

Patient data - balancing access and protection

All talk and no access?

TUESDAY, 07 MAY 2019 | 10:30 to 16:00

(REGISTRATION & REFRESHMENTS from 10:00 to 10:30)

The Wesley Hotel, 81-103 Euston Street, London, NW1 2EZ

10:00 - 10:30	Registration and refreshments
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Chair's welcome

10:30 - 10:40	Opening remarks and introduction	Mike Birtwistle Founder, Incisive Health
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Session 1 - The challenges for data controllers

10:40 - 10:55	Setting the scene Highlighting the data access problems that researchers are experiencing	Richard Welpton Senior Data Manager, The Health Foundation
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10:55 - 12:00	Panel with audience questions & answers What data is held about patients? What are the roles, controls and processes for access to this data?	<ul style="list-style-type: none">Garry Coleman Service Director (ai), Data Dissemination, NHS DigitalKirsty Irvine Chair, Independent Group Advising on the Release of Data, NHS DigitalTariq Malik Lead for Office for Data Release, Public Health EnglandJanet Messer Director of Approvals Service, Health Research Authority
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12:00 - 13:00	Lunch and networking
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Session 2 - The views of patients, carers, the public - part 1

13:00 - 13:05	Introduction	Mike Birtwistle Founder, Incisive Health
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13:05 - 13:35	Round Table discussions Facilitated group work to discuss the problems heard so far and come up with questions, suggestions, solutions or actions, to feed into the next panel discussion.
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Session 2 - The views of patients, carers, the public - part 2

13:35 - 14:15	Panel Discussion Feedback from the table discussions will be put directly to the panel for their views. <ul style="list-style-type: none">• Adam Glaser Professor of Paediatric Oncology and Late-Effects, University of Leeds• Phil Booth Coordinator, MedConfidential• Natalie Banner Lead, Understanding Patient Data• Richard Stephens Patient Advocate, use MY data
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14:15 - 14:35	Refreshment break
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Session 3 - Exploring available options

14:35 - 14:45	Introduction Mike Birtwistle Founder, Incisive Health
14:45 - 15:45	Panel Discussion with audience questions & answers The panel will contrast research data access in the different parts of the UK, including opportunities to learn. Given what has been heard so far, how are the new developments and partnerships in health research going to make a difference? What actions from this workshop do they need to take forward? <ul style="list-style-type: none">• Alex Bailey Programme Manager, Regulatory Support Centre, Medical Research Council• Amanda White Director of Communications and Engagement, Health Data Research UK• Richard Stephens Patient Advocate, use MY data

Session 4 - How can we ensure this workshop makes a difference?

15:45 - 16:00	Introduction Mike Birtwistle Founder, Incisive Health
	Are we clear about the outcomes? What are the commitments from the data access representatives (that we have heard from today)? What are the next steps and how do we ensure these happen? What are our take-home messages?

16:00	Close
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