# Understanding Patient Data
## Steering Group Meeting Minutes

Wednesday 23rd July 2025
13:30 – 15:00
Hybrid - 18 Smith Square, SW1P 3HZ and via Microsoft Teams

| Attendees: | Apologies: |
|---|---|
| Peta Foxall (NHS Confederation, Meeting Chair) [PF] | Roger Halliday (Research Data Scotland) [RH] |
| Anna Steere (UPD) [AS] | David Ford (SAIL) [DF] |
| Emma Lagerstedt (UPD) [EL] | Liz Pickworth (Department of Health and Social Care) [LP] |
| Emma Morgan (UPD) [EM] | Chris Carrigan (use MY data) [CC] |
| Charlie Wilkinson (UPD) [CW] | Emma Harris (NHS England) [EH] |
| Valerie Morton (NHS Confederation) [VM] | Layla Heyes (National Data Guardian) [LH] |
| Jeremy Taylor (National Institute for Health and Care Research) [JT] | Rebecca Asher (Wellcome) [RA] - *job-share partner EJM attended* |
| David Parkin (British Medical Association) [DP] | Frances Burns (Department of Health Northern Ireland) [FB] |
| Katie Oldfield (deputising for Roger Halliday) [LR] | Rachel Knowles (Medical Research Council) [RK] |
| Dr Ngozi Kalu (Race and Health Observatory) [NK] | Joe Watts [JW] |
| Amena Shrafeddin (Office for Life Sciences) [AmS] | |
| Mavis Machirori (Ada Lovelace Institute) [MM] | |
| Emily Jesper-Mir (Wellcome) [EJM] | |

## MINUTES

### Introductions

**Welcome, introductions and apologies**

- PF welcomed everyone to the steering group meeting as the Chair of this meeting for the last time.
- Chair noted apologies from RH, DF, LP, CC, EH, LH, FB, RK & JW
- Chair asked attendees to please raise any conflicts of interest at this time. None were raised. Chair asked people to raise any new conflicts of interest as they arise, if needed.
- Chair asked whether any attendees wanted to raise an item for AOB. No items were raised.

**Review of minutes**

- Internal version of the minutes was circulated on 30th April. A member suggested some clarifying edits and corrections which have been incorporated. Chair asked whether anyone had any comments or concerns about the minutes and whether everyone was happy for the external minutes to be published. No points were raised and it was agreed that the non-attributable minutes would be published on the website.
- PF walked the group through the actions from the previous meeting and noted that the review of the Terms of Reference would be postponed until later in the year to align with a wider review of NHS Confederation and its hosted organisation's governance but highlighted

that the focus of the group would be the same and will remain an advisory group and "sounding board" for the team.

**ACTION 20250723/01 (UPD team)**: Finalise and publish minutes from April steering group meeting

## Updates from the UPD team and discussion

### Q1 project updates

- AS gave an update on areas of focus and key projects for the team in Q1, including:
  - Recruitment of a new Policy and Communications Manager and a new UPD Chair and noted the team would update further on this in due course.
  - Developing a more dynamic evidence base with a social listening tool and sentiment tracker
  - A strategy for ongoing monitoring and evaluation
  - New resources in development and an audit of our current website and resources
- One member asked about focus, and how to ensure the right mix of breadth and depth given the small team.
  - AS said at the moment we feel this is the right focus to create foundations going forward with project delivery that will free up our time in the long run, but it is important that we focus on the project delivery we have committed to, particularly around the convening offer and state of the nation.
  - EL said that now that CW is on board and we are splitting activities by role it will help with capacity as we can better use time and resources.

### 10 Year Health Plan and Life Sciences Sector Plan

- EL gave reflections on the 10 year health plan and the life sciences sector plan, noting that the 10 Year Health Plan demonstrated a real focus on digital transformation, particularly on the NHS App and the use of AI tools, but without detail on implementation or funding. She further noted that there is more detail in the Life Sciences Sector Plan about timelines and implementation. These two strategies give UPD a clear opportunity to engage with Government and other stakeholders to shape delivery and especially communications.
- EL asked steering group members for their reflections and any work their organisations is planning in response, or changing following the publication of the plans.
  - One member said that the plan gives a fantastic hook for the work of UPD as they throw out a set of issues that are critical to implementation. They are not new issues but new impetus and the Plans give UPD a clear platform and hook.
  - Another said that the their organisation has quite a lot planned around a few aspects around patient data included in the 10-year health plan. A motion was passed to take a position that Palantir and their involvement in the NHS is unsuitable. They are doing work through the Joint GP IT Committee around single patient record and use of patient data to improve functionality of NHS app. Their organisation are clear on their position of trying to oppose Palantir's role with the NHS, but more uncertainty around work around single patient record.

