**Minutes of the Understanding Patient Data Steering Committee: Meeting 7**

**11:30-13:30, 1st November 2018, Wellcome Trust, 215 Euston Road**

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

Apologies:
Nicola Blackwood
Lorraine Jackson (Helena Feinstein attended in Lorraine's place)
Rachel Knowles (MRC)
Jem Rashbass (Sophie Newbound taking over from Jem)
Karin Woodley (Cambridge House)

**1.0    Welcome**

1.1    SM welcomed the group, and introduced Graduate Trainee, Aidan Peppin, who is working with UPD. Apologies were received from Jem, Karin, and Lorraine and Nicola Blackwood. Sophie Newbound was introduced as a new committee member to represent PHE.

**2.0    Minutes from 6th meeting**

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

       **ACTION:** Secretariat to publish shortened minutes on UPD website.

**3.0    UPD resources and activities updates**

3.1    CC gave an update of a new resource in development: a 'Who's who' of organisations at a national level that have oversight of and/or who make decisions about access to patient data. The new resource will provide details on how decisions about data are broadly made but must strike the balance between detail and accessibility. The committee suggested the resource is discussed with the NDG, NHS Digital, and PHE to inform them and to check for accuracy.

3.2    CC described work to develop a 'toolkit' that brings together all of UPD's key resources. It aims to provide responses to the most common 10 questions addressed by the UPD website in one easy-to-access document. A draft of this toolkit will be tested at an event hosted by UPD in December.

3.3    CC and NB introduced work to look at the existing identifiability spectrum to decide whether it can be refined to ensure it aligns with GDPR and the legislative terms used for different levels of identifiability.

3.4    AP gave an update from the event UPD ran on 13-14 September 2018: '*Healthcare and Data: How do we get it right?'*
       • The event was attended by representatives of NHS England, DHSC, the tech sector, academia, NGOs and charities, and the NDG.

- A key output was a set of actions centred on improving health data quality and infrastructure; effective public engagement; synthesising regulation and guidance; and developing models for collaboration on uses of health data.
- The SC asked about the mood and tone of the event. NB indicated there was enthusiasm, excitement and potential, but also recognition of the hurdles that need to be overcome.
- The group discussed the prospect of arranging a second meeting in 2019 to provide some follow-up.

**4.0    Evaluation**

4.1    PS gave an overview of the lessons learned from the evaluation of UPD and invited questions from the committee.
- Overall, UPD has achieved what it set out to do. The resources it has developed and partnerships it has formed have responded to an important unmet need.
- The evaluation identified that UPD has certain qualities - independence, experience, leadership - which has allowed it to be effective in developing resources, providing consistent messaging, supporting partnerships and building confidence.
- The committee welcomed the evaluation and expressed that the findings are positive.
- The findings support the view that UPD should continue, and not become over-governed.
- Members of the committee asked whether the methods and findings were robust enough, noting the overwhelming positivity of findings. Some sections needed further work and evidence to ensure the report is balanced. There was also a need to recognise that it's the research and process behind UPD resources and the continued engagement with them, not just the resources themselves, which have enabled UPD's success.
- SM asked if the evaluation report is sufficient for the funders. The committee felt it was proportionate and therefore sufficient.

**ACTION:** PS to reflect on the Committee's feedback to develop the evaluation into a final report.

**5.0    Forward look / future of UPD – options paper**

5.1    NB introduced a proposal for the future strategy of UPD and invited discussion. NB contextualised the strategy in the current landscape which is rapidly developing and presenting new challenges.

5.2    In light of these, UPD 'can't be all things to all people'. NB introduced a range of areas which are outside of UPD's remit going forward: tech and data ethics; national public information campaigns; exploring data philanthropy or data trusts; blockchain; genomic and other -omic data; being an ombudsman.

The committee agreed that these areas were outside of UPD's remit going forward, but noted:
- UPD can input into debates on ethics, using its position and experience to influence. However, UPD must not take on the responsibility of ensuring public trust for other organisations.
- Policing, regulating, and accrediting data use is not UPD's responsibility.

5.3    NB introduced four core pillars at the centre of the proposed strategy for UPD, and invited comments from the committee.
- The four cores are: public engagement and attitudes; new resources and horizons; partnerships and community; policy and regulation.

- The committee noted that through public engagement work and new resources, engaging with and supporting healthcare professionals (HCPs) is a crucial role for UPD.
- It was felt that the scale of policy and regulation work proposed was greater than UPD could address, but that UPD can play an important role feeding into this work.
- SM noted that an awareness of the other organisations in this space is vital to ensuring UPD has maximum impact and doesn't duplicate existing work.
- The committee discussed what UPD's role should be and the extent to which it should undertake policy and advocacy work itself.
- The committee asked UPD to consider what its deliverables needed to be while maintaining responsiveness and agility.
- The committee discussed that horizon scanning must focus on the near future and address current concerns about impending changes or impacts (i.e. <18 months).

5.4     NB introduced potential new funding structures for UPD and asked for committee feedback. NPerrin provided further detail for the committee on the proposals for the developing Wellcome Priority Area on Data for Science and Health, for context.

- NB focused on Model A from the briefing paper – detailing a structure for UPD which was embedded in Wellcome's proposed Data for Science and Health Priority Area.
- The committee were generally supportive of this model, noting that it would be cost effective and maintain the right level of governance.
- It was questioned whether a strong Wellcome focus would affect UPD's independence. NPerrin cited two other initiatives sitting within existing Wellcome Priority Areas, which operate independently. The committee agreed that if UPD had similar independence, that would be preferable.
- It was asked what would happen if the Data for Science and Health priority area is not approved. NPerrin responded that there is funding to cover staff salaries to support UPD developing a plan B post-April, should it not be approved, so until then UPD can focus its resources on developing the right proposal with Model A.
- SM summarised that it seems there's support for Model A – UPD to continue as supported by Wellcome's priority area – as long as independence is protected, and there is contingency for a plan B should the priority area not be approved.

**6.0     Public engagement research proposal**

6.1     NB introduced a proposal to work with the Public Engagement team at Wellcome, to better understand whether high quality information make a difference to peoples' confidence in data use. The committee agreed this is an interesting piece of work and supported its development.

**7.0     December Event**

7.1     NB and AP gave an update of an event with stakeholders and partners to be held on 11 December, to celebrate UPD's achievements so far and look ahead to the future.

   **ACTION:** Committee members to let NB know if they would like to give a talk at the event.

**8.0     AOB**

8.1
- The next meeting date will be on either the 13/14 February 2019.
- A second annual report would be produced for the February meeting.

   **Close**