Guideline:

Privacy Preserving Record Linkage (PPRL) at the Department of Health

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1. Background

The Information and System Performance Directorate (ISPD) with the support of the Office for Medical Research and Innovation (OMRI) from the Department of Health (the Department) have embarked on an extensive program of reform to modernise, simplify, and improve the customer experience with linked data access, aligning directly with recommendations from the 2016 Review of Western Australia's Data Linkage Capabilities and the Sustainable Health Review 2019 (SHR).

Based on these reviews, the WA Health Data Linkage Strategy 2022-2024 (the Strategy) was developed within the Data Linkage Strategy and Reform Program to reform and innovate the process for the provision of linked data in WA. As part of the Strategy, the Department is collaborating with Curtin University's Centre for Data Linkage (CDL) to progress several proof-of-concept (POC) projects to evaluate the feasibility of implementing Privacy Preserving Record Linkage (PPRL). The aim is to combine information from different sources safely and effectively, aligning with Recommendation 21 of the SHR report. The project meets the requirements of two strategic themes of the Strategy, 'Efficiency and Effectiveness' and 'Compliance'.

To facilitate this process, a Memorandum of Understanding (MoU) between the Department and CDL was signed in January 2022 to support the collaboration in relation to a variety of data driven initiatives to enable delivery of timely and more expansive data linkage services for both government agencies and research communities. This collaboration was the subject of a joint media announcement released on 19 May 2022, developed by the Department and Curtin University to highlight the privacy preserving methods and the safe and effective approach to integrate data from different sources.

There are instances where legislative barriers and other limitations prohibit the sharing of identifiable data for ordinary probabilistic data linkage by the Department or external third-party linkage agencies. For instance, the *Children's Court of Western Australia Act 1988* (WA) restricts the release of personally identifiable and other sensitive information from the Department of Justice. In this instance, the collaborative and joint PPRL is being leveraged to support data linkage, which is necessary for incorporating Department of Justice datasets into the whole-of-government initiative, People WA, prior to legislative enablement.

Currently, WA does not have local privacy laws in place. However, the Department of the Premier and Cabinet, in collaboration with WA public sector agencies, is in the process of drafting Privacy and Responsible Information Sharing (PRIS) legislation to address these restrictions. The PPRL method acts as an interim solution for data providers who have concerns about privacy and security. PPRL enables effective sharing and integration of data to support government service delivery, research, and other initiatives.

By facilitating local, multi and cross-jurisdictional linkage projects, the PPRL method aims to improve health outcomes at both the state and national level while adhering to the Australian Privacy Principles. The Department maintains a strong commitment to protecting information from misuse or inappropriate disclosure.

As PPRL is a relatively recent method for the Department, the projects listed below are currently being progressed as a POC:

- "Understanding the incidence, prevalence, and rates of progression of chronic kidney disease in Western Australia".

- "Privacy Preserving Record Linkage for Western Australian Birth Defects and Australian Pharmaceutical Benefits Scheme Claims Data".

- "Using data linkage to integrate primary and secondary data across the continuum of care to support population health planning and clinical management of chronic disease in WA".

Traditional probabilistic linkage methods which utilise full unencrypted personal identifiers is still the preferred linkage method at the Department. However, linkage quality is not compromised

with the PPRL method in comparison the traditional linkage method.[1, 2]

2. Purpose

The purpose of this document is to inform stakeholders about the proof-of-concept projects undertaken to evaluate the feasibility of using PPRL to integrate information, and to illustrate the various processes and roles involved within the Department to securely link information that is subject to legislative and policy restrictions, or security concerns.

3. Proof-of-Concept using PPRL

The Department collaborated with CDL on three POC projects. These projects aimed to assess the feasibility of advancing research projects that require PPRL. PPRL was selected as the preferred linkage method to overcome legislative, policy restrictions, and security concerns posed by external data providers.

The POC projects were conducted from June 2022 to June 2023 to determine if PPRL was viable and could be transitioned into a standard data service offered by the Department. The insights and processes gained from these projects were used to develop Standard Operating Procedures, enabling the Department to provide this service in conjunction with CDL. CDL's capability for PPRL originated from research into advanced record linkage methods that haves been directly translated into the LinXmart linkage software[3]. All POC projects were linked using LinXmart.

POC 1: Understanding the incidence, prevalence and rates of progression of chronic kidney disease (CKD) in Western Australia.

This research project required data that were not readily available within the Department and involved obtaining data from PathWest and other private pathology providers, including Clinipath, Australian Clinical Labs, and Western Diagnostic. As the Department does not have an agreement to receive private pathology datasets, PPRL was adopted as the method of choice, with CDL serving as the linkage unit.

