

Understanding Patient Data Steering Group Meeting Minutes

Wednesday 4 October 2023

1:00pm – 2:30pm

Virtual via Microsoft Teams only due to train strikes

Attendees:

Rebecca Cosgriff (NHS England) [RC]
David Ford (SAIL Databank) [DF]
Peta Foxall (NHS Confederation, Meeting Chair) [PF]
Liz Pickworth (Department of Health and Social Care) [LP]
Nicola Hamilton (UPD) [NH]
Rachel Knowles (Medical Research Council) [RK]
Emma Lagerstedt (UPD) [EL]
Emma Morgan (UPD) [EM]
Valerie Morton (NHS Confederation) [VM]
David Parkin (British Medical Association) [DP]
Jeremy Taylor (National Institute for Health and Care Research) [JR]
Rebecca Asher (Wellcome) [RA]
Roger Halliday (Research Data Scotland) [RH]
Layla Heyes (National Data Guardian) [LH]
Mavis Machirori (Ada Lovelace Institute) [MM]

Apologies:

Claire Bloomfield (NHS England) [CB]
Frances Burns (Department of Health Northern Ireland) [FB]
Emily Jesper-Mir (Wellcome) [EJM] - *Job share partner attended*
Chris Carrigan (use MY data) [CC]
Sam Rodger (Race and Health Observatory) [SR]

MINUTES

Introductions

1. Welcome, introductions and apologies

- Chair welcomed everyone to the second steering group (SG) meeting of UPD.
- Chair introduced new steering group members LP and MM who have joined the group since the last steering group meeting.
- Chair noted apologies from SR, CB, FB and CC.

2. Conflicts of interest

- Chair asked attendees to please raise any conflicts of interest at this time. No conflicts of interest were registered.

3. Minutes and actions from previous meeting

- UPD team would like to publish minutes and actions for transparency purposes. NH noted that this intention had already been expressed by email and all attendees had had the opportunity raise concerns. No concerns were raised.

- A member asked whether there would be an opportunity to discuss the updated Terms of Reference. NH confirmed there would.
- It was agreed to publish the minutes from the July meeting on the UPD website.
- **ACTION 20231004/01 (UPD team):** Finalise and publish July's meeting minutes.

4. Governance update and sign-off

- NH noted that we had conversations at the last meeting about varying expectations around the roles and responsibilities of members of the steering group. NH had discussions with many individuals since the last meeting to understand their perspectives, which generally highlighted that many members didn't feel they had the ability to be accountable for UPD in a formal sense, and some of these responsibilities (e.g. financial accountability, legal responsibility etc) lay with the NHS Confederation. Over the summer, NH produced a 'governance update' document, which was shared with the steering group in advance of the meeting. Key changes include:
 - Removal of voting/non-voting status of members
 - Clarifying the purpose of the steering group as advisory rather than decision-making/accountable for funding, and of the NHS Confed (in which a small governance group has been created) as accountable
 - Defining what independence means in the context of UPD
 - Inclusion of EDI objectives
 - Keeping the current Chair in place
- NH said that whilst it was discussed to potentially have an independent Chair that would be recruited externally, given that we have 18 months left of our current funding agreements, the team has limited capacity, and PF is an independent trustee and patient herself, it is suggested that PF remains chair going forward.
- NH noted that feedback to date on these changes have been positive but asked for the agreement of the group with regards to the approach and documentation.
- Chair made a comment about a couple of inconsistencies in the ToR that need updating.
- A member agreed, noting that the ToR includes references to "holding the team to account" and "leading" which can be seen as overstating the remit of the group.
- A member also suggested to add 'health inequalities' to the list of expertise covered by the steering group.
- A member said they were happy with the approach and the spirit of the ToR but agreed with another member that some wording needs amending. A member volunteered to support the team in making these changes.
- A member noted that there is a reference to health inequalities in the list of expertise, but it was later clarified that this was in the 'governance update' document rather than the ToR. They also lent their support to PF serving as chair.
- A member commented that the description of UPD's independence was good, but could be strengthened by adding in that the steering group is separate to the NHS Confederation, further demonstrating that independence.
- It was agreed that everyone was happy with the revised approach to governance subject to some wording changes to the ToR.
- **ACTION 20231004/02 (NH):** Make final changes to ToR (with support from the Chair and NHS Confederation representative) and re-circulate for information
- **ACTION 20231004/03 (NH):** Add governance description into independence statement and add to the website

