

# PHRN Glossary

(current as at September 2011)



<b>TERM</b>	<b>DEFINITION</b>
Activities	The activities to be carried out by the Project Participants as described in the Project Plan in the PHRN Funding Agreement.
Activities IP	Intellectual Property developed in the course of carrying out the Activities.
Ad-hoc linkage	Linkage of an external dataset (e.g. survey results) to core data collections held in a data linkage unit.
Administrative Data	Information including personal information collected by agencies for the administration of programs, policies and services.
ARIA (Accessibility/ Remoteness Index of Australia)	Values that are assigned to geocoded areas and measure geographic remoteness. ARIA codes can be assigned using 1996, 2001 and 2006 ABS census data.
Authorised person	A person who has signed a Confidentiality Agreement relating to the relevant PHRN project or application.
Authorship	An explicit way of assigning responsibility and giving credit for intellectual work.
Best practice protocol	<p>A protocol for data linkage as described in seminal paper by Kelman, Bass and Holman (2002). The protocol consists of four distinct steps. Firstly, linkage staff create linkage keys using confidential personal demographic information. Secondly, linkage staff extract, then encrypt linkage keys for each particular project. Thirdly, encrypted linkage keys are provided to data custodians so they can add them to their clinical or service details for that particular project. Lastly, researchers receive clinical or service details from each data custodian and use the encrypted keys to connect the details needed for their analyses. In this way access to identifying information is restricted to a specialised linkage team who perform the first and second steps. Data custodians are involved in the third step. Researchers are only involved in the last step.</p> <p><small>(Aust N Z J Public Health. 2002;26(3):251-5)</small></p>
Blocking	A linkage method where only record pairs in subsets of the record files that agree on certain variables (called blocking variables) are examined to determine match status in order to reduce the number of comparisons required. Pairs that do not belong to the same block are assumed to be non-matches.
Breach	The unauthorised acquisition, disclosure, access, copying or modification of data that compromises the security, confidentiality, or integrity of personal information maintained by the PHRN.
Centre for Data Linkage (CDL)	The secure data linkage facility hosted by Curtin University that will facilitate linkage between jurisdictional datasets, and between these datasets and research datasets, using demographic data.
Clerical review	The process by which potential matches are manually reviewed. Additional information may be sought to confirm a possible match, or it may be possible to confirm the link using information sourced from other records.
Commercialise	The commercial exploitation of the results of innovation and creativity including related IP rights or the licensing or sale of IP for a commercial return.

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<b>TERM</b>	<b>DEFINITION</b>
Committee	Any committees formed by the PHRN Management Council, including working groups and advisory groups.
Community	A group of people sharing a common interest – for example a cultural, social, political, health or economic interest – but not necessarily a particular geographical association.
Complainant	A person or organisation that makes a complaint regarding any aspect of a service provided by the PHRN. They may be members of the general public, data users (including researchers, health care planners and health care providers), individuals associated with any of the PHRN jurisdictional nodes, the Centre for Data Linkage or the Program Office, data providers including data custodians, UWA staff, State or Federal Government agencies, and businesses or community organisations.
Complaints	Expressions of dissatisfaction regarding PHRN services and activities.
Confidential information	Any information with restrictions placed on the communication or dissemination of that information.
Confidentialise	To remove or alter information, or collapse detail within a dataset to ensure that it does not provide sufficient information as to make it likely that the individual can be identified, directly or indirectly.
Confidentialised unit record data	Unit record data where information has been removed or altered or detail has been collapsed to ensure that it does not provide sufficient information as to make it likely that the individual can be identified, directly or indirectly.
Confidentiality	The treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be used or divulged to others in ways that are inconsistent with the understanding of the original disclosure, without permission.
Conflict of interest	A situation that has the potential to undermine the impartiality of a person because of the possibility of a clash between the person's self-interest and professional-interest or public-interest.
Consumer representative	A member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision making process on behalf of consumers. This person is usually nominated by an organisation of consumers and is accountable to them.
Consumer/community member	An individual appointed to a PHRN Management Council committee with expertise in consumer and community engagement.
Consumers	Patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.
Content data	The information in a record that contains person-specific information but does not contain identifiable data. Examples include hospital discharge codes, cancer diagnosis, cause of death, educational results.
Core data collection	Data collections that are routinely linked by data linkage units.