The insights gained from this project are invaluable in understanding the incidence, prevalence, and progression rates of CKD in WA. This will lead to a better understanding of the individual and societal burden of CKD in WA, contributing to more effective service planning and improved surveillance guidelines.

POC 2: Privacy Preserving Record Linkage for Western Australian Birth Defects and Australian Pharmaceutical Benefits Scheme Claims Data.

The undertaking of this research project required data from the Australian Institute of Health and Welfare (AIHW); Medicare Benefits Scheme (MBS) and National Death Index. Lack of privacy law in WA inhibits the Department from receiving personal and/or sensitive Commonwealth data for data linkage enabling research. To mitigate this issue, PPRL was opted as the linking method of choice.

The aim of this research project was to examine medication prescriptions during pregnancy and offer medical practitioners' guidance on monitoring medicine exposure in pregnant women. The findings and insights gained from this study can be applied to other states, fostering improved healthcare outcomes.

POC 3: Using data linkage to integrate primary and secondary data across the continuum of care to support population health planning and clinical management of chronic disease in WA.

[1] Randall, S. M., Ferrante, A. M., Boyd, J. H., Bauer, J. K., & Semmens, J. B. (2014). Privacy-preserving record linkage on large real world datasets. *Journal of biomedical informatics*, 50, 205-212.

[2] Randall, S., Wichmann, H., Brown, A., Boyd, J., Eitenhuber, T., Merchant, A., Ferrante, A. (2021) A blinded evaluation of privacy preserving record linkage with Bloom filters. *BMC Medical Research Methodology*

[3] Boyd, J. H., Randall, S., Brown, A. P., Maller, M., Botes, D., Gillies, M., & Ferrante, A. (2020). Population Data Centre Profiles: Centre for Data Linkage. *International Journal of Population Data Science*, 4(2).

This study required linkage of datasets from General Practitioner (GP) clinics and pathology with secondary care data to explore three chronic diseases: chronic obstructive pulmonary disease (COPD), diabetes type 2, and heart failure. At present, the Department does not have readily available access to PathWest data as a collection. Access to external data from private entities such as GP clinics, Silverchain, and other private providers is hindered by legislative and other perceived barriers, including considerations of patient consent and privacy. Hence, PPRL was employed as the method of choice to link these datasets.

The resulting linked information was evaluated for its usefulness in clinical management to help reduce potentially preventable hospitalisations in line with Australia's national health priorities. The benefits of integrating primary and secondary data throughout the continuum of care to support clinical management in Western Australia will be captured as part of this study.

4. Implementation of PPRL

To implement PPRL, the following measures were introduced by the Department:

Project Management Tool
The Department utilises Wrike as a project management tool to oversee the different stages of the data delivery pipeline. A new master template has been created specifically for the PPRL data delivery pipeline, incorporating the additional steps required for this linkage method.

Application Form
The Department has developed a new application form tailored for PPRL projects.

External Data Checklist
As part of the process, all external data providers must complete a checklist (Appendix 2) to ensure that the provided data aligns with the project's specifications before being encrypted and linked using PPRL. The third-party linkage agencies that will be facilitating PPRL will distribute this form to the relevant data providers as part of the ordinary workflow.

Standard Operating Procedures (SOP)
To streamline PPRL as a regular service within the Department, two SOPs have been established.

The first SOP focuses on the extraction of data for PPRL projects, outlining unique variations and dependencies specific to the PPRL process and presenting different approaches to data delivery for PPRL projects.

The second SOP documents the process of data hashing and generation of hashing keys using LinXmart, a client tool provided by the third-party linkage agencies that will be facilitating PPRL.

Information Sharing Agreement (ISA)
The Department has developed an ISA to sit alongside the previously signed MoU with Curtin University on 12 January 2022 and govern data sharing between the Department and CDL for PPRL. This fully executed ISA will facilitate sharing of information with a shared goal to maximise the value of information as an asset to improve service delivery and benefit the WA community, while protecting information from being misused or inappropriately disclosed.

The ISA aims to optimise the value, quality, and security of information, ensure compliance with applicable laws and regulations, minimise misuse and inappropriate disclosure of information, promote appropriate governance mechanisms, and foster information integrity. Schedule 2, which includes the Information Request Form, will be completed on a project-by-project basis by the Department's Client Services branch, regardless of the PPRL third-party provider.

Utilisation of Separation Principle
All stakeholders will adhere to best practice protocols, including the separation principle, to safeguard the privacy of individuals whose personal information is used or disclosed. CDL as one of the third-party PPRL service provider implements this principle by keeping encoded identifiers separate from content data (i.e., event-level service information connected to an individual's record) and maintaining

equivalent security and governance processes for encoded and un-encoded data. Once the third-party PPRL provider completes the PPRL, a linkage map is sent directly to the Department's Engineering - Data Outputs branch.

