

DARE UK (Data and Analytics Research Environments UK)

DARE UK Interest Group (IG) Charter Template

Name of proposed Interest Group: *TRE Community Information Governance Interest Group*

INTRODUCTION

The TRE Community Information Governance Interest Group addresses the critical need to support standardised Information Governance (IG) across Trusted Research Environments (TREs) for secure, efficient, and transparent research access to sensitive data. Aligned with DARE UK's mission, this collaborative group, with a flexible remit, will adapt to emerging needs in sensitive data research and promote good practices across disciplines and infrastructures.

Sound IG is the basis under which sensitive data research must be undertaken, ensuring that both organisations and individuals supporting and undertaking research and the data research environments manage information in a secure, legal and efficient way. Strong and clear IG promotes legal and ethical compliance, openness and transparency and helps to maintain public trust. There are several frameworks that broadly contribute to promote and federate IG within Trusted Research Environments (TREs), also known as Secure Data Environments (SDEs), including the Five Safes Framework, the Information Governance pillar of the Standard Architecture for TREs, as well as formal international accreditation standards such as ISO27001 or NHS Data Security and Protection Toolkit (DSPT). There are also a number of groups that aim to address various individual or high-level aspects of IG, such as the Health Research Information Governance Working Group (HRIGWG) or the Pan-UK Data Governance Steering Group.

However, as much as there are overarching frameworks and guidance groups, IG professionals within TREs must negotiate murky territory between requirements and the main challenge for them: supporting individual data controllers and Data Protection Officers (DPOs) (each of whom have varying risk appetites and interest in sharing data beyond operational requirements) of the value, permissibility and acceptability of research using secure data. Data controllers are not required to share data for research or statistical purposes and rely on IG professionals to present relevant information to allow the secure data access, and often come to significantly different conclusions when presented with the same information or framework.

IG considerations are typically context-dependent, meaning a project-by-project, data-type by data-type, or location-by-location basis approach to decision-making can be necessary. This can lead to a perception of inconsistency in decision-making and contribute to a negative perception or experience. Sharing knowledge and understanding of similarities and shared standards will help to reduce the volume of 'case-by-case' decision-making, enabling more predictability in the outcome of the IG decision-making process.

This interest group brings together IG professionals across the TRE landscape, agnostic of discipline, to collate and disseminate the different initiatives and guidance from across governance groups, and the myriad ways they have been interpreted. The main aims are to consolidate and distil information that particularly impacts TREs, working across domain specific or TRE specific groups and agree on good practices to operationalise them. By providing a space with curated initiatives and guidance, where members can develop practical, operational advice and good practice, the group will serve to improve, clarify and drive efficiency in IG within the context of sensitive data research, leading to more harmonisation and equivalence and improvements in researcher experience, governance processes within and across TREs.

Our TRE Community Information Governance Interest Group will contribute to a wider programme of federated approaches to data and infrastructure by considering governance practices within this context across organisations – a “federated governance” approach. Moreover, the sharing of practices will allow IG professionals within the TRE Community to draw upon expertise and experience to more coherently work with individual data controllers to improve access to sensitive data for research by reframing understandably individual risk appetites within the wider context of approaches used by TREs across the UK.

An initial meeting of the group identified two user scenarios and two use cases that the Interest Group would address:

User scenario 1: Researchers perceive they are receiving inconsistent advice as data controllers and IG professionals are interpreting and implementing in siloes.

IG is often used in TREs as the umbrella term to cover “everything that isn’t technical”. Thus defining what aspects of a data service, infrastructure or team make up IG becomes immediately difficult, and these aspects are implemented differently in every TRE setup. IG considerations around risk are typically context-dependent, which can lead to a perception of inconsistency in decision-making and contribute to a negative experience. It can also leave individual IG professionals feeling somewhat alone in their decision making. This can lead to delays in research permissions and lead to strikingly different processes for data production, access, and output across different TREs- causing frustration across all parties involved and reducing research scope.

Sharing knowledge and understanding of similarities and shared standards will help to reduce the volume of ‘case-by-case’ decision-making, enabling more predictability in the outcome of the IG decision-making process.

User scenario 2: TREs are requested to expand governance to cover new ground in their area at speed and therefore “bolt-on” to existing practices – creating unnecessary complexity rather than a system-wide approach.

Many IG processes in TREs are derived from health data research, but even within this domain there are different legislative, regulatory and ethical processes to follow. Clinical trials, for example, follow different IG processes than clinical service improvements, research using consented and unconsented data have established governance processes, but linking the two, especially cross domain, may mean the parallel paths are repeated. Some good practices for novel processing (e.g. to develop ML/AI) on sensitive data are being defined for TREs across the board at the egress stage (see the GRAIMatter report, SDC-REBOOT Interest Group and the SACRO project), however requirements at the researcher application stage are less defined and are being decided at the project level. Each new development is usually requested as soon as possible to remain at the cutting edge of research; therefore, processes are added cumulatively to original ways of working, rather than taking a system-wide or principles-based approach which may not support research at scale or federation.

