

**Minutes of the Understanding Patient Data Steering Committee: Meeting 5**

**11:00-13:00, 13th March 2018, Wellcome Trust 215 Euston Road**

Present:

Natalie Banner (UPD)  
Helena Feinstein (DHSC)  
Rachel Knowles (MRC)  
Sara Marshall (Wellcome) - Chair  
Sir Nick Partridge  
Nicola Perrin (UPD)  
Dr Jem Rashbass (PHE)  
Philippa Shelton (UPD) – taking minutes  
Professor Peter Weissberg

Apologies:

Lorraine Jackson (Helena Feinstein attended in Lorraine's place)  
Karin Woodley (ESRC/Cambridge House)

**1.0 Welcome**

- 1.1 SM, the new chair, introduced herself and welcomed everyone to the meeting. RK, MRC, was also introduced as a new member. Apologies from Lorraine Jackson and Karin Woodley were noted.

**2.0 Minutes from 4th meeting**

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

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

**3.0 National opt-out implementation**

- 3.1 HF gave an update from Department of Health and Social Care:

- The minister was engaging heavily with the national opt-out implementation, and the wider data agenda, with public reassurance as a high priority.
- Communication teams from NHS England, NHS Digital, DHSC were talking with charities, the Royal Colleges and patients.
- The department had decided to:
  - align the op-out implementation with GDPR on the 25th May 2018
  - use a single question
  - communicate directly with the 1.3 million people registered with a type 2 opt-out explaining how their preference would be transferred to the new national opt-out.
- It was acknowledged that the definition of what types of data are included will affect how the opt-out is communicated.

NHS communication plans:

- DCMS were leading on pan-government communications about GDPR more broadly; DHSC was linked in with the DCMS effort and were bringing in NHS Digital and NHS England as well; NHS England was leading on the wider narrative of using data, linking to "NHS at 70."
- More specific communications for the opt-out were being developed for GPs and professionals through the Royal Colleges.

- NPerrin commented that UPD felt comfortable with opt-out specific communications from NHS Digital. Concern remained about whether there was sufficient communication around the bigger picture/benefits and particularly to healthcare professionals.
- It was also acknowledged that charities were concerned about there being enough public engagement in May.
- NHS England had dedicated a named spokesperson to respond to any negative press. This was a good step forward.

Risks and vulnerabilities:

- The national opt-out programme team were managing risks and vulnerabilities, including those around communicating directly to individuals who had opted out, and the definition of data to be adopted.
- It would be helpful to have more clarity around public health uses of data, to fulfil fair processing requirements. The best place to communicate this level of detail was yet to be agreed.
- It was acknowledged that the Home Office-NHS Digital MoU was still a potential issue because it brought to light that administrative data (name, address) can still flow in some circumstances. NPerrin explained that this was a risk to the opt-out communications landing well.

#### 4.0 UPD resources

##### 4.1 Animations

- The 'Bigger picture' animation was played for the committee which started the launch of the series on the 12 March.
- Members had seen some of the animations and felt they were pitched at a good level, were informative and diverse.
- PS mentioned that NHS England was considering how they could use the series online and elsewhere (eg in GP surgeries).
- Members commented that there needed to be clarification for the devolved nations. As the opt-out was not explicitly mentioned, the series could be used beyond England.
- Initial response to the start of the launch seemed positive, sparking conversations among patients on Twitter.

Risk resource

- NPerrin presented the draft resource to help talk about risk and mentioned that it would be discussed at a patient panel the following week.
- The members acknowledged that risk is an emotive subject and the resource does try to go between facts/statistics and how people feel, but were concerned it came across as scare-mongering.
- Where possible the resource should provide a sense of proportionality with numbers.

#### 5.0 Horizon Scanning: AMS public attitudes work

- 5.1 NB described how the study was looking at attitudes to the deployment of new technology using patient data in health and research. Ipsos MORI had run six workshops in London, Cardiff and Sheffield. The workshops drew on case studies including:
- AI in antenatal research; drug efficacy; insulin pumps and lifestyle data; recruiting for clinical trials.

Overall, the workshops found that people tended to be enthusiastic about these uses but often didn't believe what could be actually done with data in terms of true outcomes and changing practice. People had concerns around surveillance and fears of losing doctor-patient relationships.

**Action:** NB to send a more detailed update with minutes.

## 6.0 Forward Look / future of UPD

- 6.1 The committee had started a conversation on the future of UPD at the last meeting. Views from advisory group echoed that UPD should continue for another year to cover all mains issues.

MRC had since taken a proposal to extend UPD funding to their board, which was provisionally agreed. In addition, there was unspent budget which could be rolled over.

Wellcome was also having a lot of internal discussion on how to shape data as a priority area. More will be presented at the next meeting when it becomes clearer how data sits within Wellcome, with NPerrin leading this work and keeping public confidence at the heart of this bid. She will start her new role formally in June and NB will take over as head of UPD.

This provided the UPD team an opportunity to refresh and think about what UPD needs to do post-GDPR and opt-out in May. For example, putting more capacity into exploring the value of data, horizon scanning and developing clinician advocates and champions.

## 7.0 AOB

- 7.1 The following additional updates were given:

- UPD's joint work looking at public attitudes with Involve and Carnegie UK had been signed off and expected to be available in April. It presented a framework to take into account when making decisions.
- UPD will support the funding of a person to work with the Discovery London programme.
- HDR UK was launching its call for second round of sites. HDR UK was planning a public engagement roundtable in May that NPerrin will attend.

**Action:** NPerrin to confirm a date for the next SC meeting in June.

**Close**