

## Understanding Patient Data Steering Group Meeting Minutes

Monday 3 July 2023

10:30am – 12:00pm

In person at 18 Smith Square, SW1P 3HZ and via Microsoft Teams

### Attendees:

Claire Bloomfield (NHS England) [CB]  
Frances Burns (Department of Health Northern Ireland) [FB]  
Chris Carrigan (use MY data) [CC]  
Rebecca Cosgriff (NHS England) [RC]  
David Ford (SAIL Databank) [DF]  
Peta Foxall (NHS Confederation, Meeting Chair) [PF]  
Adam Goodger (Department of Health and Social Care) [AG]  
Nicola Hamilton (UPD) [NH]  
Rachel Knowles (Medical Research Council) [RK]  
Emma Lagerstedt (UPD) [EL]  
Emma Morgan (UPD) [EM]  
Valerie Morton (NHS Confederation) [VM]  
David Parkin (British Medical Association) [DP]  
Rosie Richards (UK Mission to the EU) [RR]  
Jeremy Taylor (National Institute for Health and Care Research) [JR]  
Emily Jesper-Mir (Wellcome) [EJM]

### Apologies:

Rebecca Asher (Wellcome) [RA] – *Job share partner (Emily Jesper-Mir) attended*  
Roger Halliday (Research Data Scotland) [RH]  
Layla Heyes (National Data Guardian) [LH]

## MINUTES

### Introductions

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#### 1. Welcome, introductions and apologies

- Peta Foxall welcomed everyone to the first steering group (SG) meeting of UPD hosted at NHS Confederation as the chair of this meeting.
- Chair asked everyone to introduce themselves and meeting participants around the room and virtually provided their names, roles and background.

#### 2. Conflicts of interest

- Chair asked attendees to please raise any conflicts of interest at this time. No conflicts of interest were registered.

### Governance

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#### 3. Reminder of the purpose of UPD and the steering group

- NH provided attendees with a reminder of the purpose of UPD and the SG. PF asked attendees whether they had any comments or reflections on the purpose and whether this was aligned to expectations.
- One member noted that they wanted to better understand the independence of UPD, particularly in terms of its relationship with the NHS Confederation, and with UPD's funders. It was stated that this was necessary for the SG members and the public, and perhaps isn't clear enough on the website.
  - Chair acknowledged that all members should be challenging our own biases or defaults in the way in which we discuss/respond to/support subjects in relation to these organisations.
  - Another member supported this, pointing out the value that the previous iteration of UPD placed on its independence, so we must challenge ourselves on this going forward.
- Another member highlighted that there could be options for UPD to receive funding or support from corporate organisations in future, which may help with the funding gap from April 2025 onwards. They, and other members, recognised concerns about how independence, and perceptions of independence, can be affected by funding organisations, which will be important for UPD to consider. NH confirmed that one of the key projects for UPD this financial year will be looking at future funding models and a range of options will be explored.
- Another member commented that UPD's purpose in its current state does not speak to a four nations approach – for example, NI does not have the NHS so the purpose statement should perhaps refer to health and social care organisations instead.
  - Chair shared her dedication and enthusiasm for a four nations approach in our discussions going forward.
  - Another member noted that in the set-up of UPD at the NHS Confederation it was acknowledged that better representation of the four nations was needed in the steering group, so we welcome the members from the devolved nations' input going forward.
- **ACTION 20230703/01 (NH):** Make changes in the purpose statement and in our wider content regarding the independence of UPD and what this means.
- **ACTION 20230703/02 (NH):** Add into the purpose statement and 'About Us' section of the website that UPD has a four nations approach and re-circulate to SG.
- **ACTION 20230703/03 (ALL):** Continue to challenge ourselves and one another on ensuring this independence going forward.

#### 4. **Approval of Terms of Reference (ToR)**

- NH shared some of the edits that she has made/plans to make in the Terms of Reference (ToR) document, which had previously been shared with the group.
- One member commented that, whilst there is good male/female diversity in the SG, there is a lack of ethnic diversity. NH stated that there had been conversations about this issue during the steering group set up, prior to her arriving, but due to members being chosen specifically due to their role, and the unavailability of some specific suggested members, this had been an unintended consequence. However, it has been 5-6 months since individuals were approached so this could be revisited.

