Australian Bureau of Statistics

PRIVACY IMPACT ASSESSMENT

Using linked data to investigate the role of sociodemographic factors in people with cancer in New South Wales

November 2020

CONTENTS

PART A – INTRODUCTION

1.1 Background

Identification of cancer at an early stage is critical for effective treatment and recovery. Registers for various cancer types, including data from screening programs, help to identify prevalence and characteristics of people with and without cancer. The effectiveness of cancer screening depends on program reach and there is a need and an opportunity to improve the representativeness of individuals who participate in these screening programs in NSW.

There are common data gaps around demographic and socioeconomic factors in all stages of the cancer journey. While these factors play important roles in health, they are often poorly captured by administrative health datasets. The data linkage project covered by this Privacy Impact Assessment (PIA) will be important in providing additional context, and a greater understanding of the importance of sociodemographic factors (e.g. age, education level, income) on all stages of the cancer journey, from prevention through to survivorship or end-of-life. The results will be used to inform the development of cancer prevention and management programs, with the overall aim of increasing cancer screening participation, reducing cancer incidence, and improving the quality of care and outcomes for people with cancer in NSW.

The Multi-Agency Data Integration Project (MADIP) is a partnership among Australian Government agencies to combine information on healthcare, education, government payments, personal income tax, and population demographics (including the Census) to create a comprehensive picture of Australia over time. The Australian Bureau of Statistics (ABS) is the Accredited Integrating Authority for MADIP and, in collaboration with its partners, is responsible for combining the data, providing access to authorised users via highly secure ABS systems, and safeguarding privacy and confidentiality. Data custodians, or entities authorised by data custodians, share data with the ABS for MADIP. The ABS does not release data from MADIP in a manner that is likely to identify any individual. Further information on the MADIP asset and associated privacy can be found in the MADIP PIA Update.

In 2018, the ABS and Cancer Institute NSW (the Institute) commenced investigations into linking data from the Institute to the MADIP asset.

The three Institute datasets proposed for linkage in this pilot project are:

Institute datasets	Period from	Period to	No. records (approx.)
NSW Cancer Registry	Jan 1972	December 2016*	1,222,609
BreastScreen NSW (Breast)	Jan 1998	December 2016*	6,122,103
NSW Pap Test Registry (Pap)	Jul 1996	June 2017	15,075,884

*or latest at time of data delivery

Information on each of these datasets can be found here. Appendix 6 provides a summary of the linking and analytical variables of each Institute dataset.

As this is a pilot project, the linkage will be non-enduring, which means the analytical data will be available only for the purposes of this project and will not be retained beyond the completion of the project (a minimum of five years and subject to review of continuing need and subsequent approvals at that time). The minimum five-year period is in accordance with National Health and Medical Council recommendations, and all MADIP data custodians involved in the project have approved the project proposal which specifies this retention period. Once the linkage has taken

place the linking variables will be deleted and only the analytical variables will remain in MADIP for the length of the project.

A Memorandum of Understanding (MoU) between the ABS and CINSW exists for this project. The MOU outlines the purpose of the project, the data that will be used, and who will be able to access the data.

This Privacy Impact Assessment (PIA) has been prepared by the ABS, with independent advice and review on the PIA provided by external privacy adviser Privcore.

1.2 Purpose, scope and approach

The purpose of this PIA is to:

- consider the potential impacts the linkage will have on the privacy of individuals whose personal information will be provided to the ABS and whose deidentified information will be made available to authorised researchers of the Institute and ABS;
- identify privacy risk areas in relation to compliance with the Australian Privacy Principles (APPs), NSW Health Privacy Principles (HPPs) and community expectations; and
- identify, assess, and where appropriate recommend, options for managing negative privacy impacts to improve compliance and make suggestions in line with privacy best practice.

The approach taken to produce this PIA follows the Office of the Australian Information Commissioner's (OAIC's) Guide to undertaking privacy impact assessments.

The PIA describes the data and information flows in the linkage and the current infrastructure and governance arrangements that determine how the data will be managed.

The PIA's scope includes linkage of the three Institute datasets described in section 1.1 to MADIP. Linkage of MADIP datasets is not in scope of this PIA, as this is covered in the MADIP PIA Update.

The Institute has provided detailed information to demonstrate compliance with the HPPs, which has greatly aided the ABS in completing this PIA.

1.3 Legislation and applicable privacy principles

The integration of the Institute data with MADIP is being undertaken by the ABS, as the Accredited Integrating Authority for MADIP. The ABS, as a Commonwealth organisation, must comply with the *Privacy Act 1988 (Cth)*, including the Australian Privacy Principles (APPs). Compliance for the ABS is assessed against the APPs, the outcomes of which are detailed in Appendix 1.

The Institute has advised that all Institute data were collected in accordance with the Health Privacy Principles (HPPs), which are contained in the *Health Records & Information Privacy Act 2002 (NSW)* and relevant NSW legislation at the time. Aspects of the HPPs that are relevant to the linkage of Institute data to MADIP are addressed in this PIA.

Since the time the Institute data were collected, responsibility for the BreastScreen and Pap Test datasets has transferred from State to Commonwealth level (in 2019 and 2017 respectively).

Institute data will be brought into the ABS under the *Census and Statistics Act 1905 (the Act).* Subsection 9.1 of the Act provides the ABS with the legislative authority to collect data for linkage; this is the basis on which Institute datasets will be collected and received by the ABS.

> ***9 Statistical information to be collected***
>
> *(1) The Statistician:*
>
> *(a) may from time to time collect such statistical information in relation to the matters prescribed for the purposes of this section as he or she considers appropriate; and*
>
> *(b) shall, if the Minister so directs by legislative instrument, collect such statistical information in relation to the matters so prescribed as is specified in the instrument.*

While `statistical information' is not defined in the Act, the ABS considers this term to mean information that is used in the creation or compilation of statistics.

Federal privacy laws, including the APPs, are considered and adhered to when conducting research that involves Institute datasets linked to Commonwealth datasets.

1.4 Methodology and project governance

The management of data in this linkage project takes place under a number of formal arrangements between the Institute and the ABS as the Accredited Integrating Authority. These arrangements are documented in a Memorandum of Understanding (MoU) and Letter of Exchange, which clarify the understanding and responsibilities for each organisation.

The Letter of Exchange is a formal request for provision of the data in the linking and analytical files and includes provision for secure transfer of data and confidentiality requirements.

The MoU provides an overview of the project and arrangements for both parties (e.g. responsibilities, data which the Institute will provide, data which the ABS will link and how, governance to be undertaken, and legislation which covers the transfer of data). In September 2019, the ABS and the Institute signed an MoU for the project to be undertaken. This MOU will be superseded by a 3-year MOU from 2020-2023. Subsequent MOUs will be negotiated as they expire.

Both organisations also undertook their own governance work for the project.

The ABS completed this PIA and gained approval for the linkage to take place through:

- the ABS' internal governance process, using a Data Integration Plan to meet the ABS' Accredited Integrating Authority responsibilities and ensure the project is of benefit to the public; and
- coordinating research project proposals, which required approvals from custodians of the MADIP data.

Access to data is provided using the Five Safes Framework. Further information on these processes and MADIP governance can be found in the MADIP PIA Update.

This PIA covers privacy aspects associated with this project, in accordance with the Commonwealth Statistical Data Integration Risk Assessment guidelines. Under these guidelines, the sensitive nature of health data increases risk to a medium/high level, making this PIA particularly important. The PIA also draws on governance processes undertaken by the Institute.

The ABS decision to undertake the PIA internally with external review by Privcore is consistent with current best practice, the ABS' internal governance evaluation processes and OAIC's Guide to undertaking privacy impact

assessments. The PIA has been reviewed by relevant areas within the ABS, including the Data Integration Division and Policy and Legislation section.

The Institute's data is managed in accordance with their governance arrangements which are set out in its Data Governance Policy, as well as the Institute's Privacy Policy, which includes specific reference to the BreastScreen NSW privacy policy.

Governance processes undertaken by the Institute for linkage projects include seeking approval from two Human Research Ethics Committees:

- Approval from the NSW Population and Health Services Research Ethics Committee (PHSREC) is a requirement for all Institute research projects that use NSW Ministry of Health or Cancer Institute of NSW datasets. The committee undertakes scientific and ethical review of population health and/or public health research to ensure that the research is scientifically valid, and is conducted in a manner that is in line with the Health Privacy Principles. Members of PHSREC include experts in research and professional/clinical care, lay members, legal, pastoral and NSW Ministry of Health representatives.
- All Institute research projects that involve Aboriginal and/or Torres Strait Islander participants, such as this project, also require approval from the Aboriginal Health and Medical Research Council of NSW Human Research Ethics Committee (AH&MRC). This committee ensures that the research takes the needs and perspectives of Aboriginal and Torres Strait Islander people into account. Members include Aboriginal Community Controlled Health Services led by their respective Aboriginal Communities.

At the time of publishing this PIA, provisional approval from the PHSREC Committee has been received; finalisation of this PIA is one outstanding item for final approval.

Further approvals from the NSW Ministry of Health and Centre for Health Record Linkage (CHeReL) will be obtained as these are needed before the data are provided by CHeReL to the ABS for linkage. These should be fairly smooth as the Institute, CHeReL and ABS have worked closely together to ensure Governance requirements have been met.

A list of documents consulted, including legislation and other PIAs, can be found at Appendix 10.

1.5 Addressing community expectations

Addressing community expectations, privacy risks and their implications is an important component of a PIA.

While the collection, use or disclosure of personal information may be authorised by legislation, this may not necessarily mean that it meets community expectations. A key privacy right for individuals is to be aware of how personal information about them is being used. As an example, community attitudes about what constitutes an invasion of privacy may differ from those covered by law. Hence a PIA is more than a Privacy Principle (APPs or HPPs) compliance check. It also has regard to community attitudes and expectations regarding the project's privacy implications and inherent risks. This is important in the building and maintenance of public trust.

