

Alliance Board Meeting – Jan 2021

Data Access Registers

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20 January 2021

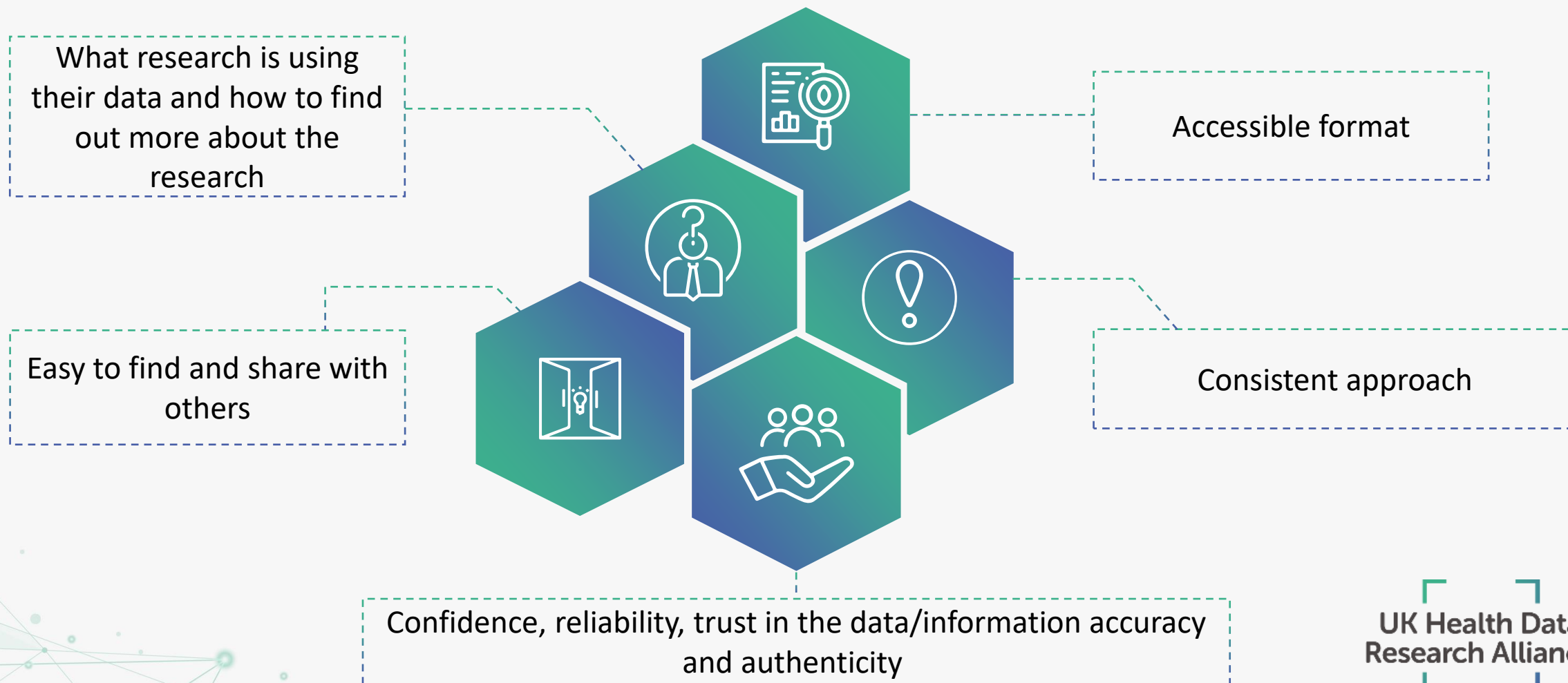


Why we need to work on Data Access Registers

- Our Alliance's Letter of Intent highlights transparency of governance and operations as one of its founding principles. It sets out that one way in which members will demonstrate the principle of transparency is by (amongst other things) publishing a register of projects accessing the data under their custodianship.
- There is a big opportunity, through data access registers to:
 - generate insight into data use and data access
 - build public trust and even advocates for the access and use of data
- Publicly available information related to approved data access requests varies significantly. We estimate that around 50% of Alliance members appear to have a public access request register and that these:
 - Are presented in a range of formats (spreadsheets, word documents, embedded on webpage)
 - Have different information on approved requests
- To fulfil our commitment to transparency we need to increase the number, quality and accessibility of public data access registers.
- Public and Patient Involvement and Engagement has the potential to shape best practice for data access registers.
- The Gateway offers a unique opportunity to bring together information about data access that is initiated via the Gateway and requests made directly to the custodian.
- This work picks up from where we left off just before the pandemic (January 2020 board meeting)

What do patients and the public want to see?

There were a number of requirements that they believe were necessary to ensure public accountability and transparency.



Next steps to move this forward...

1. Alliance members will be sent a simple survey to gather information on existing practices – **survey will be sent w/c 25 Jan 2021**
2. Alliance members to share any existing publicly available data access registers (provide links via the survey) – we propose to link through to them from Alliance member collections on the Gateway (where established) – **March 2021**
3. Run a series of workshops with data custodians and researchers to understand their requirements and any concerns – **beginning of March 2021**
4. Use workshops to determine how we can work together to 'close the loop' with Data Access Registers and role of Gateway. Ideas include:
 - Co-creating a standard for Data Access Registers
 - Exploring ways to increase transparency through the Gateway