

Pan-UK Data Governance Steering Group

Date 7th July 2025

Summary of Key Discussion Points

Chair: Andy Boyd

Welcome and Steering Group Workstream Updates: Speaker – Rachel Brophy

safeGUARDS

The information governance team are delighted to welcome Damilola Awe as an intern recruited via HDR UK's Black Internship Programme and with us from the 30th of June through to the 22nd of August 2025. Damilola will be focusing on developing the safeGUARDS toolkit, a collection of existing resources to assist with safeGUARDS adoption. More information on the safeGUARDS can be found [here](#). Based on the success of the [PEDRI good practice standards resource hub](#) we aim to develop a similar toolkit of resources for the safeGUARDS. If you are aware of any resources that could be used as part of the safeGUARDS, [please fill out this survey](#).

The PEDRI Good Practice Standards Frontiers Meeting

The PEDRI good practice standards had their inaugural frontiers meeting on the 18th of June 2025. The event included speakers from the Office for Statistics Regulation, Administrative Data Research UK, PEDRI Public Partners, Industry (IQVIA & ABPI), Centre for Ethnic Health Research, Equity Lighthouse and the University of Cambridge. The event announced the launch of the PEDRI "[From Standards to Impact](#)" funding call and the [PEDRI pledge](#). In collaboration with HDR UK, PEDRI will offer awards of up to £15,000 to support organisations to embed the PEDRI Good Practice Standards into their public involvement and engagement work.

Science Community Festivals

Over the past month, there have been several Science Community Festivals which have provided several opportunities to expand our public engagement and involvement. Over the course of the three science festivals we have had:

- At least 386 public interactions
- 6 researchers and clinicians involved in delivering activities



- 5 HDR UK/PEDRI colleagues involved in delivering activities
- 5 public contributors involved in delivering activities

The Data Access Agreement Funding Call

An update on the imminent funding call for [DAA](#) adoption was given. We are pleased to announce this is now live: See [here](#) for more details.

The HRA and Four Nations Contracting Leads have now endorsed the use of the non-personal version of the agreement, which must be used for NHS/HSC SDEs. We have also provided a personal data version where data accessed is deemed to be pseudonymised, so that all TRE/SDE DAA needs are met.

Up to £30,000 will be awarded to successful applicant organisations to assist with implementation of the DAA. Examples of the types of projects HDR UK is seeking to fund via this call for funding include:

- DAA review against current data access contracting arrangements (for established TRE/SDEs)
 - Population of customisable annexes (note: core terms are not to be modified)
 - Liaison with internal or external contracts/legal team
 - Updating associated governance processes
 - Roll-out of the DAA with organisations accessing data
 - Development of training for existing staff members on the DAA and its role within existing contracting and data access processes.
 - Website updates providing transparent and accessible information on the DAA and its role within existing contracting and data access processes in line with the [UK Health Data Research Alliance Transparency Standards](#).

The deadline for application is the 19th September 2025. The project must include plans to implement adoption of the DAA by the 28th February 2026 and to collect impact metrics until the end of project (31st August 2026).

Data Use and Access Act: Speaker – Edel McNamara

Data (Use and Access) Act 2025: Research Relevant updates

- The Data (Use and Access) Act entered into law 19 June 2025 which contains first changes to UK GDPR.

- The provisions on the definition of **scientific research** and **board consent** sit in the legislation rather than the recitals.
- There is an exemption in the **privacy notice requirements** for directly collected data and scientific research if doing so would involve a disproportionate effort.
- The Act reshuffles the test of **purpose limitation**. There will be no further processing unless the purposes are compatible. Consent and derogations are now considered to be compatible purposes. Research that is currently using consent as a lawful basis for processing must continue to use consent as their lawful basis and meet the criteria for fully informed consent.
- There is a new 'data protection test' for **international data transfers** which is met if the standard of data protection is "not materially lower" than the standard in the UK. International transfers are still subject to appropriate safeguards and the test requires data exporters acting reasonably and proportionately, considers that the data protection test is met. The Secretary of State has the power specify standard data protection clauses for "transfers of personal data generally or a type of transfer specified in the regulations."

Action: The ICO have an open [call for viewson international transfer guidance](#)Contact Edel.Mcnamara@hdruk.ac.uk if you would like to collaborate on response.

Discussion points

- HDR UK's priority within the response to the ICO on international transfers is to understand how the "*not materially lower*" threshold interacts with data being within a TRE/ SDE. Under the law, accessing a TRE/ SDE is still an international transfer but understanding how these interact will be very helpful.
- What prompted the updates provided in the Act? Specifically, what prompted the updates on international transfers? International transfers have been very difficult for many organisations across the UK and organisations often have to arrange agreements with places such as the US to share data.
- Does "*not materially lower*" mean that it would be easier to complete a data transfer from TRE to TRE? We think that this will be highlighted in the any guidance that comes out. The change in standard does feel very intentional. The UK's current adequacy standard is only in place, within the EU, until December. It is reasonable to suggest that the government are trying to make international transfers easier but without losing adequacy standards within the EU.

Workshop: ICO Guidance implementation: Speaker – Cassie Smith

There are some welcome points in the new ICO anonymisation guidance. The guidance does create clarity, it has firm guidance regarding terminology, it is contextual and practicable and includes some case studies.

