



UKRI DARE UK Programme Board Meeting

Date: 1st February 2022, 09:00 – 10:00

Location: Zoom call

Meeting Minutes

Attendees

Professor Patrick Chinnery (Chair), Medical Research Council (MRC) and University of Cambridge

Professor Felix Ritchie (Deputy Chair), UWE Bristol

Professor David Ford, Swansea University and Chair of the DARE UK Scientific and Technical Advisory Group

Public Contributors

Angela Coulter

John Marsh

UKRI

Dr Mike Ball, Biotechnology and Biological Sciences Research Council (BBSRC)

Dr Catherine Bromley, Economic and Social Research Council (ESRC)

Dr Ekaterini Blaveri (Secretariat), MRC

DARE-UK Phase 1 Delivery Team (observers)

Dr Hans-Erik Aronson, Health Data Research UK (HDR UK)

Dr Emma Gordon, Administrative Data Research UK (ADR UK)

Fergus McDonald, HDR UK

Gerry Reilly, HDR UK

Apologies

Dr Justin O'Byrne, UK Research, and Innovation (UKRI)

1. Welcome introduction and apologies

Professor Felix Ritchie chaired this UKRI Digital Research Infrastructure (DRI) DARE UK Programme Board (PB) meeting as Professor Patrick Chinnery had internet connection issues.

Members agreed that the minutes from the 10th December meeting were an accurate record of the meeting. In terms of the actions from the December meeting (tabled at the end of the **minutes paper PB-02-22-2**):

Action 1 would be covered under item 2: Matters arising – Scientific and Technical Advisory Group update

Action 2 and 3 would be covered under item 3.2: Delivery Team update – Sprint Exemplars

Action 4 is work in progress and an update will be presented at a future PB meeting

Action 5 is work in progress and an update will be presented at a future PB meeting

Action 6 is closed.

2. Matters arising

2.1. DARE UK Scientific and Technical Advisory Group

Professor David Ford provided an update from the recent inaugural Advisory Group meeting, which aimed to give its members an introduction, including relevant context, to the UKRI Digital Research Infrastructure (DRI) Strategy and the DARE UK Programme; discuss the Group's ways of working; and sign off its Terms of Reference.

All the Advisory Group members attended this first meeting and there was a great diversity of backgrounds and experience in terms of the sectors represented on this Group. However, members noted that there were some absences in terms of representation such as the industry sector, recognising that this was a broad and diverse sector, in terms of focus areas, organisations and sizes. Similarly, skills and training was another area that was not adequately represented on the Advisory Group currently. The aspects of industry and skills/training which will be useful to have represented at the Advisory Group will be discussed in more depth at its next meeting.

The DARE UK Delivery Team provided a high-level update on the Phase 1 progress to the Advisory Group. In future meetings, specific elements of this work and relevant topic areas will be discussed in more detail. In the meantime, the Advisory Group strongly suggested that the Delivery Team needed to:

- crystallise the DARE UK's scope on sensitive data types. More specifically, to clearly explain whether both personal identifiable and commercially sensitive data were included in the scope of the Programme, as the latter did not seem to feature very prominently in the Phase 1 activities currently;
- describe the DARE UK's main user groups and their user journeys;
- build on previous work and align with current relevant activities/plans (for example, Public Involvement and Engagement (PIE) relevant to NHS data use to get the most value out of respective consultations).

PB members acknowledged that the Advisory Group could provide a helpful sounding board to the PB about the shape, nature, and future direction of the DARE UK Programme. Therefore, they would identify tasks/topics which the Advisory Group could debate and provide their views, insights, and advice.

There was also agreement with the importance of pitching the scope of the DARE UK Programme unambiguously and of clarity on what constitutes sensitive data for this Programme.

The Delivery Team noted that a Phase 1 update was scheduled for the UKRI Digital Research Infrastructure Committee (DRIC) meeting in March. This provided an appropriate forum to seek advice on the scope of sensitive data for DARE UK and its interface with other relevant investments and activities of the UKRI DRI Programme. After the DRIC meeting, then there will be an in-depth discussion on this topic at the next Advisory Group before bringing all the views, insights, and suggestions to the PB members for their consideration at their next meeting.