Strategy and Projects

5. UPD Strategy

- NH gave an overview of the UPD team's work to create a high-level strategy document to guide delivery of the UPD initiative over the two-year funding cycle, adding that this builds on existing work by the previous UPD team.
- NH asked whether attendees wanted to run through the document or whether they had read it in advance as requested, but due to time the Chair suggested we focus on the questions and some key slides. The key questions were:
 - What are your thoughts on the strategy and is anything missing?
 - Do you agree with the priorities?
 - How do you think we can best measure our impact?
- On scope:
 - A member said that the "we support" section of the scope slide was unclear with regards to what it means. NH said it was intended to indicate where we do not lead but support others' work in this space.
 - A member suggested making clear what data is in and out of scope, e.g. clarifying that the focus is patient data, not other administrative data that can support health.
 - A member suggested that maybe the 'we support' section on the slide could be more about themes and approach rather than specific research topics, and mentioned administrative data (in the context of data linkage) is potentially missing.
 - A member mentioned that this might be an area where we have to be careful about language and priorities of UPD vs the priorities of the steering group members through their other roles – e.g., UPD's current slide says "we support [...] consented cohorts", but there have been challenges between the member's organisation and consented cohort projects. NH clarified that she meant that UPD supports conversations about the data involved in consented cohort studies rather than necessarily supporting all consented cohort studies, but understands the potential issue.
 - A member said that partnership-working could come out more strongly, and that PPIE engagement is not starting from a blank slate. They mentioned that that UPD's work is not just to commission new research and evidence but help consolidate and signpost to what is already there.
- On prioritisation:
 - NH gave an introduction to the table of prioritisation of projects, stating this is a guide and that this may change over the course of the funding cycle. It has been updated since the original funding applications based on the wider health data ecosystem. NH asked attendees whether this prioritisation is roughly right, or whether there are areas that should be prioritised.
 - A member said that it is difficult to challenge the UPD team's assessment and therefore had no comment on the prioritisation itself, but asked how confident NH and the team felt that they would be able to deliver all of these projects with the limited capacity they have. NH said that the benefit of the model is that some of the projects will be delivered by suppliers and that what is not reflected in the table is the timelines and scale for each area of work, which means that some might be high priority but not take that much staff time or resource.

- A member mentioned the importance of ensuring enough time is left for reactive work as this can be significant and unforeseen. They also suggested using a GANTT chart to illustrate the work over time.
- A member gave a brief overview of NHSE's plans to communicate the Federated Data Platform (FDP) announcement, in response to questions prioritisation of the FDP in UPD's workplan.
- A member mentioned the overlap between different projects and noted the need to bear in mind that the projects might impact each other.
- A member suggested we make clear in our list of projects the geographical scope (e.g. Devolved Nations) and another member suggested we make timelines more clear in the slide.
- A member suggested changing 'support' section to 'novel and bespoke' data collection more broadly as a way to simplify those points.
- Chair thanked everyone for their comments and noted that there was no significant comments on the prioritisation itself.
- NH said to defer the conversation on monitoring and evaluation for next meeting
- **ACTION 20231004/04 (NH):** Update scope slide in strategy
- **ACTION 20231004/05 (NH):** Consider other ways to demonstrate the work programme highlighting size and timings
- **ACTION 20231004/06 (NH):** Add geographical scope to projects

6. Key Projects Overview

- NH gave a brief overview of the "What Words to Use" project and noted that we have sufficient representation from the steering group on the project group but asked for questions and input.
 - A member mentioned that that adoption/uptake of the terminology that is agreed at the end of this should be a success measures, at least the backers/funders of this project, especially as this is a tangible one.
- EM gave an overview of the income generation strategy project, the status of the procurement, and timelines.
 - Two members offered to support.
 - A member asked whether UDP is taking into account ethical considerations, and EM confirmed that this is the case.
 - A member added that UPD can also work with Confed on ensuring this.
 - A member raised the need to link monitoring and evaluation to this, as it helps to demonstrate impact, and EM confirmed this is planned.
 - A member welcomed getting commercial input on future funding and said we would likely need future iterations of this project as we develop a plan, so it would be worth having a bit of money budgeted for this
- As discussion was running over, it was agreed to put the overview of the next two projects (population health and planning and ICS data) on the agenda for the next meeting but we welcomed steering group members to get in touch if they had a particular interest – a member indicated interest on planning.
- **ACTION 20231004/07 (NH):** Add success measure of 'adoption of language/terminology by steering group and others' to the "What Words to Use" project
- **ACTION 20231004/08 (NH):** Update the project steering groups

- **ACTION 20231004/09 (NH):** Send round information on the population health and planning project, and ICS data project, to enable steering group members to consider involvement

At this stage RC gave apologies and left the meeting due to an unavoidable clash.

