

Meeting Synopsis

Meeting: Data Enabled Research Advisory Group (DERAG)
Date: 25th November, 2024, **Time:** 1030-1230

Attendees

| Attendee | Constituencies Represented |
|---|---|
| Interim Chairs for this meeting | |
| Kathy Rowan | Funder - National Institute of Health Research (NIHR) |
| Michael Chapman | NHS England |
| 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 |
| 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 |
| 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 |
| Lorna Branton | NHS England |
| Sponsorship Team & Secretariat | |
| Secretariat & Sponsorship team | Dr Alex Bailey, MRC, Beccy Shipman, ESRC, Inesa Thomsen, & Sybil Clifford, DHSC & Estelle Spence, NHS England |
| Guests | |
| Laura Bellingham - presenter | NHS England |
| Joe Watts - presenter | NHS England and DHSC, Joint Policy Delivery Unit |
| Claire Newland | Government Funder – Medical Research Council (MRC) |
| Katherine Freeman | Government Funder – Engineering & Physical Research Council (EPSRC) |
| Apologies | |
| Constituencies Represented | |
| Chair - Prof Lucy Chappell | Government Funder - National Institute of Health Research (NIHR) |
| Chair - Prof Patrick Chinnery | Government Funder - Medical Research Council (MRC) |
| Ming Tang | NHS England |

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| 241125_00 | Welcome, Introductions and Apologies |
| | Kathy Rowan welcomed attendees, and a round of introductions took place. |
| 241125_01 | Update on NHSE England's Data Access Request Service (DARS) - Laura Bellingham |
| | <p>Significant changes in data access over the last 5 years - increasingly complex requests, increased data available for access (from 18 to 54 datasets), additional data access methods requiring additional governance – set the context for the discussion.</p> <p>Responding to DARS user feedback, Laura outlined improvements - user feasibility calls, drop-in clinics, an assurance and precedent framework, simplifying user rules, and working with policy colleagues (data linkage and international data sharing). These improvements have reduced the backlog and queries, unlocking resource for complex requests. Other improvements underway/ being scoped included a review of DARS Standards, potential use of AI, improving data provisioning/ delivery by addressing issues upstream.</p> |

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| | <p>Themes in the discussion included:</p> <ul style="list-style-type: none"> - Improving the governance model noting its evolution, complexity and multiple dependencies to be considered for improvement. - Prioritisation (and experience) between different groups of users: noting the sometimes erroneous separation between different user types, the importance of public benefit and patient voice, and the value of linkages subserving large communities. Prioritisation to be explored further with DERAG - Opportunities identified to make improvements included: further system collaboration (noting NIHR's pre-funding data feasibility pilot), benchmarking, accepting assurances across the system, and better communications with users, both for services and DARS improvements. To be explored further by DERAG. |
| 241125_02 | Sudlow Review discussion |
| | <p>The Sudlow Review - HDR UK - Professor Cathie Sudlow's independent review of the UK health data landscape, titled '<i>Uniting the UK's Health Data: A Huge Opportunity for Society</i>', is an independent review commissioned by the Chief Medical Officer for England, the UK National Statistician, and NHS England's National Director for Transformation.</p> <p>The review's findings set out a bold vision for overcoming the barriers and inefficiencies that currently delay the safe and secure use of health data to improve lives. It also sets out how that can be achieved, with five key recommendations to transform the national health data ecosystem.</p> <p>Recently published (8th November), the meeting provided a first opportunity for DERAG discussion, with members exchanging a variety of views.</p> |
| 241125_03 | Meeting close and AOB |
| | <p>Two items were discussed:</p> <ul style="list-style-type: none"> - Primary care data update - Michael Chapman provided an update on several areas of work connected with primary care data. In the discussion members highlighted the importance of these data, and of the benefits of the experience previously gained - Next meeting date – Michael Chapman noted that this is to be informed by other engagement activities taking place, and engagement needs. Members will be updated in due course |

Specific meeting actions

| Action Area ID | Action | Lead to scope/ initiate work |
|----------------|---|--|
| 241125_01 | DARS Prioritisation to be explored further with DERAG | Laura Bellingham & Estelle Spence, NHS England. |
| 241125_02 | DARS improvement opportunities to be explored further with DERAG | |
| | | DERAG volunteers TBC |