Programme

The impact of the genomics revolution on global health - how can governments respond?

Monday 29 February – Thursday 3 March 2016 | WP1463

Genomics – the study of an organism's complete set of genetic instructions – is revolutionising medicine. As the microscope and x-rays revolutionised medicine in the 19th and 20th centuries, so knowledge of the human genome will dramatically change medicine in the 21st century.

The ability to sequence the genetic code of a large sample of the population is revealing how small variations in our DNA can change our vulnerability to different diseases – and thus how medicine can be personalised for better prevention, diagnosis and treatment.

Knowledge of the DNA sequence has become an important part of biological research but is also vital for other research disciplines such as medicine, biotechnology and forensic science. By establishing the sequence of an individual's genetic material it is possible to identify sequences or mutations which are specific to that person. Not only can these sequences identify the cause or stage of a disease, or the risk of future disease, they can also help us to predict the likely benefits or side effects in response to a particular medication. In cancer, the individual tumours may have developed mutations which differentiate them from the patient's healthy cells. Genomics therefore heralds the shift towards personalised treatment - medicines and other treatments can be prescribed not just for their general effect on a disease, but for the way they interact with a specific patient according to their genetic makeup.

This is a huge step forward for global health as it also provides the ground-breaking opportunity to examine the underlying causes of ill-health, tackling health conditions before they have even started, rather than just identifying and managing patients once ill-health has taken hold.

This Wilton Park dialogue will be held in partnership with the Foreign and Commonwealth Office, Healthcare UK and the Science and Innovation Network (SIN). It will seek to promote international cooperation on this emerging and exciting field, with the aim of supporting the creation of a global network of genomic medicine centres, to ensure that
information and expertise can accumulate and be shared.

International participants are invited to join a study tour on Monday 29 February and Tuesday 1 March to see in practice how the UK is developing its study of genomics and introducing this into its approach to healthcare.

In association with Foreign and Commonwealth Office, Healthcare UK, Science and Innovation Network

### Sunday 28 February

**Day/night**

International participants arrive in UK and stay overnight at Macdonald Randolph Hotel, Oxford, Oxfordshire OX1 2LN

### Monday 29 February

<table>
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<tr>
<td>0800-0845</td>
<td>Check out and registration</td>
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<tr>
<td>0900</td>
<td>Coach leaves hotel</td>
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<td></td>
<td>Study tour for international participants to The Oxford Academic Health Science Network (AHSN) and NIHR National Biosample Centre.</td>
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**The Oxford Academic Health Science Network (AHSN)**

Berkshire, Buckinghamshire, Oxfordshire, Milton Keynes and Bedfordshire are home to a wealth of world-leading organisations involved in clinical care, life sciences and medical research, education and training, innovation and informatics. The Oxford Academic Health Science Network (AHSN) works to break down traditional organisational boundaries in these areas and build stronger relationships between industry, scientific and academic communities – coupled with better knowledge exchange – to bring lasting benefits as best practice is spread quickly and widely across the NHS.

**Tour details:** Room A, The Wellcome Trust Centre for Human Genetics, Roosevelt Drive, Oxford, OX3 7BN

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<tr>
<td>0930-1000</td>
<td>Tea/coffee</td>
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<tr>
<td>1000-1010</td>
<td>Welcome</td>
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<td></td>
<td>Rory Shaw</td>
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<td>Medical Director, Healthcare UK, UK Trade &amp; Investment (UKTI), London</td>
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<td>1010-1030</td>
<td>Professor Gil McVean</td>
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<td>Professor of Statistical Genetics, Wellcome Trust Centre for Human Genetics, Oxford</td>
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<td>1030-1050</td>
<td>Professor Jenny Taylor</td>
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<td>Programme Director Genomic Medicine Theme, Oxford Biomedical Research Centre, Wellcome Trust Centre for Human Genetics, Oxford</td>
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<tr>
<td>1050-1110</td>
<td>Tea/coffee</td>
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<td>1110-1130</td>
<td>Dr Anna Schuh</td>
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<td>Associate Professor for Molecular Diagnostics, Department of Oncology, Head of BRC/NHS Translational Molecular Diagnostics Centre, Oxford University Hospitals NHS Foundation Trust</td>
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NIHR National Biosample Centre, Milton Keynes
The NIHR National Biosample Centre located in Milton Keynes UK, is a facility that provides high throughput, high quality biological sample handling, storage, processing and analytical services to the academic, charity and industrial biomedical research sector. Specifically, it provides services such as:

- Receipt and processing of biological samples (such as blood, urine, saliva, biopsy samples). This may involve simple aliquotting of samples to more complex fractionation of blood to its constituent parts (plasma, white cells, red cells).
- Extraction of DNA from biological samples and the quantification and normalisation of the extracted DNA.
- Storage and curation of these samples under controlled conditions ranging in temperature from ambient to -196°C.
- Retrieval of these samples followed by dispatch to research groups requesting them.