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<b>TERM</b>	<b>DEFINITION</b>
Custodian approval	Approval obtained from data custodians for release of data for linkage research projects.
Data collection	An ongoing collection of statutory and administrative data by governments.
Data cleaning	The process of detecting and correcting (or removing) corrupt or inaccurate records from a record set, table, or database. Used mainly in databases, the term refers to identifying incomplete, incorrect, inaccurate, irrelevant etc. parts of the data and then replacing, modifying or deleting this data.
Data custodian	The organisation or agency which is responsible for the collection, use and disclosure of information in that dataset. The data custodian is responsible for contributing to the guidelines and approval processes on the use of the data, including involvement with ethics committees and input to the protocols surrounding data use.
Data dictionary	A tool that describes the meaning, relationships to other data, origin, instructions for usage and format of data elements within a data collection.
Data integration	The process of combining information from two or more data sources based on information common to the datasets, to produce new outputs.
Data user	A person who uses data in the course of a linkage project. This includes investigators, analysts and others who work for a range of organisations including academic institutions and government organisations.
Dataset	A set of data that has been collected through a one-off research process, or a subset of data that has been assembled by extracting those records or parts of records from one or more data collection(s) that the researcher has permission to see.
De-identified data	Information which has been stripped of identifiable information (eg name, address, dates of birth/death) in order to protect personal privacy; or where such details have been sufficiently altered to render the identification of individuals unlikely.
Demographic data	Demographic data should not be used as the term may cause confusion with the definition used in the context of population statistics. Instead, 'identifiable data' and 'linkage variables' should be used.
Deterministic matching	Linkage method that matches each data element of a record character by character, and although some discrepancies may be allowed, two records must either be classified as the same or not the same.
Encryption	The process of transforming information into an encoded form.
Ethics approval	A recommendation from a HREC registered with the NH&MRC that a project is ethically acceptable and compliant with the National Statement on the Ethical Conduct of Research.
Event	Event leading to a health-related record, for example, birth, death, hospital separation, prescription, diagnostic test, emergency presentation, surgery, cancer incidence. Events can be nested leading to hierarchical records.
External notification	The process of informing individuals about incidents or breaches that have caused their personal information to be accessed or acquired by unauthorised persons.

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<b>TERM</b>	<b>DEFINITION</b>
Extraction	The process of selecting records from data collections.
False positive/ false match	Records that have been brought together as a match but do not belong to the same individual.
False non-matches	Records that have not been brought together as a match but really do belong to the same individual.
Firewall	A hardware or software device which is configured to permit, deny, or proxy data through a computer network which has different levels of access. Used within the context of the Data Linkage Unit to maintain privacy and security of the data.
Frequency file	This file is sometimes provided on a data extract and contains the frequencies of each variable.
Geocoding	The process of finding associated geographic coordinates (often expressed as latitude and longitude) from other geographic data, such as street addresses or postal codes. With geographic coordinates the features can be mapped and entered into Geographic Information Systems, or the coordinates can be embedded into media such as digital photographs via geotagging.
Health data	An individual data variable or collection of data variables related to health conditions, reproductive outcomes, causes of death, and quality of life.
Health information	Means (a) information or an opinion about: (i) the health or a disability (at any time) of an individual; or (ii) an individual's expressed wishes about the future provision of health services to him or her; or (iii) a health service provided, or to be provided, to an individual; that is also personal information; or (b) other personal information collected to provide, or in providing, a health service; or (c) other personal information about an individual collected in connection with the donation, or intended donation, by the individual of his or her body parts, organs or body substances; or (d) genetic information about an individual in a form that is, or could be, predictive of the health of the individual or a genetic relative of the individual.
Health-related data	Refers to an individual data variable or collection of data variables that can be connected either logically or causally to health conditions, reproductive outcomes, causes of death or quality of life.
Identifiable data	Data where the identity of a specific individual can reasonably be ascertained.
Incident	A violation or imminent threat of violation of data protection policies, acceptable use policies or standard security practices.
Information privacy	The interest an individual has in controlling the handling of information about themselves, including the collection, use and disclosure of their information to others.
Information Privacy Principle (IPP)	The baseline privacy standards which the Australian and ACT government agencies need to comply with in relation to personal information kept in their records as set out in section 14 of the Privacy Act 1988 (Cth).

