

Understanding Patient Data Steering Group Meeting Minutes

Monday 15 April 2024

13:30 – 15:00

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

Attendees:

Alex Bailey (Medical Research Council, *covering for Rachel Knowles*) [AB]
Frances Burns (Department of Health Northern Ireland) [FB]
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]
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]
David Parkin (British Medical Association) [DP]
Liz Pickworth (Department of Health and Social Care) [LP]
Layla Robinson (Research Data Scotland, *covering for Roger Halliday*) [LR]
Joe Watts (NHS England, *covering for Rebecca Cosgriff*) [JW]

Apologies:

Rebecca Asher (Wellcome) [RA] – *Job share partner (Emily Jesper-Mir) attended*
Chris Carrigan (use MY data) [CC]
Rebecca Cosgriff (NHS England) [RC]
Roger Halliday (Research Data Scotland) [RH]
Rachel Knowles (Medical Research Council) [RK]
Sam Rodger, NHS Race & Health Observatory [SR]

MINUTES

Introductions

1. Welcome, introductions and apologies

- Peta Foxall welcomed everyone to the steering group meeting as the chair of this meeting.
- Chair asked whether anyone had any items for Any Other Business. None were mentioned.
- Chair noted apologies from Rebecca Cosgriff, Roger Halliday and Rachel Knowles and welcomed Joe Watts, Layla Robinson and Alex Bailey attending on their behalf, respectively. She also noted apologies from Chris Carrigan and Sam Rodger.

2. Conflicts of interest

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

3. Review of minutes

- NH went over the actions from the last meeting in January, noting that they have all been completed, though some from previous meetings about UPD's strategy development remained open. She mentioned that minutes and actions had been sent round, including internal and external (non-attributable) versions.
- Chair asked if attendees were happy for the non-attributable minutes from the last meeting to be published on the UPD website. It was agreed that the previous meeting's minutes are approved and ready to be published.

ACTION 20240415/01 (UPD team): Finalise and publish minutes from January steering group meeting

Programme updates

4. Updates on Year 1 projects and Year 2 plan

- EL provided a brief update on UPD work in year one to date, including key projects, stakeholder engagement, collaborations, and events, noting that in the interest of time, more information is available in the steering group pack which was circulated ahead of the meeting.
- EL talked about the key projects completed in year one, noting they are all on track and the outputs will be published in Q1.
- EL showed which projects were due to be delivered in year 2 and noted procurement had been completed for one, sharing the projected timeline for year 2 projects.
- EL opened up for any questions, and stated that given the need to move on, the team were happy to take questions offline.
- One attendee highlighted that, in addition to the projects outlined, the UPD team contributes to much more, such as requests from others in the data space to review documents, join meetings and project steering groups etc. and that this isn't easily captured in our reporting on project progress but is important nonetheless.

Income generation

5. Presentation of key findings and recommendations

- NH gave an overview of the likely funding gap(s) for UPD from April 2025, and the uncertainty that still exists. She talked through the work Eastside People had done on behalf of UPD, which included reviewing government grants, grant making trusts, and operating models such as selling services / products, developing a membership model, and pursuing corporate sponsorship. Further developing these models will take some capacity away from delivering UPD's core mission.
- NH highlighted that, in terms of income from the public and independent sector, Eastside People's review found that there were very limited live opportunities for grants, and that if UPD wanted to continue to be funded in this way, the best option would be to continue with existing funders. Other models are worth pursuing, but none on its own will be enough to sustain UPD and meet its core costs.

- NH outlined UPD's suggested next steps for future funding activities for this financial year, and asked the steering group for their thoughts on the UPD team's proposed plan of a) prioritising grant funding/public sector funding, b) exploring a membership model if this is not available, which could need to consider private sector funding if there isn't sufficient public/independent sector funding, and c) the decision to start making arrangements to close UPD down from Q3 if we don't want have a suitable way forwards.

6. Discussion

- One member of the steering group agreed that the proposed plan of action sounded sensible overall, raising some questions around the feasibility of membership model given other organisations pursuing this model, and noted that the model doesn't have to be 100% one thing. They also floated the option of formalising the "consultancy" UPD does in providing expertise for stakeholders such as NHSE as a way of raising funds. The individual also mentioned that accepting funding from private organisations might be possible, agreeing that under 50% of funding from them seems sensible.
- Another member of the steering group said that despite the funding environment being unfavourable, this is almost always the case, but the UPD offering is strong. They emphasised the challenges of team capacity for fundraising given the time commitment needed to source funding. They proposed that the team would need to generate an environment where existing funders are feeling the pressure to make a confirmed decision either way. They suggested the team could do some more work on finalising and clarifying the core offering and unique selling point for UPD to feed into the business case for future funding conversations.
- Another member noted that over £2bn is given each year in the UK by grant-making trusts to charities, and the opportunities in being creative about what we might apply for. For example, UPD might focus on charities that have an interest in a particular condition rather than one that is specifically funding data-related work, by emphasising how data is an enabler for health research and improving care. There could be merit in exploring the grant-making trusts in more detail, e.g. with a freelancer.
- One attendee agreed with others and suggested the best way forward is to ensure core funding is in place from existing funders, while project support could be more ad hoc. They also raised whether it would be possible for funders like DHSC and NHSE to make the process for securing funding easier for UPD, noting the administrative burden that comes from managing multiple processes. They suggested that a membership model can dilute UPD's voice by having multiple organisations involved, and questioned whether this was advisable.
- One individual reflected that it would be important to ensure that the options pursued are compatible and work well together if they are combined. They suggested thinking about assets, what we have that has value, namely the UPD brand and reputation. They also emphasised thinking about where the money is, e.g. almost all funded projects have an obligation to think about PPIE, so we could position UPD as a partner for researchers doing data driven health research to provide expertise on PPIE in data for funding applications.
 - These points were echoed by other participants. One person suggested working with research organisations rather than individual researchers as these relationships are easier to maintain long term. One member suggested perhaps partnering with an organisation focused on engagement and another wondered whether there might be a similar approach to take with Health Innovation Networks and the SDE Network or other NHS organisations at the level below NHSE.

