Understanding Patient Data
Steering Group Meeting Minutes

Tuesday 10th December 2024
14:30 – 16:00
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]
Emily Jesper-Mir (Wellcome) [EJM]
Dr Ngozi Kalu (Race and Health Observatory) [NK]
Emma Harris (NHS England) [EH]
Roger Halliday (Research Data Scotland) [RH]
Jonathan Smart (SAIL) [JS]
Layla McCay (NHS Confederation) [LM]

Apologies:

Chris Carrigan (use MY data) [CC]
Mavis Machirori (Ada Lovelace Institute) [MM]
Rebecca Asher (Wellcome) [RA] - *job-share partner EJM attended*
Frances Burns (Department of Health Northern Ireland) [FB]

MINUTES

Introductions

Welcome, introductions and apologies

- PF welcomed everyone to the steering group meeting as the Chair of this meeting.
- Chair noted apologies from CC and MM, and RH's notified late arrival
- Chair highlighted that the focus of the discussion will be on key updates from UPD and discussion about plans for Q4 and year 3 onwards.
- Chair asked whether any attendees wanted to raise an item for AOB. No items 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 new conflicts of interest as they arise, if needed.

Review of minutes

- Internal version of the minutes was circulated on 16th October, 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.
- JT noted a typo on his name, which UPD will correct ahead of publication.

ACTION 20241210/01 (UPD team): Finalise and publish minutes from October steering group meeting

Key updates from UPD team

- EL provided a brief update on some key changes to the health data policy environment and UPD's work in response, including the Data Bill currently going through Parliament, the Sudlow Review and the NHS Ten Year Plan working groups.
- EM gave an update on UPD's contracted projects, their status and next steps.
  i. One member of the steering group was interested in the Gypsy, Roma and Traveller ethnicity data project and asked for more information. EM to get in touch to discuss this.
- One member of the group raised a question about NHS Confed's policy around translation and accessibility, and whether videos UPD has produced, including the SDE animation, will be translated into Welsh etc. or into versions with sign language, audio description, etc in line with said policy.
  i. UPD team were unaware if there is a policy or guidelines on this
  ii. LM said she would find out from the communications team (and after the meeting provided a response that said: "the policy is for all videos to have captions/subtitles, video transcripts would be a step further (but are provided for audio), there's no fixed policy on signing or translation and typically the Welsh Confed will provide animated content in both England and Welsh").
- Someone asked whether there is merit in doing a roundup of UPD's earlier work – a "greatest hits" – that is possibly less topical but still useful, and thinking about how to highlight this
  i. Another member agreed, asking how we track how and when materials are re-used, including the original animations. EL said we keep track of the views but often rely on people reaching out to tell us about using the materials. Sometimes the team does receive feedback about suggested changes and updates.
  ii. NH and EL mentioned that there is a 'resource quick guide' that was updated with the previous year's projects, but may need to be updated again and made more prominent on the website. The team is also highlighting some of these in an advent calendar style social media campaign.
  iii. A member asked about the governance process for changing existing materials based on feedback, for example, how does the team decide if a comment that's made is appropriate to act upon, if it's correct, etc. UPD said that there was no formal process, but that we try to have versions of materials that can be edited if needed, and we consider whether the information is correct, where it's come from, what the impact might be before making changes. E.g., UPD received a comment about part of an animation from a paramedic trainer who said an aspect of the scenario wasn't correct – this felt genuine but might be difficult to fully change, so a change was made to the captions. Another example was feedback that people in

white coats shouldn't be used to represent researchers as it's inaccurate, but this suggestion came directly from the public participants of a project, therefore the team does not believe this would be a good change to make. Therefore, a pragmatic approach is taken.

iv. Someone highlighted the example of SAIL in managing materials and information as some of the information dates back 15 years and the challenge in keeping things current, for example by using DOIs. They said this is a big challenge for lots of organisations, and welcomed UPD's pragmatic approach.

