<u>Minutes of the *Understanding Patient Data* Steering Committee: Meeting 2</u>

<u>10:00-13:00, 27th March 2017, Wellcome Trust 215 Euston Road</u>

<u>Present:</u>

Lorraine Jackson (DH)
Sharmila Nebhrajani (MRC, on behalf of Research Councils UK) – Chair
Dr Jem Rashbass (PHE)
Sir Nick Partridge
Nicola Perrin (UPD)
Natalie Banner (UPD) – taking minutes

<u>Apologies:</u>

Prof Peter Weissberg
Mark Henderson (Wellcome)

1.0   Welcome

1.1   Apologies from Peter Weissberg and Mark Henderson were noted.

2.0   Minutes from 1st meeting

2.1   The group approved the minutes from the first SC meeting.

        It was agreed that UPD should publish meeting minutes on the Understanding Patient Data website in the interests of transparency.

2.2   NPerrin noted that we have successfully recruited a new Policy and Comms Officer on a 12 month basis, who will start next week.

3.0   Tools and resources

3.1   NPerrin introduced the draft website, which will be launched as a 'minimum viable product' before the UPD meeting on 6th April. This includes pages on case studies with a search and filter function, background to the initiative with key messages, some initial tools and resources, and a news function.

        The SC discussed the website and commented:

        Case studies
        - For the case studies, the group discussed what the aspiration for the case studies is and how many we realistically expect to include in total. 31 will be available at the time of launch.
        - UPD needs to consider whether the cases will be refreshed and updated or used as a 'legacy' collection to show the depth and breadth of impacts.
        - It was noted that the resource is directed predominantly at those having conversations (clinicians, researchers, media) rather than the public themselves, but that further thought should be given to how to engage a broad range of people, potentially including patient journeys and impacts.

        Key messages
        - The three draft key messages, about the importance of using data, the need for

safeguards and the right for people to know about what happens to data, are currently quite data-centric as opposed to person-centric. The group made suggestions for refining these. The meeting on the 6th will be an opportunity to get further feedback from the community on what these messages should be.

News stories
- Commenting on current and emerging news stories relating to patient data is a good way of keeping the site refreshed and relevant. UPD must be non-partisan and transparent in its commentary and views.
- NPerrin commented that some news stories can be scoped from others: e.g. a story about the Scottish SPIRE system will be sourced from the Farr Institute Scotland, in time for launch. UPD can encourage these types of contributions.

Look and feel
- The website is deliberately targeted at healthcare professionals, media etc rather than the general public but it may need a less 'corporate' look and feel in time if there is significant public interest in it.
- It needs to be clear at the launch that the website is a minimum product at present and that it will continue to be developed over time. This will ensure people are aware there is more to come and also that they have an opportunity to feed in to its development.

4.0 Developing advocates

4.1 NPerrin outlined initial plans to develop advocates for responsible use of data across the sector, including patients, clinicians and researchers. GPs are a particularly important group to reach. The breakout groups at the launch meeting will be used to source ideas about how best UPD can assist with efforts to develop advocates and identify best practice.

The focus should be on what support UPD can provide, rather than implying that UPD will be undertaking engagement activities itself. UPD can amplify or bring together existing activities and emphasise the broader picture of data sharing.

4.2 ESRC fed in the comment that the Administrative Data Research Network (ADRN) has well developed messaging around individual privacy vs research for public good.

4.3 The SC discussed what UPD can do at the launch meeting to help the process of developing advocates and changing the broad tone of discussion. It was agreed that the meeting should seek to act as a 'call for action', to energise people and motivate them to think about what they need in order to become or to develop champions for the responsible use of data.

5.0 Horizon scanning and analysis

5.1 NB provided an overview of the three strands of work comprising the horizon scanning and analysis work stream, outlined in the circulated paper:
- Balancing privacy and public benefit:
  UPD were partnering with Carnegie UK Trust and Involve to carry out a piece of work exploring how people balance individual privacy and public benefit with administrative data sharing, in housing, welfare, criminal justice and health and social care.
- Linking health data with data from different sectors:
  UPD were building examples of where linking different types of data would be of value. At this stage, UPD does not have specific activities planned.
- New and emerging digital technologies in healthcare:
- An ESRC PhD student will undertake a 3-month internship with UPD to map out the landscape of new and emerging technologies that use patient data.
- The mapping will feed into a meeting planned for 19th June at the Wellcome Genome Campus, co-convened with Wellcome, bringing together experts from the tech industry, academics and learned bodes, and government and NHS representatives to

> jointly explore the ethical and social issues likely to arise from the use of these technologies in the coming years.
> - The meeting will be an opportunity to initiate conversations to think about these future challenges, across traditional siloes.

5.2   On balancing privacy and public benefit, it was noted that the recent Home Office/NHSD MoU might affect public perceptions and perspectives on the right balance between public benefit and privacy implications – particularly as the agreement may have negative public health implications if e.g. sick people avoid accessing health services as a result.

On new and emerging technologies, it was noted that the meeting was important and that UPD should be very clear on where it wants to add value in this space. The focus from UPD's perspective should be on what new technologies mean for patients and society more broadly. This includes demystifying the technologies and enabling people to understand how data is used so they are better informed.

ACTION: Invitations to June meeting to be sent to the SC

6.0   External landscape: Update from the Department of Health

LJ provided an update on DH timelines for responding to the Caldicott Review. Other relevant activities noted were:
- The National Data Guardian Bill, which Jo Churchill will bring forward again in the new Parliamentary session
- Work was underway to publish the OLS Life Sciences strategy.

7.0   AOB

7.1   National Voices has been approached to be a supporter of UPD. The organisation is supportive of the initiative, with Hilary Newiss suggested as the key person to invite to the Advisory Group.

7.2   **ACTION:** NPerrin to confirm with Hilary Newiss that she will be on the Advisory Group

Next meeting date will be 21 June 2017.

Close