

DARE UK (Data and Analytics Research Environments UK)

DARE UK Working Group (WG) Charter Template

Name of Proposed WG: *Single Patient Record Integrity, Trust & Transparency (SPRINT)*

Affiliated DARE UK Interest Group (if applicable): *ITALO (Improving Transparency Around Linkage Outputs)*

The WHY

Introduction: [A brief articulation of what tractable challenge(s) or issue(s) the WG will address, how this WG is aligned with the DARE UK mission, and what this WG would deliver as a value-adding output or deliverable to the sensitive data research community]

(1) What is the research case? Why will the output(s) be useful and for whom?

The tractable challenge this Working Group will address is the lack of transparent, standardised measures for the quality of record linkage underpinning the Single Patient Record (SPR). As the Department of Health and Social Care drives toward an integrated, longitudinal SPR, errors in linking disparate data—both false matches (merging unrelated records) and missed matches (splitting the same individual's records)—pose serious risks to privacy, equity and care quality. Aligned with DARE UK's mission to build secure, FAIR, community driven data infrastructures, our forum will codevelop reusable linkage quality metrics, governance frameworks and public facing communication tools. By delivering code libraries, consensus guidance and infographics codesigned with lived experience contributors, we add immediate value to Trusted Research Environments, data stewards and policymakers, accelerating safe SPR rollout while maintaining public trust.

(2) Which specific [DARE UK programmes recommendations](#) is this WG's output(s) supporting to address and how so? If none, please explain why this is the case. *

Our Working Group directly advances four of the seven core Phase 1 recommendations.

- **Demonstrating trustworthiness**
 - *Recommendation:* "Consistently practice proactive transparency about what sensitive data is being used for research, how, why and by whom."
 - *How we address it:* WP2's co-designed infographics, Acceptability Matrix and plain-language briefs openly communicate linkage-quality metrics, risk thresholds and governance arrangements—building public confidence in SPR processes.
- **Core federation services**
 - *Recommendation:* "Establish core federation services that provide essential capabilities for linking and indexing records across Trusted Research Environments."
 - *How we address it:* WP1 delivers the Indexing Service Minimum Viable Products (MVP, through to production readiness), including open codes, runbooks and governance models—realising the federation layer envisioned by Phase 1.

- **Data and discovery**
 - *Recommendation:* “Develop standards for metadata, data provenance and discovery to support scalable, trustworthy linkage.”
 - *How we address it:* WP1’s Quality Assurance & Metadata stream integrates a standardized metadata schema that exposes match confidence, error rates and provenance—enabling programmatic discovery and transparent evaluation of linkage quality.
- **Capability and capacity**
 - *Recommendation:* “Build community skills, tooling and support structures to sustain a national infrastructure.”
 - *How we address it:* Through reusable code libraries, expert and public workshops, Delphi consensus exercises and training materials, we equip TRE operators, analysts and patient advocates with the skills and frameworks needed for ongoing linkage quality management.

The WHAT

- (3) A reasonably detailed description of the intended output(s) that will be delivered through this WG.

Indexing Service MVPs

- MVP 0 & 1 deployments on the Federated Data Platform
- Integrated deduplication algorithms with two additional data sources

Quality Assurance Report & Metadata Schema

- End-to-end QA findings (precision/recall, subgroup equity analysis)
- Machine-readable metadata definitions exposing provenance and quality flags

Public Engagement Deliverables

- **Public Engagement Report** (risk tolerance heatmap, equity risk register)
- Acceptability Matrix mapping error thresholds to public risk preferences
- Infographics and plain language briefs for broad audiences

Open Repository

- Public NHSE organisational GitHub with code, docs and issue tracker

The WHO

- (4) Why is this WG and its proposed members the right group to tackle this?

Proven Track Record: PI JL delivered the UCL-NHSE internship defining initial linkage quality metrics; Co-I GM at NHS England leads the team delivering the national indexing and deduplication services. Co-I LM at ONS leads the linkage quality team solving similar challenges. Co-I KH is a widely recognised field expert in linkage methods, and represents interfaces with academic users of health data. Identified Expert GH has

track record of working with NHSE, and challenging algorithmic biases. Public Co-chair Georgina has rich experience creating public facing documents, leading lay engagement planning and project delivery.

Technical & Methodological Expertise: Core team includes senior data architects, data linkage methodologists and software engineers across multiple national TREs, across government linkers and academic users.

