Understanding Patient Data

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Steering Group Meeting Minutes

Thursday 26th February 2026
10:30-12:00
Remote via Microsoft Teams

Attendees:
Angela Coulter (Chair) [AC]
Anna Steere (UPD) [AS]
Emma Morgan (UPD) [EM]
Charlie Wilkinson (UPD) [CW]
Lucy Seymour (UPD) [LS]
Xinqi Wang (UPD) [XW]
Frances Burns (Department of Health NI) [FB]
Valerie Morton (NHS Confederation) [VM]
David Parkin (British Medical Association) [DP]
Ngozi Kalu (Race and Health Observatory) [NK]
Rebecca Asher (Wellcome) [RA]
James Freed (Digital Academy NHSE) [JF]
Mavis Machirori (Ada Lovelace Institute) [MM]
Claire Bloomfield (Isomorphic Labs) [CB]
Ellie Munari (DHSC Data Policy) [EMu]
Liz Pickworth (DHSC) [LP]
Rachel Knowles (Medical Research Council) [RK]
Jessica Lawler (Office for Life Sciences) [JL] - deputising for Amena Shrafeddin
Jon Smart (taking over from DF) [JS]

Apologies:
Amena Shrafeddin (Office for Life Sciences) [AmS] - *deputised by Jessica Lawler*
Emily Jesper-Mir (Wellcome) [EJM] - *job-share partner RA attended*
David Ford (SAIL) [DF] - *taken over by JS*
Chris Carrigan (use MY data) [CC]
Layla Heyes (National Data Guardian) [LH]
Roger Halliday (Research Data Scotland) [RH]

MINUTES

Introductions

Welcome, introductions and apologies

- Chair welcomed everyone to the meeting as the Chair of the Strategic Advisory Group, and noted apologies.
- It was clarified DHSC has stood down the MIPP contract, and following JT's departure, there are other Public Partnerships leadership in NIHR who can provide advice to UPD Advisory Group as needed.
- Chair asked attendees to please raise any conflicts of interest at this time. None were raised.
- Chair asked whether any attendees wanted to raise an item for AOB. No items were raised.

Review of minutes

- Internal version of the minutes was circulated on 27th November 2025. Chair asked whether anyone had any comments or concerns about the minutes and whether everyone was happy

for the external minutes to be published. No points were raised and it was agreed that the non-attributable minutes would be published on the website.

ACTION 20260226/01 (UPD team): Finalise and publish minutes from November steering group meeting

UPD Vision, Strategy & Impact to 2030

- AS introduced UPD's simplified Theory Of Change (ToC), walking through UPD's ultimate goal, what this is enabled by, and UPD's role in that, covering how UPD's strategic functions fulfil its mission to help achieve its vision/impact.
- AS focused in on the ambition UPD has for 2030, including the nuance around its UK/England focus and how patient data will be defined, exploring where UPD is now and where it wants to be in the future. The topic then opened up for discussion.
- A member questioned whether the 'enabled by' section in the ToC should mention policy change, as this is an important lever e.g. considering broader changes in NHS and wider system.
- A member agreed that the UK-England balance is something the BMA contends with often, having a UK wide mandate but predominantly working on England policy. However, they suggested that with data mobility having a UK focus, such as deployment of AI tools, it will be important for UPD to be connected across those places.
- A member talked about how the political landscape may influence UPD, and questioned the vision point of 'trust is built and maintained' – for who and by who? The definition of trust according to health data may change, but we will want to be sure that some core values still come through. This member was interested to hear more about being part of the EHDS discussions given the UK is not a part of that.
- One member highlighted how UPD could help the system reimagine its siloed view of things like health and social care, which patients don't think about in the same separated way. On the policy influencing point, they felt that UPDs strength is in its neutrality which helps it reflect public views authentically, which could be negatively affected if it leans too much into the policy influencing space.
- A member suggested that patients affiliate to cohorts rather than geography, and agreed that stating UPD's England focus more clearly was reflective of reality. They also encouraged recognition of the nuances of NI care, such as combined health and social care services and citizens' dual use of NI/Ireland services.
- Another member appreciated the simplification and accessibility of the strategy. They emphasised that diverse voices are an important element to maintain, hearing from underserved groups who are often missing from datasets or who can tend to be more cautious around data sharing, UPD should continue to engage with them and promote others to engage. They also considered the understanding amongst the health workforce of the value of data for their work, as well as the risks. They felt that there is learning to be gained from the devolved nations, and therefore to avoid being too anglocentric.
- One member agreed with the ambitions laid out and appreciated the wording around anticipating public expectations and how those can be effectively addressed before an unravelling or crisis. With the audience-based KPIs, they suggested greater granularity is needed around who we mean by groups like 'decision-makers' or 'NHS staff' - e.g. does this mean policy makers, system leaders, etc? Regarding the topic of neutrality, they suggested that public views aren't in themselves neutral, so in UPD reflecting the public voice it cannot necessarily be neutral.

