

Meeting Synopsis

Meeting: Data Enabled Research Advisory Group (DERAG)

Date: 14th May 2024 **Time:** 2-4pm

Attendees

Attendee	Constituencies Represented
Chairs	Government Funders
Prof Lucy Chappell	National Institute of Health Research (NIHR), present in part
Prof Patrick Chinnery	Medical Research Council (MRC)
DERAG Members	
Nicola Perrin	Charity Funder, Association of Medical Research Charities (AMRC)
Prof Alison Park	Funder, Economic and Social Research Council (ESRC) & Social Sciences Research Health Data Users
David Snelson	Public and Patient Involvement and Engagement, useMYdata
Prof Kathy Rowan	Clinical Research Health Data Users
Dr Janet Valentine	Industry, Association of British Pharmaceutical Industry (ABPI)
Dr Cheryl Battersby	Platforms
Prof Cathie Sudlow	UK perspective & Clinical Research Health Data Users
Dr Michael Chapman	NHS England
Ming Tang	NHS England
Laura Bellingham	NHS England
Sponsorship Team & Secretariat	
Secretariat & Sponsorship team	Dr Alex Bailey, MRC, Beccy Shipman, ESRC, Justin Riordan-Jones, DHSC & Estelle Spence, NHSE
Guests	
Karen Gunn	Accenture, invited by NHSE
David Hurley	Accenture, invited by NHSE

Apologies	Constituencies Represented
Prof Sir Martin Landray	Clinical Trials
Dr Janet Messer	System, Health Research Authority
Dr Emma Gordon	Funder, Admin. Data Research Partnership (ADRUk) & Social Sciences Research Health Data Users
Rebecca Cosgriff	NHS England
Chris Russell	NHS England

240514_01	Welcome, Introductions and Apologies
	<p>Michael Chapman and Ming Tang, in place of the Chairs, welcomed attendees emphasising the importance of DERAG for advising on transformation, for example around the Secure Data Environment (SDE) and how to engage effectively with Researchers.</p> <p>This led to a discussion regarding the scope of DERAG, specifically in relation to data and relationship to the Data for Research and Development Programme (D4R&D) which includes Regional SDE's. In response NHS England noted:</p> <ul style="list-style-type: none"> - DERAG focus on NHSE data access through National SDE, DigiTrials and classic data access services, with a widening of data scope for example, as data available in National SDE grows (e.g. Registry data) - Acknowledged the importance of links with D4R&D and understanding how best to make these links for discussions
240514_02	NHS England's proposal: more proportionate and risk-based approach for applications - Laura Bellingham & Michael Chapman

This session aimed to advance action areas from the SRAG meeting in February 2024:

- Explore ways to improve quality and content of applications pre-submission and progress complex applications.
- Explore how to better support the system, including Researchers and Funders, to assess feasibility and benefits of applications for data from NHS England.

NHSE built on thoughts for a more proportionate risk and assurance process, highlighting the need for DERAG advice on areas for ongoing improvement – data provisioning & automation, and engagement with Researchers. In its approach to change, NHS England emphasised a preference for simplicity, with ongoing advice and iterative change, rather than previous approaches which have resulted in complexity. Improvements in the performance of data access was shared - twice as many applications are being approved as entering the service; it was noted that there may be a time lag before these benefits are experienced by longer standing applicants.

Conclusions reached during the discussion included:

Opportunities for closer working between Funders and NHSE, for example for:

- **Data request applications where Funding contract variations have been requested.** It was concluded that Funders should gain NHSE advice on the feasibility of priority applications. This will help inform both Funder contract variation decisions, and NHSE understanding of the impact of decisions.
- **Data access applications which have been declined.** Closer working was recommended to support Researchers transition towards successful applications
- **Pre data access request collaboration** – building on the example of the NIHR pilot which trials NHSE involvement prior to funding award to assess data access feasibility

Advice for successful change approaches:

- **User involvement** can support winning hearts and minds of both NHSE teams and Researchers, with Early-Stage researchers key to changing any legacy narrative of data access delays
- **Challenges of change to meet** - NHSE Data Access needs stability alongside continuous improvement
- **Transparency is needed** - including publishing data access service statistics

240514_03

NHS England – proposals for transformation within Data & Analytics Directorate – David Hurley and Karen Gunn, Accenture

Michael Chapman introduced this session, aiming to share potential proposals for transformation for his team, Data Access and Partnerships, gaining insight and thoughts from DERAG on the challenges of transformation and the proposed approach to meet them.

The proposals outlined included consideration of three key dimensions operating model: people and how they can be empowered and upskilled, transformation of processes to become efficient and effective, and unlocking technology through automation to deliver value.

Discussion themes and conclusions/ advice included:

Meeting skills needs short and long term:

- importance of specific skills - higher value analytical skills, data ethics and IG skills along with a range of skills relating to data engineering and data curation
- approach to meeting skills needs sustainably through pathways & competency models (such as the Data Analytics Academy and partnership working for secondments etc)

The importance, for outputs and longer-term outcomes realisation, specifically of:

- a roadmap to capture continuous improvement, converting it into the longer-term vision whilst balancing short- and longer-term needs
- the change programme and cultural work with senior leaders

240514_04	Discussion – opportunities for the system to work together to enable data access improvements?
	<p>This floor-led discussion was designed to surface considerations about how the system can better work together. It highlighted that by nature the system is distributed, giving various examples of data types and sources, noting that to avoid ‘boiling the ocean’ a roadmap or strategy would be helpful to guide our work</p> <p>Specific topics within the system discussed were:</p> <ul style="list-style-type: none"> - role/ importance of integration/ connection of data nodes (infrastructure & data access); noting that as nodes are dynamic there isn’t a constant list of them; - linkages – between health and non-health data, and between health data sets. For both, it was highlighted that requests for new linkages are being made whilst already linked data assets are not being used. The question was asked about how Funders can play a role in the system to change this pattern (e.g. through funding calls) - prioritising data sets to challenges in the context of key national data sets needed. It was noted that the forthcoming Sudlow review will provide insight on key data, leading to the question of data availability? - the importance of sharing good news stories
240214_05	Meeting close and AOB
	<p>No AOB raised.</p> <p>In the context of the complexities of the landscape discussed, the Chair noted the key areas for DERAG action around:</p> <ul style="list-style-type: none"> - ongoing continuous improvement and transformation approaches, with the role of DERAG as a test bed for those; - the importance of understanding how Research Funders can work more closely with NHSE, for example, today’s action to explore encouragement of the use of existing pre linked datasets; - the role of Research Users in building confidence and working with NHSE to change the view held of NHSE data access.

Specific meeting actions

Action Area ID	Action	Lead to scope/ initiate work
240514_01	<p>Research Funder led exploration of how to raise awareness, and maximise use of, existing pre-linked datasets</p> <ul style="list-style-type: none"> - Funders to explore potential for a funding call/s for pre linked datasets 	Kathy Rowan
240514_02	<p>NHSE to update information on the new way of working for Researcher engagement through DERAG and SRAG</p> <ul style="list-style-type: none"> - NHSE RAG web pages to be updated 	Secretariat & Estelle Spence with the Sponsorship team