The OAIC's Community Attitudes to Privacy Survey 2020 is a good indication of expectations held by those whose privacy may be impacted by the project. This source reported that privacy is a major concern for 70% of Australians, and almost 9 in 10 want more choice and control over their personal information. Misuse of information which doesn't seem relevant to the collection purpose is another primary concern. In this project the ABS applies several security controls, as detailed throughout Sections 2 and 3, to mitigate these concerns.

People who have, or have previously had, cancer have an increased risk of identification as part of this linkage project. This is particularly the case for women, older people, those with unique characteristics or high-profile people included in the Institute datasets. The Institute has advised however that 58% of people on the Cancer Registry are deceased, which greatly reduces the overall risk of the identification of an individual in the community from this dataset. The percentage of records in the BreastScreen NSW and NSW Pap Test Register relating to deceased people is more difficult to determine, as these registers are not routinely linked to death registrations; however it is likely that the percentage would be lower than that seen for the NSW Cancer Registry, as cancer screening programs are aimed at people who have not yet developed cancer, and these programs are targeted at younger age groups.

Public trust is critical to the ABS' reputation and willingness of individuals to participate in ABS and Government projects. Important steps in building public trust in the project include:

- Transparency (such as listing the project on the ABS Data Integration Project Register)
- Demonstrating that public benefits from the linkage will outweigh potential privacy risks; and
- Explaining how privacy risks will be mitigated (through this PIA).

A key finding of community consultation for the MADIP PIA Update was:

> *the importance of communicating the benefits of data integration to help the community understand MADIP and how it is used. Suggestions to achieve this included publishing more outputs and case studies, especially those demonstrating a tangible public benefit that has resulted from the use of integrated data.*

Use of statistical information is central to making evidence based policy decisions, which lead to better outcomes for the community. Linking datasets helps create a richer information base, and maximise use of data collected.

The linkage of Institute data to MADIP is a prime example where such results will lead to community benefit through reducing cancer incidence, and improving the quality and care of outcomes for people with cancer.

A direct community consultation process was not undertaken for this PIA. The reason for this is that community attitudes have been adequately covered in several other processes including:

- The MADIP PIA Update, which included community consultation
- Approvals through two ethics committees, which are representative of community expectations
- All data custodians, representing their community stakeholders, involved in the project have approved the MADIP project proposal.

The stakeholders consulted for the project are outlined in Appendix 11.

PART B – DATA OVERVIEW AND INFORMATION FLOWS

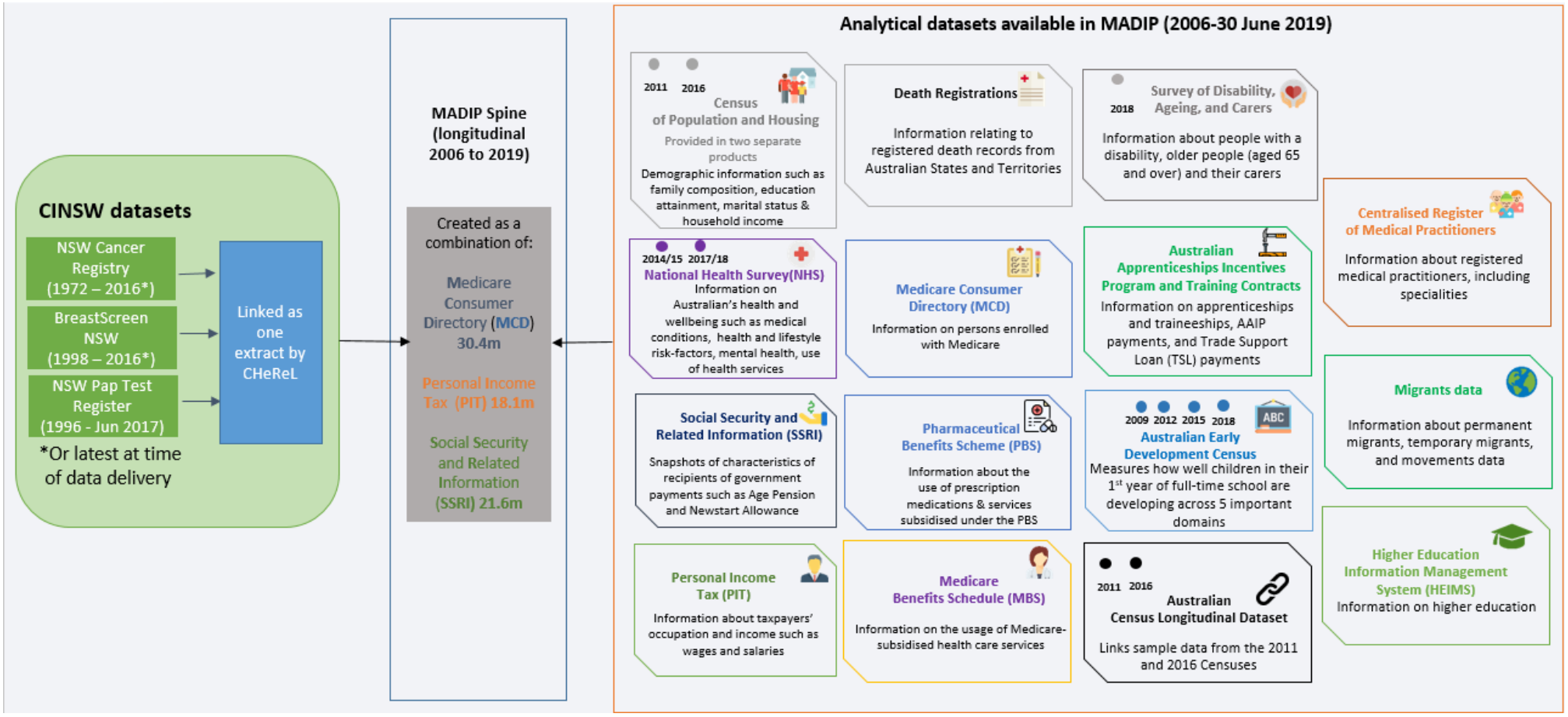
This project will use the MADIP system of governance and data infrastructure to ensure the secure integration of a broad set of person-centred Institute data for statistical and research purposes. MADIP is an enduring, longitudinal, multi-topic integrated data asset, which allows for the integration of datasets for specific projects that do not become part of the enduring asset (such as this one).

Records from the three Institute datasets will be linked to the Person Linkage Spine[1],which facilitates linkage with all MADIP datasets. More information on the MADIP asset is available on the ABS Website.

The data sharing model is centred on the ABS as the Accredited Integrating Authority for the project. The three Institute datasets will be linked together by NSW Health's Centre for Health Record Linkage (CHeReL), and an extract with the linked and unlinked records (total of around 22 million records) will be provided to the ABS. The ABS will link the CheReL data extract to the Spine, then assemble analytical MADIP microdata, and provide secure access to the microdata for authorised Institute and ABS researchers undertaking approved projects. The ABS does not share MADIP microdata outside of the ABS environment. This data linkage model is shown in Figure 1 below.

[1] The Person Linkage Spine is the central linking of identifiers for data held within MADIP. Linkage variables are encrypted and are sourced from Medicare, social security and tax information.

Figure 1: A data overview – incorporating the Institute, Spine and other MADIP datasets.



2.1 Personal information

The Institute and MADIP data include personal information such as name, address, and date of birth. This information is used to build the Spine and to link analytical variables to the Spine. The direct identifiers (personal information) in the Spine are encrypted. Direct identifiers, raw and encrypted, are stored separately from analytical variables at all times in accordance with the separation principle and are not available to researchers. The information available from the analytical variables may, in some circumstances, be considered personal information even when it is separated from direct identifiers as it may enable the re-identification of an individual (e.g. through the combination of data items). Access to personal information in the MADIP asset is strictly controlled and limited to a small team of ABS staff.

The ABS use the *Privacy Act 1988 (Cth)* definition of personal information, which states that:

> *personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable (referenced here).*

The Institute use the definition in the NSW *Health Records and Information Privacy Act (HRIPA) 2002*, which states that:

> *personal information means information or an opinion (including information or an opinion forming part of a database and whether or not recorded in a material form) about an individual whose identity is apparent or can reasonably be ascertained from the information or opinion.*

There is a scope difference between the two definitions. While all deceased persons are outside the scope of the *Privacy Act 1988 (Cth)*, the NSW *Health Records and Information Privacy Act 2002* includes those who have died in the last 30 years. Regardless of scope, the ABS practices ensure that all data for this project are kept in a secure environment and access to this data is strictly controlled.

The MADIP asset also includes 'sensitive data' (i.e. data that contains information that fits into the categories of sensitive information defined in the *Privacy Act 1988 (Cth)* even when the data does not include personal information). This includes:

- Health information;
- Ethnicity and racial background;
- Indigenous status[2];
- Religious affiliation; and
- Sexuality[3].

[2] Indigenous status is not a category of sensitive information in the *Privacy Act 1988 (Cth)* but is considered a type of personal information about ethnicity and racial background.
[3] Information on sexuality is not directly available in the MADIP asset, but it could be inferred through other information such as marital status.

The ABS implements additional principles for managing sensitive data items; these are particularly appropriate in this case given the sensitive nature of the Institute data. They are as follows:

- Data sharing is minimised so that only data that are necessary for the purposes of the project are shared and used in the MADIP asset.
- Categorised or derived indicators for sensitive data items are used where this is feasible unless sensitive data items in their original form are required for statistical or analytical purposes.
- Project proposals require specific justification for requesting sensitive data items (including level of detail requested).
- Sensitive data are destroyed where there is no compelling business case for retention, or by agreement between the ABS and relevant data custodians.

Regardless of whether the data contains personal information or not, the ABS treats all MADIP data in the ABS environment with standards appropriate for personal information.

Section 2.2 provides more detail on the flow of information through the linkage process.

