

Understanding Patient Data Steering Group Meeting Minutes

Thursday 24th April 2025

13:30 – 15:00

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

Attendees:

Peta Foxall (NHS Confederation, Meeting Chair) [PF]
Anna Steere (UPD) [AS]
Emma Lagerstedt (UPD) [EL]
Emma Morgan (UPD) [EM]
Layla Heyes (National Data Guardian) [LH]
Valerie Morton (NHS Confederation) [VM]
Jeremy Taylor (National Institute for Health and Care Research) [JT]
David Parkin (British Medical Association) [DP]
Liz Pickworth (Department of Health and Social Care) [LP]
Rebecca Atheyr (Wellcome) [RA]
Emma Harris (NHS England) [EH]
Frances Burns (Department of Health Northern Ireland) [FB]
Chris Carrigan (use MY data) [CC]
Layla Robinson (deputising for Roger Halliday) [LR] (from 2pm)
Dr Ngozi Kalu (Race and Health Observatory) [NK] (from 2:30pm)
Amena Shrafeddin (Office for Life Sciences) [AmS]

Apologies:

Mavis Machirori (Ada Lovelace Institute) [MM]
Emily Jesper-Mir (Wellcome) [EJM] - *job-share partner RA attended*
Roger Halliday (Research Data Scotland) [RH]
Jonathan Smart (SAIL) [JS]
David Ford (SAIL) [DF]
Rachel Knowles (Medical Research Council) [RK]

MINUTES

Introductions

Welcome, introductions and apologies

- PF welcomed everyone to the steering group meeting as the Chair of this meeting for the first steering group of 2025. They noted that we have two new members of the steering group with us, including Amena Shrafeddin (AmS) from the Office for Life Sciences, and Anna Steere (AS), the new Head of Understanding Patient Data.
- Chair noted apologies from MM, EJM, RH, JS, DF and RK.
- 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 11th December, no comments were received. Chair asked whether anyone had any comments or concerns about the minutes and whether everyone was happy for the external minutes to be published.
- One member asked about the purpose of publishing the minutes online, and EL said it is purely for transparency, and all identifiers (other than those belonging to the team and Chair) are removed before publication.
- EL walked the group through the actions from the previous meeting, including reviewing UPD's approach to risk management and reviewing its social media presence. PF mentioned that UPD falls under the NHS Confederation risk register so it doesn't make sense for UPD to have a fully separate risk register, and that we don't want to complicate the approach to risk management too much. PF also noted that many other organisations such as Ada Lovelace Institute and NHS Confederation have moved over to Bluesky.

ACTION 20250424/01 (UPD team): Finalise and publish minutes from December steering group meeting

New funding agreement: context, UPD deliverables and year 1 strategic priorities

- AS gave an overview of the funding, noting we had a bit more funding carried over than expected, and thanked funders for their continued support.
- AS set out the context of the current health data policy landscape, which is currently subject to very live debate, with rapid developments in legislation and policy. They noted that in the short term, UPD will place focus on responding to and shaping this live debate, and slightly less focus on resource development.
- AS gave an overview of UPD's key annual deliverables, as set out in the proposal for UPD's new funding agreement, noting that many of these are under development and will be discussed further with the steering group:
 - Developing the health data community:
 - Health Data Public Engagement Forum
 - Health data public scrutiny panel
 - Supporting the live policy debate:
 - Leveraging research and evidence to influence and advocate via steering groups, lobbying, briefings.
 - Communications: blogs, socials, events
 - State of the Nation Report
 - 2-5 new resources/research projects including developing the website as the key resource and improving tracking of use and impact of resources
 - Organisational development
 - Recruitment
 - Financial sustainability plan
 - Monitoring and evaluation plan

Year 1 strategic priorities

- AS presented the top priorities for UPD in Year 1 of the new funding settlement:

- Recruitment (Community and Partnerships Manager and Senior Communications Officer).
- Defining our convening role(s) within the health data community
 - Prioritise doing what only UPD can do.
 - Focus on outputs that demonstrate system-wide impact.
- Facing into the live debate
 - Shift towards a more proactive influencing strategy, engaging new cross sector audiences to increase breadth as well as depth of impact.
 - Develop a more dynamic evidence base (i.e. social listening tools and public sentiment trackers).
- Measuring and communicating UPD's value more systematically
 - Monitoring and evaluation strategy to support proof of concepts re: systemic value and provide insights into new revenue models for long-term sustainability.
 - Targeted audience-led communications activity, supported by media relations, UX-driven website development and resource marketing to grow reach and measurable impact.

