

Meeting Synopsis

Meeting: Stakeholder Data Enabled Research Advisory Group (SRAG)

Date: 27th February 2024 **Time:** 13:30-14:20

Attendees

Attendee	Constituencies Represented
Chairs	
Government Funders	
Prof Lucy Chappell*	National Institute of Health Research (NIHR)
Prof Patrick Chinnery	Medical Research Council (MRC)
Members & Member Deputies	
Liz Perraudin (<i>for Nicola Perrin</i>)	Charity Funder, Association of Medical Research Charities (AMRC)
Prof Alison Park	Funder, Economic and Social Research Council (ESRC) & Social Sciences Research Health Data Users
Dr Emma Gordon*	Funder, Admin. Data Research Partnership (ADRUK) & Social Sciences Research Health Data Users
Harry Hemingway	Clinical Research Health Data Users
Dr Darren Lunn	Clinical Research Health Data Users, CPRD
Prof Kathy Rowan	Clinical Research Health Data Users
Dr Janet Valentine	Industry, Association of British Pharmaceutical Industry (ABPI)
Andrew Davies	Industry, Association of British Health Tech Industries (ABHI)
Prof Matt Brown*	Platforms, Genomics England
Dr Cheryl Battersby	Platforms
Jillian Hastings-Ward*	Public and Patient Involvement & Engagement (PPIE)
Richard Ballerand*	Public and Patient Involvement & Engagement (PPIE), Use MY Data
Dr Janet Messer	System, Health Research Authority
Colin Wilson	System, Office for Life Sciences
Prof James Wilson	System, Office of the National Data Guardian
Alex Newberry	Devolved Administrations, Welsh Government
Nicola Armstrong	Devolved Administrations, Health & Social Care NI
Prof Cathie Sudlow	UK perspective & Clinical Research Health Data Users
Kirsty Irvine	NHS England
Dr Michael Chapman	NHS England
Ming Tang	NHS England
Rebecca Cosgriff	NHS England
Garry Coleman* (<i>for Jackie Gray</i>)	NHS England
Sponsorship Team & Secretariat	
Secretariat & Sponsorship team	Dr Alex Bailey, MRC, Beccy Shipman, ESRC (<i>via Teams</i>), Justin Riordan-Jones, DHSC, Alex Mousley (Secretariat), NHSE & Estelle Spence, NHSE
Guests	
Dr Michael Ball (<i>via Teams</i>)	Funder, MRC
Dr Mark Toal	Funder, NIHR
NHS England Observers	Dr Kate Pavlidou, Fiona Dodsworth* & Suzanne Hartley*

Apologies	Constituencies Represented
Nicola Perrin	Charity Funder, Association of Medical Research Charities (AMRC)
Tariq Khokhar	Charity Funder, Wellcome Trust
Prof Sir Martin Landray	Clinical Trials
Prof Gary Ford	Research Health Data Users, Academic Health Sciences Network (AHSN)

*Attended via MS Teams

Prof Danny McAuley	Clinical Research Health Data Users, NIHR
Prof Alex Markham	Clinical Research Health Data Users
Prof Sir Rory Collins	Platforms, UK Biobank
Gail Marzetti	System, Department of Health and Social Care (NIHR)
David Seymour	UK perspective, Health Data Research UK (HDR UK)
Prof Andrew Morris	UK perspective/ Devolved Administrations
Dr Alison Austin	NHS England
Jackie Gray	NHS England
Liz Gaffney	NHS England
Kathy Jeays-Ward	NHS England

240227_01	Welcome, Introductions and Apologies
	Chairs Prof Patrick Chinnery and Prof Lucy Chappell welcomed attendees to the meeting
240227_02	NHS England Data Access Briefing
	<p>Achievements in the last year during the merger were noted:</p> <ul style="list-style-type: none"> - fast pace at which NHS England was able to recommence signing agreements (4 days) minimising disruption to research - volume of agreements signed during 2023 (404) - approx. 2k publications in scientific literature - recruitment of over a million participants to Our Future Health and other clinical trials. - Improved user experience for those seeking to access data and the introduction of a new cohort management system. <p>Timelines for access outlined in the KPI Board reporting information and the wider information on progress of applications were discussed with an action to ensure both are published; noting that care should be taken in the use of averages/ means in the DARS dashboard.</p> <p>The increasing complexity of the environment, including applications and data sets (there are twice as many available as before the pandemic), was discussed in the context of process improvements already underway (such as extensions, renewals and amendments processes, and the use of precedents where possible). Limited capacity, combined with delivering services, including developing the national SDE, whilst making improvements, was highlighted as a challenge. NHS England noted senior level support for making improvements, highlighting that steps are being taken to prioritise gaining resource. It was noted that creative solutions for resourcing were welcomed from this group, as they will support creating space to collaborative solutioning for data access - e.g. prioritisation, process improvement/ optimisation/ processing mapping/ streamlining/ redesign and consideration of how other models of data access noted at the meeting work.</p> <p>The discussion provided practical steps for improvements in data access applications.</p>
240227_03	Funders priorities for data-enabled research
	<p>ESRC, MRC and NIHR provided information on themes/ priorities for data enabled research.</p> <p>ESRC - Alison Park highlighted importance of data access and data skills. Areas of health-related priorities outlined were:</p> <ul style="list-style-type: none"> - Widening access to linked de-identified health and administrative data. - Ongoing access to NHS records for sampling as well as linkage purposes - Ensuring secure access for the research community to linked research, administrative and smart data. - Forming strategic partnerships for Smart Data Research (SDR UK). <p>MRC - Michael Ball, noting the MRC Strategic Delivery Plan, highlighted Funder</p>

collaborations for infrastructure with joint activities moving towards a more connected system. Challenge areas for Digital Science (UKRI) were noted including:

- Bringing lots of disparate data sources together for prevention enabling advanced data analytics and the importance of predictive data.
- Data integration and data management in a secure environment, for example to understand inequality.
- Target identification, lead discovery and optimisation to enable drug discovery and development.