Personal information collected by the Institute and relevant Privacy legislation

The Institute collects data in accordance with the Health Privacy Principles outlined in the NSW *Health Records and Information Privacy Act 2002 (the NSW Act).* These principles apply to 'health information' which is defined in the NSW Act as:

> *(a) personal information that is information or an opinion about:*
> *(i) the physical or mental health or a disability (at any time) of an individual, or*
> *(ii) an individual's express 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, 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, of an individual's body parts, organs or body substances, or*
> *(d) other personal information that is genetic information about an individual arising from a health service provided to the individual in a form that is or could be predictive of the health (at any time) of the individual or of a genetic relative of the individual, or*
> *(e) healthcare identifiers, but does not include health information, or a class of health information or health information contained in a class of documents, that is prescribed as exempt health information for the purposes of this Act generally or for the purposes of specified provisions of this Act.*

2.2 Information flows

As mentioned above, CHeReL will prepare a data extract representing all 22 million Institute data records from the 3 Institute datasets for provision to the ABS. Obtaining the full linked dataset (including both linked and unlinked records), rather than a sample or subset, allows for the broad objectives outlined above to be met. It will also enable analysis of the relationship between sociodemographic factors and cancer incidences. There is a risk that if a sample or subset of data is used an insufficient number of people would be included in the analyses, particularly for rare cancer diseases or for population subgroups with small numbers of members. Using data from the range of data periods will allow understandings of the long-lasting impacts of cancer on an individual's life to be explored and developed.

Procedures to process, assemble and release the Institute data will be consistent with those for MADIP data. Further information can be found in the MADIP PIA Update.

The separation principle and secure data environment

Data integration for this project will be undertaken in accordance with the separation principle, which means that directly identifying variables are not held together with analytical variables. The ABS implements the separation principle through a 'functional separation' approach. Functional separation is a collection of access controls and procedures to restrict and regulate access to data. It involves use of the following discrete 'functional roles':

- Librarian: Prepares, standardises, and anonymises identifying data used for linkage. Typically the linkage data are composed of variables relating to name, address, date of birth, and sex or gender.
- Linker: Links datasets using anonymised linkage data.
- Assembler: Uses the linkage results to create linked analytical data.
- Analyst: Analyses the linked analytical datasets.

The two key tenets of functional separation are that an individual may never occupy more than one functional role at any given time, and that data passes progressively through the functions.

All Librarian, Linker, and Assembler activity occurs in an isolated secure IT environment – the Secure Data Integration Infrastructure (SDII). This environment has no external connectivity (i.e. no email, internet, etc.) so information cannot be copied to other systems or datasets. Baseline security clearance is required to obtain access to the SDII. Each functional role has separate access-controlled data holdings within the SDII.

Data collection and preparation

When the Institute data is supplied to the Librarian team for linkage to the MADIP asset, the linkage and analytical variables will be provided as separate files in accordance with best practice.

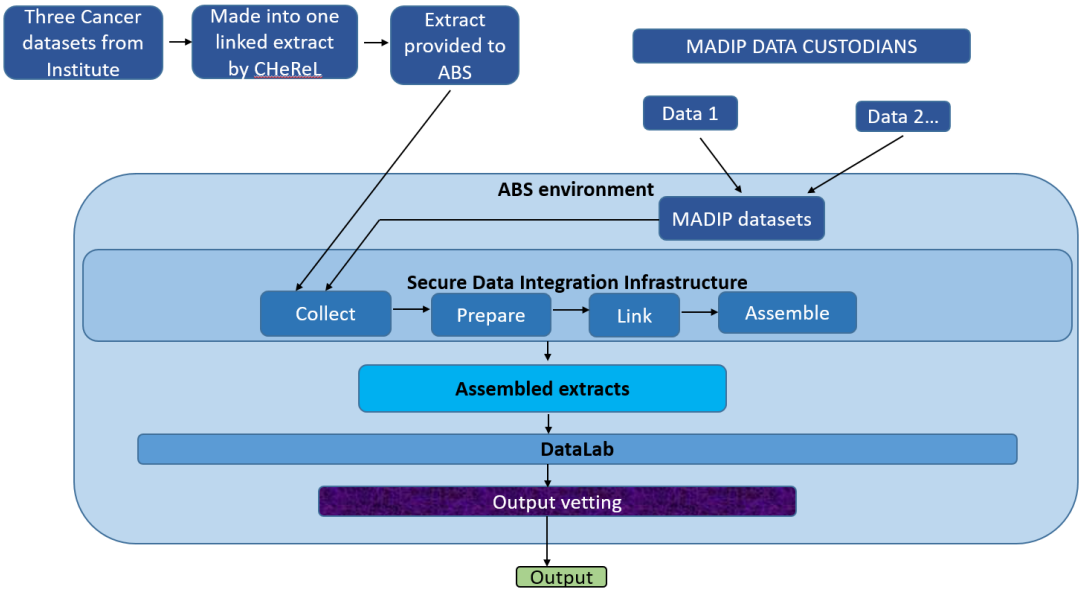
The files will be provided by CHeReL on behalf of the Institute and loaded into the ABS IT environment, through online secure file transfer portals to the ABS Secure Drop Box, and securely transferred into the Secure Data Integration Environment. Linkage data will be transferred to the Librarian holdings and analytical data are transferred to the Assembler holdings.

The linkage variables will be prepared by the Librarian and Linker teams and used to link to the Spine. The analytical file will go to the assembler team and be combined with analytical data from MADIP. Once the linkage has taken place linking variables will be deleted.

Librarian staff will clean, repair, standardise and anonymise linkage data before securely transferring it to Linker staff. Names will be cleaned to match those in master name indexes and standardised so that variations are grouped into a common name (e.g. Jess, Jessie to Jessica); this helps ensure consistency between data and maximise linkage rates. Date of birth and sex or gender will also be converted into standard formats.

Access to the deidentified integrated data will be provided to authorised researchers for approved projects in the ABS DataLab. The ABS applies the separation principle at all stages of the data integration processes to minimise handling of personal information. (See discussion under section 3.11)

Figure 2 shows how the Institute data will flow through the ABS environment.



Librarians also geocode addresses to an Address Register ID (ARID), as well as Mesh Blocks and higher geocodes from the Australian Statistical Geography Standard (ASGS). An ARID is an identifier representing a unique Australian address. Librarians anonymise ARIDs before transferring them to Linkers so that their corresponding address cannot be looked up on the Address Register.

Data linkage

The Person Linkage Spine (Spine) is the central linking of identifiers for data held within MADIP. Linkage variables are encrypted and are sourced from Medicare, social security and tax information. The ABS linkage team will link the anonymised Institute linkage data to the Spine. This will produce a 'linkage results file', which, like the Spine, is simply a concordance or map between the IDs on the Spine and the new linked dataset. No data used to perform the linkage is included on the results file. This data flow can be seen on the left side of Figure 1.

Data assembly

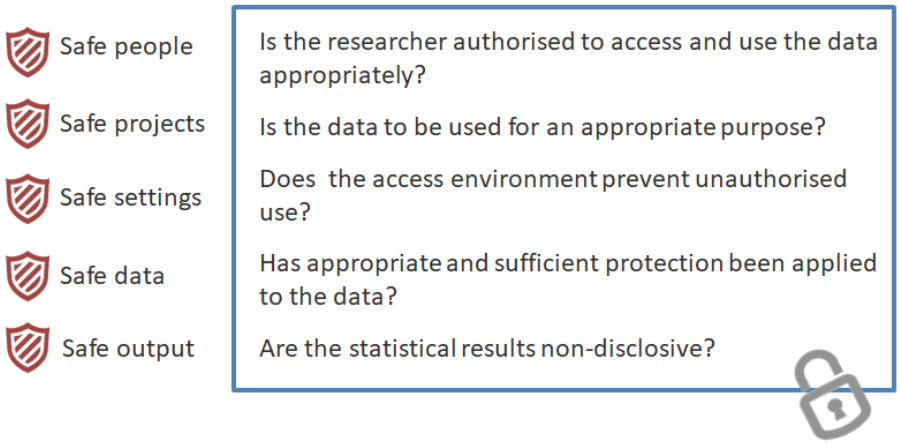
Following linkage, the Spine IDs and the linkage results will be securely transferred to the Assembler holdings. Personal identifiers are not transferred as part of this process. The Assembly team uses the transferred information to bring analytical variables from different datasets together into an Assembled Analytical File. This is conducted in line with conditions of use set by data custodians. Additional checks are applied to ensure that the IDs on the Assembled Analytical File are replaced with analytical IDs before it is transferred out of the SDII and made available to approved analysts through the ABS DataLab. Analytical variables are also checked to ensure that any data that could create a credible risk of data users spontaneously recognising individuals are detected and treated to mitigate the risk before the information is released for analysis.

Data access

The ABS provides access to the Microdata to authorised researchers in the highly secure ABS DataLab. The DataLab is the ABS' data analysis solution for high-end users to undertake interactive (real-time) complex analysis of microdata. The ABS manages access to integrated data by using the Five Safes Framework – an internationally recognised approach to managing disclosure risk summarised in Figure 3. Access to integrated data in the DataLab will be available to analysts, subject to ABS and data custodian approval. For this project, only approved researchers from the Institute and ABS will have access to the analytical data in DataLab.

Resources such as the Responsible Use of Microdata Guide and DataLab safe researcher training outline the process and limitations of using Microdata. Information on researcher access and conditions is covered in the MADIP PIA Update.

Figure 3 – The Five Safes Framework



Releasing outputs

The ABS checks all data outputs produced by researchers in the DataLab, and only aggregated information can leave the DataLab.

All outputs are vetted and if necessary treated by specialised ABS staff. This process controls the risk of individuals being reidentified through aggregate outputs, such as through unusual combinations of data items. The output vetting process assumes that the outputs will be publicly released, even if that is not the researcher's intention.

Third party requests for data

The ABS is unable to respond to law enforcement requests or the provision of data under Freedom of Information (FOI) requests. Under the *Census and Statistics Act 1905*, the ABS cannot release information in a manner likely to enable the identification of individuals and organisations. ABS and seconded officers are legally bound to uphold the confidentiality of MADIP information.

PART C – PRIVACY IMPACT AND PRIVACY PRINCIPLE ASSESSMENT

This section analyses how the Institute data linked to the MADIP asset will impact privacy, based on the Australian Privacy Principles and NSW Health Privacy Principles.