ACTION 20241210/02 (EM): Reach out to steering group member to discuss the Gypsy, Roma and Traveller ethnicity data project

Q4 plan and funding

- NH gave an overview of the funding situation, including changes to the proposed funding from NHS England, supported by the Department of Health and Social Care. The new funding arrangement would increase funding each year by £100,000 compared to the current budget, for five years which will give UPD more stability and predictability. The final meeting to decide the outcome of UPD's funding application will be on the 18th of December. She also stated that a candidate for the Head of UPD role has been identified, and an offer will formally be made once the funding is in place.

- NH gave an update on activity for Q4 2024-25, including publication of current projects, the continuation of the data security project, translations and easy read versions of existing work, and wider advocacy work, as well as planning for year 3. She also noted we have had interest from some other organisations such as Sciencewise and Cancer Research UK to collaborate on projects which could bring some additional funding.

- NH gave a brief overview of remaining funding and forecasting for funding in Q4 to provide some reassurance about the use of the grants during the transition period to a new Head of UPD and new funding arrangements. UPD is estimating that the full amount of existing grant funding will be spent and that no money will need to be recovered by funders.

Risk and issue review

Update from UPD

- NH also gave an overview of risks and issues, including possible risks to funding or deliverability, and the existing controls in place to mitigate these risks. The full breakdown of risks and controls is available in the progress report.
  - One member of the group noted that there is a difference between risks (which are possible) and issues (which are actual), and that this should be reflected in the log. They also noted that the Head Of leaving does constitute an issue, even if this will be well-managed, and this should be updated. They suggested retiring the risk around the two-year funding, but a new risk will need to be added to cover the topic of fundraising, maintaining good relationships with funders, etc – the financial risk does not go away, it just changes.
  - Someone else agreed, and added that there should be a risk around potential loss of relationships with individuals in key funding / partnership organisations if people move or there are government changes. They also suggested adding a risk around

the pipeline of projects for next year, particularly with the Head of UPD leaving. The team needs to ensure that the highest priority work is done.

- One person asked about UPD's approach to social media and how that impacts on reputation, e.g. the use of X. LM noted that the NHS Confederation has a strategy for their presence on X, and that the team could contact the Confederation communications team to share this.
- Another member said that their team have a good template for risk management, and said they'd be happy to share.
- Someone suggested UPD could take a more formal approach to risk management and the risk register in future, but appreciated it needed to remain proportionate. They also asked whether there were risks that were shared between UPD and the NHS Confederation, and if that is reflected.

ACTION 20241210/03 (UPD team): Review the approach to risk management and the risk log to take into account the suggestions above

ACTION 20241210/04 (UPD team): Contact the communications team from the NHS Confederation regarding their social media policy (especially regarding X vs Bluesky) and keep social media presence under review

ACTION 20241210/05 (UPD team): Contact steering group member regarding risk template

Chair discussion

- PF reminded everyone that we had an early conversation about having an independent chair and what this would mean now that she is reaching a natural end point of her tenure as chair. NH brought up some of the early considerations to start the discussion, and asked attendees about their reflections on what is needed in thinking about recruiting a new chair, including things like term, scope, the experience that is needed, and recruitment process.
- PF gave her reflections on her role as chair to date and the work involved, which has been very light touch. She raised the question of whether there would be an expectation that the chair represents UPD externally, which is not currently the case.
- One member raised the difference between being chair of UPD as an initiative broadly speaking, or just chairing the steering group. They suggested that maybe having a chair of the initiative who is also the chair of the steering group might be helpful as it would ensure the individual would have the requisite knowledge. They also suggested that a term of two or three years to be renewed would be better than a full five years. They further suggested that one role of the chair would be awareness of the relationship and responsibilities UPD and the NHS Confederation have to each other, e.g. policies, reputational management, etc. Also, VM issued a note of caution about recruiting someone who has knowledge of the issue (i.e, health data), as they may have an intention to make it something more than it is.
- Someone said that in developing the role profile of the chair, it may be worth looking to the UPD evaluation to ensure that they are aligned with those strengths.
- One person stated that it may be worth going back to the Terms of Reference to see what is in scope for the chair. They further noted that the comparison with a chair of a charity might be suitable as the steering group is not unlike the board of trustees of a charity, although acknowledged there might be some issues with this analogy. They also said they think there needs to be a degree of overlap between PF as chair and the new Head of UPD to ensure

continuity and to ensure that the new chair and new Head of UPD have complementary skills. The new chair would need to have governance skills, and understand their role vis a vis the role of the executive. The independence of the chair is hard to define, and might only become obvious during an interview process in terms of whether someone has unsuitable declarations of interest. They also raised the topic of chair recruitment, and whose role it would be to recruit the new chair – in the charity sector it wouldn't be normal for the Head of UPD to be on the panel, but this isn't a charity.

