

HDR UK Scientific Retreat 26-27 April 2018

Precis of event

Introduction

On 26-27 April 2018, over 80 colleagues from the six HDR UK Substantive Sites, funders and partners attended our Scientific Retreat to review the HDR UK vision, strategic objectives and to define our national scientific priorities.

Attendees included experts in health data research from across academia, research and healthcare including: professors in computer science, statistics, population health and public health; specialists in informatics, public health, genetics, biomedical science, clinical trials and ethics; chief clinical information officers; and programme managers. The event was a mix of presentations, discussions and workshops to support interaction across the Sites.



Summary

The Scientific Retreat cemented our mission as *making game-changing improvements in the health of patients and populations through data science research and innovation*. We are ambitious in our drive to achieve success – delivering value to the NHS, growing the workforce and the economy.

We are committed to building a single Institute unified by a common vision and mission and seven principles:

- (i) A relentless focus on scientific excellence
- (ii) Focused on building trust with the public through consultation and good governance on data sharing and analysis through a commitment to engage and inspire the public
- (iii) Flexibility, with the ability to quickly exploit emerging situations and technologies
- (iv) A commitment to team science delivered through mutual support and collaboration
- (v) An investment in young and emerging talent
- (vi) Novel ways of partnership working across academia, industry, the public, the NHS and the public and third sectors, to demonstrate impact and follow through to societal benefit
- (vii) A determination to support a data intensive ecosystem for health research across the UK and internationally.

There is an opportunity to become a trusted and respected voice on behalf of the research community for health data science. We have strong foundations in place – outstanding inter-disciplinary talent across our six Substantive Sites which have access to rich, multi-dimensional datasets, with the prospect of building on collective complementary strengths.

The **HDR UK Triple Aim** is (i) excellence and innovation in training; (ii) performing ambitious scientific programmes at scale; and, (iii) building a UK information commons for the trustworthy use of multi-dimensional data for research.

Training

Supporting the next generation of leaders in health data science is a key national priority and our vision is to work with NIHR and other partners to establish a supported, valued community of 200 HDR UK/NIHR Fellows in health data science.

Research

Our initial research priorities are:

- Actionable health data analytics
- Precision medicine
- 21st Century trial design
- Modernising public health: towards prevention and early intervention

The initial Substantive Site Scientific Programmes will commence on 1 May.



Speaker highlights

Welcome: **Professor Sir Alex Markham** opened the event and thanked our funders for their support. He stressed how essential team work and collaboration is to the future success of HDR UK. Sir Alex highlighted the need for great ambition – “moderate success is not good enough” – referencing the 14 Nobel Prizes that have originated from LMB, founded by Max Perutz and stated that HDR UK should be in the same league.





Building a world-leading health data science institute: Andrew Morris introduced the vision and mission of HDR UK and the opportunity to make game changing improvements in the health of patients and populations through data intensive research and innovation. Andrew stated that HDR UK would be the exemplar of how to use other people’s data for the public good. What will we be famous for? Empowering a transformation in medicine and health care through health data science, with broad societal impact.

Regional strengths, global solutions: HDR UK’s six Directors **Cathie Sudlow, Harry Hemingway, Simon Ball, John Danesh, Martin Landray** and **Ronan Lyons** joined a panel to outline the regional strengths of the HDR UK sites and the global solutions offered by working together. Key messages from the talks and subsequent discussion included: The need for a clear narrative that is understood by all, including patients; the need to deliver impact through output in the next 18 months; the imperative to collaborate across the UK; restoring trust in data; and setting clear standards that we all work to. All showed their commitment to delivering the national priorities of actionable health data analytics, precision medicine, 21st Century clinical trials, and modernising public health.



UK Digital Innovation Hubs: Andrew Morris, Tim Hubbard and Ronan Lyons discussed the development of regional Digital Innovation Hubs (DIHs), which will be interoperable through a UK-wide health research data fabric. These hubs would integrate and ingest health data and create an environment for research. Tim explained the important connections between Local Health and Care Record Exemplars (LHCRES) and the DIHs. Ronan discussed learnings from SAIL (Secure Anonymised Information Linkage), which contains data on residents of Wales. The following panel discussion involving **Helen Parkinson, Tony Brookes, Jim Davis and David Ford** focused on: strengths and expertise in regions; creating a common purpose among communities; and the need to be a trusted voice with the public around data integrity and quality.

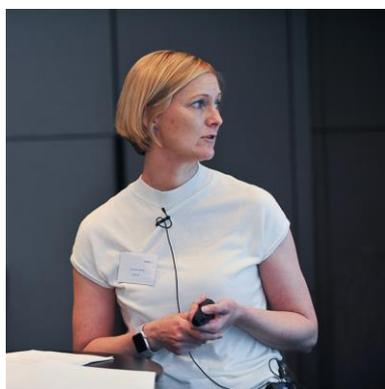


Capacity building for the next generation of health data scientists: Peter Diggle was introduced as the Director of Training for HDR UK, joining on 2 June 2018. Peter introduced **Georgina Moulton** and **Gabriella Rustici** who will be joining the HDR UK training team. A statistician by background, Peter said his first job will be to visit each of the Sites, hear what people are doing in relation to training and capacity building and put out a UK call for evidence.



Reflections on building a European research infrastructure for BioData: Dame Janet Thornton shared her learning and insights from EBML-EBI and ELIXIR including the challenges, lessons learnt, practical measures. Key points are the importance in preparing a clear scientific case; building trust within and across sites, with national bodies and funders; openness and transparency. Collaboration is not easy or quick, but it is vital to the success of HDR UK.

