EVENT REPORT

Digital Innovation Hub Programme Frontiers Meeting for Patients, Public and Charities

Introduction

On 22 January 2019, Health Data Research UK brought together over 90 patient, public and charity representatives at the Wellcome Trust and via video conference to discuss the Digital Innovation Hub (DIH) 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.**

The meeting was a mixture of talks, a panel discussion, and roundtable discussions. It was chaired by independent coach Katherine Cowan, with facilitators at each table to guide discussions. Attendees included lay members of the public and NHS patients, and representatives from a range of health charities and interest groups.

The event was supported by the Association of Medical Research Charities. Gerry Reilly, Chief Technology Officer and Health Data Research UK, summarised the event in a blog.

Speaker highlights

Professor Andrew Morris, Director of Health Data Research UK, opened the meeting. He highlighted the importance of data, and the potential opportunities to transform health through its responsible use in research and innovation. He highlighted the importance of working with the public every at every step in this project, and the crucial role patients play. The ultimate goal of the Digital Innovation Hub Programme is to ensure that people benefit from discoveries that enable earlier diagnosis of disease and access to the best medicines.

Following Andrew's opening address was a **panel discussion** chaired by Katherine Cowan, which gave the attendees the opportunity to hear from a range of perspectives. The panel members were Edward Sherley-Price, former chair and founding member of the Genomics England Participant Panel, Kerina Jones, Associate Professor of Health Informatics at Swansea University, Alison Fox, Genomics England Participant Panel and Sarah Johnson from IQVIA. The themes that were discussed on the panel were why health data is important for research; what the risks might be and how Health Data Research UK can engage with and involve patients in this important work.

Outputs of roundtable discussions

Following the opening talk and panel discussion, attendees participated in lively roundtable discussions feeding in their thoughts, hopes and concerns. The animated discussions brought up some important ideas and suggestions for the goals of the DIH programme and the way it operates. A summary of the categories of suggestions is provided here:

What opportunities from health data do you find most exciting and engaging, and why?
- Patients are essential – they are crucial to unlocking data.
- Wider inclusion: making sure the more vulnerable communities have their views heard.
- Opportunities for mental health research.
- Patients want to see what the research achieves and ensure the research is implemented.

What would you see as the main risks and public concerns about health data, and why?
- Who owns the data? It is a 'scandal' that we don't control our data and can't donate it like blood.
- Worries that commercial interest is not aligned with patient benefit.
- Security around control of data and de-identification.
- Lack of inclusion of groups in discussion and even in the data. This must be inclusive, and we must reach out to engage where people are and not expect them to come to us.
- Be honest about the use of data, why and the benefits.

How can we generate public trust and confidence in how data is collected, used and safeguarded?
- Total transparency is key.
- We must make sure bad results are published alongside the good stuff.
- Clear and accessible information at all stages and listen to feedback.
- Educating people on why decisions (that are informed by data) have a real impact.
- HDR UK should have a Patient Charter.

What are the best ways to embed public engagement in the work of the Digital Innovation Hubs?
- Need to understand difference between patient engagement through charities and public engagement.
- Need to understand that not everyone wants to engage, but they should still be fully benefited by the research.
- Need innovative ways to reach out.
- Be respectful of people time and input.
- Keep a fresh perspective.
- Cannot be tokenistic, must be inclusive, involve large groups and continue through the programme. Must include feedback to show what has been impacted by the input received.

Next steps

The feedback received at this event will be used by Health Data Research UK to shape how to embed a public voice into the Digital Innovation Hub framework.

This phase of the programme 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: www.hdruk.ac.uk/research/digitalinnovation-hubs/events-and-opportunities

If you have any questions in the meantime, contact us by email at enquiries@hdruk.ac.uk