3.1 Openness and transparency

ABS openness

The ABS Privacy Policy for Statistical Information outlines how personal information is collected and handled by the Bureau. The policy specifically references use of personal information for data integration:

> *We use your personal information only to perform our work under the Census and Statistics Act 1905 and the Australian Bureau of Statistics Act 1975. This can include combining your information with other sources of data to help policy makers and researchers gain a better understanding of Australia. This is known as data integration. This often helps reduce the number of questions you need to answer when completing a survey.*

The ABS also has privacy statements that guide how the ABS handles personal information for specific projects. Treatment of personal information in this project will take place in accordance with the MADIP Privacy Policy.

Both these policies meet the requirements of privacy policies outlined in APP 1.4:

> *1.4 Without limiting subclause 1.3, the APP privacy policy of the APP entity must contain the following information:*
> *(a) the kinds of personal information that the entity collects and holds;*
> *(b) how the entity collects and holds personal information;*
> *(c) the purposes for which the entity collects, holds, uses and discloses personal information;*
> *(d) how an individual may access personal information about the individual that is held by the entity and seek the correction of such information;*
> *(e) how an individual may complain about a breach of the Australian Privacy Principles, or a registered APP code (if any) that binds the entity, and how the entity will deal with such a complaint;*
> *(f) whether the entity is likely to disclose personal information to overseas recipients;*
> *(g) if the entity is likely to disclose personal information to overseas recipients—the countries in which such recipients are likely to be located if it is practicable to specify those countries in the policy.*

To promote transparency, the ABS' Data Integration Project Register details all approved MADIP projects, including this project.

3.2 Anonymity and pseudonymity

Use of identifying data for this project is compliant with the requirements of privacy principles and relevant legislation.

As set out in the MADIP PIA Update, APP 2 is not relevant to the day to day operation of MADIP. Some limited anonymity is provided in relation to general browsing of the ABS website and accessing information resources related to MADIP. The ABS also provides the ability in some surveys for anonymity. Otherwise, data in MADIP and the data

used in this project, is covered by the exception to anonymity and pseudonymity requirements provided under APP 2.2(b):

Two identified exceptions under APP 2.2 state that an APP entity is not required to provide those options where:

- *the entity is required or authorised by Australian law or a court or tribunal order to deal with identified individuals (a), or*
- *it is impracticable for the entity to deal with individuals who have not identified themselves (b).*

3.3 Collection of solicited personal information

Collection of data for this project meets the requirements of the privacy principles and relevant legislation.

Data collected by the ABS

ABS processes meet the requirements of APP 3, which describe the collection of solicited personal information. APP 3.3 states that:

An APP entity must not collect sensitive information about an individual unless:

(a) the individual consents to the collection of the information and:

(i) if the entity is an agency—the information is reasonably necessary for, or directly related to, one or more of the entity's functions or activities; or

(ii) if the entity is an organisation—the information is reasonably necessary for one or more of the entity's functions or activities; or

(b) subclause 3.4 applies in relation to the information.

Subclause 3.4 (a) states that an APP entity may collect sensitive information about an individual where:

the collection of the information is required or authorised by or under an Australian law or a court/tribunal

The ABS is authorised to collect, compile, analyse, and publish statistics under the *Australian Bureau of Statistics Act 1975* and the *Census and Statistics Act 1905*. In particular, the ABS is authorised by these laws to undertake surveys and the Census, to collect information from other government entities, to link Census data and other information, to produce statistics for analysis, and to publish statistical outputs. The ABS also complies with the *Privacy Act 1988 (Cth)* and handles personal information in accordance with the Australian Privacy Principles. Data collected by the ABS and used for MADIP are protected by the secrecy provisions of the *Census and Statistics Act 1905*.

As the collection of sensitive information is authorised under an Australian law the ABS is compliant with APP 3.3(b) and 3.4(a). This authority is also relevant to APP 3.5 which states that:

an APP entity must collect personal information only by lawful and fair means.

The Institute's disclosure to the ABS of its data sets is compliant with the Health Records and Information Privacy Act 2002 (NSW) (see discussion in section 3.6). As such ABS' collection of the data sets is by lawful and fair means.

APP 3.6 covers the fact that the ABS is not collecting personal information directly from individuals. In order to collect personal information collected by the Institute, the ABS relies on the impracticability of collecting data directly from individuals under APP 3.6 (b):

> *3.6 An APP entity must collect personal information about an individual only from the individual unless:*
> *(b) it is unreasonable or impracticable to do so.*

As the Accredited Integrating Authority, the ABS' collection of personal information for MADIP occurs via data that are directly collected by data custodians or entities authorised by data custodians and then disclosed to the ABS. The ABS follows OAIC guidelines and takes a broad interpretation of the term 'collection' for APP 3, and applies it to data disclosed to the ABS for MADIP.

Further information on how APP 3 relates to MADIP can be found in the MADIP PIA Update.

3.4 Dealing with unsolicited personal information

The dealing with unsolicited personal information for this project meets the requirements of the privacy principles and relevant legislation.

The data that will be acquired by the ABS in this project has been collected using predefined fields to minimize the receipt of unsolicited personal information.

The process for dealing with unsolicited information if received in this project will follow recommendations and suggestions from the MADIP PIA Update, and in accordance with APP 4.

3.5 Notification of the collection of personal information

Data collected by the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to notification of the collection of personal information.

The following recommendations are made to increase transparency about the collection and use of data for MADIP, in line with best practice.

1. **The ABS will advocate with entities responsible for collection notices to enhance transparency about their disclosure of personal information to the ABS for MADIP by taking reasonable steps to update notices or otherwise make individuals aware of data disclosure and use.**
2. **The ABS will continue to increase transparency about the collection and use of data, including personal information, for MADIP in online materials.**

The MADIP PIA Update outlines the ABS compliance to APP 5 as per the ABS' role as a data custodian and an Accredited Integrating Authority.

The ABS cannot update the collection notices of other entities that have data in MADIP, though it can request entities, such as the Institute, to review and if required update their practices prior to data integration projects commencing. It is not reasonable for the ABS to directly notify, such as through a letter, each individual who provides information for these collections. Instead, the ABS relies on the collection notices of the entities that share data with the ABS for the

use in the MADIP asset, other steps these entities may take to notify individuals, and other steps the ABS takes to build awareness of the collection and use of personal information in the MADIP asset. However, the sharing of data to the ABS by data custodians for MADIP only occurs where authorised delegates from each party have approved the sharing of the data. This is managed through the data sharing arrangements and governance documentation for MADIP.

A key privacy right for individuals is to be notified of what personal information is being collected about them, and to whom it will be disclosed amongst other aspects enumerated in APP 5.

APP 5.1 requires that the ABS takes reasonable steps to notify or ensure an individual is made aware of certain matters:

> *5.1 At or before the time or, if that is not practicable, as soon as practicable after, an APP entity collects personal information about an individual, the entity must take such steps (if any) as are reasonable in the circumstances:*
> *(a) to notify the individual of such matters referred to in subclause 5.2 as are reasonable in the circumstances; or*
> *(b) to otherwise ensure that the individual is aware of any such matters.*

Matters that are to be notified are covered in APP 5.2 and include:

> *(i) the APP entity collects the personal information from someone other than the individual (APP 5.2 (b) (i);*
> *(ii) if the collection of the personal information is required or authorised by or under an Australian law or a court/tribunal order — the fact that the collection is so required or authorised (including the name of the Australian law, or details of the court/tribunal order, that requires or authorises the collection) (APP 5.2 (c));*
> *(iii) the purposes for which the APP entity collects the personal information (APP 5.2 (d));*
> *(iv) the main consequences (if any) for the individual if all or some of the personal information is not collected by the APP entity (APP 5.2 (e));*
> *(v) any other APP entity, body or person, or the types of any other APP entities, bodies or persons, to which the APP entity usually discloses personal information of the kind collected by the entity (APP 5.2 (f)).*

In the case of this project, individuals may be aware that their information is being used by the Institute, but not necessarily for broader research purposes such as being collected by the ABS for statistical purposes including data integration activities and disclosed to authorised researchers.

The ABS will raise public awareness about the Project by including it on the MADIP Project Register.

As outlined in section 3.1, the ABS Privacy Policies reference use and disclosure of personal information for data integration.

Data collected by the Institute

The Institute has advised it is compliant with HPP 4.1, which relates to Individuals being made aware of how their personal information may be used. The HPP states:

> *(1) An organisation that collects health information about an individual from the individual must, at or before the time that it collects the information (or if that is not practicable, as soon as practicable after that time), take steps that are reasonable in the circumstances to ensure that the individual is aware of the following—*
> *(a) the identity of the organisation and how to contact it,*
> *(b) the fact that the individual is able to request access to the information,*
> *(c) the purposes for which the information is collected,*
> *(d) the persons to whom (or the types of persons to whom) the organisation usually discloses information of that kind,*
> *(e) any law that requires the particular information to be collected,*
> *(f) the main consequences (if any) for the individual if all or part of the information is not provided.*

The Institute takes reasonable steps to notify participants, in compliance with HPP 4.1. Participants in all three Institute datasets are advised that data will be used for research purposes through the Privacy Leaflet for Patients. The leaflet document provides most of the information outlined under HPP 4.1.

In relation to HPP 4.1 (d) above, the following are some of the disclosure cases outlined:

> *to State and Commonwealth government agencies for statutory reporting purposes, such as to report infectious diseases, cancer and other notifiable diseases, to report births and deaths, and to provide Medicare details to researchers for public interest research projects as approved by a Human Research Ethics Committee*

While research purposes are addressed, there is a risk that participants may not be aware that this could entail data being provided to other organisations such as the ABS. Provision of data to State or Commonwealth government agencies for statutory reporting purposes is covered, but other purposes such as research via data integration are not.

To address the above concerns, it is recommended that the ABS **advocates with entities responsible for collection notices to enhance transparency about their disclosure of personal information to the ABS for MADIP by taking reasonable steps to update notices or otherwise make individuals aware of data disclosure and use.** The incorporation of data integration as a data use would help address community expectations of how their data may be used.

