Understanding Patient Data
Steering Group Meeting Minutes

Monday 15 January 2024
13:30 – 15:00
Hybrid - 18 Smith Square, SW1P 3HZ and via Microsoft Teams

Attendees:
Frances Burns (Department of Health Northern Ireland) [FB]
Chris Carrigan (use MY data) [CC]
Rebecca Cosgriff (NHS England) [RC]
David Ford (SAIL Databank) [DF]
Peta Foxall (NHS Confederation, Meeting Chair) [PF]
Nicola Hamilton (UPD) [NH]
Layla Heyes (National Data Guardian) [LH]
Emily Jesper-Mir (Wellcome) [EJM]
Rachel Knowles (Medical Research Council) [RK]
Emma Lagerstedt (UPD) [EL]
Mavis Machirori, Ada Lovelace Institute [MM]
Emma Morgan (UPD) [EM]
Valerie Morton (NHS Confederation) [VM]
Jeremy Taylor (National Institute for Health and Care Research) [JR]
Liz Pickworth (Department of Health and Social Care) [LP]
Sam Rodger, NHS Race & Health Observatory [SR]

Apologies:
Rebecca Asher (Wellcome) [RA] – *Job share partner (Emily Jesper-Mir) attended*
Roger Halliday (Research Data Scotland) [RH]

MINUTES

Introductions

1. **Welcome, introductions and apologies**
- Peta Foxall welcomed everyone to the steering group meeting as the chair of this meeting and asked whether anyone had any items for Any Other Business.
- Chair noted apologies from RH.
- RC mentioned that she had recently been appointed as Deputy Director of Data for R&D at NHS England, marking a change in role.
- Chair asked if attendees were happy for minutes to be published on the UPD website in attributable or non-attributable form. It was agreed that non-attributable minutes would be published in the interest of timeliness and encouraging open conversation.
- It was agreed that the previous meeting's minutes are approved.

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

3. **Review of minutes**
- NH went through actions from the last steering group meeting, noting all had been actioned, except for those relating to the development of the UPD strategy, which is in progress.

ACTION 20241501/01 (UPD team): Finalise and publish minutes from October steering group meeting

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Key updates

4. **Governance update**
- NH gave an update on the Terms of Reference, noting that the final version was sent round on 23rd October 2023.
- NH advised the group that Claire Bloomfield had left the group as she has left her role at NHS England. She stated that there are two open spaces on the steering group, but proposed these be left unfilled for the time being.
- NH spoke about the need to appoint a new Vice Chair and asked if any attendees were interested in taking up the role. VM volunteered. No objections were raised. It was agreed that VM take up the role.
- NH spoke about the NHS Confederation's Equality, Diversity and Inclusion survey, and urged members of the steering group to complete this to help us understand any gaps. It was agreed that the deadline for this would be end of January 2024.

ACTION 20240115/02 (UPD team): Update website to reflect membership changes

ACTION 20240115/03 (All): Fill out ED&I survey by 31 January 2024

5. **Approach to Declarations of Interest**
- NH gave an overview of the steering group's approach to declarations of interest, asking all members to contact the Head of UPD by end of March 2024 if they, an organisation they currently work for, or friends or family members have been involved in a procurement process run by UPD since 2020. She also set out some ways of working for procurements going forwards, which have been discussed with the NHS Confederation's contracting team.

ACTION 20240115/04 (All): Contact NH if they, their organisation, or friends or family members have had any involvement in procurement processes run by UPD by 31 March 2024

6. **Health data landscape update**
- EM provided a high-level update on the health data policy landscape, including the Data Protection and Digital Information Bill, the Federated Data Platform and Opt-Out rates as well as developments in the devolved nations.
- One member of the steering group asked about levels of opt out and sought views from attendees on when this becomes problematic, and whether UPD should have a point of view. Another member said for researchers, opt-outs cause blind spots and mean that we do not know what is not captured, so if UPD were to have a view, suggest it would be that analysis is done to understand any particular characteristics of those opting out to improve

understanding. A member confirmed opt out rates are monitored by the Department of Health and Social Care.

7. **Project updates**
- EL gave an update on the status of the 'Data for Planning and Population Health' and 'ICS Data' projects, both of which have been procured and are underway with the support of external consultancies. She asked members of the steering group for expressions of interest in joining an informal project group for either project.
  - One member was interested in the planning work but wanted a further discussion given its broader definition than population health, and another expressed interest in the ICS work.

ACTION 20240115/05 (EL): Contact steering group members separately about project involvement.

UPD strategy and income generation

8. **Eastside People presentation**
- Chair reminded attendees that the conversation about funding is focused on future funding streams rather than current funding, and introduced a consultant from Eastside People, who has been working with UPD to develop an income generation strategy.
- The consultant gave an introduction to Eastside People and her background, handing over to NH who gave a brief history of UPD and the context for the project. She also explained that, before an income generation strategy could be developed, the team needed to review the basics of the theory of change / strategic direction of UPD, so we know what we would be asking people to fund.
- The consultant outlined Eastside People's approach and work to date, emphasising that the work is based on refreshing the theory of change/SWOT and determining what the UPD core offer should look like before developing options for funding models and then pursuing funding opportunities.