- One attendee suggested that with a mixed model, the core offer could be layered – e.g. by having a single organisational ‘mission’ but with a core offer for core grant funders and a different offering for other funders or clients.
- Issues identified as potentially requiring UPD expertise in the future included diversity in data, equity in medical devices (which requires data), linkage of wearable and app data with patient data etc.
- One member said that the narrative when seeking future funding would require UPD to be explicit about what will be lost in terms of resources and support for the public, researchers, clinicians and others if UPD does not have the funding to go on, and if anyone else would be able to provide any of those services.
- Another attendee raised developments like the DPDI Bill creating new opportunities for UPD providing expertise, such as providing consultancy to support research and PPIE in health related data usage outside of routinely collected health and social care data.
- One individual welcomed the conversation and said it felt like an evolution of the conversation that was held at the last steering group meeting. This person said they thought it would not be helpful to exert pressure on funders but to ensure ongoing conversation with funders and to be clear about timelines, e.g. moving away from “Q1,2,3,4” language and more of a week-by-week breakdown.
- One attendee agreed with many of the comments that have been previously raised, adding that they felt that the membership and selling products models would be tricky as many organisations would struggle to pay but still value the work of UPD.

ACTION 20240415/02 (UPD funders): Consider their timelines for making decisions about future funding and whether there are opportunities to come together and discuss the UPD funding gap and offer

ACTION 20240415/03 (NH): Further consider what a mixed model of income generation might look like and come back to steering group

ACTION 20240415/04 (UPD team): Draft a USP/value proposition for UPD and share with steering group, as well as the core offer vs additional bolt-ons

ACTION 20240415/05 (NH): Pick up point around grant-making trusts and applicability to UPD

Evaluation

7. Evaluation presentation and options

- EM gave a presentation on UPD’s emerging thinking on demonstrating the impact of UPD and evaluating its work to date, which is also a deliverable outlined in the contract with NHS England. She noted the grant agreement has provided £6365, which doesn’t allow for much, considering the best practice is to spend around 10-15% of a project on evaluation. The UPD team believe they might be able to make up to £16,000 available.
- EM outlined some options for gathering information that might be available, including: stakeholder and steering group survey, commissioning a supplier to conduct follow-up in-depth interviews with stakeholders, data analysis of resource re-use and social media, website feedback pop-ups, and systematic review of academic references of UPD and its resources.

8. Discussion

- EM asked members of the steering group for any thoughts on the evaluation process, in particular whether the scope should include UPD as a whole since its inception, since 2018, or in the last year, as well as the purpose of the evaluation (evidence for existing funders, demonstrating value to potential funders or for general learning and good practice), and when to start.
- One attendee noted that best practice around percentages of funding to be spent on evaluation depends on organisational type, we should not be too concerned about the percentage, and to adapt the work and the budget to the purpose of the evaluation.
- Another noted that evaluation and income generation are intertwined as it doesn't make sense to do evaluation if we've decided to close down. They felt it should be focused on the point of view of external stakeholders as it will be key to demonstrate the value to future funders.
- Another individual agreed with the point around focusing the evaluation on the point of view of external stakeholders and also wondered if there was a way to get the public's view, for instance comparing views on UPD materials compared to something else.
- One member raised the importance of taking a pragmatic approach given funding considerations and the key purpose being to demonstrate value to current and future funders.
- One individual agreed with previous speakers and suggested this could form part of an ongoing piece of work to generate a suite of 'marketing materials' to secure future funding. They also suggested there is a lot of value in getting testimonials from people and organisations we've worked with, especially given the reputation and relationships UPD has.
- Another member suggested developing an evaluation process that can "measure" or take into account UPD's value as a trusted resource. They also suggested an ongoing survey on public views on the use of patient data to get some baseline data for future comparison.
- There was overall consensus to start as soon as possible, not evaluate specific projects as projects but focus on UPD as a whole, and consider it more of a 'market research' activity to build an evidence base rather than viewing it as an 'end of programme review'.

ACTION 20240415/06 (UPD team): Develop and take forwards an approach to evaluation based on the information above.

AOB and meeting close

9. AOB and meeting close

- Chair opened up for any quick points from the steering group and closed the meeting

ACTION 20240415/07 (UPD team): Schedule the next meeting (July 2024)