The CDL as a third-party PPRL provider operates an information security management system certified within the requirements of ISO/IEC 27001:2013. CDL operates in a physically secure environment and maintains strict access controls when handling data, including receiving data extracts or hashed data. CDL receives hashed data from external data providers and the Department's data linkage department. Please refer to Appendix 1 for further details on the processes captured within a flowchart.

5. Roles and Responsibilities

Collaboration among the applicant, third-party linkage agencies that will be facilitating PPRL, and the Department is necessary to advance a project using PPRL. If a project necessitates the use of PPRL for linkage, it will go through the standard application process at the Department as laid out within the Research Data Services Roles and Responsibilities guide.

Research projects require involvement of several stakeholders, including the applicant, ISPD Client Services, Data Custodians, Research Governance Office (RGO), Data Engineers, and ethical bodies. If PPRL is employed for a project, there will be a deviation from the standard pipeline to allow for third-party linkage agencies that will be facilitating PPRL involvement in the pipeline.

Stage 1: Pre-Application		
Step	**Party**	**Task**
1.1	Applicant	Contact ISPD Client Services regarding data and application requirements
1.2	ISPD Client Services	Provide advice to applicant (as required); seeking feedback from Data Custodians on data queries and the Data Linkage and Data Engineering teams regarding the technical viability (if needed)
1.3	Applicant	Contact RGO to determine the project's viability and application requirements in terms of governance and ethics
1.3.1	RGO	Provide advice to applicant on ethical and governance requirements
1.4	Applicant	Submit draft data application to ISPD Client Services via email for a preliminary review
1.4.1	MILESTONE	DRAFT APPLICATION SUBMITTED

Stage 2: Preliminary Review		
Step	**Party**	**Task**
2.1	ISPD Client Services	Administrative processing
2.1.1	ISPD Client Services	Contact third-party linkage agencies that will be facilitating PPRL to advise that a research application has been received that requires PPRL and is currently being reviewed
2.2	Applicant	Apply for a login to the Research Governance Service (RGS) system to commence ethics and research governance process. Complete the New User Sign Up form and submit to the RGS Administrator for approval. If applicant is not a WA Health employee, they will also need to provide a WA Health employee as a referee / Local Contact in the form to verify the user login request (this can be the relevant ISPD Client Services Request Coordinator)
2.2.1	RGS Administrator	If the applicant is not a WA Health employee, the RGS Administrator will contact the WA Health employee who's been nominated as the local contact to verify the applicant's identity and confirm the applicant requires access to the RGS
2.2.1.1	ISPD Client Services	If applicable, verify the user login request
2.3	RGS Administrator	Approve user (applicant) request for access
2.4	Applicant	Create a project workspace in RGS
2.5	RGS Administrator	Approve the project workspace in RGS
2.6	ISPD Client Services	Conduct a preliminary review of the draft data application to ensure completeness, and assign a priority to the project in accordance with the Data Linkage Prioritisation and Costing Framework
2.7	ISPD Client Services	Collate feedback and send to applicant
2.8	Applicant	Review feedback, action necessary changes and resubmit draft data application (as required)

2.9	ISPD Client Services	Additional preliminary review of draft data application (as required). If feedback is adequately addressed, project is added to the agenda for the next available draft data application review meeting
2.10	ISPD Client Services	Administrative processing and send the draft data application to Data Custodians for review ahead of the Draft Data Application Review meeting
2.11	ISPD Client Services	Create data flow diagram specific to the project