- o Someone said that the difference between a charity and UPD is that the performance management of UPD is via the NHS Confederation, and the steering group is advisory, so it is important to ensure that the wording around the role of chair reflects the role of the steering group and the relationship with the UPD team. They would be willing to be on the panel, but the language needs to be careful, maybe it's not a 'chair', even though they would chair the group.
- o PF suggested the group review the Terms of Reference for the group as thought had gone into the purpose of the group. This document includes some content about the chair, but won't include much on recruitment.

- A member asked whether co-funders needed to come together to discuss the role of the chair, and whether we can draw on NH's experience as Head of UPD regarding what has worked well and less well regarding governance ahead of recruiting for the role.
- NH mentioned that some of the feedback from the funders and external reviewers of the current grant application asked for more information about the governance structure of UPD, and with additional funders and requests for different perspectives being in the group, it might be that the governance itself needs to change a bit. Some of the questions in the review process were about performance management and support for the Head of UPD – whilst this has been actioned to an extent in the updated grant proposal, it's still potentially an area of weakness – Head of UPD has a line manager who isn't a subject matter expert, and the group providing support.
- Someone said there are three forms of accountability. 1) reporting to a line manager, 2) reporting to funders, and 3) less formal, but important, steering group. This is enough.
- Another individual asked if there were any expectations from the funders re advisory nature of the board. The charity analogy doesn't fully work for this group, and likened it to the public panel for SAIL in terms of the responsibilities people have.
- PF mentioned that there may be too many funders / Confed members and not enough independent members in the steering group, although she will be stepping down which will free up a space.
- Someone said that in recruiting for the role, it would be worth thinking about the skills mix in the steering group broadly speaking, for instance having experience in getting an organisation to become financially sustainable, or experience working in an organisation responsible for building trust.
- A member said there could be more representation from patients and the public. They also mentioned that we don't want to change everything at once – new Head of UPD first, then agree new Chair, and then task them with updating the overall governance.
- There was then a discussion about whether PF joined as a patient representative, as this links to her role for the NHS Confederation trustee board. This isn't strictly correct in terms of UPD, as PF had a strong interest in the topic, but she does identify as a patient.
- There was then a brief discussion about when the new chair would ideally start. There is a tension between allowing PF to step down around the two year mark in April as originally

planned, and having a sufficient handover with the new Head of UPD and recruitment period for the new chair. The new Head of UPD is likely to start in February, so it may be difficult to have the recruitment completed by April, particularly if there still needs to be some definition work relating to the role itself.

- NH confirmed the key actions – any requirements / expectations from the funders are needed, NH to pull together some of her thoughts based on her learning, combine this with views from the group, introduce PF and the new Head of UPD, and work out a suitable timescale for the recruitment. NH also asked if anyone from the group was interested in helping with this, between steering group meetings, to get in touch, as that would be helpful. Two members confirmed.
- PF reminded the group that this process may need to consider the vice chair role too.

ACTION 20241210/06 (UPD team): Bring together a plan for recruiting a new chair.

ACTION 20241210/07 (SG members): Contact the UPD team if you want to be involved in the chair role development and recruitment.

AOB and meeting close

- Chair opened up for any quick points from the steering group or reflections for future meetings.
- NH thanked everyone for their help and support, and LM gave some reflections on what UPD has been able to achieve to date.
- Chair welcomed feedback about the meeting via email, thanked attendees and closed the meeting.

ACTION 20241015/07 (UPD team): Organise next meeting for April (dependent on when the new Head of is in post)