- One member said that we often use the term ‘trust’ very broadly when we might mean ‘confidence’, and they would like to see UPD be more specific and defined about what this means, e.g. accounting for research around the differences between trust and confidence. They suggested the same for defining patient data, e.g. are we including health and social care? They proposed that UPD could be a global voice for what good looks like, and be an international advisor/consultant (offering a potential revenue stream?) by expanding out to places thinking through similar issues.
- AS reflected on the comments and feedback, acknowledging the need for clearer definitions of patient data, what we mean by trust and stating that a greater UK-wide / international approach would take time and be iterative – as would an expansion to encompass social care data. She highlighted that the pack shared in advance of the meeting covers points around audiences, who UPD want to influence/involve, etc.

Workshop

- CW led a workshop, starting with sharing Slido questions to capture thoughts on:
  - which role matters most (presented here in descending order of priority as voted for by members): “evidence authority” (gold-standard public attitudes, benchmarks, trackers), “public interest advocate” (speaking truth to power, shaping debate, setting red lines), “convener and translator” (connecting public, policy, NHS, researchers, media), and “capacity builder” (tools, standards, shared resources across system).
  - to succeed in these roles, what must UPD be excellent at (% = of people who voted a skill as essential for success): strategic communication, (75%), facilitation and convening skills (75%), insight interpretation & storytelling (75%), collaboration and partnership working (67%), policy literacy (67%), stakeholder engagement and relationship building (67%), strategic thinking and prioritisation (58%), research design (50%), public speaking (42%), media handling (42%), advocacy and influencing (42%), data analysis (33%), project and programme management (25%), training and upskilling (25%).
- CW moved on to a Canva activity to help map out what success looks like, helping us understand how we generate and demonstrate impact.
  - ‘What would make us unique in how we deliver our ambition?’: Combining evidence gathering, public attitudes, and resource creation; government seeing UPD as the go to source of evidence for policy decision making; using proximity to health entities and decision makers to inform policy, etc.
  - ‘What are the most powerful measures that demonstrate UPD is making a difference?”: UPD evidence directly informing policy decisions; public awareness of UPD; changing the media narrative i.e. fewer concerns around public trust, etc.
  - “Thinking about future funding models, what must remain non-negotiable, regardless of funding source?”: independence; transparency; neutrality; due diligence, etc.
- A member pointed out UPD should think about how it defines “independence” in funding e.g. UPD can say there has been no commercial involvement but what about an NHS service funded/led by a commercial company? They also suggested UPD may achieve strong public attitudes research but the policy landscape might limit how much impact it can have, so UPD should think about defining success with that in mind.
- Another member feels “independence” is proxy for something else (e.g. integrity) – ultimately anything UPD do should be evidentially accurate and sound rather than be ‘independent’ necessarily.

- A member suggested that, in aiming to have integrity, UPD needs to develop a clear set of behaviours and model what others should be doing to be trustworthy – a culture which gives UPD the ability to be more flexible in receiving funding from different sources because we outwardly model our integrity.

Exercise

- AS asked how UPD should operate in relation to live issues in the media. The group discussed UPD's potential role in responding to growing public and media attention around Palantir, the Federated Data Platform (FDP), and the wider involvement of large technology companies in the NHS. There was broad agreement that the issue extends beyond Palantir itself and reflects wider public concerns about commercial involvement, AI, procurement, and trust in health data use.

- Several participants felt UPD could play a valuable role in helping the public better understand the landscape by providing clear, neutral and apolitical explanations of what is happening, why certain partnerships exist, and how risks and safeguards are managed. There was also discussion about whether UPD should engage proactively as media attention grows, or whether intervening too early could inadvertently amplify controversy.

- The group emphasised that UPD's contribution should focus less on political commentary and more on the underlying principles of trustworthy data use, public involvement, transparency, and future decision-making. Participants also noted the importance of considering how NHS and government approaches to suppliers, procurement, and public engagement may need to evolve over time. There was recognition that choosing not to engage could itself carry risks for public trust and for UPD's role in representing public perspectives.

EOI

- AS walked the group through UPD's project timeline, including the Health Data Compass workshops and evidence synthesis and State of the Nation, media analysis work, Monitoring & Evaluation work and Target Operating Model workshops, PPIE system analysis, Kantar tracker, and refugees and asylum seeker project.
- CW gave more detail on the Health Data Compass workshops and welcomed input and participation from the SAG on the project going forward. SAG members were advised to get in touch with CW if interested – one member expressed interest in the meeting.
- AS gave more detail on UPD's involvement in TEHDAS2 and the Target Operating Model work.

ACTION 20260226/02 (AS): AS to circulate second wave of Kantar findings

ACTION 20260226/03 (CW): CW to follow up with a member about Health Data Compass engagement

AOB and meeting close

- No AOBs were raised, Chair thanked attendees and closed the meeting.

ACTION 20260226/04 (UPD team): UPD to think about the next meeting and get in touch with the steering group with a proposed date.