Understanding Patient Data

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Steering Group Meeting Minutes

Thursday 4th June 2026
10:30-12:00
Remote via Microsoft Teams

Attendees:
Angela Coulter (Chair) [AC]
Anna Steere (UPD) [AS]
Spela Godec (UPD) [SG]
Charlie Wilkinson (UPD) [CW]
Lucy Seymour (UPD) [LS]
Xinqi Wang (UPD) [XW]
Chris Carrigan (use MY data) [CC]
David Parkin (British Medical Association) [DP]
Ellie Munari (DHSC Data Policy) [EMu]
Erinn Melville (DHSC) [EM] – *replacing Elizabeth Pickworth*
James Freed (Digital Academy NHSE) [JF]
Jon Smart (taking over from DF) [JS]
Kirstin Jones (Office for Life Sciences) [KJ] – *deputising for Jessica Lawler*
Layla Heyes (National Data Guardian) [LH]
Ngozi Kalu (Race and Health Observatory) [NK]
Rachel Knowles (Medical Research Council) [RK]
Rebecca Asher (Wellcome) [RA]
Roger Halliday (Research Data Scotland) [RH]
Valerie Morton (NHS Confederation) [VM]
Portland Communications
Dan Baker (Grant Thornton) [DB]

Apologies:
Claire Bloomfield (Isomorphic Labs) [CB]
Frances Burns (Department of Health NI) [FB]
Mavis Machirori (Ada Lovelace Institute) [MM]
Emma Harris (NHSE) [EH]
Emily Jesper-Mir (Wellcome) [EJM] - job-share partner RA attended
Eoin McShane (DHCNI) [EMs]

MINUTES

Introductions

Welcome, introductions and apologies

- Chair welcomed everyone to the meeting as the Chair of the Strategic Advisory Group, and noted apologies.
- No conflicts of interest or AOB were raised.

Review of minutes

- Internal version of the minutes was circulated on 4th March 2026. The group agreed that the non-attributable minutes would be published on the website.

ACTION 20260406/01 (UPD team): Finalise and publish minutes from February steering group meeting.

UPD updates and highlights

- AS summarised UPD's work over the past quarter, highlighting how the team has responded to a busy external environment while continuing to build evidence, engagement and communications activity across its programme. This included supporting parliamentary understanding of the proposed single patient record through briefings and parliamentary engagement in partnership with National Voices and AMRC, and insight shared with DHSC colleagues; responding to media and public debate around Palantir, UK Biobank and the King's Speech; and adding recall and response questions to the sentiment tracker to understand public reactions to recent coverage. UPD also continued to convene stakeholders through chairing forums such as the opt-out advisory group and HDRS PPIE roundtable on health data research infrastructure.
- LS outlined progress on EHDS work, including workshops with international and UK experts and a forthcoming insight report, while AS updated the group on the new audience-led website, annual report and Theory of Change.
- CW highlighted major projects on PPIE across the system, the Health Data Compass and State of the Nation report, and community engagement with people seeking refuge, with outputs planned between June and September.

ACTION 20260406/02 (UPD team): Circulate the newly designed annual report draft and ToC draft with the group for feedback.

Findings of Wave 3 Kantar sentiment tracker

- AS shared the findings from Wave 3 of UPD's public sentiment tracker, which was conducted online immediately after the King's Speech with a representative UK adult sample. Overall results were broadly consistent with previous waves, showing stable levels of awareness and support for different uses of health data. Support and awareness remain lowest for using data to develop and test digital tools, and for the NHS working with technology companies. There was a slight further decline in confidence around data security. New questions showed that while many people support data use in principle, views become more conditional when considering their own personal health data. The main concern was data being "accessed by the wrong people".
- One member asked the wording of health data in the survey, whether it was just general 'health data' or whether it was 'anonymous data' or 'de-identified' data. AS clarified that the exact wording in the survey was 'your personal health data' to avoid confusion, however, there was suggestion that we should use 'confidential patient information' to be consistent with the opt-out wording.
- AS shared that a notable finding is that people with high awareness and support still opt out, and many more believe they have opted out than is statically likely to be the case. A

significant minority are unaware that they can opt out. Overall, opt-out decisions appear to be caused more by caution and desire for control than opposition to data use in principle.

