

Minutes of the Understanding Patient Data Steering Committee: Meeting 4

14:30-16.30, 16th October 2017, Wellcome Trust 215 Euston Road

Present:

Natalie Banner (UPD)
Helena Feinstein (DH)
Mark Henderson (Wellcome)
Sharmila Nebhrajani (MRC, on behalf of Research Councils UK) – Chair
Nicola Perrin (UPD)
Dr Jem Rashbass (PHE)
Philippa Shelton (UPD) – taking minutes
Professor Peter Weissberg
Karin Woodley (ESRC/Cambridge House)

Apologies:

Lorraine Jackson (Helena Feinstein attended in Lorraine's place)
Sir Nick Partridge

1.0 Welcome

- 1.1 The chair welcomed everyone to the meeting. Apologies from Lorraine Jackson and Nick Partridge were noted.

2.0 Minutes from 3rd meeting

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

ACTION: Secretariat to publish shortened minutes on UPD website.

3.0 Annual report

- 3.1 NPerrin presented the annual report and asked whether it gave enough information to enable funders to decide whether to go ahead with the second year of funding. As funders, the SC members were happy with the way the report captured the essence of the year one and plans for year two.

The SC suggested the following amendments:

- a breakdown of non-Wellcome donations
- a more explicit note of the budget carry-over from the first year
- links to the website
- one-page summary sheet at the end.

ACTION: A public version of the annual report will be published on the UPD website.

4.0 Forward look

- 4.1 NPerrin introduced the forward look paper which detailed proposals for UPD's second year. The advisory group had commented on the paper and agreed it was suitable with some expansion on FAQs to be added to the website and more work around social care.

The SC discussed the activities and commented:

Supporting conversations

- The data citation had spread well. It had been shared with funders, data holders, journals and medical research charities.
- UPD planned to host at least one more cross-sector meeting.
- There was a growing need to work with GP community. NHS England and Digital comms teams were mainly engaging with GPs regarding plans for the opt-out, but not more broadly about why it is important to use data.
- SC discussed how to best reach out to GPs.

Independent analysis and advice

- The public benefit work was progressing. The conclusion from the workshops was that views differ greatly: there wasn't a single definition for public benefit, so there needed to be care when using it within a framework for decisions-making.
- UPD planned to do some work around what good transparency means. Many organisations were involved and NPerrin would keep the SC updated.
- The advisory group had recommended some work was needed around the value of data.
- There was some confusion between the three strands in this section - value, risk and transparency. All were interconnected and the separate lines of work needed to be brought together when presenting answers.

Engaging patients

- There was discussion around engaging different groups of people.
- NPerrin described how the Discovery programme in east London was using UPD resources. Discovery was engaging local communities who will relate to a number of these different groups.
- The SC felt UPD should partner with the right intermediaries who are already working with these groups/experts.

Horizon scanning

- NB gave an update that the public dialogue run by Ipsos Mori and led by the Academy of Medical Sciences had been delayed. Sign off was due in October. Carol Dezateux FMedSci was chairing the project working group.
- The work will cover range of ways technologies using patient data could be used in medical research and care and what people found acceptable.
- NB also described work on what an appropriate regulatory framework should look like. UPD was working with Julian Huppert and Hal Hodson to host a meeting on this involving a public forum and a more focused, closed evening session.
- The SC wanted to see more tangible outcomes from the meeting other than the possibility to feed into existing efforts. It should focus around UPD's convening role.

What next

- The advisory group had unanimously agreed that UPD should continue beyond two years, and Nick Partridge had sent similar comments in advance of the meeting. The SC felt UPD would need to look and feel different beyond its initial two years, but with GDPR and emerging technologies, the issues needed an ongoing conversation.
- The SC asked when the right time for funders to decide on extending funding would be, as this would affect how the second year was planned.
- For an extension of funding, perhaps on a year by year basis, funders would need a strong rationale, objectives and measurables.
- A mechanism was needed in which UPD work could continue through other means eg in context of other changing organisations like the NDG.
- A clear exit strategy, timeframe and way of implementing it should be prepared alongside any extended funding beyond two years.

ACTION: NPerrin to add a paragraph on communicating with researchers before sharing the forward look paper with the funders (alongside the annual report).

5.0 Tools and resources

- 5.1 Oral updates were provided as part of the discussion for item 4 but the following was also commented on:

Animations

- Needed to include a data linkage example, eg asthma and air pollution.
- To balance targeting the interested public versus informing relationships with professionals. The project was testing with GPs and healthcare professionals via PRSB.
- The potential to use these alongside PR for the NHS 70th anniversary next year. We would need to be confident that the animations are doing what we intended before further promotion.

ACTION: PS to feedback in the next meeting about how the animations were tested and how they will be evaluated.

6.0 Engaging healthcare professionals

- 6.1 NPerrin presented a proposal to collaborate with the Academy of Medical Royal Colleges to support a competition recognising and rewarding digital excellence in health and social care.

The SC suggested that financial contribution may not be the most appropriate but rather UPD should offer support in kind through our brand and reputation. There was support for the direction of travel and a suggestion that it should be explored further.

7.0 External landscape: update from Department of Health

- 7.1 HF highlighted that DH was supporting the private members bill to get the NDG on a statutory footing.

HF reiterated that implementing national opt-out and enabling sharing data underpinned the 2020 goals.

There was a separate piece of work for NHS readiness for GDPR. DH was trying to align the comms for both opt-out and GDPR.

8.0 AOB

- 8.1 NPerrin, UPD team and the SC thanked SN for her commitment to UPD as this was her last meeting as chair.

- 8.2 NPerrin highlighted that she had spoken to Nicola Blackwood (NBlackwood) and that patient data remained high in her areas of interest. It was agreed NBlackwood should be invited onto the SC after talking to DH regarding conflicts. The SC reflected that the quality of discussion was improved by including non-funders onto the group.

- 8.3 Planning for SC membership would be worked through offline, regarding the interim MRC chair and Sara Marshall returning to Wellcome.

- 8.4 The next meeting is on 14 December, 10.30am – 1pm.

Close