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<b>TERM</b>	<b>DEFINITION</b>
Integrating Authority	A service provider in which statistical integration is regarded as core business. Its role is to enable data linkage projects to be conducted in a secure environment, which reduces the risk of privacy breaches by only allowing approved researchers access to merged data sets through a 'virtual data laboratory' (ie physical and remote access).
Intellectual property	All rights resulting from intellectual activity whether capable of protection by statute, common law or in equity and including copyright, discoveries, inventions, patent rights, registered and unregistered trademarks, design rights, circuit layouts and plant varieties and all rights and interests of a like nature, together with any and all documentation relating to such rights and interests.
Jurisdiction	Jurisdiction means the extent of legal authority or control over a region or territory. For the purposes of the PHRN, a jurisdiction is the term used to describe a level of government with authority to collect and use information; for example, an Australian state or territory government or the Australian Government.
Jurisdictional linkage keys	The alphanumeric codes created and stored by jurisdictional linkage units which can be used to group records that refer to the same entity.
Jurisdictional linkage unit	The secure data linkage facility that facilitates linkage between data collections pertaining to its own jurisdiction, and between these data collections and research datasets.
Linkage variables	The variable supplied by the data custodians to the data linkage units that are used to match records from different data collections that belong to the same individual, family, place or event. Examples of common linkage variables include name, address, date of birth.
Master linkage keys	The alphanumeric codes created and stored by a data linkage unit which can be used to group records that refer to the same entity.
Master linkage map/file	A table containing the association between linkage keys and record identifiers held by a data linkage unit.
Matching score / certainty level / weight	A score derived from the comparison of two records (a record pair), giving a measure of the likelihood these records belong to the same person. This score is compared against a threshold, which determines whether the record pair is classed as a match, a non-match or a possible match.
Material	Includes documents, equipment, software (including source code and object code), goods, information and data stored by any means including all copies and extracts of the same, but excludes Personal Information.
Metadata	The underlying definition or structured description of the content, quality, condition or other characteristics of data.
Moral right	The meaning ascribed to that term in the Copyright Act 1968 [as amended by the Copyright Amendment (Moral Rights) Act 2000] and recognises three types of moral rights: (a) an author's right to be identified as the author of a work – known as the right of attribution of authorship; (b) the right of an author to take action against false attribution – known as the right not to have authorship of a work falsely attributed; and 517/2006 22 (c) an author's right to object to derogatory treatment of his or her work that prejudicially affects his honour or reputation – known as the right of integrity of authorship of a work.

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<b>TERM</b>	<b>DEFINITION</b>
National linkage keys	The alphanumeric codes created and stored by the Centre for Data Linkage which can be used to group records that refer to the same entity.
National linkage map/file	A table containing the association between the National linkage Keys, encrypted Jurisdictional Linkage Keys and the encrypted record identifiers as supplied by each jurisdiction.
National Privacy Principle (NPP)	The baseline privacy standards which some private sector organisations need to comply with in relation to personal information they hold as set out in Schedule 3 of the Privacy Act 1988 (Cth).
National Collaborative Research Infrastructure Strategy (NCRIS)	An initiative administered by the Commonwealth Department of Innovation, Industry, Science and Research (DIISR) that is providing \$542 million between 2005-2011 to assist researchers with major research facilities, supporting infrastructure and networks necessary for world-class research.
NCRIS PHRN funding	The project resources outlined in the NCRIS Project Plan including the NCRIS cash investment, co-investments and in-kind contributions.
Non-identifiable data	Data which have never been labelled with individual identifiers or from which identifiers have been permanently removed, and by means of which no specific individual can reasonably be identified. A subset of non-identifiable data are those that can be linked with other data so it can be known that they are about the same data subject, although the person's identity remains unknown.
Participants' Arrangement	Sets out the mutual obligations and operational relationships within the PHRN.
Participant organisation	An organisation that will provide services and functions to the Project Participants but will not be party to a legal contract with The University of Western Australia.
Participant's Agreement	An agreement between The University of Western Australia and a Project Participant which complies with the PHRN Funding Agreement, in which The University of Western Australia subcontracts some of its obligations under the PHRN Funding Agreement.
Peer review	The impartial and independent assessment of research by others working in the same or a related field.
Personal health information	Information or opinions that relate to the health of a person where the identity of a person is apparent or can reasonably be ascertained from the information.
Personal identifiers	Unique information that relates to a person that enables the establishment of their identity including: full names; residential addresses; dates of birth; anniversary dates; Medicare numbers; bank account or loan account numbers; tax file numbers; licence numbers; motor vehicle registration numbers; email addresses; the names of spouses, partners and children.
Personal information	Information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.

