



Registration & networking on Data Street

Palm Court

09:00 - 10:00 Registration, refreshments and a walk down Data Street

Conference Opening

Queens Ballroom

10:00 - 10:10 Welcome and setting the scene

Richard Stephens
Chair, Executive Group
use MY data

Patient Data Policy in the UK - Plenary session

Queens Ballroom

10:10 - 11:10 How do we achieve a National Health Data Service for the UK now that we have a national Health Data Research Service?

Introduction

What does use MY data want to see happen, to unify patient data across the UK? (5)

Two perspectives

What is our ambition for using your patient data? How do we intend to go about this and what do we see as the key milestones and challenges, in achieving this ambition? (10)

What do we need to do, to make people more trusting about the use of their patient data? (10)

Co-Chairs -
Debbie Keatley
Member, use MY data &
Chris Carrigan,
Data Adviser,
use MY data

Ming Tang, Chief Data
and Analytics Officer,
NHS England

Dr Nicola Byrne,
National Data Guardian
for Health & Adult
Social Care, England

The UK perspective

Moderated panel discussion with audience Q&A (30)

Session summary and close (5)

Speakers are joined by:

Roger Halliday,
Chief Executive,
Research Data Scotland

Professor Mark Lawler
Queens University
Belfast

Alex Newberry,
Head of Research
Involvement,
Governance &
Informatics
Health and Care
Research Wales

Refreshments on Data Street

Palm Court

11:10 - 11:30 Tea & coffee and leg stretch - meet the Neighbours with a quick stroll down Data Street

Queens Ballroom

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| 11:30 - 12:15 | <p>The media, the public, patient data and us - how can we influence the media to publish stories that celebrate using our patient data?</p> <p>A fireside chat featuring Rory Cellan-Jones, in conversation with use MY data & the Association of the British Pharmaceutical Industry</p> <p>What skills do we all need to be more effective patient data ambassadors, champions and advocates - what Rory has learned, approaches to take and what not to do!</p> <p>Q&A with the audience</p> | <p>Chair - Anna Steere, Head of Understanding Patient Data</p> <p>Rory Cellan-Jones Member, use MY data / Independent journalist</p> <p>Yvonne Adebola Executive Group Member, use MY data</p> <p>Dr Jim Squires, Head of Data & Digital Policy, The Association of the British Pharmaceutical Industry</p> |
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Lunch with networking on Data Street

Palm Court

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| 12:15 - 13:25 | Lunch, exhibition and networking - meet the neighbours and stroll down Data Street |
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Parallel Sessions

| | Queens Ballroom | John Charles 1&2 | John Charles 3 |
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| 13:25 - 13:55 | Stream 1 - Debate | Stream 2 - Diversity and quality of health data | Stream 3 - Workshop and shaping strategies |
| | <p>How can we establish a UK-wide data environment to help in the research of less common diseases, where a multi-nation view is essential?</p> <p>This debate will have a rare disease focus on the importance of sharing data internationally, led by a patient expert, using worked examples to explore safeguards, consent issues across nations and patient involvement. The panel will address changes, improvements, opportunities and plans, including active patient involvement.</p> <p>Session Lead: Emma Kinloch, Member, use MY data & Founder, Salivary Gland Cancer UK</p> <p>Panellists: Jo Gumbs, Executive Group Member, use MY data & Rebecca Cosgriff, Scientific Director, Data Partnerships & Portfolio Strategy, LifeArc</p> | <p>Ethnicity data in the UK is gathered in routinely collected data and electronic health records (EHRs). But how complete and accurate is this data?</p> <p>What are the variations in practices for collecting ethnicity data across different countries, and what are the issues related to the perceived trustworthiness of institutions and the lack of transparency around this data use?</p> <p>Session Lead: Dr Ash Routen, Research Fellow, University of Leicester</p> | <p>Big Data for Complex Disease</p> <p>Big Data for Complex Disease is one of five driver programmes that are part of Health Data Research UK's core funding. The goal is to work across UK population level data to support the prevention, diagnosis and treatment of cancer, cardiovascular disease and other relevant conditions. This workshop gives the opportunity for researchers to share plans and for delegates to provide feedback, to shape the direction of their work.</p> <p>Session Leads: Amy Hodgkinson, PPIE Manager, Health Data Research UK & Alexis Webb, Senior Programme Manager, Health Data Research UK</p> |

