

Population Data Science at Swansea University









The Family Justice Data Partnership

Guidance: access, governance, evidence and reporting standards

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Purpose of this document

This document sets out practices and guidance regarding research quality and assurance, utilised by the Family Justice Data Partnership (FJDP) - a collaboration between the universities of Lancaster and Swansea undertaking justice-focused research.

These standards should be adopted by:

- Researchers in the Family Justice Data Partnership (FJDP) project team who are based at Lancaster University and Swansea University;
- All other researchers who access Children and Family Court Advisory and Support Service (CAFCASS England and Wales) data within the Secure Anonymised Information Linkage (SAIL) Databank¹ who receive support from the FJDP.

Overview of family justice administrative data

Administrative data refers to information about persons or organizational activity, which is collected routinely by government, statutory or other agencies for their own organizational purposes.² Public institutions, such as the courts and allied services, typically maintain individual case records that not only contain demographic details, but also details of the individual's interaction with other services. This person-level data is hugely valuable for understanding characteristics of court users, individual pathways through justice systems, legal representation and outcomes of justice involvement. Other data includes information regarding performance produced to meet the requirements of regulatory bodies or external auditors.

The FJDP supports the acquisition and use of family justice data within the SAIL Databank, which has already brought together a wealth of routinely-collected population-scale data on health, education, governmental and social care relating to individuals living in Wales. The addition of family justice data within the SAIL Databank enables increased access to core national family justice administrative data and, for the first time, the potential for rich and novel studies through the individual level record linkage of these data.

SAIL Databank access and governance processes

SAIL project scoping

All researchers and projects wishing to access data in the SAIL Databank have a scoping discussion with a member of the team at Swansea University, and where collaboration via the FJDP is involved please email fidp@swansea.ac.uk. The project idea and viability will be discussed, and a scoping document completed setting out SAIL Databank related activities, data sources required, timescales, resource usage and costs.

¹ Further information on the SAIL Databank standards, terms, policies and procedures can be found at: https://saildatabank.com/

² Woollard, M. (2014) 'Administrative Data: Problems and Benefits. A perspective from the United Kingdom', in Dusa, A. et al. (eds) Facing the future: European research infrastructures for the humanities and social sciences. Berlin: SCIVERO, p. 49

SAIL Information Governance Review Panel (IGRP)

Following scoping, the researcher will need to complete and submit an application to the SAIL Databank, which will be considered by the independent Information Governance Review Panel (IGRP). This panel reviews proposals to ensure they comply with Information Governance principles and represent an appropriate use of data in the public interest. The IGRP includes representatives of professional and regulatory bodies, data providers including those from the NHS and the general public.

Related to methodology, the proposal provides the IGRP with a detailed outline of the aims of the project, data to be used, analysis and dissemination plans.

Once approved by the IGRP, and any data providers who require additional approvals to use their data, all named project users need to provide a copy of the CV, evidence of completion of Safe Researcher Training and complete and sign a user agreement; they will then be granted access to approved data via the SAIL Gateway.

Note, all CAFCASS data held in the Databank are core-restricted and will therefore require permission from the data providers to use them.

Further information on the process of accessing family justice data within the SAIL Databank, and the support that can be provided by the FJDP is available within our User Journey: https://popdatasci.swan.ac.uk/wp-content/uploads/2020/06/User-journey external projects-1.pdf

Population-level data

The SAIL Databank contains extensive anonymised health and administrative data about the population of Wales accessible in anonymised form via a secure data sharing platform, all underpinned by an innovative and proportionate Information Governance model. All data within the SAIL Databank are treated in accordance with the Data Protection Act 2018 and are compliant with the General Data Protection Regulation.