PB members advised the Delivery Team to develop and circulate a proposal/options on the sensitive data scope to both the DRIC and Advisory Group members in advance of these meetings so that they would have time to reflect on this matter and engage in a constructive discussion.

Also, PB members asked the Delivery Team to develop a framework of the DARE UK objectives and outputs for the different data owners and for the breadth of research community users (user personas/journeys), which will also help in defining the scope of the Programme.

Finally, it was recognised that the DARE UK Programme interfaces and overlaps with other relevant activities including the UKRI DRI Strategy; the NHS England developments coming out from NHSX and the devolved administrations; but also, international standards development for secure digital research infrastructures. To this end, PB members considered that it would be helpful if in addition to the regular Phase 1 progress updates focusing on delivery milestones and timelines, a roadmap was presented showing where the DARE UK Programme fits in terms of both the UKRI DRI Strategy, and possibly the wider landscape, indicating the gaps which this Programme will be addressing.

The Deputy Chair encouraged more engagement by correspondence between the Delivery Team and the PB members to review/provide feedback on early drafts of these documents in between PB meetings.

Action(s)	Owner(s)	Deadline/Status
<p>1. Develop a proposal/options on the scope of the DARE UK Programme on sensitive data types and seek views and advice from the UKRI Digital Research Infrastructure Committee and the DARE UK Scientific and Technical Advisory Group</p>	<p>Delivery Team</p>	<p>DRIC meeting - 3rd March 2022 STAG meeting – 30th March 2022</p>
<p>2. Develop a framework of DARE UK objectives and outputs for the different data owners and the breadth</p>	<p>Delivery Team</p>	<p>Update at the next PB meeting – 31st March 2022</p>

of research community users (user journeys/personas) of such an infrastructure		
3. Invite Justin O’Byrne (or another DRIC representative) to the next STAG meeting when discussing the scope of the DARE UK Programme to represent the overarching viewpoint as to where DARE UK fits in the broader UKRI DRI plans	Ekaterini Blaveri	11 th February
4. Following feedback from DRIC/STAG, update the proposal/options on the scope of the DARE UK Programme on sensitive data types based on the advice and feedback received and present it to the PB for their consideration	Delivery Team	Update at the next PB meeting - 31 st March 2022
5. Develop a roadmap/representation explaining where the DARE UK Programme fits in terms of both the UKRI DRI Strategy (primarily), but also the wider landscape, and indicates the gaps that are being addressed by the Programme	Delivery Team	Update at the next PB meeting – 31 st March

3. Delivery Team Update

3.1. Stakeholder engagement

Dr Hans Erik Aronson updated the PB members on the stakeholder engagement key milestones and timeline, which were split in: the listen and learn stage (October 2021 to December 2021); and the task and involve stage (January 2022 to end of April 2022).

A stakeholder map was presented, which was a first synthesis of key collaborations with organisations and initiatives relevant to the Programme and not an exhaustive stakeholder map as the engagement was still ongoing. The map was divided into five sections: Data and Discovery; Access and Accreditation; Demonstrating Trustworthiness; Digital Research Infrastructure; Capability and Capacity; and Funding and Incentives. The Delivery Team sought advice from the PB members on any major gaps or additional opportunities for engagement with specific stakeholders. The PB members commented that:

- this initial map included mainly stakeholders from the health and social sciences. Further effort was needed to engage with other research disciplines and sectors;
- it did not include any industry stakeholders, noting that even if the scope was focused only personal data /‘data about people’ this still included for example, data from social media, wearables, consumer-related activities and therefore, required engagement with the relevant industry sectors;
- under the ‘demonstrating trustworthiness’ section, to consider engaging with relevant stakeholders including the [Royal Statistical Society Data Ethics and Governance Section](#);

- under the 'data access/management' section, to consider engaging with organisations including EMBL-EBI, Genomics England and UK BioBank since they all have significant expertise in this area;
- in terms of international organisations and initiatives, to consider engaging with the Australian Research Data Commons and CADRE, and similar activities in New Zealand, which have done a lot of work around social licence for data use to support their integrated data platform;
- the UK Data Service as a data provider and accreditor of users should be under the same section on this stakeholder map as other data providers. It was also noted that as part of the UK Data Service mid-term review, 1,100 responses were received to a survey that was contacted to gather the views on this service from its registered users. This indicated that there was a potentially large untapped pool users and the DARE UK Programme should develop an effective mechanism to engage with its prospective user base.

