

Understanding Patient Data Steering Group Meeting Minutes

Tuesday 15 October 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]
Emma Morgan (UPD) [EM]
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) [JT]
David Parkin (British Medical Association) [DP]
Liz Pickworth (Department of Health and Social Care) [LP]
Chris Carrigan (use MY data) [CC]
Emily Jesper-Mir (Wellcome) [EJM]
Dr Ngozi Kalu (Race and Health Observatory) [NK]
Mavis Machirori (Ada Lovelace Institute) [MM]
Frances Burns (Department of Health Northern Ireland) [FB]
Emma Harris (NHS England)

Apologies:

Rebecca Asher (Wellcome) [RA] - *job-share partner EJM attended*
Rebecca Cosgriff (NHS England) [RC] – *EH attended on NHS England's behalf*
David Ford (SAIL)
Roger Halliday (Research Data Scotland) [RH]

MINUTES

Introductions

Welcome, introductions and apologies

- PF welcomed everyone to the steering group meeting as the Chair of this meeting, noting this is NK from the NHS Race and Health Observatory's first meeting since joining as she was not able to make the first meeting.
- Chair noted apologies from RH and DF.
- Chair highlighted that the focus of the discussion will be on findings from UPD's external evaluation, funding update and impacts, and possibly, depending on timings, a spotlight on UPD's international work.
- Chair asked whether any attendees wanted to raise an item for AOB. One member mentioned one but NH confirmed that this would be covered within an agenda item. No others were raised.

Conflicts of interest

- Chair asked attendees to please raise any conflicts of interest at this time. None were raised. Chair asked people to raise any conflicts of interest as they arise, if needed.
- NH 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. No objections were raised and the recording was started.

Review of minutes

- Internal and external versions of the minutes were circulated on 19th July, no comments were received. Chair asked whether anyone had any comments or concerns about the minutes and whether everyone was happy for the minutes to be published.
- One member noted an error on paragraph 15 of the minutes, and another raised that the capitalisation of 'use MY data' is incorrect. The UPD team will make these changes and publish the minutes.

ACTION 20241015/01 (UPD team): Finalise and publish minutes from July steering group meeting

Brief update on health data landscape

- NH gave a brief update on changes to the external environment relating to health data including the Darzi review, recent Secretary of State announcements around data controllership and a single patient record, Northern Ireland's first public data panel, national conversation around NHS in Scotland, Scottish funding for major research programmes into population health, Digital Health & Care Wales procuring software solutions for extracting GP data for individual care, and a new Data Bill being introduced to Parliament in October.
- NH asked whether attendees had any other points to raise. One person mentioned plans to review the NDG office, another made the correction that this was the National Freedom to Speak Up Guardians Office which was included in the announcement on the day of the ['Review of patient safety across the health and care landscape'](#). Someone suggested we come back to the point around the re-introduction of a Data Bill in the future when more details are known.

Evaluation findings

Update from Apteligen

- NH introduced the fact that doing an evaluation was part of the grant agreements and the NHSE contract. The scope of the evaluation was UPD as a whole rather than recent projects to help support future funding conversations. The UPD team ran a tender process and Apteligen was successful, and the team has been working with them for the last few months.
- John Newman (JN) from Apteligen gave an interim presentation about the evaluation and what has been learned.

- JN noted that the report and its findings were not in their final stage but that the learnings would hopefully still be useful for attendees. He gave an overview of the scope and purpose of the evaluation as undertaking a review of UPD's programme of work and impact from 2016 until now, establishing a baseline for future evaluation work, and providing an evidence base to support current and future funding decisions.
- JN gave an overview of the methodology of the evaluation and data sources which included an online stakeholder survey (40 full responses), interviews with 17 stakeholders, website and social media analytics, academic/grey literature review, and review of key organisational documents.
- The review found strong or promising evidence for the strengths of UPD as identified by the team. The majority of survey respondents felt UPD plays a moderately or very important role in our 5 key functions (e.g. producing resources).
- Emerging narratives
 - i. UPD is highly regarded and trusted by a wide range of individuals and organisations from across the patient and health data ecosystem
 - ii. UPD occupies a distinct and important insider-outsider position, while maintaining independence and neutrality
 - iii. Much of UPD's impact comes from its position as a boundary-spanning organisation across the patient and health data ecosystem
 - iv. UPD's work leads to patients, clinical practitioners and policy professionals being better informed about how patient data is used, increasing the trustworthiness of organisations
 - v. UPD's work 'saves' money elsewhere in the system and increases the impact of other strategic investments
- JN introduced the idea of a cycle of impact, whereby UPD's relationship building, evidence gathering, resource co-creation and direct/indirect influence combine to generate UPD's value. He also presented a diagram to visually represent how UPD performs as a boundary spanning organisation, sitting between e.g. pro/cautious use of data, public/professionals, policy makers/clinicians, and for/nonprofit.

