

## EVENT REPORT

### DIH Programme Frontiers Meeting for Industry: 27 Nov 2018

#### Introduction

On 27 November 2018, over 90 colleagues from industry, the NHS and academia came together at the Royal College of Physicians to discuss the Digital Innovation Hub Programme. This meeting was part of a series of events to discuss and shape the design of a **UK-wide initiative to enable the safe and responsible use of health-related data at scale for research and innovation.**

Attendees included experts in health data from across industry sectors including pharmaceuticals, bio technology and health technology and represented both large and small organisations. The meeting was a mix of talks, expert panels and roundtable discussions. The slides presented at the event can be downloaded from our [Dropbox](#) folder.

The event is summarised in our [blog](#) by the Chair of the meeting Gerry Reilly, Chief Technology Officer.

#### Speaker highlights



**Lord James O'Shaughnessy**, Parliamentary Under Secretary of State for Health, opened the meeting. He talked about the opportunities we have in the UK for responsible use of data to improve the health and care of citizens. He challenged the audience to ensure our work passes a basic fairness test and to ensure we bring the public with us.



**Professor Andrew Morris**, Director of Health Data Research UK, highlighted the opportunities to transform health through responsible use of data for research and innovation. He acknowledged the complex landscape in which we're working and noted the tremendous skills and expertise across the NHS, academia and industry to work together as a community. The North Star for the Digital Innovation Hub Programme is to ensure that people benefit from earlier diagnosis and access to the best medicines.

Three excellent case studies were then presented to provide a flavour of how successful collaborations across industry, healthcare and academia have delivered benefits using health data.



**Martin Gibson, Chief Executive of North West eHealth**, talked about the Salford Lung Study and highlighted the challenges and learnings from this project. **Anne Bruinvels, Founder of Px Healthcare**, talked about the app (Owise), which links patient reported data with clinical records to help improve care and outcomes for people with breast cancer. **David Atkins, Chief Executive of Congenica**, explained that exposure to large scale data is invaluable in improving diagnosis of rare diseases.



A panel discussion with our three speakers and questions from the audience chaired by **Sarah Haywood, Chief Executive of MedCity**, raised the following points: the potential for scaling genomic data will be transformative in our understanding of disease; digital apps have huge potential and we need clarity on how these are assessed; the balance of regulation needs to be managed carefully; and; we need to be more forward-looking in the UK to maximise benefits of new technologies.

## Outputs of roundtable discussions

Following the opening talks, attendees participated in roundtable discussions across three key elements of the Digital Innovation Hub Programme (see below). The discussions on the tables were lively and surfaced many excellent ideas around commercial models, the need to modernise approaches to data access and the international challenges. A summary of the categories of suggestions is provided here:

### 1. What do industry researchers and innovators need from a UK-wide infrastructure?

- A common data model for interoperability, scale and innovation
- A single data catalogue, single help desk, and one clear entry point
- Access to data in real time; from multiple, linked sources; that's structured and curated; and with access to the people who can answer questions about it
- Assurances on data security and safeguarding
- Transparency to patients and the public on how and why data is used
- Clarity on the governance of data

### 2. What should the operating and commercial models prioritise?

- An equitable approach to IP
- Transparency
- A portfolio of operating models that does not discriminate
- Capability and capacity in the NHS to ensure benefits can be realised
- Clarity on information governance and appropriate consent, security and regulatory frameworks
- Consistent, transparent approach to accessing data

### 3. How do we ensure benefits are shared to deliver value to society?

- Communication and transparency – providing feedback to patients on the benefits of data use; explaining the role of industry in developing new medicines
- Create common metrics for success, including patient outcomes, job creation, boosting industry, driving down health inequalities
- Ensuring financial returns are reinvested and the NHS benefits
- Use data to drive down health inequalities



## Next steps

The feedback received at this meeting will be used by Health Data Research UK to shape the specification the architecture; data and technical standards and governance frameworks required to build a UK-wide health research data platform.

The design and dialogue stage will continue through to the end of April 2019 and during this time there will be further opportunities to contribute to the development of the Digital Innovation Hub Programme.

To find out about future events please visit our website at <https://www.hdruk.ac.uk/research/digital-innovation-hubs/events-and-opportunities/>

If you have any questions in the meantime, contact us by email at [enquiries@hdruk.ac.uk](mailto:enquiries@hdruk.ac.uk)