Steering group discussion

UPD's convening role

- AS introduced her thinking about UPD's role as a convenor of the data community, and what that might mean going forward. They gave an overview of some of the key stakeholders in the health data community. They also raised whether the steering group needed to change to reflect the shifting landscape.
- PF opened up for reflections from members of the steering group about the role of UPD, and how that might affect the form and function of steering group membership.
- One member suggested bringing someone in from DHSC Data Policy as a connector to avoid duplication of roles and for them to bring in other Departmental voices as needed.
- Another member of the group responded to the question about what UPD does better than anyone else and should therefore focus on. They noted that UPD has a very broad network and probably has a better view of what's going on across all of data policy than most, and that UPD can play a big connecting role. They noted our discussed collaboration of a 'state of the nation report', and suggested for instance providing quarterly overviews or webinars for stakeholders to improve awareness across the sector to share best practice and what's going on across the whole picture. AS agreed that this is a great idea and that this is something we are already looking at.
- Someone cautioned against analysis paralysis when it comes to working out UPD's role, and that the mapping of the network is separate to the governance of the steering group membership. They noted that there are several different ways and purposes to convene people, e.g. knowledge sharing, consensus building, problem solving, community building etc. and that we need to think about what the purpose of convening is and how we can ensure impact. AS welcomed these points.
- Another person said they thought the mapping exercise was really useful and noted that the USP of UPD wasn't entirely clear until OLS were considering providing funding and they spoke to others who described UPD's unique connecting and convening function - so clearly

it would be good to lean into this. On the steering group point, they suggested a parallel external advisory workstream to bring particular groups together rather than all at once.

- One member highlighted that a key strength of UPD is championing public voice and was happy to see this reflected, and welcomed the additional work UPD was looking at taking forward in terms of thinking more about the proposition for different audiences and getting the most value out of resources, as well as the focus on leaning into the live debate.
- Another member said it was interesting to hear the reflections about the perceived strengths of UPD as a relative outsider and was thinking about how to map out the perceived value of UPD externally. They also noted that there is more to do in terms of the media to ensure we are involved in the media debate, thinking about news stories where it's unclear why UPD hasn't been involved. EL spoke about the work currently underway on media, stating that we are building new relationships with the media and working on briefings and resources to help upskill journalists about health data and myth-busting to help bring about a more balanced and evidence-based debate in the media.
- PF noted a slight disappointment that the stakeholder map only mentioned 'patient and public groups' under resource users/disseminators' when we are Understanding *Patient* Data. AS responded to say that this was a very valid challenge, but noted that the purpose of the internal mapping project was to capture the stakeholders active in influencing the policy debate, leading PPIE activities or developing resources - rather than the beneficiaries and end users. Patients and the public could be shown to surround the entire map to illustrate the point.
- PF asked members of the steering group whether there were any activities that members felt UPD should not focus on because others are already doing it.
- One member said the main thing UPD should not be doing is adding to the fragmentation of the system by duplicating existing work.
- Someone else reflected on the historic decision to not focus on the media and acting as spokespeople, and asked whether we had made a firm decision to be more proactive and act as spokespeople. EL said that our increasing focus on the media refers to building more relationships and being more visible to journalists but that the focus is still on providing informational and fact-based briefing rather than opinion.
- One member raised the diversity of the stakeholders on the stakeholder map, raised the importance of being selective about what we comment on given how different the landscape looks like across the UK and where we have expertise to contribute.
- Another raised capacity and the importance of linking in with other organisations like SMC and medical research charities to be able to respond in a way that preserves capacity, and that there is a key role for dispelling myths and providing information and fact-based evidence.
- AS noted her background is in communications and that hopefully this would help with capacity on the communications front along with the new Communications Officer.

