Data Access Management

Alliance Board meeting
29 April 2020

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UK Health Data
Research Alliance

The Alliance delivery sub-groups

Data standards and quality
Oversee, coordinate, and produce guidance and policy regarding data quality, standards, dataset publishing, data provenance, ontology / terminology services and use.

Aligning approaches to trusted research environments
Agree on requirements for secure analytic environments where researchers can bring analyses and algorithms to the data.

**Engaging and involving practitioners, patients and the public**
Understand the interests and values of practitioners, patients and the public in health data.

Promoting participation and improving access
Ensure consistency and harmonise principles, definitions, process steps to develop a best practice for assessing requests to access UK health data.

Supporting Health Data Innovation Gateway
A one-stop-shop destination to discover, access, manage and drive the ethical and safe use of data building on existing infrastructure and best practice.
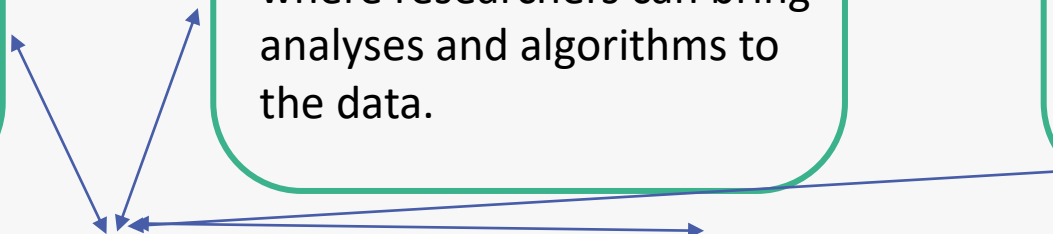
"Considering your needs for accessing health data in future, where do you feel you would need the most support?"