The following sections provide a summary of the specific notifications given for each of the Institute datasets, in addition to the Privacy Leaflet for Patients:

BreastScreen NSW

Prior to a breast screening appointment, or at the time of the appointment, individuals are provided with a fact sheet that notifies them about the personal and health data collected by the program.

Women attending screening services offered by BreastScreen NSW provide informed consent for data collection prior to participating in screening. The consent form mentions that de-identified screening records will be used to

contribute to breast cancer research and that BreastScreen data is routinely matched to other relevant databases (such as the NSW Cancer Registry).

There is an inconsistency between information provided in the Privacy Leaflet for Patients and the consent information received by Breast Screen participants (these documents can be found in Appendices 7 and 9). While the Privacy Leaflet states that the law allows personal information to be disclosed to third parties in certain situations, such as the usage cases outlined above, the Breast Screen consent form states the following, which precludes the research use outlined above without consent:

> *Unless required by law, your consent will always be obtained before your personal information is provided to any third parties outside of BreastScreen NSW.*

This may cause confusion within the community about the disclosure of BreastScreen data outside of the NSW Health ecosystem.

Detailed information on privacy of BreastScreen data is publicly available on the Cancer Institute NSW Privacy website.

NSW Pap Test Register

The NSW Pap Test Register is a statutory collection under the NSW *Public Health Act 2010*. Information such as a fact sheet (see Appendix 8) is provided to women when a cervical screening test is performed. This fact sheet and a letter sent to women after their results have been received states that the information they provided can only be disclosed to them or:

- [their] Health Practitioner;
- the laboratory that processed the test;
- ethically approved cervical cancer research projects, (such as this project).

The information contained in the Pap Test Register is collected by pathology laboratories as part of routine patient care. Informed consent is sought from the clinician collecting the pathology sample for the test to be conducted, and the clinician may include a discussion on the collection and use of data as part of this process.

Detailed information is publicly available on the National Cancer Screening Register website. A Questions and Answers page is also publicly available.

NSW Cancer Registry

The NSW Cancer Registry is a statutory collection under the NSW *Public Health Act 2010*. Information on the NSW Cancer Registry is provided to patients by the treating clinician at the time of cancer diagnosis and notifies them about the purpose of these data collections.

The information contained in this dataset is collected by mandatory notifiers from hospitals, pathology laboratories, radiotherapy and medical oncology departments, as part of routine patient care. Informed consent is sought from the clinician for clinical care to be provided, and the clinician may include a discussion on the collection and use of data as part of this process.

Detailed information on the NSW Cancer Registry is available here.

For all three datasets described above, the Institute has advised it is not reasonable to advise every person in their datasets that data is being used for this linkage project. It is worth noting that the Institute data has been collected

over a period of 45 years; use of the data has changed substantially over this time; and integration projects such as this have only become a data use in recent years. In addition to the patient leaflet and consent forms mentioned above, the Institute has information available on its website about the NSW Cancer Registry, about cancer screening services, and about its privacy practices generally, including how people may seek access to the health information held about themselves. Making this information available publicly are examples of reasonable steps the Institute takes to reassure compliance with this Privacy Principle.

3.6 Use or disclosure of personal information

This project meets the requirements of the privacy principles and relevant legislation with regards to use or disclosure of personal information.

Data collected by the ABS

ABS is collecting personal information from the Institute under section 9.1 of the *Census and Statistics Act 1905*, and is using and disclosing it for the primary purpose it was collected. That is, to prepare an integrated data asset which enables the pilot project assessing demographic and socioeconomic factors relating to cancer and cancer screening. The personal information will not be used or disclosed for any other (secondary) purpose. This is consistent with APP 6.1, which states:

> *6.1 If an APP entity holds personal information about an individual that was collected for a particular purpose (the **primary purpose**), the entity must not use or disclose the information for another purpose (the **secondary purpose**) unless:*
> *(a) the individual has consented to the use or disclosure of the information; or*
> *(b) subclause 6.2 or 6.3 applies in relation to the use or disclosure of the information.*

Data collected by the Institute

Institute disclosure of all three Institute datasets to the ABS for use in this data integration project is from the Institute's point of view a secondary purpose of their data collection. This disclosure of the data for a secondary purpose is authorised under the *Health Records & Information Privacy Act 2002 (NSW)*. In particular, HPP 11.1 (f) authorises the disclosure of Institute data for:

> *research or the compilation or analysis of statistics in the public interest where the use or disclosure is in accordance with Statutory guidelines issued by the NSW Privacy Commissioner.*

These Statutory guidelines are consistent with and mirror the guidelines developed by the National Health and Medical Research Council (NHMRC) under sections 95 and 95A of the *Privacy Act 1988 (Cth)*. Research requiring use or disclosure of personal health information will need to be considered by a Human Research Ethics Committee.

The Institute will not provide the data to the ABS for this project unless and until such ethics committee approvals are granted.

On this basis it is considered that there is a low privacy risk in relation to the disclosure of personal information for this project.

A key privacy right for individuals is to be aware of how personal information about them is being used. While disclosure of this information to the ABS may be authorised under law, this usage may not be expected by the community. This was discussed more fully in section 3.5 where a recommendation was made for the ABS to advocate for and improve awareness of how data owned by other custodians may be used or disclosed.

3.7 Direct marketing

The ABS does not use or disclose personal information for direct marketing purposes. APP 7 does not generally apply to agencies apart from some prescribed agencies (who engage in particular activities of a commercial nature). The ABS is not a prescribed agency and therefore APP 7 does not apply in general to MADIP or this project.

3.8 Cross-border disclosure of personal information

Data collected by the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to cross-border disclosure of personal information.

Cross border data transfers are not currently relevant to MADIP or this project. Data is not transferred or accessed outside of Australia for MADIP. The ABS and its secure ICT environment used for MADIP is fully located in Australia and data custodians (and authorised entities) that disclose personal information to the ABS for MADIP are also located in Australia.

International researchers can apply for access to MADIP data if they are based in Australia, and if approved, the same access provisions apply as if the researcher were Australian.

Data collected by the Institute

The Institute has advised it meets the requirements of HPP 14, in particular HPP 14(h) which states that

> *An organisation must not transfer health information about an individual to any person or body who is in a jurisdiction outside New South Wales or to a Commonwealth agency unless—*
>
> *(h) the transfer is permitted or required by an Act (including an Act of the Commonwealth) or any other law.*

As the data are being collected by the ABS under the *Census and Statistics Act 1905* this HPP is satisfied.

3.9 Adoption use or disclosure of government related identifiers

Data collected by the ABS

This data linking project does not adopt, use or disclose government identifiers.

3.10 Quality of personal information

Data collected by the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to quality of personal information, in particular the expectations defined in APP 10.

The ABS primarily relies on the MADIP data custodians to provide accurate and up to date personal information. For this data integration project, the ABS is relying on the Institute to provide accurate and up to date personal information available from the cancer datasets.

The MADIP PIA Update provides more information about APP 10 for MADIP.

Other data linkage projects undertaken by the ABS have attained a high level of accuracy and data quality; a similar result is expected with this linkage project. Use of the linked data for research purposes is contingent on a high quality data linkage, based on accurate information being available.

3.11 Security of personal information

Security processes at the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to security of personal information, in particular the expectations defined in APP 11.

All personal information collected by the ABS is protected in accordance with the Australian Government Protective Security Policy Framework and with the Australian Government records management requirements.

When no longer required, personal information is destroyed or deleted according to the Administrative Functions Disposal Authority. This is covered in the ABS' internal data retention policy.

ABS staff members undertaking a linkage project cannot see all the information together at any point of the data integration process. This is known as Functional Separation and means:

- Names and addresses are separated from other analytical information prior to integration
- Identifiable information is de-identified in the linkage process (e.g. through encoding) prior to analytical datasets being assembled
- Analytical data provided to researchers does not contain directly identifiable information.

For this project, the files will be provided by CHeReL on behalf of the Institute and loaded into the ABS IT environment, through online secure file transfer portals to the ABS Secure Drop Box, and securely transferred into the Secure Data Integration Environment. The linkage will then proceed in accordance with the ABS data integration procedures described in section 2.2.

Data is unidentified in the linkage process, prior to analytical datasets being assembled for use by researchers. The ABS also only retains personal identifiers as long as a business need exists.

Appendix 6 lists the linking and analytical variables to be provided by the Institute. Once the linkage has taken place the linking variables will be deleted and only the analytical variables will remain in MADIP, thereby further reducing privacy risks.

The linked dataset will not be retained beyond the completion of this project (a minimum of five years and subject to review and approval at that time). This is in accordance with National Health and Medical Research Council recommendations, and all MADIP data custodians involved in the project have approved the project proposal with this retention period. This period will allow for analyses to be conducted, publications to be prepared and published, feedback on these publications to be addressed, and further analyses using these data to be planned and conducted.

The ABS adheres to strong security protocols, such as functional separation of linkage data from other variables, storage of data in a secure environment which requires two separate logins and two factor authentication, and implementation of the Five Safes Framework.

This project complies with the internal ABS data retention policy which ensures that the retention of information is managed in line with the *Census and Statistics Act 1905*, *Archives Act 1983*, and *Privacy Act 1988 (Cth)*.

The MADIP PIA Update provides more information about the security of personal information in MADIP.

Security processes at the Institute

The Institute has advised its security processes are compliant with those outlined under HPP 5.

The Institute adheres to strong security protocols, such as functional separation of linkage data from other variables, storage of data in a secure environment which requires two separate logins and two factor authentication, and implementation of the Five Safes Framework.

Process in case of a data breach

The ABS process to be followed in the case of a data breach is consistent with the Notifiable Data Breaches Scheme.

In the event that an alleged incident involving MADIP data requires escalation, ABS governance processes require it to be reported immediately to relevant data custodians, ABS ICT Security, the ABS Privacy Team, and MADIP senior executive staff. The ABS Data Linkage Centre (DLC) is equipped with an Incident Response Manual, which broadly follows the steps outlined in the OIAC Data Breach Preparation and Response guide.