7. ABPI Proposal

- NH gave an overview of conversations with the Association of British Pharmaceutical Industries (ABPI) and stakeholders in the ABPI public trust steering group about the need for more coordinated, collaborative work across different groups in the sector to promote the safe and beneficial use of health data, and the resulting proposed coalition, which UPD could potentially co-secretariat. NH mentioned that UPD has submitted a bid to DARE UK to fund UPD's role in this as a community group, which would enable UPD to use resource from Confed to support with the administration if successful (therefore mitigating some of the resourcing concerns). NH asked the group for their thoughts on this proposal.
- A member said they recognised the need for engaging with industry, but said that whilst it is aligned with the UPD mission, they would like to know how it actively promotes the UPD vision and drives UPD work forward. Given capacity challenges, they said the benefit is not immediately clear compared to other activities and also asked whether the continuation of this work would be contingent on the DARE UK funding.
- A member said they feel it is potentially a good opportunity but asked what conversations NH had had with ABPI around the benefits to UPD and what the roles mean in practice.
- Chair echoed previous comments about the benefits and wanting to ensure that UPD is not there to provide credibility to an industry-led initiative (either intentionally or through perceptions).
- Members indicated support of these points.
- A member had left the meeting at this point but requested a follow up meeting, highlighting similar feelings.
- **ACTION 20231004/010 (NH):** Organise a chat with specific member on the ABPI proposal
- **ACTION 20231004/011 (NH):** Take the ABPI proposal feedback and have another conversation with ABPI, follow up with steering group offline.

Patient Data External Environment

8. Federated Data Platform and external environment

- NH discussed news about the FDP and other data-related developments, particularly in terms of how they've been playing out in the press, and the conversations NH has been involved in with other organisations on the FDP specifically. She said that the approach UPD has taken is to not weigh in too much on the procurement process (as we aren't involved in that) or potential suppliers, but instead making factual statements where necessary, advocating for clear, transparent communications, and updating / sharing relevant UPD content so it can be used proactively and reactively. NH asked attendees for any reflections.
- A member shared concerns from their organisation's perspective and a lack of reassurance based on NHS England's communications about the platform and project so far.
- A member echoed these concerns from a research perspective, particularly the implications of potentially declining trust and especially opt-outs on medical research.
- A member suggested it may be helpful to discuss as a steering group whether there should be a framework developed for UPD's engagement with the media on such topics, noting that

UPD's voice may sometimes differ from the voices of the steering group members individually. This is acceptable and important for UPD's independence, but needs to be clear to avoid any misunderstandings.

- A member suggested re-publicising and making referencing previous UPD resources to support public understanding in this area. NH said this is the case and they have been updated where possible.
- **ACTION 20231004/012 (NH):** Consider adding content to the website and social media that UPD's voice is its own and not representative of its steering group members, funders, or the NHS Confederation

Steering group reflections and AOB

9. Steering group reflections

- Chair welcomed reflections from the steering group on the discussion today, but also noted that reflections would be welcomed via email too.
- A member thanked the team and Chair for the organisation of the meetings, in particular the steering group papers as these provide a lot of information and help ensure the steering group discussion have a well-informed discussion.

10. AOB

- Due to the meeting running over, the meeting only covered NH's two short AOBs. Chair welcomed any other AOBs offline.
- NH said that the next meeting would take place in the second half of January and said a Doodle Poll with dates would be sent out in due course.
- NH also mentioned that she would like to do an Equality, Diversity and Inclusion survey of the steering group members, which is common practice across the NHS Confederation board as well as other charities, steering groups, etc. It may be supplemented by a skills/expertise survey. NH recognised that an EDI survey, even if anonymised, might unintentionally make people identifiable through their answers, so the proposal is that the responses would go directly to a member of staff of the NHS Confederation and UPD would only receive aggregated results. NH confirmed more information would follow via email.
- Chair thanked everyone for their contributions and closed the meeting.
- **ACTION 20231004/013 (NH):** NH to send Doodle Poll for next meeting
- **ACTION 20231004/014 (NH):** NH to send round information about EDI survey