9. **Future funding discussion**
- NH mentioned that the UPD team had some ideas about potential future areas of work, but first wanted to get the attendees' thoughts.
  - One member of the steering group agreed that there is a need to define UPD's offering. Noted that outcomes that are focused on the public and patient trust are harder to evidence whereas it may be easier to demonstrate UPD's impact on decisionmakers and policies. Another member agreed but emphasised bridging the gap between policymakers and the public.
  - A member suggested that what is missing so far from the process is a review of the landscape as the environment has changed significantly since 2016 and is more crowded. Noted that it would be beneficial to review what others are doing to ensure UPD is filling a niche. They also noted that there are plenty of opportunities at the intersection of AI, health and public trust at the moment.
  - A member noted that the slides felt like the beginning of a strategic approach rather than a ToC at the moment, and they're possibly lacking some areas. They highlighted

that UPD does have some unique selling points but that these need to be clearly articulated. It's independent but a trusted partner of the health data ecosystem, with a mandate from NHS England and others to provide advice and guidance that will be adopted.

- o One member said that the crowded ecosystem if anything makes the case for UPD even stronger as there is more of a need for a voice like UPD to cut through the noise and make sense of a complex environment.
- o One member said that the idea of UPD having a "mandate" of representing the public interest [in addition to UPD's agreed mandate set by funders, as previously noted by others] could be very powerful, while acknowledging significant effort involved.
- o One member suggested that maybe UPD needs to refresh the understanding of what patient / health data is, but not get caught up in the AI hype when long standing issues still haven't been resolved.

- NH then mentioned that some of the areas the UPD team had thought about recently included AI, collaborations at a local/regional level with the NHS, researching the impact of the use of health data on health outcomes, and broadening its reach internationally. She also posed questions to the group about what UPD could measure to demonstrate its impact, whether the current offer is meeting objectives, and whether there are other areas for future development.
  - o Commenting on the question about how to measure impact, a member suggested evaluating accessibility and clarity of UPD resources etc., and that UPD's work on public views to generate evidence demonstrates impact. They emphasised the continued importance of holding policymakers to account on key issues. They also said one of the key functions is supporting other organisations who are engaging directly with patients, rather than necessarily doing all the engagement ourselves.
  - o One member suggested that it may be more helpful to demonstrate where UPD can add value, rather than focusing on impact alone. There may be organisations that will pay or support the value UPD provides.
  - o One member suggested it might be worth looking into 'what does good look like' for health data public and patient engagement, unless this has already been done.
  - o One member said that from a NHSE perspective, there will be an increasing need for data to flow across borders within the UK which will require thinking about information governance, public engagement, and potential legislative change, which is something UPD could look into. They also suggested areas like synthetic data and AI.
  - o A member said that UPD could consider doing a realistic evaluation (or other comparative evaluation methodology) of what has worked, for who, and in what circumstances across the UK given that the same approaches won't work for everyone all the time, but such a resource could be very helpful.
  - o Another member suggested that what had been presented was less of a theory of change, which focuses on the levers for effecting change and more of a strategy, and suggested that UPD/CA be clear about what we mean by each document.
- Chair noted that steering group members have not had a chance to read through SWOT/Theory of Change before the meeting, and that members may benefit from reading these documents through in their own time.
- Chair closed the conversation about this agenda item and noted that Eastside People and NH will follow up with the steering group with the UPD team finishing the ToC, NH to think about

further stakeholder conversations, and NH to develop a plan to bring the next stage of the work back to the steering group.

ACTION 20240115/06 (UPD team): Develop plan for next steps on the income generation work and return to steering group.

ACTION 20240115/07 (UPD team): Consider suggestions from steering group about possible avenues for evaluation, developing the USP, etc.

Risk management

10. **Discussion of risk log**
   - Chair said that the assumption is that members of the steering group have been able to look at the risk log and opened discussion for any points from attendees. She also explained that this is a proportionate approach given the size of the team, and that wider organisational risks are held and managed by the NHS Confederation.
        - One member suggested that whilst risk registers tend to be internally focused, it may be helpful in this case to include external factors.
        - One member agreed and added that it would be helpful to add reputational risks and NH agreed, given that a lot of the value of UPD is derived from its reputation. another agreed and emphasised importance of reputation of UPD as independent from the pharmaceutical industry and the NHS itself.
        - A member noted that NHS Confederation have policies in place around managing reputational risks and ethical procurement, which could be helpful.
        - Other risks raised included political decisions around data and new technologies changing the conversation around data.
        - Chair suggested that, given the amount of work that is subcontracted, UPD should include risks relating to subcontractors, including financial or reputational, and to include any ethical risks throughout the course of public engagement. She also suggested that, given size of the team and insecurity of funding, we include risks to changes in the team such as departure of staff and also staff morale/wellbeing.

ACTION 20240115/08 (UPD team): Make edits to risk log based on conversation above.

Steering group reflections and AOB

11. **Steering group reflections and AOB**
   - Chair opened up the discussion for reflections from the steering group and any suggestions for future agenda items.
        - One member suggested that, given the current and forthcoming changes in the external environment, an agenda item focused on this and how it affects UPD be added to a future meeting.

ACTION 20240115/09 (UPD team): Send Doodle poll with suggested dates for next steering group meeting