Understanding Patient Data
Steering Group Meeting Minutes

Tuesday 16 July 2024
13:30 – 15:00
Hybrid - 18 Smith Square, SW1P 3HZ and via Microsoft Teams

Attendees:
Peta Foxall (NHS Confederation, Meeting Chair) [PF]
Nicola Hamilton (UPD) [NH]
Emma Lagerstedt (UPD) [EL]
Olivia Gomes-Baho (UPD) [OGB]
Rachel Knowles (Medical Research Council) [RK]
Layla Heyes (National Data Guardian) [LH]
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]
Roger Halliday (Research Data Scotland) [RH]
Jonathan Smart (SAIL) [JS]
Chris Carrigan (use MY data) [CC]
Rebecca Cosgriff (NHS England) [RC]
Rachel Knowles (Medical Research Council) [RK]
Harri Weeks (Wellcome) [HW]

Apologies:
Rebecca Asher (Wellcome) [RA]
Emily Jesper-Mir (Wellcome) [EJM]
Ngozi Kalu (RHO) [NK]
Mavis Machirori (Ada Lovelace) [MM]
Emma Morgan (UPD) [EM]
Frances Burns (Department of Health Northern Ireland) [FB]

MINUTES

Introductions

1. **Welcome, introductions and apologies**

- PF welcomed everyone to the steering group meeting as the chair of this meeting, including new members, NK and OGB (OGB being temporary as a summer intern).
- Chair noted apologies from those absent.
- Chair highlighted that the focus of the discussion will be on impacts following the General Election, UPD’s progress on funding and developing its value proposition, and an update on the Year 2 projects. To enable everyone to speak freely during the agenda item on the general election, it was agreed that comments will either be anonymised (in line with usual practice) or not minuted if it still could be possible to work out someone’s identity from what they say.
- Chair asked whether any attendees wanted to raise an item for AOB; a member said they had an item.

- Chair also asked if everyone was happy with the meeting being recorded in order to take the minutes, and then delete it afterwards. This will help with ensuring accuracy of the minutes and enabling the team to contribute effectively to the meeting. All agreed and the recording was started.

2. Conflicts of interest

- Chair asked attendees to please raise any conflicts of interest at this time. One member said that their organisation was also going through a process to review future funding so noted that this could potentially pose a conflict as there may be potential funders in common, but this is already known and managed.

3. Review of minutes

- NH apologised for the error in the April minutes regarding a conversation about PF staying on as Chair. NH stated that, in the July 2023 meeting, the group had agreed to do a light touch review of the decision regarding PF as Chair in a year's time, which is now. No concerns have been raised, and no other members have requested to take on the Chair role.
- NH advised that the recommendation is for PF to remain as Chair until at least April 2025, given this is when the current funding arrangements end.
- NH stated that members could get in touch with her if they have any questions or concerns, or if they would like to take on the role, within one week (by COP 23/07/24).
- One member said they would be happy for PF to continue, and no objections were raised. Otherwise, no comments on minutes, so will make the correction to the minutes and upload on the UPD website.

ACTION 20240716/01 (UPD team): Finalise and publish minutes from April steering group meeting

General election

4. Presentation

- OGB presented their analysis of the impact of the general election results on health data policy and practices, focusing on the impact of Labour's main policy pledges around NHS data. This mainly focused on the manifesto commitments relating to a national data library, syncing up data between different health and care services, and transforming the NHS App, as well as some of the public announcements since the new Government started, such as the Health Secretary's visit to a GP, his early call with National Voices, his speech at the Tony Blair Institute conference, etc.

5. Discussion

- One member suggested it could be helpful to get the perspective of Joe Harrison (Chief Exec of Milton Keynes Hospital, Trustee of NHS Confederation, and NHS England's "National Director for Digital Channels") on these topics, maybe via a written briefing or they could attend a steering group meeting.
- One member wondered whether there had been any discussion or thoughts around the potential for the National Data Opt Out to be reviewed or revisited. They suggested it's not being used in the dynamic way that it initially was being presented as (i..e people not opting back in) and in turn poses a risk to research if it continues this way.

