

# OpenSAFELY Oversight Board Meeting Notes

13-05-2022

*Ratified at 06-10-22 Oversight Board*

<b>Date &amp; Time</b>	<b>13/05/22 10:00-12:00pm</b>
<b>Attendees</b>	<ul style="list-style-type: none"><li>• Prof. Nigel Shadbolt (Chair)</li><li>• Prof. Ben Goldacre (OpenSAFELY PI)</li><li>• Seb Bacon (OpenSAFELY CTO)</li><li>• Jess Morley (OpenSAFELY; Policy Lead, Bennett Institute)</li><li>• Amir Mehrkar (OpenSAFELY Head of IG and external relationships)</li><li>• Nicky Brassington (Deputy Director of Data &amp; Analytics, NHSX)</li><li>• Sean Kirwan (OpenSAFELY NHSX IG; Senior Data Sharing and Privacy Manager, NHSX)</li><li>• Mark Coley (GP, BMA)</li><li>• Kevin Minier (Expert patient representative)</li><li>• Jeni Tennison (Open Data Institute)</li><li>• Stephen Evans (OpenSAFELY researcher; Professor of Pharmacoepidemiology, LSHTM)</li><li>• Sam Smith (MedConfidential)</li><li>• Tariq Khockhar, Head of Data for Science and Health at Wellcome Trust</li><li>• Laurie Tomlinson (OpenSAFELY researcher; Associate Professor, LSHTM)</li><li>• Julia Wilkins in lieu of Rony Arafin (ApHA)</li><li>• Johnny Stewart (GP, RCGP)</li></ul>
<b>Apologies</b>	<ul style="list-style-type: none"><li>• Chris Bates (OpenSAFELY-TPP; Director of Research and Analytics, TPP)</li><li>• Shaun O'Hanlon (OpenSAFELY-EMIS; CMO EMIS)</li><li>• Alex Freeman (Executive Director, Winton Centre for Risk &amp; Evidence Communication, University of Cambridge)</li><li>• Wendy Harrison (OpenSAFELY NHSE IG; Senior Lead – Data Governance / Deputy Head of Corporate Information Governance, NHSE)</li></ul>

## Documents circulated in advance:

- Meeting notes 27-01-22 OpenSAFELY Oversight Board (for approval)
- Pre-read update from OpenSAFELY

**Agenda:**

<b>Item</b>	<b>10:00 - 12:00</b>	<b>Topic</b>
1	10:00 - 10:10	Introduction from the Nigel Shadbolt (chair) <ul style="list-style-type: none"><li>● Request for AOB</li><li>● Review actions</li></ul>
2	10:10 - 10:30	From pre-read update:  New developments and progress against milestones (Ben Goldacre) <ul style="list-style-type: none"><li>● Resource</li><li>● Staff</li><li>● Structures (owners for copiloting, output checking, curation)</li><li>● Datasets</li><li>● Research outputs / onboarding external researchers</li><li>● Tech (Sebastian Bacon)</li></ul>
3	10:30 - 11:00	OpenSAFELY new installations deep dive and discussion
4	11:00 - 11:10	BREAK
5	11:10 - 11:30	Continue discussions (other topics may include stable funding).
6	11:30 - 11:50	Post-COPI legal basis for OpenSAFELY-TPP and OpenSAFELY-EMIS and discussion (Nicky Brassington)
7	11:50 - 12:00	AOB (ALL)

**Item number: 1** - Introduction from the Nigel Shadbolt (chair)

*Decisions:*

- Meeting notes ratified

*Discussion points:*

- A Patient Advisory Group (PAG) has been established as part of wider OpenSAFELY PPIE activity; their views will feed into relevant discussions held at the Oversight board. PAG, will represent the lay member voice for OpenSAFELY. There will be no specific lay member on the core group.
- Close action 10 - whilst is ongoing, board can be drawn on as needed.
- Close action 18 - goals will primarily be KPIs in the TOR.
- Close action 19 - on today's agenda.

*Actions:*

- Action 20 - update TOR to reflect PAG involvement

**Item number: 2** - review of OpenSAFELY activities from previous board

*Decisions:*

- None

*Discussion points:*

- Pre-reading material reviewed
- Goldace review published - <https://www.gov.uk/government/publications/better-broader-safer-using-health-data-for-research-and-analysis>
- The OpenPrompt study, which will involve TPP's Personal Health Record app, involved PPIE activities for both OpenSAFELY platform discussions as well as project specific PPIE.