Parallel Sessions

| 14:00 - 14:30 | Queens Ballroom (TBC) Stream 4 - Roundtables | John Charles 1&2 (TBC) Stream 5 - Discussion | John Charles 3 (TBC) Stream 6 - Innovation |
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| | <p>Roundtable discussions about patient data</p> <p>Dynamic tables, each with a different patient data topic - visit two tables (10 minutes at each) for sparkly discussions.</p> <p>APBI</p> <ul style="list-style-type: none"> Communicating the public benefits of pharmaceutical industry use of health data <p>Cancer Research UK</p> <ul style="list-style-type: none"> Theme to follow <p>The Participant Panel of Genomics England</p> <ul style="list-style-type: none"> Hear how the Participant Panel, a key advisory group for Genomics England, influences how participant data is used <p>Dr Stewart Manning GP (retired) & Member, use MY data</p> <ul style="list-style-type: none"> Using data and statistics with groups whose first language is not English and groups with learning disabilities <p>National Pathology Imaging Cooperative (Leeds), Patient Public Advisory Group</p> <ul style="list-style-type: none"> The importance of PPIE for digital pathology (and AI in pathology) <p>Ming Tang, NHS England</p> <ul style="list-style-type: none"> 10 Year Health Plan working group - Data & Technology - "This group will consider how the NHS should focus its resources to ensure it maximises the impact of data and technology. This includes how we can make life easier and more productive for those who work in the NHS, and how we can use data more effectively to plan, manage and deliver services" <p>Macmillan Cancer Support</p> <ul style="list-style-type: none"> How should we measure what matters to people with cancer? Share your views on the best ways for the NHS and charities to collect data, to better understand you and your needs. | <p>How to involve people in their data choices</p> <p>What happens when you give people a choice about whether they want their data to be used?</p> <p>Hear from the patients involved about the approach that Leeds took in including patients throughout the design of a proposed research programme with a commercial company, and how that shaped the eventual solution.</p> <p>What do you think of the approaches taken, and the findings?</p> <p>Session Leads: Linda Galbraith, Member of Flatiron Patient Voices Panel & Name TBC Leeds Teaching Hospitals NHS Trust</p> | <p>Health Data Literacy in younger people</p> <p>Is it possible to engage young, school-aged people about the potential uses of their health data? Should we get them interested? What's the benefit of doing so?</p> <p>Hear how Sheffield Springs Academy has engaged its students about health data literacy. How did the initiative start - can it be an exemplar? What are the results?</p> <p>Session Lead: Dr Richard Fitton, GP (retired)</p> |

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| <p>Office for National Statistics</p> <ul style="list-style-type: none"> Theme to follow <p>South West Secure Data Environment (SDE)</p> <ul style="list-style-type: none"> Hear from the core Digital Critical Friends - patient and public representatives - about their involvement and work with the SDE <p>Promptly Health</p> <ul style="list-style-type: none"> Building Trust: How patients, NHS and industry can collaborate on safe health data use <p>UK Biobank</p> <ul style="list-style-type: none"> Theme to follow <p>UCL Partners Health Innovation</p> <ul style="list-style-type: none"> Learn how the Health Innovation Network, in London, involved their local public in the design and delivery of the Artificial Intelligence for Urgent and Emergency Care programme. The programme uses anonymised and confidential data to identify potential at-risk patients via an Artificial Intelligence algorithm. | | |
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Networking on Data Street

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| Palm Court | |
| 14:30 - 15:00 | Tea, coffee and networking - meet the neighbours and stroll down Data Street |

Patient Data Soapbox

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| Queens Ballroom | | |
| 15:00 - 15:20 | <p>It's Your Shout! - Our Patient Data Soapbox</p> <p>Hear all about it! Five speakers will have the floor for two minutes each, to deliver their view on celebrating the use of patient data.</p> <p>Please vote for the speaker who makes the most impact on you - the winning speaker and one lucky voter will receive a prize!</p> | <p>Facilitator - David Snelson, Executive Group Member, use MY data</p> <p>Bell ringer - Moira Auchterlonie, Member, use MY data</p> |

Plenary session - Innovation and patient data

Queens Ballroom

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| 15:20 - 16:05 | Me, my data and (A)I Introduction (5) Delivering the benefits of AI for the NHS (15) <ul style="list-style-type: none">- How do we move AI from proven in the lab to delivering benefits at scale in the wider NHS- How do we influence public attitudes towards the need, role and patient benefits of AI in patient data- Can we use AI for exploring NHS patient data to see if there are signals in pathways that we might currently miss - are there things that predict treatment failures or relapses or risks? Q&A and discussions (20) Summary and Close (5) | Chair - Westley Igbo, Senior Communications and Engagement Manager DARE UK Pearse Keen Professor of Artificial Medical Intelligence at UCL Institute of Ophthalmology Joined by: John Marsh, Executive Group Member, use MY data & Name TBC Commercial company |
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Closing talk - What next?

Queens Ballroom

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| 16:05 - 16:15 | Summary of the day and take-home tasks | Richard Stephens Chair, Executive Group use MY data |
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Data Street Party - meet and greet on the street

Palm Court

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| 16:15 - 17:00 | One last stroll down Data Street for networking with drinks & nibbles |
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