Rather than reinventing the wheel, a group of professionals that are able to understand both how basic principles apply in different situations, the nuances of different data controllers, and can create framework approaches, principles or Codes of Practice to reduce unnecessary governance while maintaining scrutiny at different risk appetites.

Use case 1: New guidance developed by steering or policy level groups is not shared/known by the IG professionals who put it into practice – with no feedback mechanism to the groups creating it on whether it is implementable - leading to duplicated effort (at TRE level) and potentially impractical guidance.

Many existing IG groups operate in silos, or at a level to provide broad guidance (e.g. the Pan-UK Data Governance Steering Group, which is open to HDRUK Alliance members only) and therefore guidance may not be accessible, implementable or even known by some TREs. There is no working “reference list” of the various IG groups across the UK and how (or if) they consider TREs within their groups. If the organisations and the information they produce are not signposted, then they are an unknown resource for the community, particularly those new professionals in the IG TRE space. TREs will benefit greatly by policy suggestions promoted by expert high-level groups but if guidelines and recommendations do not reach the “on-the-ground” IG practitioners, then consistent practical solutions and implementation options may never be created. Likewise, how the IG processes and common frameworks reinforce TRE federation is an essential element of future research infrastructure and research innovation. Engaging the TRE IG community is the essential starting point for this key work.

We aim to collate and document IG norms and requirements across different domains, data collection methods which will lead to more transparency in IG processes for organisations with varying appetites to follow.

Use case 2: Individual data controllers or Data Protection teams with little knowledge of the safeguards in place in TREs, the published guidance, or the need for TREs to evolve add unnecessary hurdles to research.

TRE staff are responsible for translating the technical and methodological requirements to Data Protection teams, who often have a “zero-risk” approach to sensitive data research. Yet any research, particularly research that is attempting to innovate new methodologies, will have a degree of risk, which can be sufficiently mitigated by TREs. IG professionals need space and fora for advice on how best to present the use cases to teams with differing risk appetites and knowledge but considerable power.

This group aims to bring together experienced IG professionals that can facilitate clear, expert ways of presenting solutions that facilitate proportionate risk mitigations to enable research innovation.

OBJECTIVES

Some initial themes have emerged from IG professionals within the TRE Community that this Interest Group will consider to address the scenarios – with the expectation that the group will have spin-out working groups around these themes:

User Scenario 1: Perceived inconsistency/working in silos

- Establishing and recognising equivalence of IG across TREs / organisations (e.g. how IG and associated frameworks such as the Five Safes and SATRE models have already been implemented, recognising that there may be various approaches but that there are clearly defined equivalencies, and opportunities to modify processes easily to achieve equivalence. This will support TREs aiming to complete federated analysis.
- Promoting learning and development opportunities to support IG career development and the professionalisation of IG roles within the TRE landscape – through linking with the Data Research, Access and Governance Network (DRAGoN), UKRI funded Future Data Services projects, ESRC Odyssey and other groups.

User Scenario 2: Rapid expansions and bolt-on processes

- Develop a data risk classification, principles and balanced controls that apply across scenarios so that the right questions are asked at the right level, despite any varying risk appetite.

- Further develop the existing roadmap for interoperable, federated data architecture by crafting TRE-specific IG advice and guidance – including around novel technologies (AI), and proportionate governance (e.g. risk assessment of synthetic data, precedent based risk approvals),
- Adapt and align TRE-specific IG in a way that makes it easy to achieve and verify.

Use case 1: High level guidance is not collated, implementation not fed back

- Utilising established links from members with strategic level (e.g. Pan-UK Data Governance), domain specific (e.g. HRIGWG), issue specific (e.g. SDC-reboot) or wide but related (UK TRE Community) groups:
 - Signpost to synthesise and align published guidance
 - Provide discussion fora for implementation differences of the above
 - Feed back to relevant groups implementation case studies.

Use Case 2: Lack of support for DPOs with varying interest in sharing/understanding of TREs

- Identify governance issues with research and the need for TREs – as highlighted in the recent Sudlow Report (specifically Chapter 6).
- Align operational requirements to legal, regulatory and ethical policies and to enhance data controller understanding of how TREs use IG effectively as a risk-management strategy.

OUTCOMES:

The main outcomes and deliverables this group aims to achieve are as follows:

- Maintain an index of all IG-related groups across disciplines, updating as required and categorising by discipline, focus and contributions to IG policy.
 - Maintain a central repository of IG guidance, risk approaches and policies produced by external groups – crucially highlighting guidance specifically applicable to TREs, even if TREs are not explicitly a consideration within the guidance/policy.
 - Where gaps in guidance for TREs are identified by the group, this 'Community of Expertise' will provide support to produce TRE-specific guidance and suggestions for implementation – the group specifically could help either by canvassing organisations' established working practices, or by convening a Working Group or session to devise new solutions for implementation for TREs to incorporate into their organisations. Tangible working group outputs already suggested include:
 - A Code of Practice/Risk Management Framework
 - A skills and competency framework/career pathway for IG professionals
 - Along with SDC-REBOOT community colleagues/following up the GRAIMatter report – understand and develop guidance for considerations for TREs and governance groups supporting AI/ML development
 - Support other funded projects (both Interest and Working Groups, as well as the DARE UK Core Components programme) as a sounding board on an ad hoc basis to provide focused advice and guidance on operational TRE IG issues for novel practices.
 - An annual TRE-IG conference, to formalise clear and transparent guidance for data providers and users accessing sensitive data within TREs, including consistent and explainable legislative, regulatory and ethical guidance.