If a breach occurred as part of research with Institute data it would be reported to the Data Governance team at the Institute, PHSREC, and the AH&MRC Ethics Committee. The research team would be guided by these groups in terms of immediately managing the breach and implementing mitigation methods to prevent any additional breaches from occurring.

3.12 Access to personal information

Data collected by the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to access to personal information, in particular the expectations defined in APP 12.

The ABS has a general exemption to access requests to personal information used to construct and maintain the MADIP asset. For further details see the MADIP PIA Update.

3.13 Correction of personal information

Data collected by the ABS

This project meets the requirements of the privacy principles and relevant legislation with regards to correction of personal information, in particular the expectations defined in APP 13.

The ABS has policies and procedures in place for complaints and the correction of inaccurate data. For details please see the MADIP PIA Update. The MADIP Privacy Policy provides information about requests to correct personal information. In accordance with this policy, the ABS will not be in a position to correct the personal information received from the Institute.

PART D – CONCLUSION

The assessment undertaken in this PIA indicates that measures to be undertaken for this project are appropriate, and that the ABS and Institute are compliant with privacy requirements. Some risks have been identified, particularly in relation to notification that personal information collected will be used and disclosed for data linkage, and recommendations have been suggested to address the concerns.

The PIA Response, which accompanies this PIA, outlines the ABS response to the recommendations made in this PIA, and progress which has already been made towards them.

The ABS will report on the implementation of these recommendations within one year of publication of this PIA.

PART E – APPENDICES

Appendix 1 – Australian Privacy Principle compliance summary

The following table provides a summary of APP compliance for linkage of the Institute data to the MADIP asset. A detailed discussion of each APP can be found in Part C of the report.

APP	Compliance
APP 1 – Openness and transparency	Compliant
APP 2 – Anonymity and pseudonymity	Compliant
APP 3 – Collection of solicited personal information	Compliant
APP 4 – Dealing with unsolicited personal information	Compliant
APP 5 – Notification	Compliant
Recommendations: **1. The ABS will advocate with entities responsible for collection notices to enhance transparency about their disclosure of personal information to the ABS for MADIP by taking reasonable steps to update notices or otherwise make individuals aware of data disclosure and use.** **2. The ABS will continue to increase transparency about the collection and use of data, including personal information, for MADIP in online materials.**	
APP 6 – Use or disclosure of personal information	Compliant
APP 7 – Direct marketing	Not applicable
APP 8 – Cross border disclosure	Compliant
APP 9 – Government related identifiers	Compliant
APP 10 – Quality of personal information	Compliant
APP 11 – Security	Compliant
APP 12 – Access to personal information	Compliant
APP 13 – Correction of personal information	Compliant

Appendix 2 – Acronyms

Acronym	Term
ABS	Australian Bureau of Statistics
APP	Australian Privacy Principle
CHeReL	NSW Health Centre for Health Record Linkage
DIP	Data Integration Plan
HPP	NSW Health Privacy Principles (from *Health Records & Information Privacy Act 2002 (NSW)*)
HREC	NSW Human Research Ethics Committee
MADIP	Multi-Agency Data Integration Project
MOU	Memorandum of Understanding
NHMRC	National Health and Medical Research Council
OAIC	Office of the Australian Information Commissioner
PIA	Privacy Impact Assessment
SDII	Secure Data Integration Infrastructure
the Institute	Cancer Institute NSW

Appendix 3 – Glossary

Term	Description
Accredited Integrating Authority	An agency authorised to undertake high-risk data linkage projects involving Commonwealth data for statistical and research purposes.
Administrative data	Data maintained by governments and other entities, including data used for registrations, transactions, and record keeping, usually during the delivery of a service.
Australian Privacy Principles	Principles contained in the *Privacy Act 1988 (Cth)* that regulate the way personal information is collected, stored, accessed, used and disclosed.
Data custodian	The agency that collects or generates data for any purpose, and is accountable and responsible for the governance of that data.
Data minimisation	The principle of only authorising the collection, sharing and using data that is reasonably necessary for a permitted purpose.
De-identified data	Personal information is de-identified 'if the information is no longer about an identifiable individual or an individual who is reasonably identifiable' (section 6(1) of the Privacy Act). (De-identified data is different to unidentified data - see the meaning of unidentified data.)
Direct identifier	Information which, by itself, is able to identify an individual, organisation, or other entity.
Five Safes Framework	An internationally recognised approach to managing disclosure risk – each 'safe' refers to an independent but related aspect of disclosure risk.
Functional separation	A collection of access controls and procedures to restrict and regulate access to data. Staff are allocated different roles so that no one has the ability to access the identifying details of an individual at the same time as accessing other information about that individual or business.
Interoperability	The ability of data integration systems to exchange and make use of existing linkage results.
Memorandum of Understanding	An agreement between two parties for data to be provided and used for a specific purpose.
Microdata	Data in a unit record file that provides detailed information about people, households, businesses or other types of records.
Personal information	As defined in section 6(1) of the *Privacy Act 1988 (Cth).*
Person linkage Spine	The Person Linkage Spine is the central linking of identifiers for data held within MADIP. Linkage variables are encrypted and are sourced from Medicare, social security and tax information.
Privacy Impact Assessment	A systematic assessment of a project that identifies the impact that it might have on the privacy of individuals, and sets out recommendations for managing, minimising, or eliminating that impact.
Sensitive data	Data that would be considered sensitive information under the *Privacy Act 1988 (Cth)* if the data included personal information
Sensitive information	As defined in section 6(1) of the *Privacy Act 1988 (Cth).*
Separation principle	No individual can access both the identifying information used for linkage, such as name, address and date of birth, together with the analytical information which does not contain direct identifiers.
Unidentified data	Data is considered 'unidentified' when direct identifiers such as name and address are removed or altered into an unidentifiable form. Further confidentialisation or safeguards (such as access controlled through the Five Safes Framework) are often required for the data to be considered de-identified.

Appendix 4 – Summary of the Australian Privacy Principles (APPs)

Principle	Title	Purpose
APP 1	Open and transparent management of personal information	Ensures that APP entities manage personal information in an open and transparent way. This includes having a clearly expressed and up to date APP privacy policy.
APP 2	Anonymity and pseudonymity	Requires APP entities to give individuals the option of not identifying themselves, or of using a pseudonym. Limited exceptions apply.
APP 3	Collection of solicited personal information	Outlines when an APP entity can collect personal information that is solicited. It applies higher standards to the collection of sensitive information.
APP 4	Dealing with unsolicited personal information	Outlines how APP entities must deal with unsolicited personal information.
APP 5	Notification of the collection of personal information	Outlines when and in what circumstances an APP entity that collects personal information must tell an individual about certain matters.
APP 6	Use or disclosure of personal information	Outlines the circumstances in which an APP entity may use or disclose personal information that it holds.
APP 7	Direct marketing	An organisation may only use or disclose personal information for direct marketing purposes if certain conditions are met.
APP 8	Cross-border disclosure of personal information	Outlines the steps an APP entity must take to protect personal information before it is disclosed overseas.
APP 9	Adoption, use or disclosure of government related identifiers	Outlines the limited circumstances when an organisation may adopt a government related identifier of an individual as its own identifier, or use or disclose a government related identifier of an individual.
APP 10	Quality of personal information	An APP entity must take reasonable steps to ensure the personal information it collects is accurate, up to date and complete. An entity must also take reasonable steps to ensure the personal information it uses or discloses is accurate, up to date, complete and relevant, having regard to the purpose of the use or disclosure.
APP 11	Security of personal information	An APP entity must take reasonable steps to protect personal information it holds from misuse, interference and loss, and from unauthorised access, modification or disclosure. An entity has obligations to destroy or de-identify personal information in certain circumstances.
APP 12	Access to personal information	Outlines an APP entity's obligations when an individual requests to be given access to personal information held about them by the entity. This includes a requirement to provide access unless a specific exception applies.
APP 13	Correction of personal information	Outlines an APP entity's obligations in relation to correcting the personal information it holds about individuals.

Source: Office of the Australian Information Commissioner, Australian Privacy Principles Quick Reference.

The Australian Privacy Principles are detailed in Schedule 1 of the Privacy Act 1998 (Cth).

Appendix 5 – Summary of the NSW Health Privacy Principles (HPPs)

Collection	
Lawful	An agency or organisation can only collect your health information for a lawful purpose. It must also be directly related to the agency or organisation's activities and necessary for that purpose.
Relevant	An agency or organisation must ensure that your health information is relevant, accurate, up-to-date and not excessive. The collection should not unreasonably intrude into your personal affairs.
Direct	An agency or organisation must collect your health information directly from you, unless it is unreasonable or impracticable to do so.
Open	An agency or organisation must inform you of why your health information is being collected, what will be done with it and who else might access it. You must also be told how you can access and correct your health information, and any consequences if you decide not to provide it.
Storage	
Secure	An agency or organisation must store your personal information securely, keep it no longer than necessary and dispose of it appropriately. It should also be protected from unauthorised access, use or disclosure.
Access and accuracy	
Transparent	An agency or organisation must provide you with details regarding the health information they are storing, why they are storing it and what rights you have to access it.
Accessible	An agency or organisation must allow you to access your health information without unreasonable delay or expense.
Correct	Allows a person to update, correct or amend their personal information where necessary.
Accurate	Ensures that the health information is relevant and accurate before being used.
Use	
Limited	An agency or organisation can only use your health information for the purpose for which it was collected or a directly related purpose that you would expect (unless one of the exemptions in HPP 10 applies). Otherwise separate consent is required.
Limited	An agency or organisation can only disclose your health information for the purpose for which it was collected or a directly related purpose that you would expect (unless one of the exemptions in HPP 11 applies). Otherwise separate consent is required.
Identifiers and anonymity	
Not identified	An agency or organisation can only give you an identification number if it is reasonably necessary to carry out their functions efficiently.
Anonymous	Give the person the option of receiving services from you anonymously, where this is lawful and practicable.
Transferrals and linkage	
Controlled	Only transfer health information outside New South Wales in accordance with HPP 14.
Authorised	Only use health records linkage systems if the person has provided or expressed their consent.