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<b>TERM</b>	<b>DEFINITION</b>
PHRN Funding Agreement	An agreement between the Commonwealth of Australia as represented by the Department of Innovation, Industry, Science and Research and the University of Western Australia regarding funding for implementing an Investment Plan for the National Collaborative Research Infrastructure Strategy's Research Capability known as Population Health Research Network, executed 12 March 2009.
PHRN infrastructure	The basic physical and organisational structures needed for the operation of the PHRN.
PHRN Management Council	The group established under the PHRN Funding Agreement to oversee the implementation of PHRN infrastructure in accordance with the NCRIS Investment Plan.
PHRN Participant	A group that includes all Project Participants and participant organisations as described in the PHRN Funding Agreement.
PHRN-specific publications	Publications that are developed to assist in the provision of training by the PHRN to its various target groups and nontechnical publications addressed to the general public including newsletters, brochures and information kits. This category also incorporates Annual Reports and Annual Business Plans.
Policy	A statement of purpose and one or more broad guidelines as to how the purpose is to be achieved which, when taken together, provide a framework for the operation of an organisation or program.
Positive Predictive Value	The proportion of linked records that are valid links.
Pre-existing IP	Intellectual Property developed prior to or independently of the Activities which the Project Participants have agreed to contribute to outlined in the PHRN Funding Agreement.
Principle	The fundamental premises/concepts that a policy and associated procedures and guidelines are based on.
Principal Investigator	The person(s) responsible, either as an individual or as the leader of researchers within an institution, for the conduct of a research project at that institution.
Privacy	The right or expectation to be let alone or not interfered with and includes information privacy.
Privacy Impact Assessment	The assessment of actual or potential effects on privacy, and how they can be mitigated.
Probabilistic matching	A linkage method that derives a weight for each data element of a record based upon the probability that agreement or disagreement on this element increases or decreases the probability that the two records refer to the same person; the likelihood that two records match is related to the sum of these weights.

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<b>TERM</b>	<b>DEFINITION</b>
Procedural fairness/ natural justice	The procedures used by a decision-maker, rather than the actual outcome reached. It requires that a fair and proper procedure is used when making a decision. A decision-maker who follows a fair procedure is more likely to reach a fair and correct decision. The term procedural fairness is thought to be preferable when referring to administrative decision making because the term natural justice is associated with procedures used by courts of law. However, the terms have similar meaning and are commonly used interchangeably.
Project material	All Material:(a) brought into existence for the purpose of performing this agreement; (b) incorporated in, supplied or required to be supplied along with the Material referred to in paragraph (a); or (c) copied or derived from Material referred to in paragraphs (a) or (b).
Project Participant	A party to a PHRN Participant's Agreement who is approved by the Commonwealth.
Project-specific linkage key	An encryption of a National Linkage Key or Jurisdictional Linkage Key that is provided to a researcher for a specific approved data linkage project.
Project-specific linkage map	Table containing the association between project specific linkage keys and jurisdictional linkage keys (for projects involving a single jurisdiction) or national linkage keys (for projects involving multiple jurisdictions).
Publication	The printing and distribution of published documents, or publication of a journal article, book or book chapter.
Record	Data pertaining to an event.
Record descriptor variables	Variables in a record which describe the record, for example: record type, date of event, source system identifier, encrypted source record identifier, encrypted person identifier from source system.
Refereed scientific publications	Publications that are addressed to the international scientific community and undergo a formal peer-review process.
Re-identifiable data	Data from which identifiers have been removed and replaced by a code, but it remains possible to re-identify a specific individual by, for example, using the code or linking different datasets.
Research	The original investigation undertaken to gain knowledge, understanding and insight.
Researcher	A researcher is a person who is a student or teacher either enrolled at or employed by a university or research institute or other comparable institution. A researcher may also include an employee of a government department or an independent contractor (or an employee of that contractor) who undertakes analyses solely for bona fide research or statistical purposes pursuant to the functions and duties of that government department.
Researcher member	An individual appointed to the PHRN Management Council due to their knowledge of health data linkage systems and methods and the analysis linked datasets.