Other tasks of this second stakeholder engagement stage included drafting an initial strategic science/business case and a 'blueprint' on best practice although, further community testing would be needed to inform both these activities.

In terms of the draft strategic science/business case, PB members expressed concerns on the rapidity of this activity in the absence of a clear scope in terms of sensitive data and lack of engagement with all the relevant communities to feed into the evidence and requirements gathering needed to inform what was a very complicated system with considerable overlaps. Hence, it was agreed to discuss its development process in more detail at their next meeting.

Action(s)	Owner(s)	Deadline/Status
6. Intensify stakeholder engagement efforts to include initiatives/organisations such as: the Royal Statistical Society Data Ethics and Governance Sector, UK BioBank, Genomics England, industry and international initiatives/organisations (e.g. EMBL-EBI, Australia Data Commons and New Zealand); but most importantly engage with stakeholders beyond the health and social care disciplines.	Delivery Team	Update at the next PB meeting - 31 st March 2022
7. Propose a mechanism/approach to engage with prospective users	Delivery Team	Future PB meeting
8. Present current thinking on the development of a strategic science case and blueprint	Delivery Team	Update at the next PB meeting - 31 st March 2022
9. Discuss the process of developing a 'blueprint' and strategic science/business case and its content and timeline	All	Update at the next PB meeting - 31 st March 2022

3.2. Public Involvement and Engagement (PIE)

An update on the key PIE activities was provided informing the PB members that a total of five public contributors were providing input to Phase 1 and the Delivery Team had bi-monthly consultation meeting with all of them.

In terms of the DARE UK Public Dialogue activities, two workshops took place on 13th and 14th January 2022 with a total of 45 members of the public; and a follow-up workshop was scheduled for 22nd February. The aim of these events was to explore issues of data security, access and trustworthiness with the public. The social research consultancy Kohlrabi Consulting had been commissioned to support these events and produce a findings report to be published in early Spring 2022, which will be shared with the PB.

The Delivery Team was also hosting regular public webinars with the first one held on the 7th December 2021, followed by a 'Meet the Sprints teams' webinar scheduled for the 8th February 2022 and bi-monthly public webinars thereafter.

Action(s)	Owner(s)	Deadline/Status
10. Share with the PB the Public Dialogue Report, which Kohlrabi Consulting will be produced based on the workshops hosted as part of the DARE UK PIE activities	Delivery Team	Early Spring 2022

3.3. Sprint Exemplar Projects

All nine Sprint Exemplar Projects started in January 2022. At their previous meeting, PB members requested a detailed portfolio of these projects describing their objectives, outputs (in terms of products, functionality, policies, and services), lessons learnt and potential benefits for the rest of the community (Action 11 from the December 2021 meeting). As part of this, the Delivery team had produced a Venn diagram showing where the Projects fell in terms of the following common thematic areas (see also Appendix 1): Cloud-enabled infrastructure (2 projects); Federated analytics (3 projects); Artificial Intelligence (1 project); Privacy Risk Assessment and Privacy Enhancing Technologies (3 projects); Governance Frameworks and Best practice tools (4 projects) whilst PIE was a thematic area across all the projects.

The projects had the opportunity to meet during the internal launch event in early January 2022 with the next public-facing event planned for the 8th of February; and a Mid-Sprint Exemplar day on the 21st April. Additional plans for sprint project collaboration and support included:

- Monthly light-touch meetings per project with the Delivery Team members
- All-inclusive Slack channel with Sprint participants to encourage organic collaboration
- Delivery team acting as a broker, where feasible, to connect projects across investments
- Onsite exemplar days, where possible, to encourage collaboration and networking

The PB requested from the Delivery Team to develop a Knowledge Exchange plan pulling out the experience from the Sprint Exemplar Projects to capture important learnings, which may not be explicitly mentioned as key outcomes. Taking the PPIE as an example, the following three methodological questions were considered critical to inform future direction:

- How do you involve lay people meaningfully?
- How do you engage with underrepresented groups? and
- How to access public views and measure trust?