- One member explained that government departments are likely to be awaiting ministerial steers, and there remains a lot of questions, e.g. what a National Data Library would involve in relation to health data. The Secretary of State for Health and Social Care has outlined vision of DHSC as a wealth and economic growth catalyst, with an aim to bring together life sciences with health systems. UPD has a clear role in making sure there is the public communication, involvement and confidence there to support with moving forward on that.
- One member said the new government is bringing a reframing and new energy to health landscape, but there will likely be a lot of continuity with previous policy. They wondered whether it is legitimate / useful for UPD to present policy asks and influence.
- One member said they wanted to know more about the scope of National Data Library and its alignment with the Office of National Statistics' Integrated Data Service (predominantly administrative data), and the perceived legislative barrier between sharing of health and administrative data for research that currently doesn't affect some of the Devolved Governments.
- One member agreed that the National Data Library is awaiting detail, and said as far as they're aware some of the organisations who may have been asked to work on this include the Economic and Social Research Council, the Medical Research Council, and NHS England. This might be an area to pursue influencing and networking.
- One member gave an overview of ministers likely to be involved in this - Patrick Vallance (worked with the Tony Blair Institute on their recent proposal around a health data trust) working with Peter Kyle in the Department of Science, Innovation and Technology (likely to be leading on national data library). In the Department of Health and Social Car, Karen Smith is the Minister responsible for data, Baroness Merron responsible for life sciences, and the Secretary of State is also interested in life sciences. If UPD were to write to ministers, it would be prudent to write to all of them given these portfolios. The DHSC Secretary of State's first meeting was with National Voices, so this sets a positive tone for the relationship with civil society. It would also be helpful for UPD to acknowledge the progress that has been made in recent areas of work, as well as advocating for public engagement strategy and delivery to be ongoing rather than a one and done.
- One member remarked that regardless of the ministerial steers, there is a recognition of patient voice, barriers in sharing data, and the importance of patient and public engagement. As far as they are aware there haven't been any decisions regarding the future of the National Data Opt Out at the moment, although it is an area of interest.
- One member said they may request a meeting with the Secretary of State for an introduction, and suggested that any UPD approaches to ministers should align with other similar organisations so there aren't multiple approaches.

UPD value proposition and future funding

6. Update on funding situation

- NH explained that there have been no changes to the funding situation, so there is still no funding confirmed for April 2025 onwards yet. NH acknowledged and appreciated the conversations that some funders are starting to have internally about this.
- NH summarised the view to increase the size and capacity of the team, with a mixed model of core funders supporting UPD's core offer, while developing additional funding opportunities through consultancy/service provision, training provision, partnerships, contributions and independent grants.

- NH pointed out that it is hard to make progress with these areas while also delivering the current programme with the capacity the team has. Longer term funding and capacity is required to develop these areas to an extent where they can be relied upon, and government / NHS grants can be reduced.
- NH explained that at the last meeting colleagues had been asking if we had a written document about UPD's unique selling point, its track record, and what is specifically needed. They discussed the shared 5-year view document which covers these points and outlines what the proposed 5-year programme potentially would involve and would cost.

7. Discussion on mixed model proposal

- One member said the mixed model makes sense but there is a chicken and egg issue of getting funding to allow greater capacity but not having the capacity to seek that funding. They were reminded of a previous funding model at another third sector organisation which involved a mixture of approaches - it works well when the different strands support and mutually reinforce each other. They suggested that the funding proposition could benefit from demonstrating some leverage for the public purse, i.e. there's a good additional value for money offer for main funders that investment of £x brings in £xx to others who would also benefit, stacking up on the back of the funding they give.
- One member said that their organisation has a similar model that works well: 1/3 core funding, 1/3 long term grants, 1/3 from short term consultancy / training. It can be difficult to have the skills in the team to win business, write convincing bids etc, and they offered to put UPD in touch with some training providers they've used. They suggested having a sort of "shopping list" so that we can move quickly if there are opportunities available. They said they would be happy to contribute RDS input to consider scope of all this, i.e. how much we stretch the patient out to health and care or beyond that.
- One member explained that their organisation diversified 10 years ago, with 1/3 of each type of funding as well, but acknowledged that sustainability is never just income generation. They suggested doing an analysis of which are quick wins, with partnership with research organisations standing out, particularly integrating with those with larger grants such as Health Data Research UK and Administrative Data Research UK.
- One member questioned whether the appetite for the proposed services has been tested in the field. NH explained that this has not necessarily been done yet, but will form part of the evaluation piece to come. In terms of the core offer, the member said the NDG office had thoughts about the risk of duplication in how the unique selling points had been worked (e.g. the National Data Guardian is also independent) and offered to work together to ensure the wording is clear and not duplicative, and that the boundary between amplifying and duplicating is agreed. NH clarified that it is the combination of 'USPs' together that separate UPD rather than individual points such as being independent but agreed it would be helpful to continue this conversation about specific phrasing.
- One member said that the language in the proposition paper of 'patients and publics' seemed new. They wondered whether UPD is maximising its mandate on who its representing, perhaps 'communities' is a more powerful description whilst 'public' is more abstract particularly with increasing focus on inclusion issues. The terminology could be clearer and widened to consider the various groups being represented.
- One member questioned whether the wider health data patient and public engagement community needs to challenge itself as a community about defining what everyone is doing, where our specialisms are and overlaps are in terms of UPD, uMd, NDG, etc, to demonstrate

