

Realising patient and NHS benefits from health and care data – From policy to practice

22nd January 2020, Academy of Medical Sciences

Objectives:

To ensure that we derive appropriate value for all from use of health and care data, by:

1. Bringing together key stakeholders to share perspectives, lessons learned, motivations and objectives.
2. Defining the practical steps that reflect agreed guiding principles (refer to pre-reading material), and identifying any aspects that merit reconsideration, to enable effective translation of policy into practice.
3. Identifying areas where experience is still developing (i.e. 'known unknowns') and agreeing a target timeframe for their resolution.

Outputs:

- Development of a guiding framework to manage risk and value sharing between partners
- A CASMI/HDR UK/AMS joint workshop report on the meeting, focussed on realising the objectives above
- A network of engaged attendees for future communications (subject to appropriate consent)

8:30am	REGISTRATION & REFRESHMENTS	(30)	
9:00am	Welcome and introduction	(5)	John Tooke, CASMI
Session 1 Part 1: From policy to practice: Three perspectives			
Chair: Ara Darzi			
9:10am	Health Data Research Hubs: commercial challenges	(15)	Andrew Morris, HDR UK
9:25am	From Policy to Practice: the NHS strategy for making better use of data for research	(15)	Dido Harding, NHSE & NHSI
9:40am	Findings of the UPD commissioned public dialogue on commercial models for accessing NHS data	(15)	Natalie Banner, UPD
9:55am	Questions & Answers	(15)	
Session 1 Part 2: Panel Discussion - Upholding the ethos of the NHS: the purposes, benefits and values of using health data			
Chair: Carol Dezateux			
10:10am	<p><i>A panel to explore the public, patient and societal context for commercial access to health and care data and the acceptability criteria for commercial access to health and care data.</i></p> <ul style="list-style-type: none"> • <i>How do we ensure appropriate benefit share across the health and care system from these approaches?</i> • <i>How do we ensure appropriate patient and public involvement and transparency to maintain trust?</i> 	(40)	<p>Natalie Banner, UPD Hilary Newiss, National Voices Aisling Burnand, AMRC Amy Darlington, Imperial College Health Partners and OneLondon's Public Engagement Programme Jonathan Montgomery, Healthcare law</p>
10:50am	BREAK	(15)	

Session 2: Practical interpretations and learning from experience

Chair: Julie Moore

11:05am	The value of data	(15)	Bryan Williams, UCLH BRC
11:20am	Preparing NHS data sets for entering commercial partnerships	(15)	Pearse Keane, Moorfields <i>on curation for Google DeepMind partnership</i>
11:35am	Pharmaceutical Industry perspective	(15)	Carole Longson, Chief Scientific Officer, ABPI
11:50am	Panel discussion: Perspectives on sustainability opportunities across the Health Data Research Hubs	(55)	Chair: Julie Moore, Warwick University 7 health data research hub leads: Charlie Davie, DATA-CAN Axel Heitmueller, Discover-NOW Aziz Sheikh, BREATHE John Bradley & Mary Kasanicki, Gut Reaction Alastair Denniston, INSIGHT Martin Landray, NHS DigiTrial Elizabeth Sapey, PIONEER

12:45pm LUNCH (with hub stands) (60)

Session 3: Building a framework – interactive session

Chair: Caroline Cake

1:45pm	Overview of commercial framework: objectives and questions	(15)	Caroline Cake, HDR UK
2:00pm	Break-out workgroups <i>Review draft commercial framework (pre-reading) and hub use cases (pre-reading):</i> <ul style="list-style-type: none"> Given the types of use cases that the hubs are envisaging, what are the benefits and risks associated with the proposed Commercial Framework, and have we missed any important elements? How should we engage and involve members of the public, patients and practitioners in the ongoing development and delivery of this approach? 	(50)	<i>Five break-out groups:</i> <ul style="list-style-type: none"> Each delegate is assigned to a group, indicated by the colour on their badge. Each group will go to a different room to discuss and reflect on discussions. Each group will have a facilitator and note-taker present to record discussion and feedback to the delegation.
2:50pm	Groups return to the Council chamber	(5)	All delegates to return to the main room for the reporting back session.
2:55pm	Reporting back session	(20)	Group facilitators report back key points

3:15pm BREAK (30)

Session 4: Feedback and closing remarks

Chair: John Tooke

3:45pm	Review of key themes and additional discussion	(45)	The co-chairs present the collated feedback from the break-out sessions and invite additional comments from the delegation.
4:30pm	Closing remarks	(15)	John Tooke and Andrew Morris

4:45pm MEETING ENDS