Minutes of the Understanding Patient Data Steering Committee: Meeting 8

11:30-14:00, 13th February 2019, Wellcome Trust, 215 Euston Road

Present:
Natalie Banner (UPD)
Clare Curtis (UPD)
Helena Feinstein (DHSC)
Rachel Knowles (MRC)
Sara Marshall (Wellcome) - chair
Sophie Newbound (PHE)
Sir Nick Partridge
Aidan Peppin (UPD/Wellcome)
Nicola Perrin (Wellcome)
Philippa Shelton (UPD) – taking minutes

Apologies:
Lorraine Jackson (Helena Feinstein attended in Lorraine's place)
Karin Woodley (Cambridge House)

1.0 Welcome

1.1 The Chair welcomed attendees and noted it was potentially the last meeting of the steering committee in its current form, and thanked the committee members for their support to date.

The Chair indicated that Nicola Blackwood has resigned from the Committee, having taken up a ministerial post in the House of Lords. The committee noted their thanks for her service.

2.0 Minutes from 7th meeting

2.1 The committee approved the minutes of the seventh meeting with no amendments.

ACTION: Secretariat to publish shortened minutes on UPD website.

2.2 It was commented that the UPD event on 11 Dec 2018 went well. The panel session moved discussions around public engagement onto the practicalities, the stands worked well to engage attendees, and attendees fed back it was a helpful networking opportunity.

3.0 Annual report

3.1 NB talked through the annual report which was late coming to the committee because the evaluation was completed first. The report showcased UPD's highlights from year two.

3.2 The committee asked about UPD's relationship with the Caldicott Guardian network. NB had spoken to a few individual Caldicott Guardians who had a mixture of positive attitudes and concerns about information governance and data use. UPD had spoken once in front of the UK Council of Caldicott Guardians. It was suggested building relationships with, and creating champions of, a number of interested Caldicott Guardians would be a good approach.

3.3 NB ran through the budget. Due to the complexity of carry over budget from year one to year two to pay for the animations, the budget was presented as the complete actual spend for the time of the Memorandum of Understanding between the funders (Jan 2017 – Jan 2019). Wellcome agreed to fund staff costs fully once the MoU ended but this was in Jan 19, so between Sept 18-Jan 19, UPD had used carry over from projects to cover contract

staff costs. There had therefore been a change in how staff costs were reported compared to the previous annual report, which the committee was asked to note.

3.4   The budget showed how much funding was left to support UPD functions until Sept 2019. On top of that, there was also an underspend for the Financial Year 18-19. This was because UPD's small team made it difficult to administer the collective funding.

3.5   The committee requested the followed amendments were made:
- Clarifying acronyms.
- Add text to explain why there was an underspend.
- Clarify the financial year as Sept-Sept.

The committee agree the contingency plan fund could be used to wrap up current projects or be absorbed into new core funding. The committee agreed to the way costs had been reported, confirmed the annual report and budget should be made public once amendments were made.

ACTION: Following amendments, publish the annual report on the UPD website.

4.0   Data for Science and Health priority area

4.1   NPerrin gave an update on the development of the priority area:
- The proposal was in its final stages before being seen by Wellcome's executive team in mid-March and Board of Governors at the end of April.
- The ambition was to help health data innovation benefit everyone. The priority area focused on where Wellcome can add value which was in bringing trust and innovation together.

4.2   The priority area will work on three areas:
1. Engaging society
   a. UPD was at the heart of this theme but would retain its focus in the UK
   b. Public attitudes observatory
2. Build capacity in the workforce who are innovating for public benefit
   a. To tackle concerns that data scientists move to industry by helping them to innovate in public and health sectors
   b. Tool development funding
   c. Community hubs.
3. Demonstrating data innovation creates health impacts
   a. Global programme of data challenges.

4.3   Overall, the priority area will demonstrate data innovation can, in practice, be done in a trustworthy way.

5.0   Strategy and next steps

5.1   NB described a new outcomes framework and theory of change for UPD. This was developed to help the team be clear on what it does and doesn't do, and to provide some accountability as UPD moved away from being a purely responsive model.

5.2   It was agreed that it was out of UPD's remit to tackle issues of inaccurate research, including coding bias. It was important for UPD to be aware that this would have an impact on how people view the use of data. UPD could explore attitudes around these issues.

5.3   The committee suggested the followed edits to the outcomes framework:
- Under policy and governance, decision-making should be cognisant of diversity.
- The comms and media function needed to be considered further. It is not clear that UPD should seek to hold others to account and call out negative data uses.

