Population Health, Wellcome Trust

Erica Pufall joined the Wellcome Trust in January 2017 as a Science Portfolio Adviser in Population Health, where she advises on Wellcome's funding of population health research in the UK and in low and middle income countries.

Erica has an undergraduate honours degree in Molecular Biology and Genetics and an MSc in Epidemiology from the University of Guelph in Canada, and a PhD in Epidemiology from Imperial College London. She was previously a Research Associate at Imperial College, where her research interests included using advanced statistical methodologies to investigate the social determinants of health, patient experience, sexual risk behaviours among people living with HIV, and the role of education on HIV risk in sub-Saharan Africa. She has also worked at the Public Health Agency of Canada, where she helped to develop scenarios around population health topics of interest such as food security and climate change.

Cohorts at UCL

UCL curates or takes a leadership role in the following large cohorts:

Population Cohorts

- 1958 National Child Development Study - Professor Alissa Goodman
- 1970 British Cohort Study - Dr Alice Sullivan
- British Regional Heart Study - Professor Goya Wannamethee & Professor Peter Whincup
- British Women's Heart and Health Study - Professor Juan Pablo Casas
- English Longitudinal Study of Ageing (ELSA) - Professor Andrew Steptoe
- Gemini: Health and Development in Twins - Dr Clare Llewellyn
- Health, Alcohol and Psychosocial factors in Eastern Europe (HAPIEE) Study - Professor Martin Bobak
- Millennium Cohort Study - Professor Emla Fitzsimons
- MRC National Survey of Health & Development 1946 (NSHD) - Professor Nishi Chaturvedi
- Next Steps - Dr Lisa Calderwood
- Northwick Park Heart Study - Professor Steve Humphries
- ONS Longitudinal Study - Dr Nicola Shelton
- Southall and Brent Revisited (SABRE) - Professor Nishi Chaturvedi
- UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) - Professor Usha Menon
- Whitehall II (Stress and Health Study) - Professor Mika Kivimaki

Clinical Cohorts

- AALPHI: Adolescents and Adults Living with Perinatal HIV Cohort - Dr Ali Judd
- Antiretrovirals, Sexual Transmission Risk and Attitudes (ASTRA) - Dr Fiona Lampe
- Clinical Cohorts in Coronary disease Collaboration (4C) - Professor Harry Hemingway
- Concerted Action on SeroConversion in AIDS and Death in Europe (CASCADE) - Professor Kholoud Porter
- Collaborative HIV Paediatric Study (CHIPS) - Dr Ali Judd
- Data Collective on Adverse Events of Anti-HIV Drugs (D:A:D) - Professor Caroline Sabin & Professor Andrew Phillips
- European Pregnancy and Paediatric HIV Cohort Collaboration (EPPICC) - Dr Claire Thorne & Dr Ali Judd
- EPICure: Population based studies of survival and later health status in extremely premature infants - Professor Neil Marlow
- EuroSIDA - Professor Amanda Mocroft
- European Collaborative Study - Dr Claire Thorne
- Hypertrophic Cardiomyopathy Outcomes (HCMO) - Professor Perry Elliott
- Italian Cohort of Antiretroviral Naïve Patients (ICONA) - Dr Alessandro Cozzi-Lepri
- Management of Post-Transplant Infections in Collaborating Hospitals (MATCH) - Professor Amanda Mocroft
- National Study of HIV in Pregnancy and Childhood (NSHPC) - Dr Claire Thorne

Cohorts at UCL

- National Institute for Cardiovascular Outcomes Research (NICOR) Registries - Professor John Deanfield
- Obesity and Bariatric Surgery Cohort - Dr Rachel Batterham
- A Prospective, Observational Study to Examine the Effects of Ageing on the 'Pharmacokinetic and Clinical Observations in People Over Fifty' (POPPY) - Professor Caroline Sabin
- Royal Free Hospital Cohort - Dr Fiona Lampe & Dr Colette Smith
- UK Collaborative HIV Study (UK CHIC) - Professor Caroline Sabin & Professor Andrew Phillips
- UK Seroconvertors Rehttp - Professor Kholoud Porter
- Ukraine Paediatric HIV Cohort Study - Dr Claire Thorne
- ZIKAction: pregnancy and paediatric cohort studies on zika, dengue and chikungunya viruses - Dr Claire Thorne, Dr Eleni Nastouli & Dr Heather Bailey

Electronic Health Records Data

- CALIBER - Professor Harry Hemingway
- UK HIV Resistance Database - Professor David Dunn

This is not an exhaustive list so please contact Sarah Welsher (s.welsher@ucl.ac.uk) if you lead a cohort at UCL that you think should be included.

For more information about Cohorts at UCL please see:

<http://www.ucl.ac.uk/research/domains/populations-and-lifelong-health/research/themes/cohorts>

