

Inside Research: Identifying inequalities in health and care: the power of health data, 2 March 2022.

Summary of discussion in the breakout sessions

In the breakout sessions of this Inside Research seminar ([see programme](#)) each group was invited to explore the following questions:

1. How would you like to see health data used to address health and care inequalities? What areas of care should we target?
2. How should researchers communicate and engage with the public on the use of routinely collected health data?

Here is a summary of the discussion from the breakout groups around these questions.

Q: How would you like to see health data used to address health and care inequalities?

- Establish where health inequalities are. Sometimes there isn't an effective data link between departments (eg mental health and physical health) to give proper overview of inequalities
- Consider linking data (eg on ethnicity) with patient reported outcome measures and quality of life information, to help focus on what matters most to people
- What principles should be used to decide what is researched? Perhaps areas in which certain groups have poorer outcomes than others
- One of the issues with health inequalities is the uneven representation in data. Especially when it comes to ethnicity. We need to look at how people's ethnicity is classified
- Informatics is reliant on good quality data in the record. This data relies on people actually being in the service – which excludes some marginalised people
- Not every patient is registered for primary care services (speaking for Canada). In the UK, the government provides incentives for people to register, including the homeless, who can use their GP practice as an address
- Negative bias towards minorities makes those minorities suspicious of health data collection. Two clinicians spoke of their difficulty to get buy-in from patients about why demographic data is collected
- Clinicians need to be aware that sensitivity is required when collecting data from patients
- In the new NHS app, it is now easier for patients to see what data is available against their record. Patients can raise any inaccuracies in their records
- Advances in technology have opened possibilities for research using health data which would have been impossible a few years ago; patient and public contributors can have a valuable input
- While levels of involvement in research vary, there are examples of good practice (eg involving black men with cancer from the outset in creating support groups)

Q: What areas of care should we target?

- Significant inequalities in access to digital dialysis, especially for renal replacement therapy and kidney transplants
- Elderly care: diabetes, kidney and heart care inequalities
- Patient safety: address negative outcomes for vulnerable adults
- Eating disorders (ED) – currently the focus is on a narrow definition of serious mental illness. ED is overlooked. Better use of health data could allow early screening, using data in the health record to inform earlier interventions - to help primary care colleagues and Black, Asian and minority ethnic patients, who often struggle coming forward with eating issues

- Potentially also linking diabetes and ED – a large comorbidity

Q: How should researchers communicate and engage with the public on the use of routinely collected health data?

Approaches to communicating and engaging with the public:

- Important to get more input from diverse communities, patients, service users and carers
- Important to target those difficult to reach and harder to engage. Broaden engagement to places like gaming platforms where people are away from a health context
- The power of data doesn't tend to reach staff on the ground. This is needed for quality inputting of data, and recruitment to trials; staff can reach out to the community and explain the benefits. Getting information to local GP practice staff and clinicians as well as patients is important
- For people who are suspicious about data use, larger scale comms with different communities may be helpful
- Recent experience with commissioners and other service user forums has shown audiences are interested in place-based conversations. Present research in local areas and attract community interest. Researchers can also show that they're interested in the population in front of them
- Frame it to make it relevant to individuals

Communicating the benefits of collecting health data:

- Explain to the public how researchers are trained on using data and that it is all anonymised
- Produce information sheets, posters, web content, informed by health professionals
- Distribute leaflets and posters at churches, libraries and other public places
- Use public webinars to engage: explain to people what the research is for and show what we have found based on using their data for research
- Get the public on board with big changes rather than announcing things without context (see 'Great Data Grab' story of 2021)
- We need to increase awareness of health data being used by health care professionals for research, including big pharma companies
- Success stories need to show how it is making a difference to ordinary people

Addressing issues of trust:

- People fear that data is used by private pharmaceutical companies. It should be made clear at all stages that data is for analysis only and it should never be identifiable
- One group member felt that pharma was unfairly stigmatised and that its contribution to developing new drugs should be more widely acknowledged
- People don't always trust their GP or health professionals, or indeed government, so it is important to work with local communities, community leaders and local groups
- Some people, for example those with mental health issues or illegal immigration status, exclude themselves from registering for services for fear of being deported or stigmatised. Clinicians need to be transparent and explain to patients how the data is going to be used, stressing that it is not shared with the police, tax office, immigration service, or pharmaceutical companies
- If the public feel suspicious about their health data being collected, they can be directed to [Healthwatch](#)