- PPIE work (e.g. surveys or workshops) with members of the professional and public community to focus on IG related issues for more understanding of the acceptability of the implementation of the Five Safes Framework in different scenarios – for example, deidentification of data for different data types, open synthetic data risks, assessment of risks of ML and TRE responsibility.

PARTICIPATION AND COLLABORATION

Groups already showing interest in the group include:

- Health TRE service and infrastructure providers (DPUK, Francis Crick Institute)
- Cross discipline/University TRE service and infrastructure providers (Smart Data Foundry, Universities of Leeds, Bristol)
- Domain specific national data infrastructure (UK Data Service)
- Data governance academic researchers (UWE, Cardiff University)
- Private sector governance professionals (Arcturis)
- Governance consultancies (RISG Consulting)
- Public engagement groups (Research Data Scotland's Scotland Talks Data group, South Yorkshire Public Engagement group)

In addition to the above, we will look to recruit at a Member of the Public to act as a co-lead on the TRE Community Information Governance Interest Group to help inform any solutions or guidance provided to TRE IG professionals, and link to TRE users through links to existing governance groups. This co-creation of information will ensure that any operational solutions has had input from the users of the services, data custodians, and the public.

MECHANISMS FOR SUCCESS

We see the group functioning very similarly to the very successful UK TRE Community Group and other DARE funded projects, i.e.:

- Monthly meetings to discuss member-suggested topics, updates on guidance, working group suggestions/progress – already invited to joint-host UK TRE Community event in March 2025.
- Fortnightly 'updates' emails (updates on new advice/guidance, repository updates, etc.
- Jisc-mail service open to all group members to pose ad-hoc questions and develop connections
- Annual TRE IG workshop as face-to-face networking and collaborative working opportunity. Ideally, we would like to schedule this as a 'bolt on' to the TRE Community Annual Meeting, to encourage as many attendees as possible.

Potential members:

FIRST NAME	LAST NAME	EMAIL	(Co-)Chair / Member
Katherine	O'Sullivan	k.k.osullivan@sheffield.ac.uk	Co-chair
Amy	Tilbrook	Amy.tilbrook@ed.ac.uk	Co-chair
Pete	Barnsley	peter.barnsley@crick.ac.uk	Co-chair
Felix	Ritchie	Felix.ritchie@uwe.ac.uk	Co-chair

Will	Crocombe	willc@risgconsulting.co.uk	Member
Tim	Machin	t.machin@ucl.ac.uk	Member
Liz	Merrifield	merrifielder@cardiff.ac.uk	Member
Kate	McBay	kate.mcbay@researchdata.scot	Member
Katie	Oldfield	katie.oldfield@researchdata.scot	Member
John	Latham-Mollart	john.latham-mollart@arcturidata.com	Member
Cristina	Magder	dcmagd@essex.ac.uk	Member
Hannah	Woodward	Hannah.woodward@bristol.ac.uk	Member
Akansha	Singh	Akansha.singh@durham.ac.uk	Member
Sharon	Bolton	Sharonb@essex.ac.uk	Member
James	Walker	Aalconltd@gmail.com	Member
Diane	Brown	diane.brown@abdn.ac.uk	Member
Phil	Quinlan	Philip.quinlan@nottingham.ac.uk	Member
Patricia	Ruddy	Patricia.ruddy@smartdatafoundry.com	Member
Liz	Merrifield	Merrifielder@cardiff.ac.uk	Member
Martin	O'Reilly	Moreilly@turing.ac.uk	Member
Elen	Golightly	Elen.golightly@swansea.ac.uk	Member
Anca Daniela	Vlad	Anca.vlad@cancer.org.uk	Member
Tim	Machin	t.machin@ucl.ac.uk	Member
Mark	Mumme	Mark,mumme@bristol.ac.uk	Member
Helena	Ahlfors	Helena.ahlfors@bioresource.nihr.ac.uk	Member
Marian	Aldhous	Marian.aldhous@nhs.scot	Member
Jonathan	Tedd	Jonathan.tedds@elixir-europe.org	Member
Ryan	Bremner	Ryan.bremner@researchdata.scot	Member
Pamela	Linksted	Pamela.linksted@ed.ac.uk	Member
Jackie	Caldwell	Jackie.caldwell3@phs.scot	Member
Penny	Wright	penny.wright@gov.scot	Member
Anthony	Chuter	Chuter@me.com	Member