- One member noted we may benefit from a specific Equality, Diversity and Inclusion (ED&I) statement in our ToR, and another suggested a goal or responsibility in relation to ED&I in the ToR both in terms of the members but also in the focus of UPD's work.
- Another member felt uncomfortable about the reference to membership 'by invitation', as it can risk being or appearing cliquey, and not transparent. Instead, membership is because of role/organisation.
- One member questioned the role of observers and their ability to contribute to the meetings.
  - Chair clarified that observers are welcomed and encouraged to contribute to discussions, the distinction is that they cannot vote on matters requiring a vote.
  - Another member noted that this distinction is only important if voting actually occurs, and it may need considering whether it is in fact a meaningful distinction depending on the extent to which voting will be required or if there are other ways of distinguishing the roles.
- One member noted that the scope of organisations we work with as noted in the ToR needs broadening to include things like local authorities, research community, data science community, etc.
  - Chair noted this scope would also benefit from ensuring it reflects a four nations approach as discussed earlier in the meeting.
- One member questioned the lack of voting member from NHS Confederation in terms of governance.
  - Chair noted that VM is the elected Trustee from the board of NHS Confederation – expressions of interest were sought and VM was elected. VM will report back to the board and hold the chair responsible in their role. This needs working into the ToR and consideration given to which organisations can vote and why.
- Other minor comments on the ToR made by members included:
  - ToR currently says "independence as an independent" which is redundant. The member also noted the need to define clearly what we are independent from.
  - A suggestion was made to define what is *not* in scope for the purpose of UPD
  - On section 7, a reference is made to the "NHS Confederation steering group", however the NHS Confederation has a board, not a steering group.
  - A suggestion was made to re-visit the language around the role of observers to ensure this reflects expectations.
- **It was voted that a revised version of the ToR would be needed before approval could be given.**
- **ACTION 20230703/04 (NH):** Follow-up on invitation for individual with health inequalities experience to join the Steering Group, ideally someone that also helps with achieving more ethnic diversity in the group
- **ACTION 20230703/05 (NH):** Make the suggested changes to ToR: ED&I statement and goals, update information about membership, update information about the role of observers, add explicit statement about taking a four nations approach, remove the additional "independent" point, consider adding what isn't in scope, and update "NHS Confederation steering group" to "board".
- **ACTION 20230703/06 (NH):** Consider role of the NHS Confederation in governance and ensure this is reflected in the ToR
- **ACTION 20230703/07 (NH):** Consider roles of voting/non-voting members

- **ACTION 20230703/08 (NH):** Send revised ToR to members via email for approval

#### 5. Appointment of Chair and Vice Chair

- NH outlined the need to appoint a Chair and Vice Chair, noting that there had been one expression of interest in Vice Chair role from RC, and none for Chair. PF happy to fill role for one year if no other options.
- One member suggested a process of open recruitment for the Chair role, with PF continuing in the role until then. Another pointed out there would need to be a more detailed role description in the ToR (and that the SG should be given sight of this). It was highlighted that managing the process for an open recruitment needs to be balanced with the capacity of the UPD team and steering group members to support this, particularly considering UPD currently only has two years' worth of funding
- Another member questioned the Vice Chair being part of a funding body, as if they had to take over the chairing role in the Chair's absence this could impact on the appropriateness of them having a casting vote.

It was voted that RC should continue in the VC role, and PF should continue in the Chair role at least for the foreseeable, while in the meantime:

- **ACTION 20230703/09 (NH):** explore options for open recruitment, to be decided at the next meeting in October