Stage 3: Data Custodian Feasibility Assessment		
Step	Party	**Task**
3.1	Data Custodians, Data Linkage, Data Engineering, third-party linkage agencies that will be facilitating PPRL & RGO	Review draft application for technical feasibility and against data use and disclosure requirements, including relevant legislation, data sharing agreement and policy frameworks which apply to the data asset in question, and conduct technical feasibility; provide feedback, recommendations and/or comments for the applicant in preparation for the Draft Data Application Review meeting (as necessary)
3.2	MILESTONE	DRAFT APPLICATION REVIEW MEETING
3.3	ISPD Client Services	Provide the applicant with consolidated feedback from Data Custodians, Data Linkage, Data Engineering and third-party linkage agencies that will be facilitating PPRL
3.3.1	Applicant	Review feedback provided by ISPD Client Services and resubmit revised draft data application (this is an iterative process which may require multiple reviews)
3.3.2	ISPD Client Services	Process and check revised draft data application, before providing to relevant Data Custodians for additional review (as required)
3.3.3	ISPD Client Services	Coordinates technical feasibility review between third-party linkage agencies that will be facilitating PPRL, Data Linkage and Data Engineering - Data Outputs. Provide the PPRL data checklist for third-party linkage agencies that will be facilitating PPRL to circulate to external data providers
3.4	MILESTONE	DATA CUSTODIAN IN-PRINCIPLE SUPPORT
3.4.1	Data Custodians	Once satisfied that feedback has been addressed, advise ISPD Client Services of "in-principle support"
3.5	ISPD Client Services	Calculate cost estimate for Department services only in accordance with the Data Linkage Prioritisation and Costing Framework
3.5.1	ISPD Client Services	Inform third-party linkage agencies that will be facilitating PPRL cost estimate is being calculated and will be provided to applicant directly
3.5.2	Third-party linkage agencies that will be facilitating PPRL	Third-party linkage agencies that will be facilitating PPRL to calculate the cost estimate for PPRL services only and provide the cost estimate and details of how to accept it directly to the applicant.
3.6	ISPD Client Services	Prepare feasibility letter confirming "in-principle support" from Data Custodians to enable applicant to proceed to the Department's HREC review (ethics application)
3.6.1	ISPD Client Services	Provide cost estimate and feasibility letter to the applicant confirming "in-principle support" from Data Custodians for project to proceed ethics application for the relevant HREC review (cc the Department's HREC). Include the latest data application form and data management plan in the email NB: Inform the applicant that third-party linkage agencies that will be facilitating PPRL will be providing a separate cost estimate for the PPRL services
3.6.2	Applicant	Upload final data application form, data management plan, variable lists, extraction forms and feasibility letter into RGS

		Stage 4: Ethical Approval
Step	Party	Task
4.1	Applicant	Contact RGO and inquire on all required ethical approvals as well as clarifications on whether a Data Transfer Agreement (DTA), an 'Access request Form', or 'Site Specific Assessment Form' are required for the project
4.2	Applicant	Submit ethics application and the final approved data application documents to the Department's HREC for review and approval via RGS
4.3	Ethics Executive Officer	Review ethics application to ensure completeness and validity, requesting further information from applicant if required
4.3.1	Ethics Executive Officer	If feedback is adequately addressed, project is added to the agenda for the Department's next available HREC meeting
4.4	The Department's HREC	Participate in the Department's monthly HREC meeting to discuss and review research ethics application
4.4.1	Applicant	If a significant amendment to the ethics application is required following ethical review, the applicant may have to revert to Stage 3 and resubmit draft data application
4.4.2	Applicant	If application requires minor amendments, the applicant can amend ethics application and resubmit for ethical approval (Step 4.1)
4.5	Other HRECs	If applicable, the applicant must submit an additional ethics application to other HRECs for review and approval
4.5.1	Applicant	If a significant amendment to the ethics application is required following ethical review, the applicant may have to revert to Stage 3 and resubmit data application
4.5.2	Applicant	If application requires minor amendments, the applicant can amend ethics application and resubmit for ethical approval (Step 4.4)
4.6	MILESTONE	ETHICS APPROVAL GRANTED
4.6.1	Ethics Executive Officer	Provide letter to the applicant confirming ethical approval via RGS within five (5) working days of the Department's HREC meeting
4.6.2	Other HRECs	If applicable, provide letter to the applicant confirming ethical approval
4.6.3	Applicant	Upload other HREC approval letter/s (if applicable) via RGS

		Stage 5: Data Custodian Formal Review
Step	Party	Task
5.1	The Department's HREC	Notify applicant of ethical approval via email with the following attachments: • Data application that was approved by HREC • HREC approval letter
5.1.1	Applicant	Applicant to notify ISPD Client Services of ethical approval.
5.2	ISPD Client Services	Cross-reference the HREC-approved data application against the IPS application to identify any significant changes
5.3	ISPD Client Services	Request formal Data Custodian approval from all Data Custodians/Stewards
5.3.1	ISPD Client Services	Advise the relevant Data Custodians of any significant changes to the application between IPS and HREC approval
5.3.2	ISPD Client Services	Advise third-party linkage agencies that will be facilitating PPRL of any technical changes or variations to the proposal that was made during the HREC process.