*Actions:*

- None

**Item number: 3 and 5** - OpenSAFELY new installations deep dive and discussion

*Decisions:*

- None

*Discussion points:*

- OpenPrompt
  - OpenSAFELY's first project involving patient reported outcomes, OpenPrompt, will also collaborate with TPP's Personal Health Record app. This is being supported by TPP pro-bono.
  - PPIE focus group mentioned: that there is value in reporting to patients how their contribution has advanced knowledge.
    - Patient Advisory Group have discussed options for reporting back, which might include the TPP app; these comments have been fed back to the study investigators.

- OpenSAFELY-EMIS
  - The OpenSAFELY - EMIS collaboration has been mutually beneficial, for example, it has also further developed the EXA platform (on AWS).
  - EMIS have requested cost recovery for AWS running costs. This is understandable and reasonable but the exact costs are unclear.
  - OpenSAFELY is looking to develop a per project costing / charging model.
  - It is also possible that funding might be obtained from AWS grants.
- OpenSAFELY-NHSD
  - OpenSAFELY has been installed in NHSD for some time. However, NHSD has not yet approved any analyses to run using OpenSAFELY-NHSD.
  - DARS is the current process for access to NHSD data. One incentive for using OpenSAFELY-NHSD is that it might enable lighter-touch IG process.
  - It has also been suggested to NHSD that OpenSAFELY could be used as the access mechanism for the GDPR data extract.
  - BMA/RCGP has requested a DARS project to be run through OpenSAFELY-NHSD as a pilot; NHSD, however, reported that their priority is to tie the use of OpenSAFELY-NHSD platform to a lighter IG process first before running a study with it.
- Other installations
  - We are currently working with groups in Singapore and Germany to install OpenSAFELY.
  - OpenSAFELY has been installed in Cheshire and Merseyside ICS TRE (<https://www.cipha.nhs.uk/> which uses Graphnet).
    - First federated analyses on vaccine coverage has been conducted; Cheshire and Merseyside manage all the IG and output-checking as they are the data controllers.
    - Excellent technical engagement and collaboration with Graphnet.
  - Manchester ICS keen to install OpenSAFELY but HDRUK grant was not successful. Prof. Tjeerd van Staa team at Manchester has also already used OpenSAFELY-TPP.

*Actions:*

- None

**Item number: 6** Post-COPI legal basis for OpenSAFELY-TPP and OpenSAFELY-EMIS and discussion

*Decisions:* None

*Discussion points:*

- Current COPI arrangements
  - NHSE recognises the important value of OpenSAFELY-EMIS and OpenSAFELY-TPP for patient care and the wider system with respect to research and service planning.
  - Current legal basis depends on COPI, which *requires* health and care organisations to share confidential patient information. It also negates the need to seek individual practice consent..

- Relying on COPI does, however, mean that all research conducted by OpenSAFELY must be related to COVID-19
- The current COPI is also set to expire in June.
- Reasons for seeking an permanent legal basis:
  - Research enabled by OpenSAFELY-EMIS and OpenSAFELY-TTPD has a direct clinical impact
  - The data made accessible via OpenSAFELY-EMIS and OpenSAFELY-TTP provides researchers with a unique opportunity to answer important public health questions, including for randomised trials and research related to rare diseases.
  - OpenSAFELY is helping restore and build public trust in the use of data for secondary uses, its loss would have significant implications for public trust going forward.
  - The clear strategic direction from the centre, as established in Data Saves Lives, and other strategies is that all research using GP data should be conducted inside a TRE (SDE in NHS terminology)
- Options for establishing a permanent legal basis:
  - Extension of COPI - for a select number of analysis activities/organisations.
  - CAG support - these are *permissive* powers, however, meanings GP practices could switch off data flow. Also, typically a short term approval.
  - Direction to NHSD under s254 set by Secretary of State; again *requires* GP practices to flow data for purposes set out by Secretary of State.
- Engagement:
  - Decisions regarding the permanent legal basis for OpenSAFELY should not be made behind closed doors. Ongoing engagement with patients, publics, professionals, and privacy specialists will be essential.

**Actions:**

- Arrange emergency meeting with board members if there is any risk that an ongoing legal basis may not materialise before June 30th 2020 (the current end of the Covid-19 COPI regulations).

Item	Action	Owner	Status Notes
10	Draft a letter from Nigel and the Board to key stakeholders to gain support.	BG	<b>Closed</b>
18	Create a small set of goals that act as thoughtful measures as a trigger for further discussion and agreement.	BG	<b>Closed</b>
19	A deep dive into OpenSAFELY's strategy and modularisation to be	SB	<b>Closed</b>

	included at the next board meeting including what OpenSAFELY is learning from external projects.		
20	Update TOR to reflect Patient Advisory Group involvement	AM/JM	<b>Open</b>

**END**