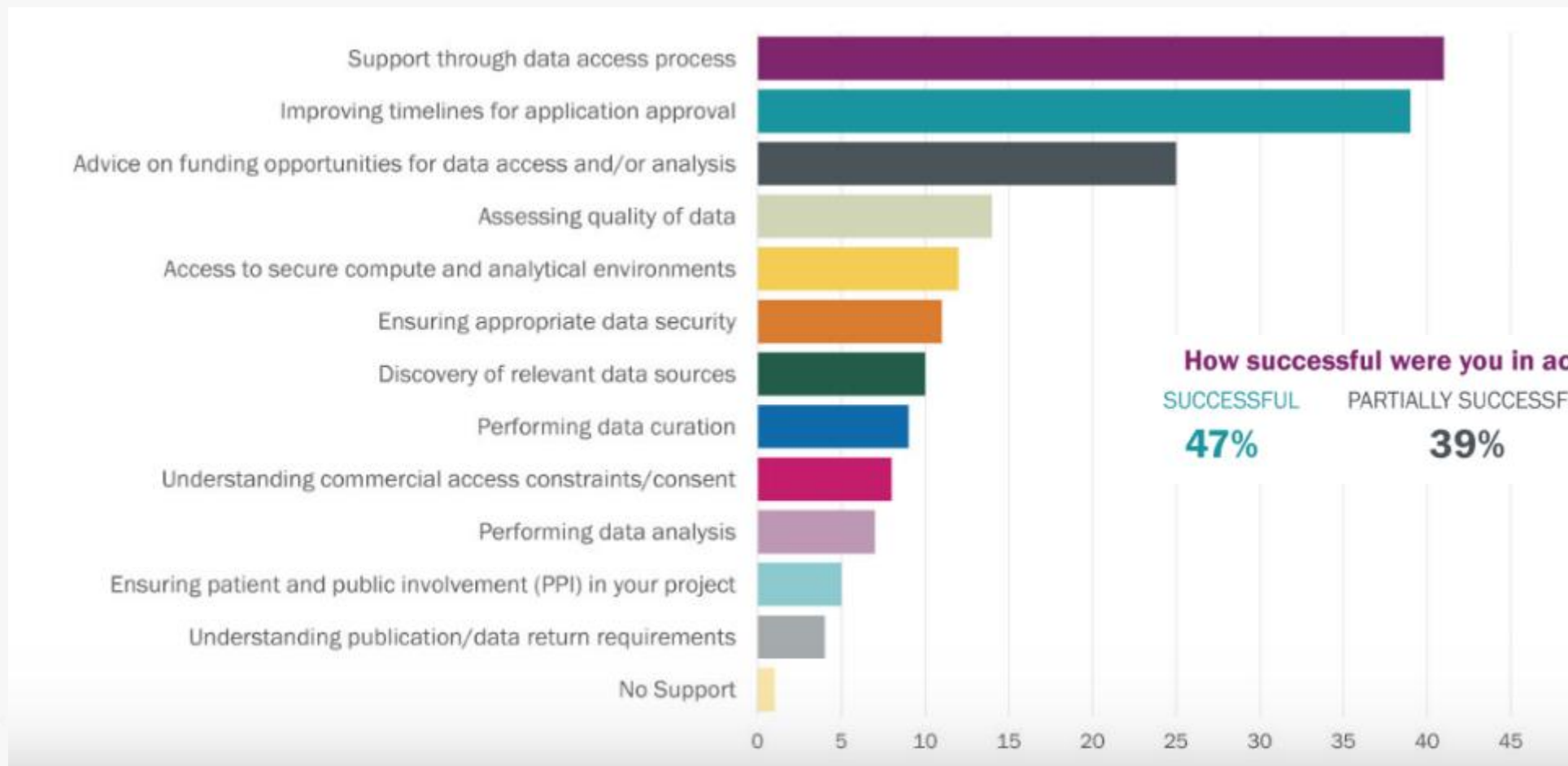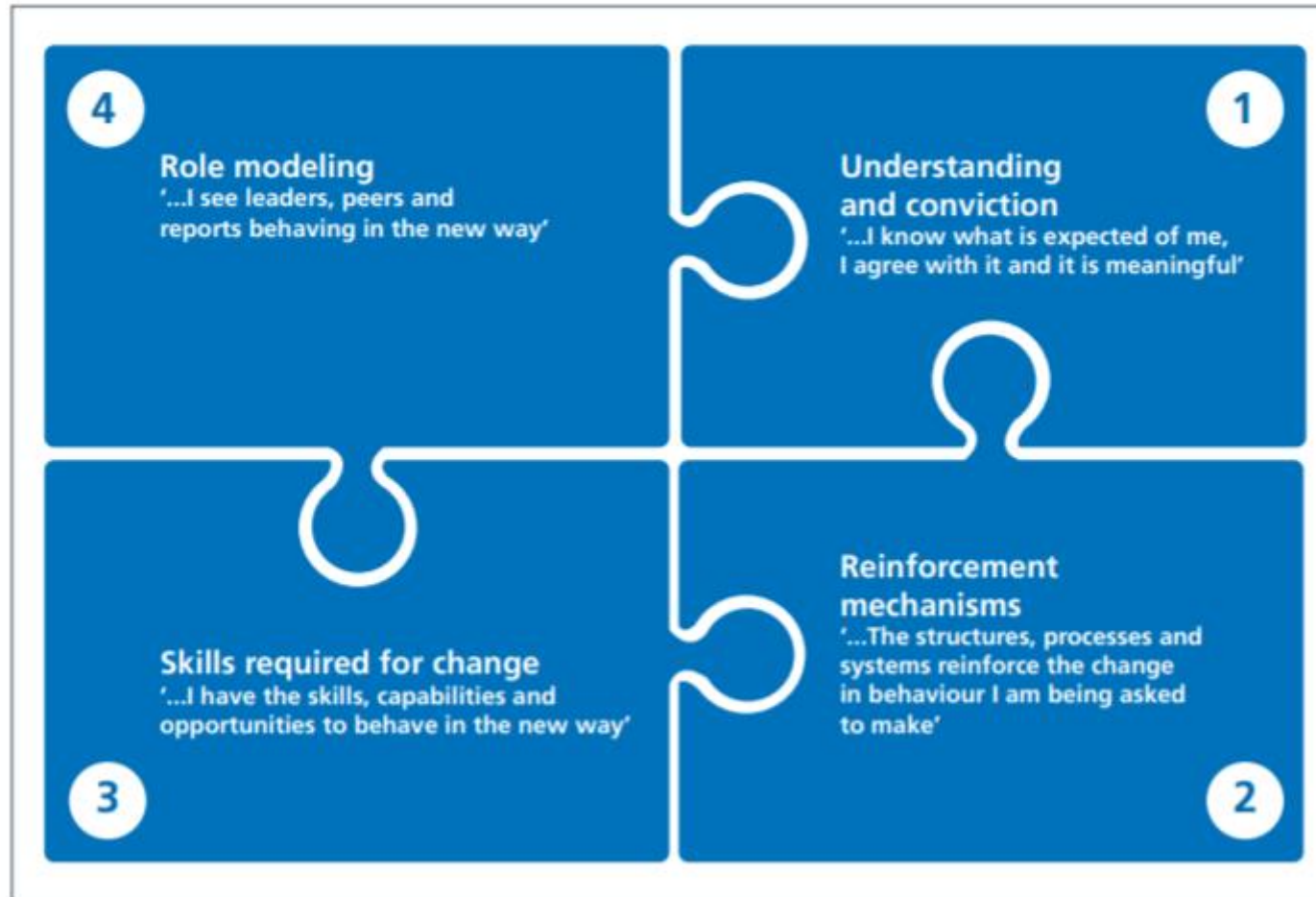

Source: National Cancer Research Institute Survey exploring researchers' experiences when accessing health data

Improving data access management requires holistic approach to achieve the required change

- RAG Streamlining and Ethics group
- Hubs
- HQIP
- SAIL
- UK Biobank

Communication of benefits

4 Role modeling
'...I see leaders, peers and reports behaving in the new way'

1 Understanding and conviction
'...I know what is expected of me, I agree with it and it is meaningful'

3 Skills required for change
'...I have the skills, capabilities and opportunities to behave in the new way'

2 Reinforcement mechanisms
'...The structures, processes and systems reinforce the change in behaviour I am being asked to make'

Keller and Price (2010)

Training
Accredited 'safe' User

Innovation Gateway development

Data Access work will inform development of the Health Data Research Innovation Gateway

- Our ambition is for the Gateway to support a **streamlined**, **proportionate approach** to access requests based on the **five safes model** for research and innovation uses with a clear **public benefit**, in line with the **Principles for Participation**.