- One member raised work done from Scottish government around public participation, and said it might be interesting to see how this has progressed as would be useful to look at in relation to Pulsar work: CivTech Challenge 10.7 — public participation in decision making — CivTech They said they can pass on contact with the relevant people if helpful.
- Another - in response to the point raised above – said that UPD is part of the Confed which has ethical policy for who we will partner with in relation to Palantir and is aware of the sensitivities.

**Community and Partnerships update and State of the Nation**

- CW, UPD's new Community and Partnerships Manager, introduced themselves and presented current thinking on UPD's convening and partnerships offer and timelines for progressing this work
- CW and EM presented UPD's thinking on developing a "State of the Nation" annual report on the state of health data attitudes work, gap analysis and collaboration. As part of this, they presented forthcoming UPD evidence and insights from a new survey with Kantar on public attitudes towards health data programmes, and a social listening tool.
- They asked the group
    - Are we going about this in the right way to achieve the strategic purpose, and meet the needs of various audiences?
    - How can we make sure UPD are adding value in this space?
    - How can the group help us with delivering this process, particularly convening and setting up the strategic partner group?
    - How can we make the work relevant across all four nations?
- One member asked about corporate partners and if this was a gap in thinking around state of the nation, EM mentioned that we are splitting this broadly into two main groups around SotN but the audience is wider. Corporates fall into PPIE and representative groups. The member clarified that she meant what the role of corporate organisations is in our community/audiences, and AS said this is still being worked out but noted the importance of engaging with the private sector, especially groups that are themselves representative groups (e.g. ABPI for the pharmaceutical industry).
- On the four nations question, a member noted that there are equivalent committees for all four nations (i.e. GP committees for all four nations), and combined committees across all four nations which may be able to help with convening function. They also said that on the 10 Year Health Plan, it outlined an increasing role for patients to have oversight of their own data and noted this can't happen without greater education and awareness.
- Another member asked about linkage of health and non-health data – what is the risk that non-health data by default gets sucked in with health data (i.e. demographics) - AS said there needs to be clarity around governance for these structures based on different use cases, this will be the next planned large scale public engagement to understand this.
- One member noted the importance of clarifying and communicating effectively about what the 10 Year Health Plan means for data, and particularly as more and more data is being brought into the Single Patient Record and the different thoughts people might have about data depending on the source. A couple of members also both raised the importance of thinking how the 10 Year Health Plan is going to impact health inequalities.

- On the convening offer, one member asked whether anyone doing anything like this and said it feels like a very distinctive offer.  AS said lots of people are very in support of this convening work, and we are working very closely with partners on its development, this will be a co-production exercise, the critical thing is how we go about it.
- A member asked CW whether there is anything that the steering group could provide that would be useful to help the community and partnerships work. CW said that he'd continue to reach out to people for meetings and asked members of the group to share anything that might be interesting for him to read or people for him to speak to.
    - One member suggested we speak with the Wellcome Global Monitor team in relation to state of the nation report and also suggested meeting with the Civic Data Initiative in Leeds who are doing great engagement work – CW and EM to action.
    - Another mentioned PEDRI tools and resources.
    - One member said it it will take us several months to keep shaping state of the nation – we don't need all the answers now, but keep us in mind and come back to us if you ever think of something that might be useful for us in the development of SotN.
    - Another flagged a POSTNote from April on the topics of wearables and data that may be of interest.
    - One member welcomed CW reaching out to her as their organisation are going through a similar process so there may be some learnings that can be shared.
- One member welcomed the focus on more ongoing evidence generation as a way to generate a drumbeat of information to communicate about and that having a flagship piece could be incredibly valuable as people will be looking to it on a regular basis and it will be a valuable string to our bow.

**ACTION 20250723/02 (UPD Team)**: CW and EM to reach out to members of the group for feedback on this work as it develops and provide updates to the group.


**AOB and meeting close**

- Chair opened up for any further reflections or AOBs from the steering group or reflections for future meetings.
    - One member to send report on public sentiment they have delivered.
- AS noted it was PF's last meeting as Chair and thanked her for all her hard work and help. Everyone thanked PF who said it had been a pleasure to lead the meetings and that she would keep supporting the work of UPD from afar.
- Chair welcomed feedback about the meeting via email, thanked attendees and closed the meeting.

**ACTION 20250723/03 (UPD team)**: UPD to think about the next meeting and get in touch with the steering group with a proposed date.