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<b>TERM</b>	<b>DEFINITION</b>
Research infrastructure	The assets, facilities and services which maintain the capacity of researchers to undertake research and deliver outcomes.
Socio-Economic Indexes for Area (SEIFA)	Values that are assigned to geocoded areas and measure socioeconomic conditions. SEIFA codes can be assigned using 1996, 2001 and 2006 ABS census.
Sensitive information	Means (a) information or an opinion about an individual's: (i) racial or ethnic origin; or (ii) political opinions; or (iii) membership of a political association; or (iv) religious beliefs or affiliations; or (v) philosophical beliefs; or (vi) membership of a professional or trade association; or (vii) membership of a trade union; or (viii) sexual preferences or practices; or (ix) criminal record; that is also personal information; or (b) health information about an individual; or (c) genetic information about an individual that is not otherwise health information.
Statistical data integration	A set of procedures that link personal unit record data from two or more administrative, clinical and/or survey sources to provide new merged data sets for socio-economic, population health and clinical research purposes.
Statistical disclosure	Re-identification of data subjects or respondents (or their attributes) even though direct identifiers such as names and addresses have been removed from the data file.
Threshold	The number with which a score is compared. There is usually a threshold above which a record pair is considered a match and another threshold below which a record pair is considered not to be a match. Between the two thresholds a record pair is considered a potential match, and may require clerical review.
Unique record identifier	An alphanumeric code adopted, used or disclosed in conjunction with or in relation to an individual's information contained within a database by an organisation for the purpose of uniquely identifying that individual.
Unit record data	Records of information pertaining to a single individual or entity. These data may be fully identifiable, as found in original data collections, or not identified as, for example, in records supplied to researchers where identifying information including names, addresses and dates of birth have been removed. Also referred to as 'patient-level data' in the context of health research.
Vexatious or frivolous complaints	Complaints lodged with a primary purpose to harass, annoy, delay or cause detriment rather than genuinely intending to resolve the grievance. They also include complaints which are instituted or pursued without reasonable grounds.

## PHRN COMMONLY-USED ACRONYMS



<b>ACRONYM</b>	<b>FULL NAME</b>
ABS	Australian Bureau of Statistics
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
ARC	Australian Research Council
ARIA	Accessibility/Remoteness Index of Australia
AVCC	Australian Vice Chancellors' Committee
CDL	Centre for Data Linkage
CHeReL	Centre for Health Record Linkage
CHF	Consumers' Health Forum of Australia
DAL	Data analysis laboratory
DDS	Data Delivery System
DHHS	Department of Health and Human Services
DIISR	Department of Innovation, Industry, Science and Research
DLU	Data linkage unit
DOHA	Department of Health and Ageing
EIF	Education Investment Fund
HiL	Health Information Linkage
HCCWA	Health Consumers' Council of WA
HPPPC	Health Policy Priorities Principal Committee
HREC	Human Research Ethics Committee
JLK	Jurisdictional Linkage Keys
JLM	Jurisdictional Linkage Map
JLU	Jurisdictional Linkage Unit
MRI	Menzies Research Institute
NCRIS	National Collaborative Research Infrastructure Strategy
NH&MRC	National Health and Medical Research Council
NLK	National Linkage Keys
NLM	National Linkage Map
PHRN	Population Health Research Network
PO	Program Office
QH	QLD Health
RLG	Research Linkage Group
SDE	Secure Data Exchange
SEIFA	Socio-Economic Indexes for Area
SLA	Statistical Local Area
SURE	Secure Unified Research Environment
TDLU	Tasmanian Data Linkage Unit
TICHR	Telethon Institute for Child Health Research
UniSA	The University of South Australia
UQ	The University of Queensland
UWA	The University of Western Australia
VDL	Victorian Data Linkages
WADLB	WA Data Linkage Branch
WADOH	WA Department of Health