- One member raised that reported opt-out rates likely exceed actual figures, noting alternative opt-out routes and possible overestimation in surveys. They suggested a one-off deeper exploration, as people may assume they have opted out despite not completing the required steps.
- One member asked whether any statistical confidence intervals were applied to the smaller percentage changes to determine whether they are statistically significant. AS confirmed that this has been included in the full report, and that it will be stated where it's statistically different.
- One member raised that if people could not see whether they have opted out, then this would mean that they would not be able to opt in. They asked whether this has been picked up in the discussions with the policy team reviewing the National Data Opt-Out.
- AS confirmed that people can see their opt-out status online so they can opt back in if they want to, and that the policy development intent is to make it easier for people to see this status and reverse their choices.
- One member enquired the reason behind the paradox where 42% of those who have opted out are supportive of patient data being used to develop and improve digital tools.
- AS said that the reason behind this is still yet to be understood and that we would be adding more questions and potentially do focus group to understand this.
- One member raised that the same paradox appears on members from their organisation and that they were looking to delve deeper into this, which may link into UPD's work.
- One member raised that to inform another nation's opt-out work, they will learn from organ donation transition, exploring messaging, awareness, and population-level challenges around communicating choices, benefits, and decision-making.
- AS shared that there is significant variance in the results related to demographic differences E.g. Women report lower awareness and lower levels of opt out (and yet are statistically more likely to opt out); younger, London, BAME and LGBTQ groups show higher awareness and engagement but are also more likely to opt out. AS also shared that consistent trend across waves highlighted priority demographic groups for deeper research.
- Awareness of large national programmes is stable, with highest being single patient record and FDP, while support is lowest for AI use in healthcare, with mixed awareness and support for the NHS working with Palantir.
- AS noted that while UK Biobank and Single Patient Record stories increased support, Palantir coverage showed more mixed sentiment. Palantir stories notably influenced opt-out behaviour too, with 41% saying coverage made them more likely to opt out versus 29% who said it did not. The increase in opt-outs is modest compared to historical spikes.
- One member asked whether there is confusion from the public between FDP and Single Patient Record and whether the public believed that Palantir is involved in both. AS said that there was no evidence showing this being a public concern currently.
- One member said that conducting qualitative follow-up research or focus groups with survey respondents would help illuminate why people pick certain answers, and suggested recruiting respondents from the current survey for deeper conversations. AS said she would explore this with Kantar, though she noted the core questions show consistent results across

waves, indicating attitudes remain stable. She explained that while survey responses might reflect momentary reactions, the repeated consistency of awareness and support questions across different respondent groups suggests genuine patterns rather than survey artifacts.

- One member questioned whether negative incidents fundamentally undermine public confidence in data sharing, regardless of their scale. They said this revealed the fragility of people's willingness to share data and that any negative event causes immediate reconsideration of participation. AS acknowledged the point but hesitated to speculate without deeper qualitative research. She emphasised the need for more investigation to understand these contradictions and reactive behaviours.
- One member shared personal experience checking the NHS app and discovering they hadn't actually opted in despite assuming they had. They expressed concern about public understanding of opt-out mechanisms. AS acknowledged this reflects broader confusion about the policy and noted discussions at the Opt-Out Advisory Group about improving clarity and enabling people to check and reverse their status.

Media analysis of UK reporting on health data – and strategies to shift the narrative

- Portland Communications shared preliminary findings from their media analysis of reporting and conversations around the use of health data. The media and digital landscape around patient data have shifted since they last conducted analysis during the pandemic in 2021. The objectives and methodology of this analysis was shared.
- Portland Communications presented findings showing positive stories confined to specialist outlets while risk-led narratives dominate mainstream media with 95 times greater reach, creating a significant bias in the public information environment.
- One member raised that media coverage tends to highlight clinical breakthroughs while downplaying the critical role of data.
- This was seconded by AS and another member, who then suggested it would be useful to emphasise the significant role of data in those stories.
- One member asked whether the media analysis included specialist outlets targeting particular communities. Portland Communications confirmed they reviewed nationals, specialist healthcare media, and campaigning outlets, finding positive stories gained traction in specialist press but not mainstream outlets. The member offered to share their comms team's list of community-focused outlets. AS proposed correlating these findings with UPD's sentiment tracking to identify targeted media opportunities for reaching groups disproportionately concerned about data use.
- One member said Palantir has damaged patient trust beyond repair and recommended a clean break rather than reframing narratives. They emphasised that patient concerns are legitimate and that abandoning Palantir would enable trust-building around the single patient record.
- AS noted benefit stories cannot extinguish risk concerns and stressed the need for direct, honest, transparent debate addressing trade-offs and pros and cons rather than trying to mitigate or balance worries.
- Portland Communications reported AI models provided balanced, accurate answers on patient data use, pulling from reputable sources. ChatGPT was most balanced and policy focused. Models explained Palantir's controversies neutrally. This presents opportunities to optimise content for AI discovery and citation to improve public information accessibility.