1430
Arrive at Biosample centre – main reception

1445-1500
**Presentation on drivers, aims and achievements**

1500-1545
Tour of Biosample centre

1545-1615
**Q & A Session**
Tea/coffee available

1615
Participants depart Biosample centre

1630
Coach leaves for London

1800
Arrive and check in at Hotel Russell, 1-8 Russell Square, London WC1B 5BE

1900
Dinner in the Virginia Woolf Suite, Hotel Russell
Pre-dinner speakers

**Professor Chris Born**
Managing Director, Healthcare UK, London

**Sir John Burn**
Professor of Clinical Genetics, Newcastle University; Medical Director and Head of the Institute of Human Genetics; Lead Clinician National Health Service North East, Newcastle upon Tyne

**Tuesday 1 March**

0800-0845
Check out
0900
Coach leaves hotel

Study tour for international participants to Great Ormond Street Hospital and Guy's and St Thomas' NHS Foundation Trust

**Great Ormond Street**

Great Ormond Street Hospital (GOSH) provides a full range of paediatric sub speciality services to patients from the UK and internationally who have rare or complex conditions. This patient population offers a unique opportunity for research and innovation in new treatments and diagnostic testing, and this is particularly true in the areas of clinical and molecular genetics. The hospital provides services from pre-natal testing, diagnostics and treatment throughout childhood and adolescence and eventually transition to adult services. GOSH hosts the North Thames Regional Genetics Laboratory which is an accredited service comprising of molecular and cytogenetics laboratories as well as clinical genetics. The service has a staff of approximately 80 including consultant clinical geneticists, state registered clinical scientists and genetic technologists. The laboratory service processes over 26,500 samples per year and issues approximately 18,500 analytical reports. Through pioneering research, the laboratory at GOSH has developed Non-invasive Prenatal Diagnosis (NIPD) - a unique and safe alternative to traditional invasive prenatal tests. NIPD requires only a blood sample from the mother, from which cell free fetal DNA (cffDNA) is tested to analyse the baby's DNA. GOSH is the only centre worldwide offering this unique service to UKAS ISO15189 standards. GOSH is also the only institute worldwide to offer the GOSHome test with a paediatric focus designed for specific clinical areas. The GOSHome is a post-natal diagnostic test for children and adults who have an unknown condition, and is designed to help confirm a genetic diagnosis. The test targets around 5000 known disease-causing genes. The test covers rare conditions that are known to be caused by multiple genes, for which it is difficult to make a definitive diagnosis.

**Tour details:** Charles West Board Room, Paul O'Gorman Building, Great Ormond Street Hospital, Great Ormond Street, London, WC1N 3JH

0915-0930
**Welcome and introduction to genetics services at Great Ormond Street Hospital (GOSH) and Institute of Child Health (ICH)**

**Professor Lyn Chitty**
Professor of Genetics and Fetal Medicine, Great Ormond Street Hospital (GOSH)

0930-1000
**Clinical genetics**

**Dr Richard Scott**
Consultant in Clinical Genetics, Great Ormond Street Hospital (GOSH); Honorary Senior Lecturer in the Clinical and Molecular Genetics Unit, Institute of Child Health (ICH)

1000-1030
**Genetics and laboratory services**

**Lucy Jenkins**
Director, North East Thames Regional Genetics Laboratory, Great Ormond Street Hospital (GOSH) and Consultant Clinical Scientist for Molecular Genetics