NIHR - Mark Toal contextualised the importance of data driven research across multiple Government Strategies with investments to connect the data driven research ecosystem noted. 4 priorities, related to NIHR's Strategy 'Best Research for Best Health':

- Enhancing data skills, capacity and capability – to power data driven research.
- Maximising the use of health and care data in research – incl. data driven trials.
- Collaborating with others – investments in Data for R&D Programme, funding with MRC and in collaboration with NHSE.
- Encouraging collaborative & Open Research - effective and safe reuse of NIHR funded data outputs and encouraging NIHR & SDE network infrastructure convergence.

Discussion highlighted challenges and opportunities through partnership working:

- Increasing the number of datasets available for research in an agile way.
- More upstream work on data available for research.
- Pre application feasibility assessments (pilot noted between NIHR and NHSE).
- Collaborative prioritisation/ triage - data access for PhD's via the national SDE.
- Balancing delivery of high-volume straightforward requests with capacity, capability and space needed for innovation or other complex work such as linkages.
- Ensuring questions from other Funders, such Charities, are included in discussions about priorities.

240227_04

SRAG and DERAG – way of working and priorities.

This session aimed to understand the value of the two groups - SRAG and the Data Enabled Research Advisory Group (DERAG) - including how they would function, if/ how they are distinctive, and the value they add to NHSE. It was noted that there is senior level endorsement for this work in NHSE and would be senior level presence.

The consensus reached was that SRAG offers distinct value in the ecosystem with overlap with other groups not evident. Distinct value centred on the granular, rather than policy level discussion, with production of practical actions and opportunities to collaborate as a system specifically to improve NHSE's data access.

SRAG aim to meet every 6 months to provide a state of the nation and some high-level updates clarified with actions identified to be progressed using smaller, flexible groups including SRAG members; with progress discussed at the DERAG meeting in May. This approach is intended to be collaborative and agile to reflect changing system needs.

Some attendees took the opportunity during this session to relay thanks to NHSE data access teams. It was noted that NHSE's collaborative spirit and shared goals were evident, with everyone moving in the same direction for public and patient benefit. Examples of NHSE improvements were noted, such DARS online, and thanks paid to the continuing professionalism of staff particularly during this time of transition where they were doing work under considerable pressure.

Thanks were relayed from attendees for the new way of working, with a note from the Chair that work with Members between meetings will be important to maintain momentum, with work sequenced, as will be checking that this way of working remains relevant as the system evolves further

240227_05	Meeting close and AOB
	<p>No AOB raised.</p> <p>The Chair noted that the meeting reflected a combined approach of making the current system better alongside longer-term visioning with enthusiastic engagement from all present to help streamline/ support redesign of the DARS system. The draft actions will be issued rapidly</p>

Meeting Actions

These are categorised into:

- near term areas for action, which incorporate practical and shorter-term suggestions made at SRAG
- broader areas/ ideas which would benefit from discussion at DERAG

Nearer Term Areas for Action

Action Area ID	Nearer term Areas for Action	Lead to scope/ initiate work
240227_01	<p>Explore ways to improve quality and content of applications pre-submission and progress complex applications.</p> <p>Examples SRAG members suggested:</p> <ul style="list-style-type: none"> - Publish frequently occurring ‘blockers’ to data access approvals. - Publish ‘model answers’ to application questions (to drive up standards). - Early triage of applications (e.g peer review and checklists). 	NHSE
240227_02	<p>Explore how to better support the system, including Researchers and Funders, to assess feasibility and benefits of applications for data from NHS England.</p> <p>Examples SRAG members suggested:</p> <ul style="list-style-type: none"> - Publish (improved) information on data access timelines. - Learn from NIHR feasibility pilot to pre-screen applications. - Publish benefits gained from research using data accessed from NHSE (e.g. use cases/ stories) <i>[Post meeting note – Harry Hemmingway has provided information on Impact Case Studies from Research Excellence Framework 2021 where HES data have played a vital role, 6/03/24]</i> 	NHSE
240227_03	<p>Put in place a task and finish group to advise on developing ‘champions’ to advise/act as an interface in major Institutions.</p>	TBC – Volunteers sought to work with NHSE on this action
240227_04	<p>Raise awareness and maximise use of existing pre-linked datasets</p> <p>- Funders to consider SRAG member ideas of:</p> <ul style="list-style-type: none"> - targeted Funding calls to maximise exploitation of pre linked datasets. - only approving PhD projects on already established pre-linked datasets. 	Funders

Areas for discussion at DERAG

- **Potential for system level re-design to improve data access (approvals through to data access applications.**