5.4	Data Custodians	After HREC approval(s) are finalised and all relevant criteria satisfied, review the HREC-approved data application forms and provide formal Data Custodian approval
5.5	MILESTONE	DATA CUSTODIANS' FORMAL APPROVAL GRANTED
5.5.1	ISPD Client Services	Notify applicant that formal approval has been granted, including advice to engage with RGO regarding research governance approval application requirements, and to add ISPD Client Services Request Coordinator as 'Data Custodian' on the Access Request Form or Site-Specific Assessment Form and Budget Form as applicable
5.5.2	ISPD Client Services	Contact third-party linkage agencies that will be facilitating PPRL to ensure Information Sharing Agreement (ISA) Schedule 2 is completed before hashed data is passed on to third-party linkage agencies that will be facilitating PPRL. Schedule 2 of the ISA will be completed on a project-by-project basis.
5.5.3	Third-party linkage agencies that will be facilitating PPRL	Start contractual agreement with Applicant to deliver PPRL service.
Stage 6: Governance Approvals		
Step	**Party**	**Task**
6.1	Applicant	Ensure all ethic approval letter/s (if applicable) have been uploaded into RGS
6.2	Applicant	Liaise with RGO to complete the draft DTA (if the applicant is external to the WA Health [4] system). DTA template can be obtained from RGO
6.3	Applicant	After being advised of Data Custodian formal approval, submit the DTA (if applicable) and relevant site authorisation form via RGS, and add the relevant Request Coordinator as the "Data Custodian" (if applicable)
6.3.1	ISPD Client Services	Approve the applicant's Access Request Form submission (if applicable) to trigger RGO review, and upload Data Custodian Approval for Research Project document via RGS
6.4	Applicant	Project Principal Investigator to sign the Access Request, Site Authorisation, and Budget form(s) and complete the submission to the Department's RGO via RGS.
6.5	RGO	Review DTA (if applicable) and request further information from the applicant (as required)
6.5.1	LLS/ICWA	Significant changes to a DTA (if required) are referred to Legal and Legislative Services (LLS) and/or the Insurance Commission of Western Australia (ICWA) for review and/or advice as appropriate
6.6	RGO	If the project requires a DTA, prepare a Briefing Note for approval by the delegated authority.
6.7	Director, Information and Performance Governance (IPG)	Reviews and approves the DTA
6.8	RGO & Applicant	Complete site authorisation process within 60 days of receiving request from applicant, notwithstanding time taken for feedback and requests for further information
6.9	RGO	Write a recommendation to the DDG (or delegate, if appropriate) that

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[4] WA Health – per s19 of the Health Services Act 2016, the WA Health System is comprised of:
(a) the Department; and
(b) health service providers; and
(c) to the extent that contracted health entities provide health services to the State, the contracted health entities.

		they consider providing site authorisation for the project and for data to be released
6.10	DDG (or delegate)	Use RGS to indicate if site authorisation is (or is not) granted for the project.
6.11	MILESTONE	GOVERNANCE APPROVED
6.11.1	RGO	Provide finalised DTA (if applicable) and letter to the applicant confirming site authorisation via RGS
6.11.2	RGO	Notify ISPD Client Services of research governance approval and provide a copy of site authorisation via email

Stage 7: Data Linkage		
Note this stage only applies to applications for linked data. Applications for unlinked data may progress to Stage 8: Data Extraction.		
Step	**Party**	**Task**
7.1	ISPD Client Services	Prepare for project kick-off, and schedule data linkage and extraction work in project queue
7.2	Data Linkage, ISPD Client Services & Data Engineering	Evaluate request and project requirements with support from ISPD Client Services and Data Engineering as required.
7.3	Data Linkage	Provision of ad-hoc data from datasets for project-specific linkage (if applicable)
7.4	Data Linkage, ISPD Client Services & Data Engineering	Linkage project planning meeting
7.5	Data Linkage and/or Data Engineering	Perform cohort selection (if applicable)
7.6	Data Linkage	Generate hashing key and provide to external data provider(s)
7.7	Data Linkage	Perform extraction and hashing of data before sending to third-party linkage agencies that will be facilitating PPRL NB: This task is performed within the WA Data Linkage System managed by the Department
7.8	Data Linkage	Send hashed Data to third-party linkage agencies that will be facilitating PPRL and notify ISPD Client Services that hashed data has been sent.
7.9	Third-party linkage agencies that will be facilitating PPRL	Perform PPRL Linkage NB: CDL as the third-party agency providing PPRL services confirm to ISPD CS if applicant has signed the contract and PPRL work can be performed.
7.10	ISPD Client Services	Provide a project status update to the applicant via email
7.11	Data Linkage	File all linkage-related project email correspondence as per standard recordkeeping process

Stage 8: Data Extraction		
Step	**Party**	**Task**
8.1	Data Engineering, Data Linkage & ISPD Client Services	Project planning meeting for clarification of data request
8.1.1	Third-party linkage agencies that will be facilitating PPRL	Provide mapping file and README document to Data Engineering
8.1.2	Third-party linkage agencies that will be facilitating PPRL	Email to Data Outputs and ISPD Client Services to confirm that the data has been sent
8.2	Data Engineering	Data extraction of requested datasets NB: The Data Extraction function held by the Department is related to Health Datasets only.
8.3	Data Engineering	Merging of data (if required)
8.4	MILESTONE	LINKAGE AND EXTRACTION COMPLETE
8.4.1	ISPD Client Services	Provide a project status update to the applicant via email
8.5	Data Engineering, Data Linkage & ISPD	Quality assurance project planning meeting

