

Final Programme

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 the key stakeholders involved 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 Sam Roberts, Accelerated Access Collaborative
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	<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>	(40)	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
	<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> 		

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
11:50 am	Panel discussion: Perspectives on sustainability opportunities across the Health Data Research Hubs <i>Hubs to provide a high-level overview of their service, example use cases and audience to Q&A on hub emerging approaches to sustainability.</i>	(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 role	(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"> <i>What are the values and risks associated with each of these models?</i> <i>Are there additional models that should be considered?</i> <i>Are there particular models that should be avoided or discouraged and if so why?</i> 	(75)	<i>Five breakout groups of ~16.</i>
3:15pm	BREAK	(30)	
Session 4: Feedback and closing remarks			
Chair: John Tooke			
3:45pm	Presentation of collated framework and additional discussion	(45)	<i>The co-chairs present the collated framework from the break-out sessions and invite additional comments</i>
4:30pm	Closing remarks	(15)	John Tooke and Andrew Morris
4:45pm	MEETING ENDS		