- We aim to make life easier for both requestors and decision makers through a combination of **automation**, **built-in validation**, **transparency of progress** and the capability to host **virtual data access request panels**.

- The intention is to build on existing **cross-sector best practice** both **nationally across the UK** and **internationally**.

Building on existing tools and best practice within UK health data

Health Data Access Toolkit developed by the **MRC Regulatory Support Centre**

- **Health Research Authority** provides a number of decision support tools:

  - Ethics: http://www.hra-decisiontools.org.uk/ethics/

  - Confidential Advisory Group (CAG): http://www.hra-decisiontools.org.uk/cag/

  - What is research: http://www.hra-decisiontools.org.uk/research/

  - Managing consent: http://www.hra-decisiontools.org.uk/consent/

- **NHS Digital** has produced guidance on the information expected in the various sections of a DARS application, named 'Standards'.

And cross-sector and international

- **The Office for National Statistics Secure Research Service** (SRS) gives accredited or approved researchers secure access to de-identified, unpublished data in order to work on research projects for the public good.

- The **METADAC** (Managing Ethico-social, Technical and Administrative issues in Data ACcess) is a multi-agency multi-study data access structure that services several of the UK's major cohort studies and provides a scalable mechanism to incorporate additional cohorts in the future.

- **Data Access Support Hub (DASH)**: a one-stop shop for requesting access to multi-jurisdictional data across Canada

- **Data Use Oversight System:** Expediting data access for researchers, by facilitating and enhancing data access committees' workflows

Three intended use cases

1. **For data custodians with existing 'in house' web-based workflow solutions** (e.g., NHS Digital, SAIL), the module would provide validated inputs to their approvals processes and receive time stamped progress updates for key process points.

2. **For data custodians with 'MS Word' based documentation and offline workflow** (e.g., HQIP and most other custodians) it would help them harmonise and streamline their approach and provide a scalable, web-based workflow.

3. **For new data custodians** (e.g., some health data research hubs, NHS Trusts, other organisations that have not routinely made data available previously) it would provide the opportunity to move straight to a 'best of breed' web-based access management request solution.

Innovation Gateway Phase 2 with Technology Partner will develop data access management module

High level timeline

From March 2020	HDR UK engaging data custodians, data users, health data research hubs to understand current practice and map end-to-end approval journeys
May 2020	Propose design for an access request form and workflow that could be integrated in the Gateway based on community input
June 2020	Provide our Technology Partner with the proposed requirements resulted from community engagement exercise
June-October 2020	Technology Partners to build Gateway access request module based on community feedback and input received
October 2020	Gateway Phase 2 completed: infrastructure will support workflow management and rules-based pre-validation based on existing best practice management processes

As part of this work we are also engaging the Hubs, Alliance members and potential users.

Main outcomes from first Data Access previous workshop

HDRUK
Health Data Research UK

1. Transparency is key to ensure public trust
It is important to communicate clearly who can access the data, what data and what level of data can be shared, for instance if aggregated data or not, and where the responsibilities lie

2. Pre-submission stage and user support are crucial
Understanding what is required, clear communication from data custodians, accreditation, training and guidance are essential to ensure good applications

3. Common project identifiers to link information
Connecting information through different systems (e.g. to pull through relevant approvals) would be extremely helpful to streamline processes

4. Standard Data Sharing agreements and common legal definitions
Uniform data sharing agreements might be helpful to speed up the legal process and negotiations

5. Sharing progress and intelligence across the system
With sufficient commonalities across systems there is scope for the Gateway to connect individual systems in an automated manner and report that progress (including DSPT accredited researchers/breaches)

High level process with Five Safes at its core

Pre-submission → Application submission → Review and advice → Approval → Data access granted → Audit, checks & renewals

Safe projects	Is this use of the data appropriate?
Safe people	Can the users be trusted to use it in an appropriate manner?
Safe settings	Does the access facility limit unauthorised use?
Safe data	Is there a disclosure risk in the data itself?
Safe outputs	Are the statistical results non-disclosive?

Desai, Tanvi; Ritchie, Felix; Welpton, Richard (2016). "Five Safes: designing data access for research". Bristol Business School Working Papers in Economics

Next steps

- Develop a 'wire frame' of the data access request form that will be available through the Gateway that includes:

    - Harmonised set of questions common to all or most data custodians.

    - A customisable component to enable individual data custodians to customise data request forms based on organisation or use case requirements.

- Develop workflows for the two main use cases (linkage to 'in house' process and delivery of 'end to end' process) that includes approach to validation and verification wherever possible

- With our use cases in mind – going forward we would like a group of users from the data custodians community to engage with us and our Technology Partner and accompany us in the process of designing the Gateway module. What level of involvement can you offer?