

Minutes of the Understanding Patient Data Steering Committee: Meeting 1

10:00-13:00, 20th December 2016, Wellcome Trust 215 Euston Road

Present:

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

Apologies:

Sir Nick Partridge
Prof Sara Marshall (Wellcome)

1.0 Introductions

1.1 Apologies from Nick Partridge were noted.

2.0 Update from Department of Health

2.1 LJ noted the Department's support for this initiative. She provided an overview of DH's activities since the publication of the National Data Guardian's (NDG) Review in July.

LJ outlined the Private Member's Bill to put the NDG on a statutory footing, being led by Jo Churchill MP. The Bill is fully supported by the Government.

2.2 NP noted that UPData produced a briefing for Parliamentarians, in partnership with AMRC, supporting the Bill.

2.3 It was noted that the National Information Board has been renamed the Digital Delivery Board.

3.0 Understanding Patient Data (UPD) – an overview

3.1 NP presented an overview of the initiative, setting out its rationale and the programme of work that is underway and being planned.

An overview of the vocabulary work done to date was presented at the end of the meeting.

4.0 Aims and objectives

4.1 The group discussed UPD's aims and objectives:

- It was agreed that UPD's starting point is that better use of patient data is important and valuable and we are strong advocates of it being used responsibly. Candour and impartiality about risks and benefits is crucial, and UPD should seek to provide objective information.
- Amendments to the draft aims and objectives were agreed, aimed at clarifying that UPD is supporting objective discussions and providing evidence for people.
- It was agreed that UPD should seek to make existing initiatives on patient data complementary, rather than coordinating them.

- The group discussed the oversight and level of input it wanted into the work and outputs of UPD. It was agreed that ‘independence’ for UPD means ‘independent of the views of any of any one of its funders and supporters’.
- Key audiences for UPD are the public, patients and health professionals, and policy makers.
- It was agreed that if UPD is to have impact, it needs to be clear about the issues and the potential problems if data is not well used to help advance research and healthcare.

4.2 It was suggested that as the programme develops, it could be asked to provide a service for answering questions and concerns about what happens to patient data. It could also offer consultancy for organisations testing out possible ideas for uses of patient data to gauge public views and concerns. No decisions were made on these types of support, which will be deferred until UPD is more established.

5.0 Governance

5.1 The group discussed the composition of the Steering Committee (SC) and considered what further representation there should be.

- It was noted that ESRC strongly advocated for a social science champion on the SC and had produced a shortlist of possible names. There is also a need to ensure expertise on hard-to-reach communities.
- Wellcome representation on the SC was discussed. As the SC would benefit from having a media/journalist perspective, it was agreed that Mark Henderson, Chief Communications Officer at Wellcome, should be invited.

5.2 The composition and role of the Advisory Group was discussed. It was agreed that:

- The group needs more representation from clinicians and patients, particularly from hard to reach groups.
- Medical speciality societies may provide more on-the-ground expertise than the Royal Colleges.
- Specific GP system suppliers and behavioural insights expertise would be helpful additions.
- Members need to be formally invited with clarity provided over their role.

5.3 It was agreed that more full time resource was needed for the programme and that an officer-level role should be recruited to cover policy and comms work for 12 months.

5.4 Branding of UPD was discussed, including whether to call it an initiative, collaboration, programme or something else. No firm decision was reached on the term, but collaboration was considered a possibility.

It was agreed that UPD needs to have its own authority and does not need to include logos of funders in outputs. The Committee agreed to sign off on the logo rather than require input into its development.

5.5 The SC agreed to quarterly meetings, and that the group or individual members could be convened in the interim by phone or email as needed to provide input on specific issues and support. It was agreed that the SC does not need to be consulted on every issue and should not be a brake on progress.

5.6 **ACTION:** UPD to invite a social science champion to the SC, on the advice of ESRC. Mark Henderson (with Wellcome’s approval) to join the SC. UPD to invite people to be members of the advisory group.

6.0 Work programme

The SC discussed the three key strands of the work programme.

6.1 *Tools and resources*

- There was consensus that the development of tools and resources needs to anticipate future data flows and how permission/buy-in for these could and should be sought. This includes flows in social care organisations (i.e. beyond the NHS).
- It would be helpful to consider what tools and resources other countries and health systems use, and other comparable examples such as organ donation.
- Case studies should be included of things that have gone wrong as a result of data not being properly used and shared, to help make the case clearly for why responsible data sharing is beneficial.
- The issue of public benefit also needs unpacking:
 - NP has been in discussion with Simon Burrall from *Involve* about work they're undertaking with the Carnegie Trust to explore public attitudes to novel data use in different sectors. UPD could contribute to and support this by extending the work into attitudes towards health data use. The group agreed that NP could decide whether and how to commit to supporting this work.
- The group discussed whether UPD could be a source of impartial advice and information on 'live' issues. This would depend on UPD being established as an authoritative, legitimate source of information independent of vested interests.

6.2 *Stakeholder engagement*

- Priorities for engagement are healthcare professionals and the media, because people's exposure to these issues is via their GPs and press stories. UPD needs to carve out a unique role here and not duplicate NHS/DH efforts. The group agreed this engagement should focus on providing additional resource and building advocates within the profession, including nurses.
- Patients and the general public should be considered separately (although they overlap enormously) as they have different routes to engagement and experiences to draw on.
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6.3 *Horizon scanning/analysis*

- This scanning should include synthetic data and new developments in privacy and security measures as well as innovations in data use.
- An important part of the conversations will need to be about navigating the changing boundaries of the data landscape (of which patient data forms only a small part).

7.0 Comms update

7.1 NP outlined the plans for developing a website and social media activity, highlighting that a media strategy will be key to UPD's success. There will need to be a close working relationship with the SMC and journalists.

7.2 A 'launch' cross-sector meeting should use the vocabulary as a hook. It was agreed that March would be a feasible timetable for a cross-sector, public facing meeting to launch the initiative.

8.0 What does success look like?

8.1 Success metrics were discussed, with agreement that in this complex area there should not be too much onus on a formal evaluation process. Measurements should focus on awareness of data use, not understanding or support for it.

It was agreed that it is not feasible to attempt to capture baseline data for public attitudes.

The group agreed that the key for UPD is to identify what utility looks like just as much as success: all activities should have a plan for how we think about showing whether the activity is working or not.

9.0 AOB

9.1 The vocabulary work was presented. Key comments were:

- More work needs to be done to check the language with patient communities, especially the mental health community.
- The pictures do a huge amount of work and are very valuable: communications should start with them
- Leaders in the sector need to be targeted to get them to adopt the language quickly so that there is clear leadership that will encourage others to shift in tone.

ACTION: Minutes and slide decks to be circulated in the new year, and the series of meeting dates to be put into the diary

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