



**Registration & networking on Data Street**

**Palm Court**

**09:00 - 10:00** Registration, refreshments, then take a stroll down Data Street

**Conference Opening**

**Queens Ballroom**

**10:00 - 10:10** Welcome and setting the scene - have your Slido ready!

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)

**Perspectives from NHS England and the National Data Guardian**

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 -  
Jo Gumbs,  
Executive Group,  
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

**Can the United Kingdom unite around our data?**  
Moderated panel discussion with audience Q&A (30)

**Summary and takeaway actions for speakers and delegates (5)**

Speakers are joined by:

Roger Halliday,  
Chief Executive,  
Research Data Scotland

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

**Refreshments on Data Street**

**Palm Court**

**11:10 - 11:30** Refreshments, leg stretch and a quick neighbourly visit to Data Street

## Queens Ballroom

11:30 - 12:15	<p><b>The media, the public, patient data and us - how can each one of us influence the media to publish stories that celebrate using our patient data?</b></p> <p>A fireside chat featuring journalist, broadcaster and use MY data Member Rory Cellan-Jones, in conversation with Yvonne Adebola from our Executive Group, and Jim Squires from the ABPI offering the viewpoint from the pharmaceutical industry.</p> <p>What skills do we each need to be more effective patient data ambassadors, champions and advocates. What Rory has learned - approaches to take and what not to do! And, how we might we work more closely with the pharmaceutical industry - if we wish to do so?</p> <p>Q&amp;A with the audience</p> <p><b>Summary and takeaway actions for speakers &amp; delegates (5)</b></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, use MY data</p> <p>Dr Jim Squires, Head of Data &amp; Digital Policy, The Association of the British Pharmaceutical Industry</p>
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## Lunch with networking on Data Street

## Palm Court

12:15 - 13:25	Lunch, exhibition and more opportunities to meet new friends, strolling down Data Street
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## Parallel Sessions

	Queens Ballroom	John Charles 1&2	John Charles 3
13:25 - 13:55	<b>Stream 1</b> <b>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?</b>	<b>Stream 2</b> <b>Ethnicity data in the UK is gathered in routinely collected data and electronic health records (EHRs). But how complete and accurate is this data?</b>	<b>Stream 3</b> <b>Big Data for Complex Disease</b>
	<p>This discussion will have a rare disease focus on the importance of sharing data internationally, led by a patient expert, using worked examples to explore safeguards and consent challenges across nations. The panel will address changes, improvements, opportunities and plans, including active patient involvement.</p> <p>Session Lead: Emma Kinloch, Member, use MY data &amp; Founder, Salivary Gland Cancer UK</p> <p>Panellists: Jo Gumbs, Executive Group Member, use MY data &amp; Rebecca Cosgriff, Scientific Director, Data Partnerships &amp; Portfolio Strategy, LifeArc</p>	<p>What are the variations in practices for collecting ethnicity data across different countries, what are the challenges related to the perceived trustworthiness of institutions and the lack of transparency around this data use, and what suggestions can delegates make to improve the situation?</p> <p>Session Lead: Doreen Tembo, Head of Public Involvement and Engagement, Health Data Research UK &amp; Strategic Lead, PEDRI</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 &amp; Alexis Webb, Senior Programme Manager, Health Data Research UK</p>