- AS raised UPD's new website will prioritise AI optimization, recognizing increasingly people ask chatbots or are presented with AI-enabled search summaries rather than visiting websites directly, fundamentally changing information provision strategy.
- One member noted a paradox where people are willing to send samples to commercial companies for condition screening while distrusting NHS data sharing. They questioned whether this reflects greater trust in commercial entities or lack of risk consideration compared to sharing with reputable UK organisations.
- Portland Communications then presented media reality versus behavioural impact. Risk-led stories dominate with 95 times greater reach than benefit stories. However, public recall of these stories is modest (31-40%), and behavioural response varies. Support is conditional and stronger when public benefit is immediate and clear, weaker with commercial actors involved.
- One member requested Portland to include both supportive and less supportive percentages for all stories in final reports to avoid misinterpretation of data.
- Portland presented recommendations on communications on patient data across three channels. For media: target mainstream outlets with patient impact stories and pre-empt negative narratives with prepared responses. For social media: engage on platforms like TikTok and Reddit with credible voices and digestible content. For AI: optimise content for machine readability through schema and position UPD as authoritative source. He emphasised matching channel formats and giving audiences concrete positive actions to take.

ACTION 20260406/03 (UPD team): Circulate the full report from Portland Communications with the group.

Target Operating Model update

- AS introduced Grant Thorton to share an update on the target operating model, regarding UPD's future income and diversification sustainability, and invited group member's feedback.
- Grant Thornton presented UPD's future funding and operating model recommendations.
- Grant Thornton outlined a hybrid funding approach combining core grant funding with income generation through bespoke services, matched project funding, and potentially a supporter model. Subscription and paywall models were rejected as they do not align with UPD's mission and values. The roadmap spans three years: Year One focuses on planning and piloting different models to test assumptions and market interest. Year Two emphasises implementing and scaling successful approaches, particularly matched funding and bespoke services. Year Three involves investment decisions informed by learnings, positioning UPD to present a robust case for future funding cycles. The implications of this model include service segmentation between core public services and commercial offerings, clear governance and process controls, robust systems and reporting, capability assessment, and maintaining UPD's mission-driven culture. It was emphasised growth must be mission-led rather than finance-focused, leveraging UPD's credibility, independence, and public service orientation to guide partnership decisions and commercial expansion.
- One member emphasised UPD's integration within NHS Alliance governance while maintaining independence. They highlighted existing Alliance infrastructure, including professional income generation teams, subsidiary boards, and investment processes, which UPD could leverage. They said that reputational risk management requires Alliance coordination and alignment on risk appetite.

- AS acknowledged these points but clarified UPD can pursue different partnerships than the Alliance for distinct purposes. She stressed the need to discuss how UPD positions itself publicly versus Alliance alignment on governance and systems. It was agreed that collaboration would maximise benefits while maintaining UPD's distinct identity and approach.
- One member endorsed the funding proposition, noting that support from Alliance partnerships for business development, revenue raising, and delivery skills would strengthen UPD's model and help secure necessary capabilities.
- One member praised the thinking behind the funding model, particularly its mission-driven approach and acknowledgment of UPD's strong culture. They asked for clarification on the supporter model.
- AS explained that it is not fully developed idea and would only be mobilised if needed. She outlined that commercial organisations couldn't be core funders due to independence concerns but could contribute to a broad supporter base without specific tangible returns, similar to the Science Media Centre model. Supporters might receive newsletters or association benefits. AS emphasised this approach maintains open access while enabling funding from organisations uncomfortable with one-on-one partnerships.

AOB and meeting close

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

ACTION 20260406/04 (UPD team): UPD to think about the next meeting and get in touch with the steering group with a proposed date.