- It should be made clearer how UPD worked with other platforms (beyond media) where people get their information from.

5.4 Most of the proposed funding will go towards the resources and attitudes workstreams. The committee previously suggested UPD should have less focus on policy and governance. But after talking to stakeholders, the UPD team argued that this work does add value and kept it in the outcomes framework. Policy and governance work would be enabled by personnel resource rather than significant budget.

5.5 NB provided a rationale for how UPD wanted to work with others across three different types of relationships: Funder, Partners and Supporters. UPD would not be commissioned to do projects but will work and co-commission with others. UPD needs an equitable balance of core funders as well as Wellcome being the principle funder. There needed to be clarity on how UPD related to HDR-UK. Further clarity was needed to define comms and media roles of UPD versus the Data for Science and Health priority area.

5.6 The proposed budget required UPD to secure core funding from others (beyond Wellcome) which would contribute towards the resource workstream and website development. To ensure UPD's independence, the UPD team suggested it should no longer receive funding directly from the Department of Health and Social Care, but if feasible via a research funding body (e.g. NIHR). The committee suggested larger charities may consider funding UPD.

5.7 As part of UPD's governance structure (steering committee and advisory group), the team decided not to have a separate patient panel but have patient representatives on the steering committee (minimum of two) and advisory group (unlimited number). Patients would continue to be part and parcel of UPD's daily workstreams and activities. This decision was made so that the patient voice wasn't isolated or made to be standalone. The steering committee also suggested the advisory group should include a Caldicott Guardian and a data scientist.

6.0 Office for Life Sciences engagement work

6.1 NB provided background for why the Office for Life Sciences (OLS) were publishing a policy framework on commercial models for industry and NHS partnerships. There is currently no advice for NHS organisations who want to work, and partner, with tech companies involving the use of patient data.

6.2 OLS aimed to publish a policy framework having consulted with industry and academia. UPD wrote a joint letter, with others, to the Secretary of State in December 2018 calling for public and patients to be engaged and involved in the policy framework. UPD were in discussion with OLS after proposing to do some deliberative public engagement work with support from a staff member (1/2 day a week) from the Ada Lovelace Institute. This work would take a minimum of four months and UPD had offered to contribute £40K if OLS provided matched funding. UPD would commission and project manage the work.

6.3 The committee discussed the reputational risk for UPD if:
- UPD didn't step in to help OLS and no significant public engagement was done or done poorly;
- UPD did step in but public engagement findings were not taken on board in the policy framework.

6.4 It was generally agreed UPD should try and help get this right given the sensitivities around data use by commercial entities, so long as its independent voice could be maintained.

7.0   Transparency project

7.1   PS gave a summary of recent scoping work which looked into how UPD can add value to discussions around transparency and best practice. There was a sense that the patient data community needed to share a common understanding of what was meant by transparency.

7.2   Transparency was being considered as the way data use was processed and governed as well as communicated. At this very broad definition, organisations sometimes found it difficult to know where to concentrate their efforts.

7.3   A meeting will be organised in Mar 2019 to explore this collectively and to help define boundaries to the way transparency is approached.

8.0   Engagement project update

8.1   CC gave an update on a project exploring UPD's assumption that providing information about patient data uses affects public confidence. It aimed to identify other factors that determined confidence, such as the messenger, people's experiences and how the information was delivered. The project was in partnership with Wellcome's Public Engagement team.

8.2   An agency called Spotless had been commissioned and had carried out:
- 30 patient interviews in Leeds, London and Bristol
    - Interviewees were a mix of those who had high and low amounts of interaction with healthcare.
- 9 health care professional interviews across England.
- Public workshops in London and Bristol.

8.3   Next Steps were a full analysis and debrief from Spotless, further work with Wellcome's public engagement team to draw out key messages, and to identify ways of implementing the findings in UPD's work and dissemination.

9.0   Resource 'quick guide' update

9.1   CC gave an update on the toolkit to bring together UPD's resources. Following extensive feedback from the Dec 2018 event, it was found that a 'quick guide' would be more helpful. UPD partners and stakeholders found it hard to share resources with people less familiar with UPD, and to navigate the website quickly.

9.2   CC demonstrated what the quick guide would look like. It would provide high level information and key messages about each UPD resource and direct users to the relevant sections on the website.

9.3   The committee asked about clinical audiences who were less familiar with using data for research. The quick guide may need further testing with these potential users. Clinical audits were mentioned as a potential hook for health care professionals.

10.0   AOB

10.1   There was no other business. The Chair thanked all the committee members for their efforts over the last 2 years, and the meeting was closed.

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