1030-1100
**Next generation genetic testing**

**Dr Hywel Williams**
Genetics and Genomic Medicine Programme, Institute of Child Health (ICH)

1100-1115
**Discussion**

1115
Depart to Guy's & St Thomas’

1200
Participants arrive at reception (Guy's Tower) and meet Colin Carmichael
Guy’s and St Thomas’ NHS Foundation Trust is a centre of excellence for clinical services, education and research with a proud history of over 900 years. Their clinical services are delivered from two of London’s best known teaching hospitals, Guy’s Hospital and St Thomas’ Hospital, where the Evelina London Children’s Hospital is also located. They are part of King’s Health Partners, one of only seven academic health sciences centres in the UK. They are pioneers in health research, provide high quality teaching and education, and have a workforce of the highest calibre in national and international healthcare. Guy’s and St Thomas’ are the lead organisation for the South London Genomic Medicine Centre which has been set up to help deliver the 100,000 Genomes Project. The Trust is a leader in mainstreaming genomic medicine into clinical practice. Guy’s and St Thomas’ has a history of collaboration and partnership, working successfully with partners in the UK and internationally across all spheres of their work: clinical, educational and research. These partnerships draw on their breadth and depth of experience across a wide range of clinical specialties.

1215-1240  Lunch in the Robens Suite, 29 Floor

1240-1245  **Introduction and welcome**  
*Professor Sean Whittaker*  
Consultant Dermatologist; Clinical Lead, South London Genomic Medicine Centre, London

1245-1300  **Using genomics in the clinical genetics pathway and the role of education and training**  
*Dr Melita Irving*  
Consultant Clinical Geneticist; Joint Head of Service for Clinical Genetics, Guy’s and St Thomas’ NHS Foundation Trust, London

1300-1315  **Using genomics in the cancer pathway**

1315-1330  **The application of bioinformatics in genomics**  
*Joo Wook Ahn*  
Head of Bioinformatics, Viapath, London

1330-1345  **Developments and issues in next generation sequencing**  
*Dr Graham Taylor*  
Scientific Director of Clinical Genomics, Viapath, Guy’s and St. Thomas’ Teaching Hospitals, London

1345-1415  **Q & A Session**

1415  Participants depart the Robens Suite

1430  Coach leaves for Wilton Park

1700  Participants arrive at Wiston House, West Sussex

1800-1820  **Welcome to Wilton Park**  
*Robin Hart*  
Director of Programmes, Wilton Park

*Rory Shaw*  
Medical Director, Healthcare UK, UK Trade & Investment (UKTI), London
Welcome video
George Freeman
Parliamentary Under Secretary of State for Life Sciences, Department for Business, Innovation and Skills and the Department of Health, London

1820-1900
1. Introduction and opening discussion
Ajay Kakkar
Professor of Surgery, University College London; Member, House of Lords, London
Richard Barker
Chairman, Precision Medicine Catapult, London

1900
Reception followed by dinner

Wednesday 2 March

0800-0845
Breakfast

0900-1030
2. Genomics - outlining the UK experience
This session will offer an overview of the current state of genomic medicine in the UK, looking at objectives and how best to achieve them as well as obstacles, whilst exploring how the UK is approaching the area.

Why is genomics important? What is realistic and achievable and in what time frame? What are the opportunities afforded by the genomic medicine and how to maximise them? What blockages might impact upon the effective delivery of national and international initiatives?

Alistair Burt
Minister of State for Community and Social Care, Department of Health, London

John Chisholm
Executive Chairman, Genomics England, London

Sue Hill
Chief Scientific Officer, NHS England, London

1030-1115
Photograph followed by tea/coffee

1115-1300
3. Changes to the practice of medicine as a result of genomic and personalised medicine
Genomic technology offers the opportunity for personalised medicine for better prevention, diagnosis and treatment of a range of conditions. This session will look at the clinical benefits of genomic technology.

UK experts will examine some of the services being established in the UK, followed by an open discussion about how this might change clinical care in different country contexts.

Chair: Patrick Maxwell
Head, School of Clinical Medicine, University of Cambridge

How will the long term care of children with rare diseases change with access to genomic testing?
Richard Scott
Consultant, Clinical Genetics, Great Ormond Street Hospital for Children, London

How does a modern cancer service use genomic information and how will this develop as more precision medicines are developed?
David Waugh
Director and Professor of Molecular Oncology and Therapeutics, Queen's University Belfast
**How can genomic information enable safer drug prescribing?**

**Munir Pirmohamed**  
David Weatherall Chair of Medicine and NHS Chair of Pharmacogenetics; Associate Executive Pro-Vice Chancellor for Clinical Research, University of Liverpool

Conversations on the clinical aspects of genomics to be continued over lunch

1300-1430  
**Lunch**

1430-1500  
**4. Clinical Education**

**Liz Hughes**  
Director and Dean, Education and Quality (London and South East); Lead Director and Dean, International Programme, Health Education England, Birmingham

1500-1615  
**5. Genomics and economic growth**

A plenary discussion about how genomics and personalised medicine can drive economic growth. How can industry support genomics and personalised medicine? What products and services need to be developed and how can this be achieved? What Government strategies can be used to develop economic growth from this area of the Life Sciences Sector?