During the anonymisation process of data sources within the SAIL Databank, individuals are assigned an anonymised linking field (ALF) based on their National Health Service number or a combination of their name, sex, date of birth and postcode. This anonymisation and linkage methodology has previously been described. Projects and researchers do not have access to personal identifiable data. ALFs can be used to link data sources within the SAIL Databank - a list of available data sources and metadata can be found at the SAIL Databank website and the innovation gateway:

SAIL Asset Manager https://data.ukserp.ac.uk/Organisation/Index/0

Health Data Gateway https://web.www.healthdatagateway.org

The Children's Social Care and Family Justice Data User Group (Wales)

A social care and family justice data user group for Wales has been established by the FJDP and colleagues at Cardiff University, in close liaison with the Social Care Data User group for England, led by colleagues at the universities of Oxford and UCL. The explicit purpose of the Welsh group

is to support and build capacity among the community of researchers and analysts seeking to use the Cafcass and related social care, health, education and demographic data.

Reporting and publishing research: standards

All FJDP outputs are informed through close collaboration with data providers, practitioners and clinicians. To ensure the integrity and credibility of research, all publications should make transparent the methodology and any study limitations. Given increasing commitment to dual publication and the need to make research available for academic, professional, policy and lay users, it will be necessary to adapt methodological description for specific purposes. FJDP reports are all peer reviewed by other academics in the field and policy/practice experts and shared with CAFCASS prior to publication. Where FJDP publishes research in scientific journals, team members adhere to individual journal publication policies and peer review processes.

Advice is set out below for policy reports and academic journal articles, including authorship policy.

For reports

Accessible reports and briefing papers should contain an abridged version of methods but must make clear all project approvals (ethics and governance), project objectives, all data sources, data quality issues, all definitions and measures, methods of analysis and any limitations thereof, peer review process. A supporting technical appendix is a useful way of providing supplementary material.

For journal articles

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)² statement provides a checklist of recommended items to be included in observational studies, pertaining to the article title and abstract, introduction, methods, results, discussion and other information.

The REporting of studies Conducted using Observational Routinely collected Data (RECORD)³ statement should also be consulted, which addresses specific reporting issues relevant to research using routinely collected health data.

The UK Statistics Authority has also published a useful Toolkit (2019) for working with Administrative Data, to include guidance on quality appraisal and liaison with data providers;

https://osr.statisticsauthority.gov.uk/wp-content/uploads/2019/02/qualityassurancetoolkit updated Feb19 2.pdf

The Administrative Data Research Partnership also publishes a wealth of resources: https://www.adruk.org

General publication guidance and authorship policy is set out below:

Authors must:

• Demonstrate that the work has been have formally approved by relevant ethical committees or set out reasons why this is not the case;

- Submit work that is original unpublished work and not being submitted for publication elsewhere;
- Provide written permissions regarding the use of tables or images or extensive quotes, not produced by the authors;
- Ensure that there is nothing libellous;
- Ensure that work does not infringe on any rights of others, including privacy rights and intellectual property rights;
- Any real or apparent conflicting or competing interest is clearly stated on submission of material (this would include funding assistance);
- Acknowledge any limitations inherent in the use of admin data.³
- Contact the FJDP team to identify and correct any material errors upon discovery, whether prior or subsequent to publication of their work.

Acknowledgements / authorship

- Authors must acknowledge any work by others that has contributed to the research/analysis / reporting.
- Authorship should correspond to existing policy (of the FJDP or other organisations).
 Authorship on scientific papers should meet journal criteria; see, for example, International Committee of Medical Journal Editors guidelines.⁴
- Funders should also be acknowledged.

For FJDP researchers, acknowledgements should be as follows:

Nuffield Family Justice Observatory (Nuffield FJO) aims to support the best possible decisions for children by improving the use of data and research evidence in the family justice system in England and Wales. Covering both public and private law, Nuffield FJO provides accessible analysis and research for professionals working in the family courts.

Nuffield FJO was established by the Nuffield Foundation, an independent charitable trust with a mission to advance social well-being. The Foundation funds research that informs social policy, primarily in education, welfare, and justice. It also funds student programmes for young people to develop skills and confidence in quantitative and scientific methods. The Nuffield Foundation is the founder and co-funder of the Ada Lovelace Institute and the Nuffield Council on Bioethics.

Nuffield FJO has funded this project (FJO/43766), but the views expressed are those of the authors and not necessarily those of Nuffield FJO or the Foundation.