Funders panel discussion: Anna Vignoles (ESRC), Philippa Hemmings (EPSRC), Ekin Bolukbasi (Wellcome), Rhoswyn Walker (MRC) and Tom Barlow (CSO Scotland) joined the panel chaired by Martin Landray to outline funders expectations of HDR UK. The panel members recognised the need to work together across the funding partners to prevent competing demands. There will be areas that are specific to funders, but there is a single vision and we have the right agreements in place. Training and capacity building in the research community is a common expectation of the funders.



Communications – our approach to delivering global impact: Amanda White highlighted the importance of communications in delivering the HDR UK vision, building on the references to collaboration and team work mentioned by other speakers. Creating a compelling narrative and use of story telling will help bring the work of HDR UK to life and can engage our audiences. Discussion focused on the public voice of HDR UK (a trusted voice); co-branding communications with other organisations such as BioBank and Genomics England to gain international recognition; and building on successful activity that exists within our partner organisations for patient and public engagement.

Building strategic partnerships – **Jeremy Pearson (British Heart Foundation), Kay Boycott (Asthma UK), Tom Denwood (NHS Digital) and Chris Holmes (The Alan Turing Institute)** joined our panel, chaired by **John Danesh**, to highlight the importance of strategic partnerships with HDR UK. Each of the panel members stated their commitment to support HDR UK’s aims and outlined their approach. This included a joint research opportunity with Asthma UK focused on smart inhalers; collaboration with NHS Digital to ensure more effective access to data for research purposes (data services platform with top 30 datasets expected to launch by the end of 2018); creating a centre/network to accelerate link to make CVD research work; and a joint programme on AI/machine learning with the Turing Institute.



Workshop sessions: Defining national strategic challenges

One panel session and four workshops took place to enable colleagues to define the national strategic challenges for HDR UK.

1. Multi-omics and the phenome at scale

Adam Butterworth, Aroon Hingorani, Phil Quinlan, Cecilia Lindgren, Albert Tenesa and Mark Lawler joined a panel chaired by **John Danesh and Paul Elliot** to discuss the regional strengths in -omics for bridging gaps between genotype and disease, and opportunities for scaling across HDR UK. Discussion focused on co-ordinated generation of multi-omics data across Sites; joint analyses; discovery of novel pathways; and harnessing the power of the NHS to deliver patient/population cohorts at scale linked to biological samples.

2. Data analytics and NLP

Moderated by **Simon Ball and Mauricio Barahona** with talks from **Helen Parkinson, Richard Dobson, Georgios Gkoutos, Aiden Doherty, Cathie Sudlow and Ronan Lyons**.

All six Sites have strengths and want to be involved. Our action is to convene a team in next 2-3 weeks to engage with the wider community (including commercial, academic and international) on the topic. An invitation is extended to anyone across the Sites with an interest/expertise in this area.

3. Developing eCohorts for public health in 2040

Moderated by **David Ford** with talks from **Ruth Gilbert, Tony Brookes, Jim Davis, Colin McCowan and Dermot O’Reilly**.

Our current access to data is sufficient to start work in this area, and to consider the development of a trans-national cohort to look at the challenge of multi-morbidity.

4. EHR informed trials – making the UK more globally competitive

Moderated by **Max Parmar and Martin Landray** with talks from **Sylvia Richardson, Liam Smeeth, Keith Abrams, Louise Bowman, Ewan Pearson and Mark Lawler.**

We have many opportunities to work together and we should produce initial results in the next 1-2 years. Opportunities are 1) data is fundamental to clinical trials and 2) how we attract pharma to conduct clinical trials in the UK. Other outputs included the need to improve recruitment (site selection) and converting this into an industrial process; how we add value to phenotyping; and ensuring we have the right people involved.

5. Imaging linked to EHR at scale

Moderated by **Theo Arvanitis and Daniel Rueckert** with talks from **Fiona Gilbert, David Edwards, Theo Arvanitis, Tom Nichols and Simon Thompson.**

We should look at how imaging is linked in a co-ordinated way and how we harness other data that is connected to imaging. The outputs of data research need to be interpreted to inform care (currently we take anonymised data out of the clinical sphere and it's difficult to feed back in).

Priority setting

The focus for HDR UK as prioritised by colleagues at the end of the Scientific Retreat are categorised under the following themes:

- **Training and capacity building** – creating new career paths; offering job-shares and exchanges; exchange fellows between Sites; support along the whole pathway from early career, through to Masters students and post Docs; reward and recognition
- **Collaboration between Sites** – create projects across multiple Sites; identify exemplars of shared projects; broad engagement/inclusive network; build on existing expertise; avoid too much top-down; create a culture of sharing
- **Collaboration between HDR UK and national bodies** – work with local authorities, NHS, CCGs, patient groups, pharma, NICE, MHRA; shared datasets; genuine collaboration with vertical exemplars e.g. asthma and CVD
- **Become a trusted voice** – full engagement with patients and the public; co-produce research questions; trusted access and authentication; be transparent – show how we work and focus on how we are perceived; produce case studies to demonstrate value of data to patients and the public
- **Creating the right environment, systems and infrastructure** – find implementation projects that demonstrate early impact; more effective access to the data; link health data and molecular science at scale; be ambitious but realistic; balance between centralised and federated; leverage more funding; design the architecture for the data platform; mapping the current complex landscape.