

Minutes of the Understanding Patient Data Steering Committee: Meeting 6

11:30-14:00, 31st July 2018, Wellcome Trust 215 Euston Road

Present:

Natalie Banner (UPD)
Nicola Blackwood
Clare Curtis (UPD) – taking minutes
Helena Feinstein (DHSC)
Professor Sara Marshall (Wellcome) - Chair
Sir Nick Partridge
Nicola Perrin (Wellcome)
Philippa Shelton (UPD)
Professor Peter Weissberg
Karin Woodley (Cambridge House)

Apologies:

Rachel Knowles (MRC)
Dr Jem Rashbass (PHE)

1.0 Welcome

- 1.1 SM opened with a welcome to the group and introduction of new committee member Nicola Blackwood. Apologies from Jem Rashbass and Rachel Knowles were noted.

2.0 Minutes from 5th meeting

- 2.1 The group approved the minutes from the fifth SC meeting.

ACTION: Secretariat to publish shortened minutes on UPD website.

- 2.2 Reflections on the national data opt-out were discussed. Despite the risks and vulnerabilities raised in the last steering committee meeting, the consensus was the opt-out had landed well.
- HF commented on UPD's positive role in helping to shape communication of the opt-out.
 - NBanner explained the previously mentioned risk around the Home Office – NHS Digital Memorandum of Understanding (MoU) had been reduced because the MoU had since been suspended for amendment, with the threshold for requesting data made significantly higher.
 - NPerrin mentioned that following the letter mailed to people holding a type 2 opt-out, there had been an unexpected number of people opting back in.
 - HF responded to questions about the narrowness of definitions of confidential and administrative data, explaining the definitions were supported by the National Data Guardian. NPerrin said that that the definition was explained in a clear way throughout the opt-out's launch.
 - Several members commented that it would be interesting to see any trends emerge around reversals of opt-outs.

3.0 UPD resources updates

- 3.1 PS gave the following update on resources:
- The animations have been very successful. They have been viewed 1.5 million times collectively, far exceeding targets, doubling traffic to the website and introducing UPD to new users.

- Five case study videos were almost finished. Based on stakeholder comments to see more human stories about patient data uses, we anticipate these will be well received.
- Resources on weighing up risk and on the national data opt-out have been produced. There is a long read-time for many pages of the website.
- The UPD website and some of its resources have featured on external guidance for key groups, such as the Royal College of Nursing and Royal College of General Practitioners.
- UPD's resources and approach were having increasing influence such that other organisations have been asking us for advice on how to create similar resources.
- New resources have been added to the *supporting conversations* section of the website that bring together work on how people feel about patient data use.

4.0 Horizon scanning

4.1 NBanner gave an update, including:

- The report *Data for Public Benefit* was launched with Involve and the Carnegie Trust and included an accompanying animation. The aim was to explore what public benefit means in a range of sectors, including health. A framework was created from this work, which is designed to assist in making practical assessments of whether an example of data sharing was for public benefit.
- The public dialogue work with the Academy of Medical Sciences will be published in November. It is exploring how the public, patients and clinicians view new technologies that use healthcare data. There will also be a policy report setting out principles for data-driven technologies in healthcare and research. There is an opportunity for this work to feed in to the Code of Conduct for AI which is currently being developed by NHS England.
- NBanner is scoping whether there is something UPD can offer to the current debate on the value of patient data, and is in discussion with OLS about public engagement work on this.
- UPD will be exploring what transparency in the use of patient data means. This is a term in frequent use and UPD will look at what different expectations about transparency might be and what good transparency in the use of data means.

5.0 Evaluating UPD

5.1 PS asked the committee to consider the purpose of the upcoming UPD evaluation and for key questions to answer. The following were suggested:

- The evaluation should consider what would have happened if UPD had not been created and ask who else may have done this work.
- The evaluation should not just assess against the original objectives but help to develop our understanding of what we might do next.
- The evaluation should capture that there was a need for an organisation to take a lead in providing commentary.
- What role UPD's independence from other organisations plays, for example in bringing them together.
- When discussing metrics NPerrin reminded the committee that a behavioural outcome – based on numbers of opt-outs - was deliberately not agreed upon when UPD first started as that is not a fair metric for assessing whether people are more informed.

The committee agreed that the evaluation will serve as a learning tool, looking at how well UPD did what it did and what it could do differently in any future projects.

6.0 Forward look/ future of UPD

- 6.1 NBanner asked the committee for feedback on the future of UPD as its initial period of funding is almost complete.

Three broad potential options were given:

1. For UPD to wrap up and to divide its resources between other interested organisations who could continue to use and promote them through their own channels.
2. For UPD to be amalgamated into another organisation as part of a wider relevant area of work.
3. For UPD to continue to operate as an independent initiative with new objectives, and contingent on new sources of funding.

There were mixed views, but there was an agreement that option 1 was not ideal at this stage. The consensus was that there was still a role for UPD. The committee discussed the following:

- The independence of UPD and freedom to take views without a vested interest are key. If UPD works more closely with/is part of another organisation in the future, it should retain its independence.
- It feels like there is still a lot left to do: conversations about data use are increasing, particularly in light of GDPR and various data scandals.
- Being able to respond flexibly and foresee problems in advance is a very useful function.
- The patient voice is important, and UPD has a particular role in helping ensure patient and public perspectives is fed into policy and processes around how data is used.
- The UPD mission has been specific and if its focus was broadened or diluted it may not be as effective.
- The current model is very cost effective, and Wellcome's in-kind contribution to staff support, admin, office space etc has been crucial to UPD's effectiveness.

ACTION: NBanner to further develop options 2 and 3 for discussion at the next committee meeting.

7.0 Steering committee composition

- 7.1 PW is stepping down from the steering committee. He was thanked for his contribution to UPD's work.

NBanner suggested some potential new committee members who had clinical expertise.

8.0 AOB

- 8.1 Because this meeting had been delayed from June, NBanner suggested the next meeting is rearranged later as the September date felt too soon.

Close