	Client Services	
8.6	Data Engineering	Quality assurance review
8.6.1	ISPD Client Services	Administrative processing

Stage 9: Data Delivery		
Step	**Party**	**Task**
9.1	Data Engineering	Provide data extractions to ISPD Client Services
9.1.1	Data Engineering	Include mapping file provided by third-party linkage agencies that will be facilitating PPRL with the final data extract.
9.2	ISPD Client Services	Prepare data for delivery to applicant, including encryption of the data
9.3	ISPD Client Services	When all required approvals are complete and the approved recipient has confirmed contact details, release data to the recipient via MyFT or an e-Research platform
9.4	MILESTONE	DATA DELIVERED
9.4.1	Applicant	Receive data via secure online file transfer or access data via an e-Research platform once all documents have been approved

Stage 10: Invoicing		
Step	**Party**	**Task**
10.1	ISPD Client Services	Calculate the final cost to charge the applicant (if applicable) NB: This task is restricted to Department of Health services only.
10.1.1	ISPD Client Services	Investigate any significant changes from the cost estimate
10.2	ISPD Client Services	Send final cost to applicant with explanation for any significant variances from initial cost estimate via email (if applicable)
10.2.1	Third-party linkage agencies that will be facilitating PPRL	Provide separate Final invoice to applicant as per agreement with third-party linkage agencies that will be facilitating PPRL (see point 3.5.2)
10.3	Applicant	Review and confirm final cost, and provide Purchase Order number if relevant
10.4	ISPD Client Services	Prepare S60 Debtor Advice Form for progression to Department's Accounts Receivable team to generate invoice
10.5	Accounts Receivable	Issue invoice to applicant's designated contact
10.6	Applicant	Pay invoice within designated timeframe
10.7	ISPD Client Services	On a quarterly basis, collate a list of all projects awaiting payment confirmation, and provide to Accounts Receivable via email to confirm payment has been received
10.8	Accounts Receivable	Respond to ISPD Client Services, confirming whether payment has been received from each applicant in the list
10.8.1	ISPD Client Services	If payment hasn't been received, follow up with the applicant

Stage 11: Project Closure		
Step	**Party**	**Task**
11.1	RGO	Site-specific monitoring of the conduct of research projects, to ensure that projects RGO authorise are conducted with integrity and in compliance with relevant procedural requirements
11.2	Applicant	Provide annual progress reports to the Department's HREC via RGS or as per the HREC's conditions of approval

11.2.1	The Department's HREC	Monitor the applicant's research to ensure approved projects are conducted ethically in adherence with relevant conditions
11.3	Applicant	Submit Site Final Report to RGO via RGS after the completion of the project analysis
11.3.1	RGO	Validate, review, and authorise/approve the Site Final Report submitted by the applicant via RGS
11.4	Applicant	Upon approval of Site Final report, submit Project Final Report via RGS
11.4.1	The Department's HREC	Validate, review, and authorise/approve the Project Final Report submitted by the applicant via RGS
11.5	ISPD Client Services	Send Client Feedback Survey to applicant to assess the quality of services provided by the Department
11.6	Applicant	Provide a copy of project draft outputs (study article, etc.) to ISPD Client Services via email for review prior to publication
11.7	ISPD Client Services & Data Custodians (if applicable)	Coordinate review of project draft outputs and complete Draft Output Review Checklist. ISPD Client Services to liaise with Data Custodians (if applicable) to review project draft outputs.
11.7.1	ISPD Client Services	If the applicant has requested to publish small cell counts in their output(s), submit the output(s) to the Department's HREC for review in the monthly meeting.
11.7.2	The Department's HREC	If applicable, review draft output(s) in the monthly HREC meeting and provide outcomes to ISPD Client Services.
11.8	ISPD Client Services	Provide feedback to the applicant regarding publication of project outputs
11.9	Applicant	Provide a copy of project outputs (study article, etc.) to ISPD Client Services after publication
11.10	All (excl. applicant)	Ensure all project records are saved into the Electronic Document and Records Management System (TRIM) in adherence to the *State Records Act 2000*
11.11	ISPD Client Services	Liaise with third-party linkage agencies that facilitated PPRL to seek review of outputs or publications from the project.

7. References

Legislation and Regulations

- *State Record Act 2000* (WA): Retention Period of a record and definition of a state record: a parliamentary record or a government record.