### Strategy and Delivery

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#### 6. UPD's updated plan

- NH provided a high-level overview of the plan for UPD's workstreams for the next year, including health data policy, infrastructure, population health, and sustainability of UPD.
  - Chair asked for clarification about whether these workstreams were in the remit of the grant contracts. NH confirmed this was the case.
- There was concern from a few members about capacity to fulfil all items in what appears to be an ambitious plan given the limited timescale and resources and whether additional feasibility assessments would be required.
  - One member was interested in what 'building the health data community' means, who attends what events and conferences etc, as each of these things could be a significant amount of work.
  - One member noted that it is very likely that the UPD team would be asked to support with more and more pieces of work that are not in the original plan, so we need to decide how to respond to such requests.
    - NH clarified that in Q1 we have been saying yes to almost all meeting invites/events to get UPD out there again, but going forward we'll prioritise more and learn when to say no.
  - Another member suggested identifying the top three priorities to alleviate the capacity risks. Another felt that in deciding priorities we don't want to lose the focus on advocacy around patient data, as this reduced significantly during UPD's transition phase – this should remain in the priorities.
  - One member noted the significant amount of patient data related work underway at the moment, and in deciding on priorities we should consider the uniqueness of UPD, focusing on what we can bring that others can't.

- One member raised a question around the process for media commentary and how UPD decides its positions on key matters.
  - NH assured this is a work in progress, although difficult, and will take the previous UPD team's positions and update where necessary.
  - Members agreed that “drafting by committee” should be avoided and the core UPD team be empowered to have their own authentic voice.
- One member raised the need to be very clear on the goals, stakeholders and key performance indicators for each workstream, on the steering group level as well as the operational level.
- One member raised the need to be mindful of language to ensure it is representative of a four nations approach – e.g. the SDE terminology is NHSE/England focused (whereas elsewhere the term TRE is used).
- **ACTION 20230703/010 (NH): UPD team to define top three priorities and share ahead of the next steering group meeting**
- **ACTION 20230703/011 (NH): Ensure that project scopes take a four nations approach to language use and have clear goals / key performance indicators**
- **ACTION 20230703/012 (NH): Create strategy document that brings together the projects with UPD's ultimate goals and strategic direction**

## 7. Progress to date

It was agreed not to discuss this section due to time limitations, but many areas of progress had already been discussed throughout the meeting and progress updates have been shared via email.

## 8. Risks and issues

- NH provided an overview of the risk register for UPD, which has previously been shared with the SG, and asked for comments on risk appetite or risk management from the SG.
- One member noted the need to be clear about the mitigation strategies in place, not just identifying the risks. NH confirmed that mitigation is part of the risk register and the mitigations can be made clearer in the steering group pack for the next meeting.
- One member noted an additional risk that is presented by having a steering group that significantly outnumbers the team, as meetings can end up generating extra suggestions of work. It was agreed that the group should be mindful of this, and the team remain empowered to treat any suggestions as steers, not instructions.
- **ACTION 20230703/013 (NH): Add additional risk to UPD risk register**

## 9. Finance

- NH explained the sources of grant funding and highlighted that spending so far related to non-project costs, e.g. staff salaries, travel and subsistence, etc. It was confirmed that the Q1 finance report will be shared around once this is complete.
- One member queried whether underspend can be carried over into the second year. NH and RR confirmed that, with the group's approval, this can be done, namely within the project budget. RR explained that costs can't change category though – project budget can't be carried over into staff budget.
- Chair queried if funding comes in annually or quarterly – NH explained that this varies depending on the funder.

- One member questioned whether the NHS Confederation takes any overhead for the support they provide UPD. NH explained that there is a portion of funding that contributes to HR, IT costs etc. RR explained that, by hosting, the NHS Confederation is allowing UPD to draw on their support and resources but there's no financial incentive.
- **ACTION 20230703/014 (NH): Share Q1 financial report when available**

## Steering group reflections and AOB

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### 10. Steering group reflections

- Chair asked members for their reflections on the meeting and whether they were generally happy with the running of the SG. Members agreed that the meeting had been useful and were positive about the future of the initiative. Members felt the discussion time was particularly valuable and should continue in further meetings. The hybrid approach worked successfully also.
- One member said it would be helpful to reflect further on how the SG operates and clarify roles and expectations, as in their view it seems it is an unusual hybrid between a programme board (which has ultimate responsibility) and an advisory group (which provides independent advice).
- **ACTION 20230703/014 (NH):** Reflect on definition for the SG and get back to members.

### 11. AOB

- Chair asked members for any AOBs. There were no AOBs raised. Chair thanked everyone for their time and contributions and closed the meeting.