



Pan-UK Data Governance Steering Group

1st of April 2025

Summary of Key Discussion Points

Chair: Andy Boyd

Welcome and Steering Group Workstream Updates: Speakers – Andy Boyd, Rachel Brophy and Edel McNamara.

The Data Access Agreement Template (DAA)

There is a new version of the Data Access Agreement (version 6.0 available here: [TRE Data access agreement template](#)). The core principles of the DAA remain the same but the latest iteration has two versions; one to be used when non-personal data is going to be accessed within the TRE and therefore it doesn't include any clauses around controllership, the other, for use where personal data is going to be accessed.

The research project sponsor is now signatory in line with the recommendations made by the HRA. We will be checking the DAA for alignment with the new ICO anonymisation guidance. With thanks to James Squires for coordinating Industry needs from the template; we have ensured that the DAA is multi-project. We are hopeful for integration of the template within IRAS and will launch a funding call at the end of the month.

GUARDS

The GUARDS principles were launched at the Frontiers event in January as an overarching governance framework applicable to the whole data science community. The GUARDS stand for Guided, Understandable, Aligned, Responsible, Deliver and Stewardship and come together with the 5 safes to make the "safeGUARDS". A website landing page is now available [here](#) and we are developing a communications plan to develop this further. We have hired an intern from HDR UK's Black Internship Programme to work over the summer to help collate a resource toolkit and conduct a gap analysis to assist in widescale adoption of the framework. We have also consulted with stakeholders to discuss adoption. The paper will be circulated for comment shortly before submission.

PEDRI

The PEDRI Frontiers meeting will be held on the afternoon of the 18th of June at the Wellcome Trust. The event will provide an opportunity to discuss the evolution of the standards, launch the evaluation framework and funding call. There will also be talks from sector leaders such as Professor Andrew Morris and Ed Humpherson.



SOURSD

Previously known as the researcher registry, this project is one of the four projects funded by UKRI for a better and safer use for research. The overall goal of this project is to create a common consistent framework across organisations to simplify the decision-making process around responsible access. One of the key goals was to create a common model to define key criteria for verifying users and organisations via a software solution to allow data custodians to assess if these users and organisations are “safe”.

The minimum viable product is now available for user testing and if you would like to be part of the user testing group, please contact Edel at Edel.McNamera@HDRUK.ac.uk

We have also released guidance in partnership with the project for assessing safe people and organisations. The guidance document is available [here](#) and details what information should be considered when assessing safe people and organisations. Any feedback on the guidance would be greatly appreciated, please find the feedback from [here](#). Members of the Steering Group have also been involved with delivering this project, so your feedback is very welcome and greatly valued.

ICO Anonymisation Guidance

The ICO Anonymisation Guidance was published on Friday the 28th of March. We are awaiting research provision guidance which will include the TRE case study submitted by this group. The guidance clarifies the use of some key terms. For example, effective anonymisation refers to anonymisation being conducted effectively, rather than the data being “effectively” anonymous in the hands of the researcher. The term that should be used is functionally anonymous, which refers to the idea that the data may not be fully anonymous but can be considered anonymous in this specific scenario. The guidance specifically discourages the use of the term de-identified data, favouring the use of pseudonymisation. The guidance also acknowledges that the spectrum of identifiability is a difficult grey area and aims to provide advice on how to manage/ assess the grey area without definitive definitions and hard lines.

Discussion points

- The ICO guidance states that doctors can be classified as unlikely to be motivated intruders to SDEs due to their code of conduct relating to confidentiality. Therefore, would it be possible to classify users of SDEs as unlikely motivated intruders given that they have similar codes of conduct and data access agreements? In order to promote classifying researcher data scientists as unlikely to be motivated intruders a professional standard for the research data scientist communities could be created.
- The guidance has provided clarity on a lot of issues but the anonymisation flowchart still requires individual judgements to be made regarding anonymity. Therefore, case studies in these areas would be useful to prevent misinterpretation. The Steering

Group has submitted a case study to the ICO which will be released with the research provision guidance. Some members of the group feel that the guidance does not provide enough clarity regarding anonymisation. The additional research provision guidance will be released in draft form for consultation, allowing an opportunity to feedback on the guidance and case study. The Steering Group could be used as a forum to take the guidance further and unpick the interpretation of the guidance and its implications.

Speakers: Emily Almond, Joseph Watts, Jamie Neale, Daniel Higgins, Dan Beck

Secure Data Environment Self–Accreditation framework

The shift to SDEs

The data access and public engagement team are involved in the policy and strategy side of the transition to SDEs as recommended in the Goldacre review in 2022. The Goldacre review encouraged the adoption of SDEs as the standard methods of accessing health data for research. Prior to this recommendation the data access and public engagement team worked on the NHS digital TRE launch in 2021. Following the Goldacre review, the team helped launch the Data for R&D programme which increased investment in national and regional SDEs. Between 2022-23, 12 policy guidelines and data access policy documents were published and large-scale public involvement has also been conducted. The Sudlow review was also published at the end of 2023, making clear recommendations on SDE accreditation and standardisation.