- *Health Services Act 2016* (WA) and *Health Services (Information) Regulations 2017* (WA)

- *Freedom of Information Act 1992* (WA)

Policies and Procedures

- See Department of Health WA, Information Management Policy Framework

- All Data Applicants must read and adhere to the Practice Code for the Use of Personal Health Information.

- Additional assistance on writing security plans can be found at the Department of Health WA's HREC website.

- See Department of Health, Research Governance Policy

Guidance Documents

- Research Data Services Roles and Responsibilities Guideline

8. Acronyms and Definitions

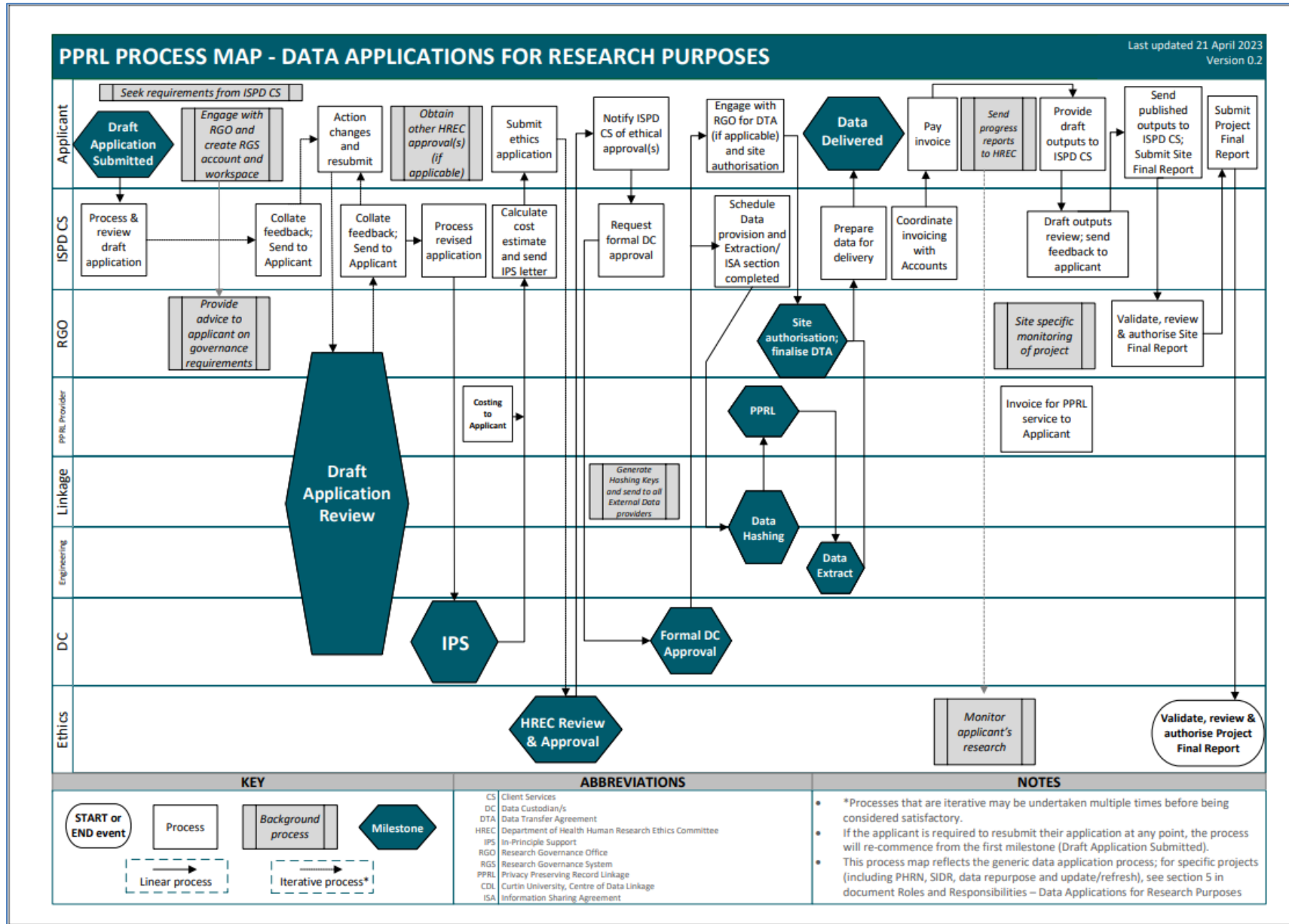| Acronyms	
AIHW	Australian Institute of Health and Welfare
BAU	Business-as-usual
CDL	Curtin University Centre of Data Linkage
CKD	Chronic kidney disease
COPD	Chronic obstructive pulmonary disease
The Department	Department of Health WA
DTA	Data Transfer Agreement
EDDC	Emergency Department Data Collection
EDRMS	Electronic Documents and Record Management System
GP	General Practitioner
HMDC	Hospital Morbidity Data Collection
HREC	Human Research Ethics Committee
ICWA	Insurance Commission of Western Australia
IPG	Information Policy and Governance Unit, Department of Health WA
IPS	In-principle support
IRA	Information Release Agreement
ISA	Information Sharing Agreement