## Parallel Sessions

	Queens Ballroom (TBC)	John Charles 1&2 (TBC)	John Charles 3 (TBC)
14:00 - 14:30	Stream 4 Roundtable discussions about patient data	Stream 5 How to involve people in their data choices	Stream 6 - Health Data Literacy in younger people
	<p>Dynamic tables, each with a different patient data topic - visit two tables (10-12 minutes at each) for sparky discussions.</p> <p><b>APBI</b></p> <ul style="list-style-type: none"> <li>Communicating the public benefits of pharmaceutical industry use of health data</li> </ul> <p><b>Cancer Research UK</b></p> <ul style="list-style-type: none"> <li>What does ethical and responsible use of AI mean to you?</li> </ul> <p><b>The Participant Panel of Genomics England</b></p> <ul style="list-style-type: none"> <li>Hear how the Participant Panel, a key advisory group for Genomics England, influences how participant data is used</li> </ul> <p><b>Dr Stewart Manning GP (retired) &amp; Member, use MY data</b></p> <ul style="list-style-type: none"> <li>Using data and statistics with groups whose first language is not English and groups with learning disabilities</li> </ul> <p><b>National Pathology Imaging Cooperative (Leeds), Patient Public Advisory Group</b></p> <ul style="list-style-type: none"> <li>The importance of PPIE for digital pathology (and AI in pathology)</li> </ul> <p><b>Ming Tang, NHS England</b></p> <ul style="list-style-type: none"> <li>10 Year Health Plan working group - Data &amp; 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"</li> </ul> <p><b>Macmillan Cancer Support</b></p> <ul style="list-style-type: none"> <li>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</li> </ul>	<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 Teaching Hospitals Trust took in including patients throughout the design of a proposed research programme with a commercial company (Flatiron), and how that shaped the eventual solution.</p> <p>What do you think of the approaches taken, and the findings? What role could you play if your NHS Trust wanted to do something similar?</p> <p><b>Session Leads:</b> Linda Galbraith, Member, Flatiron Patient Voices Panel &amp; Dr Helen Bulbeck, Member, Flatiron Patient Voices Panel</p>	<p>Hear how Sheffield Springs Academy has engaged its students about health data literacy.</p> <p>How did the initiative start? How does it fit with other school-based data activities (e.g., safeguarding)?</p> <p>What are the results and could this be an exemplar for others?</p> <p><b>Session Lead:</b> Dr Richard Fitton, GP (retired)</p>

	<p>understand you and your needs.</p> <p><b>Office for National Statistics</b></p> <ul style="list-style-type: none"> <li>Unlocking insights through health to non-health data linking: Discover how ONS is responsibly connecting data sets for evidence-based policy-making and public understanding.</li> </ul> <p><b>South West Secure Data Environment (SDE)</b></p> <ul style="list-style-type: none"> <li>Hear from the core Digital Critical Friends - patient and public representatives - about their involvement and work with the SDE</li> </ul> <p><b>Promptly Health</b></p> <ul style="list-style-type: none"> <li>Building Trust: How patients, NHS and industry can collaborate on safe health data use</li> </ul> <p><b>UK Biobank</b></p> <ul style="list-style-type: none"> <li>What counts as health data in the digital age?</li> </ul> <p><b>UCL Partners Health Innovation</b></p> <ul style="list-style-type: none"> <li>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.</li> </ul>		
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### Networking on Data Street

#### Palm Court

14:30 - 15:00	Refreshments and rambling - which part of Data Street have you still to visit?
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### Patient Data Soapbox

#### Queens Ballroom

15:00 - 15:20	<p><b>It's Your Shout - Our Patient Data Soapbox</b></p> <p>Hear all about it!</p> <p>Five speakers will have the floor for two minutes each, to deliver their view on celebrating the use of patient data.</p>	<p>Facilitator - David Snelson, Executive Group Member, use MY data</p> <p>Bell ringer - Moira Auchterlonie, Member, use MY data</p>
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## Plenary session - Innovation and patient data

Queens Ballroom		
15:20 - 16:05	<p><b>Me, my data and (A)I</b> Introduction (5)</p> <p>Delivering the benefits of AI for the NHS (15)</p> <ul style="list-style-type: none"> <li>- How do we move AI from proven in the lab to delivering benefits at scale in the wider NHS</li> <li>- How do we influence public attitudes towards the need, role and patient benefits of AI in patient data</li> <li>- 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?</li> </ul> <p>Q&amp;A and discussions (20)</p> <p>Summary and take-away actions for speakers &amp; delegates (5)</p>	<p>Chair - Westley Igbo, Senior Communications and Engagement Manager DARE UK</p> <p>Pearse Keane Professor of Artificial Medical Intelligence at UCL Institute of Ophthalmology</p> <p>Joined by: John Marsh, Executive Group, use MY data &amp; James Peach, Chief Operating Officer, OutSee Ltd / Associate Member, use MY data</p>

## Closing talk - What next?

Queens Ballroom		
16:05 - 16:15	Summary of the day and take-home tasks	Richard Stephens Chair, Executive Group use MY data

## Data Street Party - meet and greet on the street

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