

**Minutes of the Understanding Patient Data Steering Committee: Meeting 3**

**11:00-14:00, 21st June 2017, Wellcome Trust 215 Euston Road**

Present:

Natalie Banner (UPD)  
Alex Mankoo (UPD)  
Sharmila Nebhrajani (MRC, on behalf of Research Councils UK) – Chair  
Sir Nick Partridge  
Nicola Perrin (UPD)  
Dr Jem Rashbass (PHE)  
Philippa Shelton (UPD) – taking minutes  
Professor Peter Weissberg  
Karin Woodley (ESRC/Cambridge House)

Apologies:

Mark Henderson (Wellcome)  
Lorraine Jackson (DH)

**1.0 Welcome**

- 1.1 The chair welcomed Karin Woodley who joined the Steering Committee (SC). Karin is a Council member of ESRC, and Chief Executive of Cambridge House, a South London charity.

Apologies from Mark Henderson and Lorraine Jackson were noted.

**2.0 Minutes from 2nd meeting**

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

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

**3.0 Tools and resources**

- 3.1 NPerrin introduced plans to develop a 'toolkit' to support conversations. It included ten resources covering questions the public are most likely to ask such as how data is used, and the risks of using and not using data.

The SC discussed the tools and commented:

*Why it is important to use patient data?*

- UPD had already received positive feedback from users on the bank of case studies. Professionals had begun to use them, as well as significant dissemination to DH and NHS comms.
- It was agreed more examples were needed on mental health, sexual health and routine care such as maternal health.

*What happens to your data (and who sees it)?*

- This resource would be a series of animations explaining what happened to data beyond the point of care, where it went, why and how, presented in a simple and engaging way.
- The resource needed to be realistic and address the demand for what the public wanted to know.
- It was important to show where people have choices, and where they don't, who does (ie the governance and safeguards).

*What are the risks?*

There was a large gap in being able to talk openly and honestly around the risks and safeguards. NPerrin was speaking to David Spiegelhalter, Winton Professor of the Public Understanding of Risk at the University of Cambridge to identify the best way to talk about risk.

- It was agreed that UPD was explicit that it was not possible to quantify statistical risks of data use. Instead, it was better to present risk within examples the public related to such as talking to their GP about clinical risks.
- In addition, it was essential UPD communicate that risk cannot be eliminated entirely.

**ACTION:** As it develops, share with the SC the rationale on how to talk about risk to ask questions for guidance on direction.

*Is the data identifiable?*

- There were two issues with the identifiability spectrum –
  - The location of the ‘anonymised’ bracket: this will be clarified by animating the image which will put how the data is used in context and highlight the safeguards.
  - Where pseudonymised data sits on the spectrum: Under GDPR, pseudonymised data can fall across the boundary. It remained a grey area which the images tried to be more open about.
- Overall, the image aimed to portray a spectrum, not distinct boxes.
- Technical stakeholders often wanted the images to go into more granular detail; however, it was important to make sure public conversations were based on current public understanding.

#### 4.0 Supporting conversations

- 4.1 NPerrin outlined plans for developing advocates and supporting local conversations. There was a consensus at the launch meeting for UPD to support local level conversation, rather than a national, top-down approach.

The SC discussed the activities and commented:

*Key messages:*

- Comments from the launch meeting led to the three key messages being adapted slightly. They were subsequently tested with patients.
- The third message needed to capture where people had a choice, where they don't and why they don't. There was a need to be more open about the limited boundaries of choice/ opt-out.

*Provide analysis and advice to inform public engagement activities*

- NPerrin gave an update on six workshops with Involve and the Carnegie Trust looking at how people understand public benefit and, issues when weighing up privacy and public benefit.

*Engaging with healthcare professionals*

- NPerrin had initiated conversations with the Royal Colleges. All were supportive to get resources to their memberships, such as CPD and training modules.

*Engage with researchers*

- NPerrin highlighted that the Farr Institute was looking at how they create an engaged research community by being upfront on what they expected from their researchers.
- The SC were supportive of the principles, but cautioned further thought was needed on how this was done in practice.

#### 5.0 Horizon scanning and analysis

- 5.1 NB and AM gave an update on the outcomes of the new digital technologies conference, which took place on 19 June, and initial plans on working with the Academy of Medical Science (AMS) on a public dialogue on this topic.

**ACTION:** NB to circulate the SC presentation slides and slides from the new tech meeting.

The meeting asked participants where UPD should focus regarding a public dialogue on uses of new digital technologies and patient data. The SC felt more clarity was needed on what exactly UPD wanted to understand from the public. It was suggested case examples were tested with patient panels. The UPD team will complete further scoping with AMS.

NPerrin informed the SC that a series of think pieces would be commissioned, to introduce complicated new technologies in an accessible way as well as outline their strengths and weaknesses. After 'synthetic data' was mentioned at the launch, a proposal was received. The SC felt a wider call for proposals should be circulated.

## 6.0 Developing a voice

- 6.1 NPerrin asked the SC for guidance on whether UPD should have role in publicly commenting on news in general. In addition, it was asked whether UPD should provide comment on particular stories such as the NHS Digital audit of Harvey Walsh, and the MoU between the NHS and Home Office.

On providing a voice in general:

- There had been a number of opportunities for UPD to respond to or flag recent news items, including the recent cyber-attacks and concerns about Royal Free and DeepMind.
- It was reiterated that part of UPD's role was to challenge the media when its view was not balanced or correct.

The SC suggested that:

- UPD document and present impartial comments on the evolving debate through a timeline on its website.
- UPD should consider producing a position statement where there was confusion or the debate was not resolved.

**ACTION:** Curate a timeline of the issues raised by such cases on the UPD website.

## 7.0 Annual report

- 7.1 The SC agreed that a short annual report was necessary to release the second year of funding, but that it need only be one or two pages. It was agreed that a high-level statement on UPD expenditure should be included, showing balances and UPD categorisation of spend. It was suggested the report mention the value added by UPD talking to people and different stakeholder groups.

It was agreed that the Advisory Group must also be given early sight of the annual report before it publication on the website.

**ACTION:** A draft annual report will be prepared as a paper for the September SC meeting.

Beyond the annual report, the SC requested further evaluation on what UPD had achieved, what works, what doesn't work and against chosen metrics. This will be undertaken in year two.

## 8.0 External landscape: update from Department of Health

- 8.1 DH were not in attendance to update the SC. The new DH Minister with responsibility for data is expected to be Lord O'Shaughnessy.

## 9.0 AOB

- 9.1 The Chair asked whether UPD had secured a dialogue with the BMA. This was expected to be soon.

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