- Identifiability is a spectrum and the grey area that we grapple with is in the middle of the spectrum. At one end, we have information that is “directly identifiable”, with data with all identifiers and can be defined as personal data. On the other end we have “impossible to identify” and data protection laws do not apply, but this status needs to be kept under review as appropriate. The guidance makes it clear that a number of factors should be taken into account (including the data, the technical and organisational measures applied)

Once all of these factors have been considered, you then conclude whether the data is likely or unlikely to be identifiable in the hands. This was previously called “*considering the data functionally anonymous*”. If the data is deemed unlikely to be identifiable then the data is anonymous and data protection law does not apply, this should be kept under review.

There are a couple of challenges within the guidance. Firstly, the guidance makes statements about assessing people’s motivations to break rules but does not describe what information can/ should be collected to understand the risk.

If you look throughout the guidance on linkability, different parts of the guidance may come across as stating different stances if read in isolation. It is important to read the guidance in full to understand the position on linking data and how that impacts identifiability.

The guidance advises that identifiability should be re-assessed every time you give access to a new individual. This could be a very onerous process for TREs because researchers join and leave projects quite rapidly.

The guidance states that whilst data can have different identifiability status in the hands of independent data controllers, the status of the data cannot be different in the hands of joint controllers or controller/ processors.

Discussion points

- Could we develop some case studies that would show how the guidance relating to understanding people’s motivations to break rules would be implemented? We would need to further explore examples of this issue and how people have dealt with it.
- Could the Safe People registry help with this issue? The GDPR issues around collecting infringement information in the safe people registry is very challenging, but we are working closely with the Safe People team.

- How do you assess a motivation? For example, if you are slowing down a researcher's publication by conducting good due diligence on an output check, could you consider that researcher motivated to break the rules?

Case Studies

Case studies were presented highlighting potential problem areas with the “whose hands” test and joint controllership.

Discussion points

- What are the practical implications of joint controllership and the subsequent identifiability status of the data? It means that data protection law applies, so you must do a data protection impact assessment for each project within the TRE and comply with GDPR. If you allow international access, it is then considered an international data transfer. This changes a lot of the best practice actions to mandatory. Organisations would also have to create a joint controllership agreement which could be lengthy and time consuming.
- There are some specific instructions on processing activities so we may need to drill down into the detail of the processing activity. A key output of this community needs to be guidance on how we can identify the controller and joint controllers.
- Where do we place the responsibility of the case studies? What controls are available to ensure that each party is carrying out their responsibilities e.g privacy notices.
- If the data is deemed personal, then it will have ramifications for which data access agreement template is the one that should be used. Although, the test for whether you need NHS REC approval is actually to do with the common law, it could lead to some guidance being required around if you're using the personal data access agreement template, whether you need REC as well.

Four nation update – NHS SDE Network: Speaker – Claire Edgeworth

The network is aiming to simplify access to data from the NHS and drive consistency across the SDEs to increase transparency with users and the public. Progress has been made in conversations for federation across the SDEs in terms of data supply. This will be done on a per project basis. Federation will also bring consistency to key criteria and products being used across the network and use common solutions such as data access forms, agreements and committees.

Four nation update – Public Health Scotland: Speaker – Carole Morris

Public Health Scotland (PHS) have started discussing federated information governance with the NHS Scotland Public Benefit and Privacy Panel and other regional TREs in Scotland.



Working closely with Research Data Scotland to align approaches to accessing health and non-health data. Instead of focusing on the Digital Economy Act as it is, PHS are working with their health colleagues to streamline access to health data so if data is being accessed for linkage, the process of planning these projects is more streamlined while still doing due diligence. Conversations are still ongoing on the governance of a national primary care data set, across data boards and the GP community. With aims to develop a data access committee and keep the processes to access the data streamlined.

Four nation update – Honest Broker Service: Speaker – Alan Harbinson

The Health and Social Care Institute has a new Research Governance Framework and Research and Development Offices in each of the Trusts. Key roles within these include R&D directors and managers. The Office for the Research Ethics Committee for Northern Ireland (ORECNI) support NI involvement in the REC infrastructure across the UK. A new central approvals office has been established within the Public Health Agency to provide regional advice. There are various networks such as the NI Clinical Research Network. These support establishment of clinical trials and studies within the region and advise the Honest Broker Service through the HSC Data Access Committee.

Four nation update – Welsh Government: Speaker – Alex Newberry

Preparing for the Health Data Research service by looking at what reforms will take place in order for the service to be stood up; Potentially COPI reforms. The Welsh Government, with the HRA and the NDG, have also been engaging with the public around implied consent and who can access information about people and trials that might be related to their care. A report on this consultation is due to be published soon.

Prioritisation Exercise: Speaker – Yemi Macaulay

The prioritisation exercise consisted of asking the questions in the [survey here](#). Please do submit your responses via the questionnaire.



In attendance:

Name	Organisation
Alan Harbinson	Health and Social Care Northern Ireland
Claire Edgeworth	NHS England
Alison Knight	Health Research Association
Carole Morris	Public Health Scotland
Fergus McDonald	DARE UK
James Heatherington	University College London
Amy Tilbrook Cassie Smith Edel McNamara Rachel Brophy Damilola Awe Bethany Gilbert	Health Data Research UK
Alex Newberry	Welsh Governement
Sam McGregor	SDR UK
Katherine Evans	UK LLC
James Squires	ABPI
Will Navaie	Genomics England
Alex Bailey	Medical Research Council
Elena Beratarbide	Digital Health and Care Directorate
Ed Humpherson	Office for National Statistics
Garry Coleman	NHS England
Andy Boyd	UK LLC