Also, it would be helpful to have a plan for drawing out the general lessons from the Sprints Exemplar Projects experience, and in particular PIE. It was also suggested that a guidance should be provided to Sprint Exemplar Projects teams on the content of their PIE final reports to ensure that these address key questions as the ones mentioned above.

Action(s)	Owner(s)	Deadline/Status
11. Present a plan on how to capture the general 'lessons learnt' from the Sprint Exemplar Projects	Delivery Team	Update at the next PB meeting - 31 st March 2022
12. Develop a guidance/skeleton on the content of the Sprint Exemplar Projects' final PIE report	Delivery Team	Update at the next PB meeting - 31 st March 2022

4. AOB

None was raised.

5. Date of next meeting

The next Programme Board meeting is scheduled on the 31st March 2022 (the day after the second Scientific and Technical Advisory Group meeting) and its duration will be extended from one hour to one hour and a half due to allow adequate time for all the agenda items.

Action(s)	Owner(s)	Deadline/Status
13. Extend the next PB meeting by half an hour	Secretariat	15 February 2022

Appendix 1 - Summary of the actions from the 1st February 2022 DARE UK Programme Board meeting

Actions	Owner	Deadline/Status
1. Develop a proposal/options on the scope of the DARE UK Programme on sensitive data types and seek views and advice from the UKRI Digital Research Infrastructure Committee and the DARE UK Scientific and Technical Advisory Group	Delivery Team	DRIC meeting - 3 rd March 2022 STAG meeting – 30 th March 2022
2. Develop a framework of DARE UK objectives and outputs for the different data owners and the breadth of research community users (user journeys/personas) of such an infrastructure	Delivery Team	Update at the next PB meeting – 31 st March 2022
3. Invite Justin O’Byrne (or another DRIC representative) to the next STAG meeting when discussing the scope of the DARE UK Programme to represent the overarching viewpoint as to where DARE fits in the broader UKRI DRI plans	Ekaterini Blaveri	9 February 2022
4. Following feedback from DRIC/STAG, update the proposal/options on the scope of the DARE UK Programme on sensitive data types based on the advice and feedback received and present it to the PB for their consideration	Delivery Team	Update at the next PB meeting -31 st March 2022
5. Develop a roadmap/representation explaining where the DARE UK Programme fits in terms of both the UKRI DRI Strategy (primarily), but also the wider landscape, and indicates the gaps that are being addressed by the Programme	Delivery Team	Update at the next PB meeting – 31 st March
6. Intensify stakeholder engagement efforts to include initiatives/organisations such as: the Royal Statistical Society Data Ethics and Governance Sector, UK BioBank, Genomics England, industry and	Delivery Team	Update at the next PB meeting - 31 st March 2022

international initiatives/organisations (e.g. EMBL-EBI, Australia Data Commons and New Zealand); but most importantly engage with stakeholders beyond the health and social care disciplines.		
7. Propose a mechanism/approach to engage with prospective users	Delivery Team	Future PB meeting
8. Present current thinking on the development of a strategic science case and blueprint	Delivery Team	Update at the next PB meeting - 31 st March 2022
9. Discuss the process of developing a 'blueprint' and strategic science/business case and its content and timeline	All	Update at the next PB meeting - 31 st March 2022
10. Share with the PB the Public Dialogue Report, which Kohlrabi Consulting will be produced based on the workshops hosted as part of the DARE UK PIE activities	Delivery Team	Early Spring 2022
11. Present a plan on how to capture the general 'lessons learnt' from the Sprint Exemplar Projects	Delivery Team	Update at the next PB meeting - 31 st March 2022
12. Develop a guidance/skeleton on the content of the Sprint Exemplar Projects' final PIE report	Delivery Team	Update at the next PB meeting - 31 st March 2022
13. Extend the next PB meeting by half an hour	Secretariat	15 February 2022

Appendix 2 – DARE UK Sprint Exemplar Projects – Portfolio view