**Sarah Wordsworth**  
Associate Professor, Nuffield Department of Population Health, Medical Sciences Division, University of Oxford

**Fahd Al-Mulla**  
Professor of Molecular Pathology, Faculty of Medicine, Kuwait University; Director, Genatak, The Center of Genomic Medicine, Kuwait City

**John McKinley**  
Chief Executive Officer, Precision Medicine Catapult, London

1615-1645  
Tea/coffee

1645-1800  
**6. Harnessing the full potential of genomic medicine**

A short introduction to the challenges faced by small countries in developing genomic medicine, followed by parallel regional working groups to explore opportunities and challenges in specific country contexts.

**Chair: Adrian Bull**  
Managing Director, Imperial College Health Partners, London

**Regional groups**

- Gulf countries
- Europe
- Asia
- Latin America and South Africa

**Regional chairs to be identified**

**UK Experts supporting the chairs:**

Andrew Riley, Julian Barwell, Nick Housby, Liz Mear
Questions to be addressed by the groups include:

- How is your country approaching genomic technology?
- What are the opportunities and challenges for genomics in your country?
- What is the economic case?
- What are the next steps?

1800-1815
Tea/coffee available

1815-1845
7. Feedback and discussion from working groups
Chair: Adrian Bull
Managing Director, Imperial College Health Partners, London

1915
Reception followed by conference dinner hosted by Richard Burge, Chief Executive, Wilton Park
Speaker at dinner
Malcolm Grant
Chairman, NHS England, London

Thursday 3 March

0800-0845
Breakfast and checkout

0900-0910
8. Genomics: a patient journey
A short video from a patient discussing how their life changed as a result of the use of genomics.
Robin Hart
Director of Programmes, Wilton Park

0910-1000
9. The role of government in genomic education, regulation and infrastructure: introduction
5 minute introductions from experts in plenary
Regulation and inspection
Sarah Ellson
Partner, Fieldfisher, Manchester

Peter Thompson
Chief Executive, Human Fertilisation and Embryology Authority (HFEA), London

IT and data security
Martin Dennys
Programme Director for I&A Business Transformation, Health and Social Care Information Centre, Leeds

Integration of genomic and clinical data
Jem Rashbass

Research and development: building academic institutions and partnerships
John Tooke
Executive Chairman, Academic Health Solutions; Past President of the Academy of Medical Sciences, London
1000-1055

10. The role of government in genomic education, regulation and infrastructure: discussion

World café format in the Great Hall – experts “host” discussions on their theme including discussion on how to overcome challenges and opportunities for governments. Participants will be able to choose 3 themes during the session and discuss these in more details with the “hosts”.

**Regulation and inspection**
Sarah Ellson
Partner, Fieldfisher, Manchester

**Peter Thompson**
Chief Executive, Human Fertilisation and Embryology Authority (HFEA), London

**IT and data security**
Martin Dennys
Programme Director for I&A Business Transformation, Health and Social Care Information Centre, Leeds

**Integration of genomic and clinical data**
Jem Rashbass

**Research and development: building academic institutions and partnerships**
John Tooke
Executive Chairman, Academic Health Solutions; Past President of the Academy of Medical Sciences, London

1055

Feedback and plenary discussion in the Great Hall
(Coffee and tea available throughout)

1105-1230

11. What is the role of international partnerships in developing genomics and personalised medicine?

Plenary discussion on the role of international partnerships in planning and developing genomic services, and supporting the widespread introduction of personalised medicine.

**Chair: Malcolm Grant**
Chairman, NHS England, London

**Contributors to include:**
Colin Carmichael
Genomics Programme, Guy’s and St Thomas’ NHS Foundation Trust, London

Alasdair Gaw
Lead Specialist, Stratified Medicine, Innovate UK, Swindon

Helen Wells
Science and Innovation Policy and Programme Manager, Foreign and Commonwealth Office, London

1230-1300

12. Conclusions and next steps

**Discussion, actions and commitments**
Rory Shaw
Medical Director, Healthcare UK, London

Completion of eQuestionnaire

1300

Lunch

1400

Participants depart