For all other researchers supported by the FJDP:

This work was supported by the Family Justice Data Partnership, a collaboration between Lancaster and Swansea University with Cafcass and Cafcass Cymru as integral stakeholders. It is funded by the Nuffield Family Justice Observatory and provides the NFJO with ground-breaking analysis about the family justice system.

• SAIL acknowledgements:

³ Johnson RD, Ford D V, Broadhurst K, et al. Data Resource: population level family justice administrative data with opportunities for data linkage. Int J Popul Data Sci 2020; 9: 1339

"This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) Databank. We would like to acknowledge all the data providers who make anonymised data available for research." Publications should also cite the relevant primary SAIL publications:

- Ford DV, Jones KH, Verplancke JP, Lyons RA, John G, Brown G, Brooks CJ, Thompson S, Bodger O, Couch T, Leake K. The SAIL Databank: building a national architecture for ehealth research and evaluation. BMC Health Services Research 2009;9:157 http://www.biomedcentral.com/1472-6963/9/157
- Lyons RA, Jones KH, John G, Brooks CJ, Verplancke JP, Ford DV, Brown G, Leake K. The SAIL databank: linking multiple health and social care datasets. BMC Medical Informatics and Decision Making 2009; 9:3. http://www.biomedcentral.com/1472-6947/9/3
- Jones KH, Ford DV, Jones C, D'Silva R, Thompson S, Brooks CJ, Heaven ML, Thayer DS, McNerney CL and Lyons RA. A case study of the Secure Anonymous Information Linkage (SAIL) Gateway: a privacy-protecting remote access system for health-related research and evaluation, Journal of Biomedical Informatics: special issue on medical data privacy (August 2014) http://dx.doi.org/10.1016/j.jbi.2014.01.003
- Jones KH, Ford DV, Thompson S and Lyons RA (2019) A Profile of the SAIL Databank on the UK Secure Research Platform. IJPDS, 2:4, doi: https://doi.org/10.23889/ijpds.v4i2.1134

If completing RALF/Geographic based research:

- Rodgers, S.E., Demmler J., Dsilva R., Lyons R. Health and Place. 28 Sept 2011, Protecting health data privacy while using residence-based environment and demographic data. Health and Place doi: 10.1016/j.healthplace.2011.09.006
- Rodgers SE, Lyons RA, Dsilva R, Jones KH, Brooks CJ, Ford DV, John G, Verplancke JP. Residential Anonymous Linking Fields (RALFs): a novel information infrastructure to study the interaction between the environment and individuals' health. Journal of Public Health (Oxf). Dec 31 (4): 582-588, 2009.

Mitigating risk of disclosure in all outputs

Products of data analyses (such as tables, graphs and other statistical outputs) must be submitted via the SAIL disclosure control process known as "data out" which requires two SAIL disclosure control team reviewers to review and approve the request based on the DEA (Digital Economy Act) approved process. In the case that these two reviewers disagree, a third reviewer from the SAIL senior analyst group will also review and consider. Following review and consideration, all successful requests will be extracted from the privacy protecting SAIL Gateway environment for use in publications, reports and related outputs. All outputs are reviewed to ensure they meet the disclosure control requirements, i.e., do not contain small numbers or inadvertently disclose identifying information.

Dissemination

A copy of all reports, briefing papers, journal articles, and other outputs produced by the FJDP, or supported by the FJDP, should be sent to Jane Huddleston (Project Officer, FJDP) j.huddleston5@lancaster.ac.uk.

References

1. Jones KH, Ford DV, Thompson S and Lyons RA (2019) A Profile of the SAIL Databank on the UK Secure Research Platform. IJPDS, 2:4, doi: https://doi.org/10.23889/ijpds.v4i2.1134

- 2. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP; STROBE Initiative. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. Int J Surg. 2014 Dec;12(12):1495-9.
- 3. Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM; RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) statement. PLoS Med. 2015 Oct 6;12(10):e1001885.
- 4. International Committee of Medical Journal Editors (ICMJE) see http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html