Background and overview of the accreditation

As we move towards a system of data access, assurance that the SDEs are safe is critical. Interpretation of guidance by making it clear and easy to understand is also critical. These improvements also bring health in line with other factors that are going on for the wider public sector. However, health data TREs are currently excluded from the existing DEA accreditation.

The team worked closely with the UKSA to co-design an amended version of their highly regarded DEA 2017 Accreditation framework for SDEs. An interim self-assessment will be put in place, and it will cover security, cybersecurity and governance and transparency capabilities.

The self-assessment sets out some indicators of good practice and core principles, this is very similar to the existing framework. SDEs will have a set of categorical statements to choose from that demonstrate how they have achieved the principle. There is no official pass or fail and the team are looking to stress test the accreditation to help shape future iterations of the criteria. Rollout of the self-assessment will go to the SDE network and the

accreditation criteria has been shared with other key stakeholders. The team are still aiming to stand up a fully external audited SDE accreditation function with the UKSA in 2026. The team are aiming to avoid duplication by recognising equivalence within the accreditation.

Discussion points from break out rooms

- **Room 1** – Discussed the scope of the DEA, how much there is to learn from Scotland and the breadth of the current legislation. UK based processing does limit access to data for health research to UK based researchers which is a real challenge for policing and policy. Health data research does generally have a global lens therefore, an updated version of the current provisions to include this would be helpful moving forward. The accreditation needs to accommodate the wide range of TREs and how they are set up.
- **Room 2** – Discussed scope and commented on policy around commercial and NHS-led SDEs and how these two different types of SDEs could interpret the accreditation framework. Self-assessment needs to be managed with comms. Blogs could help set some expectations/ understanding of the self-assessment. The accreditation also must not undercut any other systems in place to ensure that public trust is maintained (i.e. NHS opt out). There are legislative barriers across the 4 nations and the accreditation also needs to accommodate 4 nation differences where possible.
- **Room 3** – Discussed recognising equivalence as a sufficient level of detail and assurance. Equivalent standards provide opportunities to emphasize to the public that you are already meeting standards. The findings of the accreditation, at the moment, won't be shared and an explanation as to why and, potentially, move to sharing these findings in future to ensure long term public assurance. It was also made clear that it is important who operates the SDEs, how identifiable the data they host is and how much PPIE they engage in. The accreditation should also include points around continuous improvement. In terms of key barriers, a point was raised about having an accreditation pathway beyond the SDE network.
- **Room 4** – Discussed the potential for individuals can come up with ways of answering self-assessments to strengthen their position assurances behind the accreditation need to be made clear. Expanding the accreditation outside of the SDE network could be difficult due to capacity. A solution could be well established accredited TREs helping and encouraging good practice were applicable. A discussion was held around legislation and what can be considered mandatory and voluntary within the accreditation. The need for extensive regular testing was also highlighted. For example, cyber penetration testing, testing with the systems information governance.

Summary and next steps



The focus of the team is moving toward wider information governance data access which includes reviewing and mapping accreditation, promoting federated decision making and improving output checking within the SDE network. The team are also working toward a more cohesive risks-based approach. To encompass all of these objectives a strategic review and reform of data access committees is being conducted to ensure data access is generally easier.

AOB and Closing remarks

- A general point that the steering group is there to help and support. We are happy to review any further work from the DHSC team.
- A short prioritisation exercise was undertaken with views gathered from the Steering Group via a Figma board. Answers will be reviewed ahead of the next meeting.
- The Data Use and Access Bill is in its last stages and should be widely available shortly.



In attendance:

Name	Organisation
Alan Harbinson	HSCNI
Alex Newberry	Welsh Government
Alison Knight	Health Research Authority
Andy Boyd	UK LLC
Bethany Gilber Cassie Smith Rachel Brophy Edel McNamara Doreen Tembo	Health Data Research UK
Charlotte Allen	Our Future Health
Claire Edgeworth	NHS England
Dan Beck Nicola Shearman Steph Jacobs	Office for National Statistics
Emily Almond Joseph Watts Jamie Neale Daniel Higgins	Department of Health and Social Care
Fergus McDonald	DARE UK
Garry Coleman	NHS England
James Hetherington	University College London
Jack Squires	ABPI
Joe Cuddeford	UKRI
Katherine Evens	Bristol University
Nick Maltby	Genomics England
Paul Jackson	Research Data Scotland
Ruth Gilbert	University College London
Sharon Heys	Swansea University
Tim Hubbard	Genomics England
Pamela Linkstead	DataLoch