Source: NSW Information and Privacy Commission, HPPs explained for members of the public

The Health Privacy Principles are detailed in Schedule 1 of the Health Records and Information Privacy Act 2002 (NSW).

Appendix 6 – Linking and analytical variables

Linking variables to be provided for all datasets

- Full name
- Name history (five most recent records)
- Address
- Address history (five most recent records)
- Sex
- Date of birth
- Estimated year of birth (based on age for those with missing date of birth)

Analytical variables to be provided

NSW Cancer Registry

Demographic data elements	Number of primary sites	Remoteness calculation method
Gender	Registry derived-stage (STaR)	Socioeconomic position - IRSAD deciles (ASGC, ASGS)
Country of birth	Registry derived staging basis (STaR)	Socioeconomic position - IRSAD quintiles (ASGC, ASGS)
Aboriginal and Torres Strait Islander status	Mortality data elements	Socioeconomic position – IRSD deciles (ASGC, ASGS)
Year of birth	Year of death	Socioeconomic position – IRSD quintiles (ASGC, ASGS)
Month of birth	Month of death	Socioeconomic position calculation method
Date of birth validity code	Day of death	Local health district
Cancer diagnosis data elements	Age at death	Primary health network
Year of diagnosis	Cause of death cancer type	Episode of care data elements
Month of diagnosis	Cause of death clinical cancer group	Data source type
Day of diagnosis	Cause of death topography code (ICD-O-3)	Episode modality
Date of diagnosis validity code	Cause of death topography code (ICD-10-AM)	Episode start date
Age at diagnosis	Place of death group	Episode end date
Cancer type	Geographical data elements (based on residence at diagnosis)	Facility name
Clinical cancer group	LGA 2006 (ASGC)	Local health district of Facility
Topography code (ICD-O-3)	SLA 2006 (ASGC)	Degree of spread at episode
Topography code (ICD-10-AM)	Remoteness 2006 (ASGC)	TNM staging group
Morphology code (ICD-O-3)	Socioeconomic position – IRSD quintiles (ASGC)	TNM edition
Morphology code 4 digit (ICD-O-3)	LGA 2016 (ASGS)	TNM staging basis
Behaviour code	SA2 2016 (ASGS)	TNM staging timing
Best basis of diagnosis	SA3 2016 (ASGS)	TNM staging date
Degree of spread at diagnosis	SA4 2016 (ASGS)	MDT date
Laterality	GCCSA 2016 (ASGS)	Performance status (ECOG)
Breslow thickness of melanoma / Size of breast cancer	Remoteness (ASGC, ASGS)	

BreastScreen NSW

Client Segment	Assessment Visit Segment	Histopathology Segment
Date of Birth (Year, Month)	Date of first attendance for assessment	Reason for histopathology
Postcode of usual residence	Percutaneous needle biopsy performed	Date of diagnosis of interval cancer
Main language other than English spoken at home	Percutaneous needle biopsy guidance method	Histopathology of non-malignant lesions
Indigenous status	Percutaneous needle biopsy result	Histopathology of Malignant Lesions
Family history of breast cancer	Final result of assessment visit	Size of tumour
Family history of breast cancer—relationship	Recommendation—assessment	Histological grade
Family history of breast cancer—age at diagnosis	Assessment visit—date	Primary Treatment Segment
Family history of breast cancer—laterality	Local Excision of Lesion Segment	Nature of primary treatment
Previous history of breast cancer	Local excision performed	Date of commencement of treatment
Previous history of breast cancer—year	Date excision performed	Side of malignancy
Round number	Marking method	Surgical treatment
Symptom status	Lesion removal	Radiotherapy
Screening Visit Segment	Local excision result	Chemotherapy
Appointment Booking Date	Date of definitive diagnosis	Metastasis—distant
Date of first attendance for this episode	Recommendation—definitive	Death Segment
Recommendation—screening		Date of Death
		Underlying cause of death

Pap Test Registry

Date of Birth (Year, Month)	Overall Cytology Result	Overall Histology Result
Age at Test	Cytology Type code	Histology Codes (up to 10 SNOMED International codes)
Residential Postcode at time of test	Cytology Site code	HPV Test Type code
Cervical Test Data	Cytology Squamous Cell code	HPV Test Result code
Date of Test/Test Request Date	Cytology Endocervical code	HPV Sampling Method code
Cervical Test Type (Cytology, Histology or HPV DNA)	Cytology Other/non-cervical code	
	Cytology Recommendation code	

Appendix 7 – CINSW Privacy Information for Patients leaflet

Security of your health information

We follow strict government standards regarding the secure storage of your health information in all formats. We regularly enhance and audit our systems in order to protect your information from unauthorised access, loss or other misuse.

NSW public health services hold health information in paper records, on local electronic medical record systems and the NSW HealtheNet.

HealtheNet is a secure state-wide electronic record used by the NSW public health service. HealtheNet contains a summary of your health information, for example, your discharge summaries, pathology and diagnostic test results and medication information.

If you attend a public health service anywhere in NSW, in most cases this summary information will be available to your treating clinical staff via HealtheNet.

My Health Record

My Health Record is Australia's national digital health record system. All Australians have a My Health Record, unless you choose not to have one.

If you have attended a NSW public health service, a summary of your health information will be sent to your My Health Record. NSW public health staff may also view, and send information to, your My Health Record.

If you have a My Health Record, but do not wish for your information from a particular doctor's appointment or hospital visit to be included in your My Health Record, you must inform the health provider at the beginning of your visit.

For further information about My Health Record, telephone 1800 723 471, or go to: www.myhealthrecord.gov.au

NSW GOVERNMENT | Health

Contact us

If you have questions or a complaint about the privacy of your health information, please contact the Privacy Contact Officer at the NSW Health agency which holds your health information.

Please go to: www.health.nsw.gov.au/patients/privacy/Pages/privacy-contact.aspx

Translating and Interpreting service

If you require assistance with contacting the above services or require translation, please call the Translating and Interpreting Service (TIS) on 13 14 50.

For a privacy information leaflet in other languages, visit the Multicultural Health Communication Service at:

www.mhcs.health.nsw.gov.au

Privacy Leaflet for Patients

How we protect your health information

NSW GOVERNMENT | Health

Collection of your health information

To provide you with appropriate treatment, we may collect a range of health information about you. This may include information about your health, your pathology and diagnostic test results, x-ray and other imaging, and information about your medication.

We collect health information directly from you wherever possible. If this is not possible, or in an emergency, we may refer to your previous health records, other health care providers and your My Health Record.

We may also need to collect information from a family member, friend, carer or other person such as an interpreter who can help us to provide you with appropriate health care.

Use or disclosure of your health information

Your health information may be used by the NSW public health service, or disclosed outside the health service, to enable appropriate care and treatment to be provided to you.

For example, your information may be used or disclosed as follows:

- to other health services, hospitals or medical specialists involved in your health care.
- to your nominated GP, including information provided with your discharge referral documents.
- to the Ambulance Service of NSW.
- to My Health Record.
- to contact you at home regarding follow-up appointments.
- to your carer to assist with your care.
- to contact you for feedback on the services you have received.
- to pastoral care workers, including hospital chaplains, providing spiritual and pastoral care.
- to students and other staff for training purposes.
- to other health services and authorised third parties to help prevent a serious and imminent threat to someone's life, health or welfare, such as in an emergency.
- for purposes relating to organ or tissue donation. This may include next of kin contact details.
- for operational and management activities, including funding, planning, safety and quality improvement.
- to investigate a complaint or incident.
- to manage a legal action or claim brought by the patient against the health service.

If you do not wish for us to collect, use or disclose certain information about you, you will need to tell us and we will discuss with you any consequences this may have for your health care.

The law also allows or requires your health information to be disclosed to other third parties, for example:

- to State and Commonwealth government agencies for statutory reporting purposes, such as to report infectious diseases, cancer and other notifiable diseases, to report births and deaths, and to provide Medicare details.
- to researchers for public interest research projects as approved by a Human Research Ethics Committee.
- to other health services or law enforcement agencies, such as the police, if you provide us with information relating to a serious crime, including serious assault, domestic violence or child abuse.
- to other agencies where the information relates to the safety, welfare or wellbeing of a child or young person.
- to comply with a subpoena or search warrant if your health information is required as evidence in court.

National Disability Insurance Scheme

If you, or someone on your behalf, provide us with a copy of your NDIS Plan or other NDIS documents, we may use or disclose this information for purposes related to your health care and social services. This may include sharing information with other government agencies, private sector or non-government organisations to help health and non-health services meet your needs.

Access to your information

You are entitled to request access to your health information held by us. Normally you will be asked to apply for access in writing and provide identification. You may be charged a fee if you request copies of your health record. We respond to requests for access to information as soon as possible, and in most cases no later than 28 days.

Access to your information may be declined in special circumstances, such as where giving access would put you or another person at risk of mental or physical harm.

If you believe the information we hold about you is incorrect or an error has been made, please let us know and we will correct it or add a notation to your health record.

Requests for access to your health record should be addressed either to the Medical Records Department or to the manager of the health service facility you attended.

Appendix 8 – NSW Pap Test Register leaflet

Where can I have a Pap Test?

Please Note: The NSW Pap Test Register does not make appointments.

Most women have their Pap test taken by a general practitioner. Some women prefer to attend a community health service or a women's health centre, where Pap tests are usually taken by specially trained Women's Health Nurses.

To find somewhere to have your Pap test please visit our online provider directory at www.csp.nsw.gov.au or ring the NSW Pap Test Register Information Line on 1800 671 693 (free call in NSW).

What should I do if I change my name or address?

Please inform the Register if you change your name or address so that you can receive follow-up or reminder letters when required.

