

Understanding Patient Data Steering Group Meeting Minutes

Wednesday 19th November 2025

11:00-12:30

Hybrid - 18 Smith Square, SW1P 3HZ and via Microsoft Teams

Attendees:

Angela Coulter (Chair) [AC]
Anna Steere (UPD) [AS]
Emma Morgan (UPD) [EM]
Charlie Wilkinson (UPD) [CW]
Lucy Seymour (UPD) [LS]
Valerie Morton (NHS Confederation) [VM]
David Parkin (British Medical Association) [DP]
Roger Halliday (Research Data Scotland) [RH]
Ngozi Kalu (Race and Health Observatory) [NK]
Emily Jesper-Mir (Wellcome) [EJM]
James Freed (Digital Academy NHSE) [JF]
Claire Bloomfield (Isomorphic Labs) [CB]
Ellie Munari (DHSC Data Policy) [EMu]
Lorna Branton (Data for R&D team at NHSE) [LB]
Eoin McShane (deputising for Frances Burns from HSC NI) [EMc]
Alex Bailey (deputising for Rachel Knowles) [AB]
Liz Pickworth (DHSC) [LP]
Chris Carrigan (use MY data) [CC]
Layla Heyes (National Data Guardian) [LH]
Guest: John Newman (Apteligen) [JN]
Guest: Dina Gojkovic Grimshaw (Apteligen) [DGG]

Apologies:

Jeremy Taylor (National Institute for Health and Care Research) [JT]
Amena Shrafeddin (Office for Life Sciences) [AmS]
Mavis Machirori (Ada Lovelace Institute) [MM]
Rebecca Asher (Wellcome) [RA] - *job-share partner EJM attended*
Frances Burns (Department of Health Northern Ireland) [FB] - deputised
Rachel Knowles (Medical Research Council) [RK] - deputised
David Ford (SAIL) [DF]

MINUTES

Introductions

Welcome, introductions and apologies

- AC welcomed everyone to the meeting as the Chair of the Strategic Advisory Group for the first time, and asked everyone to introduce themselves.
- Two members noted potential future conflicts of interest in conversations such as commercial interests and involvement
- Chair noted apologies from those absent.
- Chair asked attendees to please raise any conflicts of interest at this time. None were raised. Chair asked people to raise any new conflicts of interest as they arise, if needed.
- 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 14th 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.
- AS walked the group through the actions from the previous meeting and how progress has been made on each.

ACTION 20251119/01 (UPD team): Finalise and publish minutes from July steering group meeting

Updates from the UPD team and discussion

Audience insights work

- AS highlighted key activities from the last quarter before introducing key pieces of ongoing insights and evidence work. This includes website UX work, designing UPD's convening offer, Pulsar social listening tool, and Kantar public sentiment tracking.
- CW led the section on website UX and audience research. They have been working with Invuse since August to map and understand key audience engagement and needs/motivations to engage with our content and website, as well as how we could support that better e.g. accessibility. The suppliers will be providing actionable evidence-based recommendations for next steps.
 - CW walked the group through specific audience insights, including PPIE leads, representative advocates (e.g. charities), policymakers/influencers, media, healthcare professionals, and the public.
 - CW presented some key insights and takeaways, such as the need for full web redevelopment, a public-facing resource depository supported by a public advisory group, and convening projects to support particular audiences.
 - CW gave an update on progress with such convening projects such as State of the Nation, and the findings of ongoing community engagement on these ideas to support their design.
- LS led the section on the Pulsar social listening tool. They will be using it to track digital conversations, posts, and stories about health data, to see how perspectives vary or change, explore hot topics, differences between social and traditional media, etc. They explained the opportunities for these insights to influence UPD comms in response to misunderstanding or misinformation, but also opportunities for other stakeholders who may find the findings valuable.
 - LS shared an example report on the findings it can give on specific topics, like FDP
- AS highlighted how insights from the Kantar public sentiment tracker can offer additional insights as this internal evidence base is being built. AS will share findings from the first wave after the meeting. They summarised key takeaways from this insights and evidence work.
- *Questions & reflections*
 - A member thought UX personas presented by CW were interesting, but suggested that UPD resources tend to go through intermediary organisations, so refocusing the website to cater to the public could carry risk. Another member agreed on this point about questioning where the public fit into UPD's audience work, and also whether media are a target audience or an intermediary. Another member echoed this

sentiment, suggesting building connection and use with intermediaries was key given lack of direct public interest. One member suggested in the chat that competing on brand with the NHS could cause confusion and lack value add.

- AS clarified in the chat that rather than making it a public facing site it is more about determining the clarity of information and resources across audiences so that public-facing resources are collated and accessible. They also confirmed that the objective with media is to build knowledge and encourage balanced journalism rather than gain media coverage. CW clarified in the chat that making the website user friendly and accessible also benefits other audience groups.

- One member highlighted that their organisation are figuring out similar options around audience groups, for example choosing to phase their engagement platform in stages, starting with researchers to corner their main target market, and then down the line tailor to other audiences and providing multiple versions of the same resource to provide layered access.

- One member pointed out that the ToC expresses who we are and what we want to achieve so that conversation later in the meeting will help to determine what we should be focusing on

- One member supported the idea that UPD is a source that others come to which is a USP, so it shouldn't necessarily branch out to direct public engagement. They suggested it is important to work out who are the best leverage partners, potentially more localised organisations like ICBs rather than central.

ACTION 202501119/02 (AS): Share first wave of Kantar findings with the group.

Monitoring & Evaluation

- EM introduced M&E project objectives, particularly around establishing a more sustainable approach to M&E over the next strategy period, and the timeline for this work
- DGG introduced what UPD and Apteligen have been working on so far: workshops to determine high level aims and objectives, translating these into more detailed and measurable outputs, indicators and data collection methods, and working versions of the ToC. They introduced reasons for the importance of creating a ToC, such as providing a clear and consistent story, focusing priorities, evidencing impact, and offering stronger funding and partnership conversations.
- JN shared a series of visuals of the ToC and cycle of impact, emphasising that the attempt is to get to something 'good enough' to start focusing on data collection tools and metrics but that it can still evolve and adapt. They sought feedback mainly on the ToC's strategic focus, measurements, and presentation.
- *Questions & reflections:* [note, LB not present hereafter]
 - A member felt most value is in the detailed version of the ToC diagram, and suggested it helps to focus the debate about audiences to focus on. They were most interested in the outcome for the policymaker and regulator userbase, suggesting a measure of policy impact based on UPD influence and evidence would be the most valuable metric, though would need a lot of work to determine.
 - One member highlighted that since the funders' agreement acknowledged scaling size of UPD, what 'good' looks like should acknowledge growth of capability but also help appoint resources in the most productive yet efficient direction. They also

pointed out that measuring policy impact is challenging in terms of cause and effect.

- One member mentioned in the chat that their organisation is doing some ToC work, and can introduce UPD to the lead for this work to share presentation ideas. They suggested the presentation styles will differ across audiences, and a headline graphic for external presentation would be ideal.

- AS concluded by acknowledging the tensions between what would be good to measure and what is feasible, but that we need to focus on looking to the future and setting up the groundwork to prove UPD's worth to future funders.

-AC and AS agreed all of this is an ongoing conversation which we will continue to share with the group, and welcome future discussion about our focus and priorities either collectively or individually.

ACTION 202501119/03 (One member): Introduce UPD to their organisation lead for their ToC to share ideas.

AOB and meeting close

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

ACTION 202501119/04 (UPD team): UPD to think about the next meeting and get in touch with the steering group with a proposed date.