Discussion

- Chair thanked JN for his presentation and opened up for feedback or questions from attendees. Chair expressed she particularly liked the boundary spanning idea.
- One member said it was validating to see that the evaluation confirmed what he felt members of the steering group believe/hope for. He suggested Apteligen flesh out the cycle of impact in the full report as it is interesting and would enable the UPD team to have the self-awareness to build on what is working and understand what might not be working.
- Another attendee asked about whether the work to represent underrepresented views in its research was reflected in the evaluation findings, whether stakeholders recognise this work that has been done and the impact this work has had. JN explained that from the survey alone we can't get more information about awareness around specific resources, but he can return to the interviews to see where this topic came up and make sure it is reflected in the final report.
- One attendee felt it was a positive evaluation and particularly liked the boundary spanning idea, and drew out all the roles UPD plays and the different impacts of those. They were interested in the suggestion that there could be a broader scope for UPD and would be

interested to hear more about that. JN confirmed he could draw out more on this in the final report.

- Chair welcomed EH at this point who had just joined, and there was a brief recap of the presentation JN had given. JN then left the meeting.

Funders' update

Update on funding situation

- Existing funders provided an update on their positions as regards to future funding of UPD. This was provisional at the moment as organisations were going through internal approvals, so it's not included in the minutes to protect these internal processes. Any final funding decisions are still subject to reviews of the application and internal governance in each funding organisation.
- All funders are intending to continue funding, with some at slightly different levels, as well as the addition of a new funder.
- Whilst the proposed funding at this stage would give slightly more funding per year compared to existing funding, it's still significantly lower than what was originally requested. This also doesn't make best use of one of the funders' intentions to match fund the contributions of others up to a limit. However, everyone understands that it is a difficult climate at the moment and the length of the funding agreement (potentially 5 years) brings other non-financial benefits to the team.
- NH also stated that some other organisations are willing to provide small contributions or collaborate on projects (including co-funding), which will need to be outside of the core funding but could still be a useful income stream, potentially as part of a supporter / collaboration model.

ACTION 20241015/02 (NH): Organise meeting between UPD, Wellcome and NHSE re: funding.

Impact of funders' update on UPD activities

- NH outlined what these decisions mean for the next six months of UPD in terms of programme activity, organisational activity, and the work plan.
 - The work plan until April 2025 will include a project on data security and data breaches, potentially another resource on Secure Data Environments (easy read guide), finishing the GP data project and supporting some engagement work on the European Health Data Space. It will also include options for securing additional project-based co-funding where possible.
- NH also announced, having shared the news with the funders, that she will be leaving UPD at the end of the calendar year and that the recruitment of a new Head of will commence soon, once funding is confirmed and the advert is ready.
- Chair raised that her role as Chair of the UPD Steering Group is set to end in April 2025 and that a conversation around replacing the holder of this role will need to be had closer to the date. This can also fit neatly with the new five-year funding period.
- One participant said that steering group members would likely be able and willing to feed back on the Head of UPD job description and promote the job listing once live.
- NH outlined the main components of the Five Year Plan based on ~£700k a year income, which may need to be reviewed depending on the final funding amount. This included:

- Changes to the team structure: a Senior Policy Advisor and a Project and Communications Support Officer. The Head of UPD role could be re-banded to a grade A at the NHS Confederation.
- Projects: the team would aim for 3-6 projects a year, 2 focusing UK-wide and one focusing on an underrepresented group, and these might attract co-funding from other organisations. UPD would also look to develop a state of the nation report on health data each year.
- Income generation: there would be a small income generation development budget.
- UPD-run groups: create a policy and public engagement forum and public scrutiny panel, the latter including more sceptical / unsure perspectives. The policy and public engagement forum proposal has a letter of support from CC based on a recent workshop he chaired with multiple organisations working on health data.
- One attendee welcomed the idea of a state of the nation report, as it would be a useful output and would help associate UPD with a tangible, regular output, thus raising UPD's profile. They also welcomed the idea of a public scrutiny panel and the importance of engaging more extensively with people who are more sceptical, as it is important to discuss the negatives and 'worst case scenarios' in addition to the opportunities of the use of patient data.
- Another member suggested creating an internal synthesis of UPD's achievements and aims, as a sort of horizon scanning activity to demonstrate the value in what we're delivering. She also suggested focusing some work on research inclusion.
- NK mentioned that the RHO will be doing some work on research inclusion with the NIHR and will be looking to convene stakeholders in the sector so can look to involve UPD to avoid being duplicative.

AOB and meeting close

- Chair opened up for any quick points from the steering group or reflections for future meetings.
- Chair noted that the next steering group meeting is planned for 10th December, earlier than usual to reflect on the work to date and as NH won't be around for the usual date in January. NH said she would send an invite and confirm availability.
- Chair welcomed feedback about the meeting via email, thanked attendees and closed the meeting.

ACTION 20241015/03 (NH): Organise next meeting for December