that we're making the best use of the funding we have. We're all looking for extra funding from the same or similar funders, so we're likely to have more traction if we have a collective explanation and offer of what each organisation is and what they do.

- One member noted that a key point from the document is the point around the importance of and need for coordination.
- One member said that there are lots of organisations in this space, but not a lot of shared awareness and objectives or mission between them. Maybe a mapping exercise of the collective voices on patient data across the UK would be helpful.
- One member said that for the NDG, it's easier to clarify what they do from a legislative perspective. They have done this recently, revisiting the vision, mission, strategic objectives and work plan within that – they are happy to share this with the group.
- One member thought it was interesting to hear ideas about collaborations, and reflected on how multiple charities can be focused on the same issue but taking different approaches to it and this helps them maximise on funding opportunities by having different focuses while also collaborating on tackling the broader issue. Grant-making trusts would need to be for very specific areas of work, e.g. mental health, children, etc.
- One member shared that when they worked in third sector, collaborations focused more on information sharing / awareness about opportunities and what the landscape looks like.
- NH closed by thanking everyone for their contributions to the discussion and expressed her hope that by the next meeting the plan for future funding would be clearer and more stable.

ACTION 20240716/02 (NH): NH to update the proposal document with the feedback from the meeting and from follow up conversations.

Progress updates

8. Year 2 timeline

- EL gave an overview of the timeline for Year 2 projects and how they are planned to progress over Q2, Q3 and Q4.
- NH talked through the Gypsy, Roma and Traveller Ethnicity Data Collection project; one member raised a question about the ethical approval needed, and NH clarified that because University of Worcester is delivering the project they would require approval from their internal Research Ethics Committee at the university.
- NH talked through the SDE/TRE Animation Development project, and the Evaluation project, both of which are progressing as planned.
- EL talked through the GP Data project, including how it was not intended to test specific models or replicate previous questions of understanding public attitudes to specific uses of primary care data, and is instead more about particular areas such as sensitivity, decision-making roles, etc.
- One member wondered if it was a missed opportunity not asking the same questions that have been asked before, as views might have changed particularly since the pandemic. EL explained there is still time to define specific questions so this will definitely be considered, but we want to ensure it adds something to existing research too.
- One member agreed that we shouldn't take existing research for granted and it might be worth exploring this again. They wondered whether people really know what 'data' even

means – EL explained that this concept can be featured in the research too, trying to clarify people’s current understanding before co-creating factsheets.

- One member felt this was a fantastic project idea, as they have seen members who think their whole record is there across all services and this needs clarifying.
- One member pointed out that while there are those who do not interact as much with the NHS to know that records aren't joined up, whereas other groups such as people with chronic health conditions or disabilities will have different experiences and may have much more awareness of this. We should try and break down the work by experiences with the health service. EL acknowledged this and also highlighted that she has reached out to a digital exclusion charity to make sure that inclusion is captured.
- One member mentioned that 10% of people signed up to Our Future Health are from disadvantaged communities, and most people signing up to that are those with some interest in or understanding of data and its use.

AOB and meeting close

9. AOB and meeting close

- One member had an AOB – they have a request from members to put on a patient data conference, planning this for June next year. It would be a good opportunity to think about and tell people about what we each do and contribute. They will be emailing various members about involvement over the coming weeks.
- PF opened up for any quick points from the steering group. One member mentioned it would be good next time to keep an item about the emerging policy environment. One member reflected that it was great to reconnect and catch up on what everyone is doing.
- PF closed the meeting.

ACTION 20240716/03 (UPD team): Schedule the next meeting (October 2024)