Equity & Public Engagement Leadership: dedicated public cochair(s) ensure lived experience perspectives shape every deliverable; strong commitment and track record of Public Engagement.

(5) Which communities will be involved and what relevant skills/knowledge/experience do they have?

TRE Operators: SAIL Databank, ONS and NHS England engineers—deep knowledge of secure environments, data ingestion and indexing.

Academic Researchers: UCL, HDR UK, ADR UK, UK LLC and ECHILD network experts in statistical linkage, bias analysis and metadata standards.

Patient & Public Advocates: Members of HDR UK PPIE, PEDRI network, to reach out to lived-experience champions to co-designing risk thresholds and communication.

Policy & Standards Bodies: NHS England, DHSC, Government Data Quality Framework representative, aligning outputs with national policy and interoperability requirements.

Technical Community: ITALO list of 40+ linkage specialists—continual feedback loop for tool refinement and broad community buy-in. Close relationship with established ONS Data Linkage Champions, NHS England Data Linkage Hub (led by Co-chair GM).

The HOW and WHEN

(6) What related initiatives/groups/work – not represented through this WG or related IG membership – will the group engage with? Are there other adjacent or relevant WGs this group will coordinate and/or collaborate with?

This WG will also collaborate with International Population Data Linkage Network (IPDLN) and international collaborators & governments using similar approaches to establish national spine for linkage.

This WG will work closely with ADR UK, HDR UK and its initiatives on dataset enrichment, working on timeline, processes and impact of using index service to improve existing linkage pipelines when refreshing health data linkages.

This WG will seek support and collaborate with Public Engagement experts such as PEDRI, HDR UK and ADR UK PAB. We have consulted with lead public engagement leads at both HDR UK and ADR UK.

(7) Describe how often the group will meet and sustain progress between meetings?

Full WG Meetings: 6-8 weeks (1.5 hr) to review progress, unblock issues and make key decisions.

Work Package Subgroups: Every 3-4 weeks (1 hr) to advance technical and public-engagement plans

Steering group – wider ITALO community: Quarterly knowledge sharing and update to wider ITALO community

- (8) A high-level work plan describing intermediate milestones and output(s) that will be developed during the WG's work, and the overall timeframe (max. 12 months) for the WG to deliver the proposed output(s).

Q4 2025 (Oct–Dec):

- *Milestone:* Indexing Service MVP 0 live; Appoint Public co-chair; Workshop 1 planned

Q1 2026 (Jan–Mar):

- *Outputs:* QA report published; Workshop 1 (Risks & Choice) delivered

Q2 2026 (Apr–Jun):

- *Outputs:* Indexing Service MVP 1 released; Workshop 2 (Equity Safeguards) delivered

Q3 2026 (Jul–Sep):

- *Outputs:* Workshop 3 (Co-Design Communication) delivered

Q4 2026 (Oct):

- *Milestone:* Production ready Indexing Service; Public Engagement reports finalised.

- (9) Do the output(s) have potential for adoption by the target beneficiaries articulated in (1)? What is the adoption or implementation plan for WG member organisations? Such adoption or implementation should start before the WG timeframe is complete.

The output is core to the entire delivery of the 10-year health plan and the establishment of a trustworthy SPR. All existing research using linked health data relies on Patient Demographic Service, and the improved indexing service would boost confidence of linkage in future linked studies. Public Engagement on SPR should be picked up by DHSC and government to be repeated on a larger national scale, supplement to consultation carried out by NHS but not fully informed of the technical challenges.

Potential members: [Including a minimum of two proposed chairs and all members who have expressed interest]

FIRST NAME	LAST NAME	EMAIL	(Co-)Chair / Member
Joseph	Lam	Joseph.lam.18@ucl.ac.uk	Co-chair
Katie	Harron	k.harron@ucl.ac.uk	Co-chair
Giulia	Mantovani	Giulia.mantovani1@nhs.net	Co-chair
Leah	Maizey	leah.maizey@ons.gov.uk	Co-chair
Georgina	Ferguson-Glover	georgina.fg@sky.com	Co-chair
Shayda	Kashef	Shayda.Kashef@esrc.ukri.org	Member
Mike	Edwards	michael.edwards@swansea.ac.uk	Member
Richard	Beare	Richard.beare@monash.edu	Member
Ester	Bellavia	ester.bellavia@hdruk.ac.uk	Member

** Note, please do not hesitate to point out gaps in the current DARE UK set of strategic themes and/or recommendations that the programme should consider as it continues to evolve these. Community feedback and input is welcomed.*