ISPD	Information and System Performance Directorate, Department of Health WA
ISA	Information Sharing Agreement
LLS	Legal and Legislative Services, Department of Health WA
MBS	Medicare Benefits Scheme
MNS	Midwives Notifications System
MoU	Memorandum of Understanding
OMRI	Office for Medical Research and Innovation, Department of Health WA
PII	Personally Identifiable Information
PPRL	Privacy Preserving Record Linkage
POC	Proof-of-concept
PRIS	Privacy and Responsible Information Sharing
RGO	Research Governance Office, Department of Health WA
RGS	Research Governance Service
SOP	Standard Operating Procedure
SHR	Sustainable Health Review 2019
WA	Western Australia
WARDA BD	WA Registry for Developmental Anomaly Birth Defects

Definitions	
Bloom filter	Bloom filter is a space-efficient probabilistic data structure that is used to test whether an element is a member of a set. It is a hardening method involving modifications of bit-arrays representing identifiers to make attacks more difficult
Cohort	A collection of people who share an experience or characteristic over time and is often applied as a method of defining a population for the purpose of research.
Data	The term 'data' generally refers to unprocessed numbers, facts or statistics, while the term 'information' refers to data that has been processed in such a way as to be meaningful to the person who receives it. The terms 'data' and 'information' are often used interchangeably and should be taken to mean both data and information
External Data Providers	Data providers located outside of the Department of Health WA
Hashed Data	In cryptography, hashing is a process that allows you to take data of any size and apply a mathematical process to it that creates an output that's a unique string of characters and numbers of the same length. The hashing process is virtually irreversible, which means that hashing is a one-way cryptographic function.
Linkage Map	A Linkage Map groups together records for individuals from the WA population based on common Linkage IDs.

Personally Identifiable Information (PII)	Includes information connected with an individual's name, image, date of birth or address; information that contains a unique personal identifier when the holder of the information also has the master list linking the identifiers to individuals; and information that the holder can merge or link to other information they already hold, enabling them to identify individuals
Personal Information	Defined in the *Freedom of Information Act 1992* (WA) as information or opinion about an identified individual.
Privacy Preserving Record Linkage (PPRL)	A method for linking sensitive databases across organisations without the need to reveal any private or confidential information. The most popular version of binary string encodings for PPRL are Bloom filters. The attractive main property of Bloom filters is that they can be used to encode strings in a similarity-preserving way
Separation principle	The separation principle is a mechanism to protect the identities of individuals and organisations in datasets, applied as part of the data linkage and data integration process used to form the integrated dataset.

9. Appendices
Appendix 1: PPRL Flow chart

PPRL PROCESS MAP - DATA APPLICATIONS FOR RESEARCH PURPOSES
Last updated 21 April 2023
Version 0.2

Appendix 2: External Data Providers checklist

Government of Western Australia
Department of Health

Privacy Preserving Record Linkage (PPRL)

EXTERNAL DATA PROVIDER CHECKLIST		Last updated: 12 July 2023

Instructions: Please fill the below checklist with information on the data you are providing

Purpose: The quality and feasibility of performing linkage of data is dependent on the quality of data received from data providers. Hence, this checklist is developed to ensure minimum requirements are met to facilitate linkage.

Element	Format or Example	Value
Date range (based on event date)	DD/MM/YYYY - DD/MM/YYYY	
Age range	XX - XX	
Specific Codes list or range (if applicable)	ICD Codes: A00 - B99, E00, L10 - L14 Pathology Codes: FBE, blood film, ECU, LFT, LDH, B12, Folate, TSHAIF, PCA, EPG, FLC, HaptoglobinBone marrow biopsy FBE, IS, ECU, LFT FOB, EPG, Hb-electrophoresisBlood Lead FBE, Reticulocyte count, ESR, ECU, CRPIS, B12, folate, LFTEPG, Bone marrow biopsy	
Sex/Gender distribution	Male = [n], Female = [n], Unknown = [n]	
Number of records/people provided	Records: [n] People: [n]	
Date of participant consent range (if applicable)	DD/MM/YYYY - DD/MM/YYYY	

Completion Date: _____

Printed Name: _____

Organisation: _____

Signature: _____

10. Document Control

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