UPD steering group

- PF introduced the topic of governance and the steering group, noting that there might be a need to review the role of the steering group, focusing less on the governance and progress reporting which is covered in conversations with the NHS Confederation and funders, and focusing more about advising on key issues related to policy.



- AS suggested that the role of the UPD steering group should maybe be less on governance and funding, and more on strategy, projects, etc. PF opened up for views on the purpose of the group and membership.
- One attendee agreed that the current steering group is a bit of a hybrid, being partly about governance, funding and strategic oversight, and maybe funders and the host can have other ways of holding UPD to account, leaving more room for the group to be a strategic sounding board. On the other hand, they thought the group had worked quite well to date, and said they do not think we need to be wedded to the current shape of the group. They acknowledged that the team should have a say in the type of steering group it needs and wants.
- Another attendee said they felt the steering group meetings had been valuable and productive, but that it is important to avoid analysis paralysis and overworking decisions, particularly in a small organisation.
- Someone said that whilst we do not need to make a wholesale change to the group, it's important to recognise the different needs of funders versus others, and suggested we keep the core of what's worked well in terms of the strategic sounding board to maximise the value of the group.
- Another member asked what AS and the team would like from the group and what we would value most, and stressed the importance of basing the steering group on what the team needs. AS said they felt the most important role going forward is providing strategic guidance on UPD's activities - including advice on navigating the policy debate and supporting the project work that UPD leads, rather than conversations around governance and funding, and that if that's what we decide to do, we can think about what changes in structure etc. are needed to reflect that. Someone else echoed this and stressed the importance of focusing on what's helpful to the team rather than the other way around, even moving regularity of meetings, changing the length of time, it can be flexible.
- Another attendee said that given funders receive regular reports, they didn't see the need to have ongoing conversations about funding and governance in meetings.
- Someone asked a steering group member with experience working at a hosted organisation, who said they had been trialling asking individuals about specific topics that are suited to their interests and skillsets, and that it's good to think about whether there are different ways of working with people from the group more flexibly to pick their brains on particular issues. Someone else echoed this experience of setting up subgroups to pull smaller groups together between full steering groups.

Chairing

- Someone raised the point about whether, with this in mind, we need a chair for the initiative. We need a chair for meetings, but asked whether we've fallen into the trap of being wedded to a certain structure, given UPD doesn't need a chair for governance reasons.
- PF noted that the meeting chairing is more about managing the hybrid conversation and this could be organised on a rota basis. EM pointed out the supportive role that a stable chair offers the Head Of role in helping shape the meetings to be most productive, engaging and helpful. AS also noted the advocacy element of having a chair who can champion UPD.
- PF asked whether there was anything further the team needed input on, or whether the team felt they had the clarity needed. AS thanked everyone for their contributions and said they would follow up with everyone with some suggested changes to our approach and ToR.

- PF and others encouraged not getting too bogged down with the ToR and thinking more broadly about the purpose.

ACTION 20250424/02 (UPD team): Review the aims and organisation of the steering group and share back proposed approach going forward.

AOB and meeting close

- Chair opened up for any further reflections or AOBs from the steering group or reflections for future meetings.
- One attendee asked about the working groups feeding into the 10 Year Plan and whether UPD has been able to gain insights about this following Nicola Hamilton's (who sat on the data and digital working group) departure. EL said that we have spoken to NH about this since her departure, and our understanding of the process for drafting the 10 Year Plan is that once the groups reported back, they haven't been given any more intel about what will be in the Plan, but that we are actively monitoring its development to the extent that we can.
- One attendee asked about the timing of the next meeting and whether this has been scheduled yet. EL said that it hadn't been decided yet but that the team would follow up about the next meeting offline.
- Chair welcomed feedback about the meeting via email, thanked attendees and closed the meeting.

ACTION 20241015/03 (UPD team): UPD to think about the next meeting and get in touch with the steering group with a proposed date.