

The patient voice in the expanding data world

Thursday, 22 November 2018

10:00 to 16:00

John Charles Suite, Queens Hotel, City Square, Leeds LS1 1PJ

10:00 – 10:30 Registration with refreshments

10:30 – 10:35 Chair's welcome & overview of the day

Workshop Chair Dr Helen Bulbeck
Patient Advocate, use MY data
Director, brainstrust

10:35 – 11:20 **Session 1**
Can Data Volunteering, Data Donation and the National Data Opt-out empower citizens to optimise data use? We have organ donation, but not data. Why?

Speaker Emma Summers
Programme Delivery Lead – McNeil Review Implementation &
Data Volunteering & Data Donation Discovery Project, NHS Digital

11:20 – 12:05 **Session 2**
The Local Health and Care Record Exemplars (LHCRE) programme – the joined-up Yorkshire and Humber engagement

Speaker Rebecca Nichells
Communications Lead, Yorkshire & Humber Local Health & Care Record

12:05 – 13:00 Lunch and networking

13:00 – 14:15	Session 3 Auditing your own health record – how, what, why? What is proposed, what are the plans, and how do you get involved?
Session Chair	Will Turner User Researcher, Experience Design, Digital Delivery Centre, NHS Digital
14:15 – 14:30	Refreshment break
14:30 – 15:15	Session 4 General Data Protection Regulation, Common Law, Consent – where are researchers struggling and how could the patient voice help?
Speaker	Professor Adam Glaser Leeds Institute of Cancer & Pathology Research Lead, Leeds Children's Hospital
15:15 – 15:50	Session 5 Take-aways and next steps – how do we use what we've learned today to make a difference?
Workshop Chair	Dr Helen Bulbeck Patient Advocate, use MY data Director, brainstrust
15:50 – 16:00	Closing remarks
Speaker	Chris Carrigan Expert Data Adviser, use MY data