To update your details on the Register:

- Visit our website and submit your request online.
- Complete and send the "Change of Name or Address Advice" slip on the back of the Pap Test Register envelope.
- Send an email to nswpaptest@cancerinstitute.org.au.
- Ring the Information Line on 1800 671 693 (free call in NSW)
- Post your request to the Register.

Sometimes the Register may update your information

To enable us to contact you when necessary the Register may check your address details with the NSW Electoral Roll and/or Medicare to ensure we have the correct information – for example when letters we send you are returned.

The NSW Pap Test Register values your privacy

Remember - We're here to help

The Register operates a free call Information Line on 1800 671 693 which you can call between 9:00am and 5:00pm Monday to Friday if you require further information about the Register or have any questions.

If you would like this information in your own language, please call the Translating & Interpreting Service (TIS) on 13 14 50 between 9:00am and 5:00pm Monday to Friday.

How to contact the Register

Mail: NSW Pap Test Register
Locked Bag 9014
Alexandria NSW 1435

Ph: 1800 671 693 (free call within NSW)
(02) 8374 5692
Fax: (02) 8374 5695

Email: nswpaptest@cancerinstitute.org.au
Web: www.csp.nsw.gov.au

Additional cancer screening and prevention information can be found at www.cancerinstitute.org.au

The Cancer Institute NSW is responsible for the management of the NSW Pap Test Register which is a key component of the NSW Cervical Screening Program.

NSW Pap Test Register

We're Here to Help

Pap Test Register

NSW GOVERNMENT

cancer institute NSW

The NSW Pap Test Register:

We're Here to Help

What is the NSW Pap Test Register?

The NSW Pap Test Register is a secure and confidential database of women's Pap tests and related follow-up test results. The Register was established by the NSW Public Health Act 1991 and commenced operation in July 1996.

The Register is key to the NSW Cervical Screening Program which aims to reduce the incidence of, and mortality from preventable cervical cancer.

The Register provides a follow-up and reminder service to encourage women to have regular Pap Tests.

The NSW Pap Test Register is operated by the Cancer Institute NSW as part of the Commonwealth and State funded NSW Cervical Screening Program.

How can we help?

The Register is a health safety net that can help you by:

- sending you a reminder letter if you are overdue for your next Pap test;
- working with your health practitioner to make sure you have had follow-up care if you have an abnormal test result;
- keeping a history of your results to provide information to help both the laboratory analysing your Pap test and your health practitioner;
- assisting in the gathering of information that will help improve our understanding of cervical cancer and its treatment.

All women aged 18 to 69 who have ever had sex are advised to have a Pap test every two years - even if you have had the Human Papilloma Virus (HPV) vaccination.

The Choice Is Yours

Being included on the Register is voluntary, almost 100% of all women who have a Pap test are on the Register. If you do not want your name and address to be included on the Register, **tell your health practitioner at the time of your test** and ask them to mark your test clearly "not for Pap Test Register".

When you have a Pap test, cervical biopsy or HPV DNA test, your information will automatically be sent to the Register by the laboratory processing your test.

You will be sent a 'Welcome' letter the first time the Register receives your personal details so that you know that you have joined the Register.

You can withdraw your details from the Register at any time by writing to the Register. Your name and address will then be removed. However, your date of birth and test results will remain on the Register to assist in monitoring and evaluating the Cervical Screening Program.

If you choose not to participate in the Register you will not be sent a reminder letter when you are overdue for a test. Also, your test histories will not be available to assist the laboratory in analysing any new cervical test.

What information is recorded on the Register?

- Your name, address, ethnicity, and date of birth;
- Details of the health practitioner who took the test;
- The date of the test and the name of the laboratory that processed it;
- The results of Pap tests, cervical histology tests or HPV DNA tests.
- Your HPV vaccination status.

Please contact the Register if you wish to access any of your information recorded on the Register.

The NSW Pap Test Register is a health safety net for NSW women.

A Pap smear every two years can prevent the most common form of cervical cancer in up to 90% of cases and is the best protection against cervical cancer.

Are my results kept confidential?

Yes. The Register will ensure that all your information is only disclosed to you or:

- your Health Practitioner;
- the laboratory that processed the test;
- ethically approved cervical cancer research projects;

in accordance with the NSW Public Health Act 2010 and the NSW Health Records and Information Privacy Act 2002.

Why should I have a Pap Test?

A Pap test can detect early cell changes in the cervix long before you would notice any symptoms. Most of these changes are **not** cancer, but may lead to cancer later on, if they continue to progress. These changes can be monitored or treated before cancer has a chance to develop.

Who should have a Pap Test?

All women aged 18 to 69 who have ever had sex are advised to have a Pap test every two years or as recommended by your health practitioner - even if you have had the Human Papilloma Virus (HPV) vaccination.

Please remember that a Pap test is a screening test, and may fail to detect abnormalities in a small number of women.

If you have symptoms, such as unusual bleeding or discharge, see your health practitioner as soon as possible, even if your last Pap test was normal.

Appendix 9 – NSW Breast Cancer consent form

Consent for Screening Mammogram

Please read the information below and overleaf before signing the consent statement and bring this with you to your appointment.
If you have any questions please ask one of the staff before signing it.

General Information

BreastScreen NSW is part of a national program, BreastScreen Australia, which is jointly funded by the Federal and state and territory governments. The BreastScreen NSW Coordination Unit is managed by the Cancer Institute NSW and has oversight of the program in NSW. Screening mammograms and any other clinical procedures required for a diagnosis, are delivered by Screening and Assessment Services which are located in all metropolitan and rural regions and are managed within the NSW Local Health Districts.

What should I do before my appointment?

- You should wear a skirt or trousers and a top rather than a dress as you will need to undress from the waist up for the mammogram
- Please do not wear deodorant, talcum powder or creams on the day of your mammogram
- Complete the registration form and bring it to your appointment
- If your last mammogram was not at BreastScreen NSW, please bring any images (breast x-rays) with you when you come for your appointment.

What will happen at BreastScreen NSW?

Your appointment will take about 20 minutes. The receptionist will collect your forms and explain the screening process to you. The female radiographer will take you into the x-ray room. She will lead you to a private area where you can undress from the waist up.

During your mammogram the radiographer will take at least two x-rays of each breast. Your breast will be firmly compressed for about 10 seconds while the x-ray image is taken. This compression may be uncomfortable, but is only for a brief time. If you feel any discomfort, tell your radiographer. You can stop the mammogram at any time.

Is it safe?

As with any x-ray, a very low amount of radiation is needed when taking a mammogram. Research shows the benefits of having a mammogram to find the breast cancer early far outweigh any possible risks from radiation. Occasionally the compression can result in breast tenderness or bruising but this does not last for very long.

How will I get my results?

At least two specially trained doctors will independently read your x-ray images. You will receive **the results of your mammogram in writing within 2 weeks.** With your permission, the results will also be sent to your doctor.

How often should I have a screening mammogram?

If you are aged 50-74, regular screening is important and we recommend screening every two years. If you have a family history of breast cancer or have previously had breast cancer or other breast disease, BreastScreen NSW will assess how frequently you should be screened.

Can every breast cancer be found?

A mammogram is the best way of detecting cancer early, but like other screening tests, is not 100% accurate.

Not all cancers will be detected through screening. Some cancers cannot be seen on a mammogram or can develop during the time between mammograms. There is also a small chance that a cancer could be missed on a mammogram.

Most breast cancers found through BreastScreen NSW would grow and be life-threatening if not treated. However, some breast cancers that are found and treated may not have become life-threatening. At this time, it is not possible to tell exactly which breast cancers are life-threatening and which breast cancers may not be. More information about mammographic screening for women can be found on the BreastScreen NSW website in the "BreastScreen and You" brochure.

As well as having a regular screening mammogram every 2 years, it is important you get to know the normal look and feel of your breasts. If you find a breast change that is unusual for you, we recommend that you do not visit BreastScreen NSW, but see your doctor without delay.

Information Privacy

What information does BreastScreen NSW need and how is it used?

Your privacy is important to BreastScreen NSW. The information collected enables us to provide you with a high quality screening service. We are committed to protecting your privacy and ensuring that your information is secure and safe at all times.

In accordance with the Health Records and Information Privacy Act 2002 we follow strict rules and policies regarding the secure storage of personal information in all formats in order to protect your information from unauthorized access, loss or other misuse. To enable appropriate health care to be provided to you, your personal information may be shared by health organisations, for instance, between a private service provider, the Local Health District and Cancer Institute NSW and other state BreastScreen services. Unless required by law, your consent will always be obtained before your personal information is provided to any third parties outside of BreastScreen NSW.

The NSW Health Privacy Leaflet for Patients provides further information. This is available from the NSW Health website www.health.nsw.gov.au or you can ask the BreastScreen service staff for a copy.

Your name and address is stored on the confidential BreastScreen NSW database so that BreastScreen NSW can send your mammogram result and contact you for any other follow up if needed. If you are aged 50 - 74, the information is also used to remind you when your next screening mammogram is due. BreastScreen NSW needs the results of any additional breast tests needed after your screening mammogram, as these results help complete our records and determine when your next screening mammogram is due.

Can I access my records?

You are entitled to request access to all personal information including your health records held by BreastScreen NSW. Normally you will be asked to apply for access in writing and provide identification. You may be charged a fee if you request copies of your personal information or health record. Requests for access to information will be responded to as soon as possible, or in most cases no later than 28 days.

If you believe the information we hold about you is incorrect or an error has been made, please let us know and we will correct it or add a notation to your health record.

Requests for access to your health record should be addressed to your local screening service.

If you have a general privacy enquiry or a complaint, please contact:

The Privacy Officer
Cancer Institute NSW
PO Box 41, Alexandria NSW 1435
Tel: (02) 8374 5600
Email: information@cancerinstitute.org.au

SMR020.175

Holes Punched as per AS2828.1: 2012
BINDING MARGIN - NO WRITING

NH&MRC 241116

How does BreastScreen NSW use my screening records?

BreastScreen NSW will use your de-identified mammogram and other health information for:

- training purposes
- monitoring and reporting our performance to organisations such as the Australian Institute of Health and Welfare
- improving the quality of BreastScreen NSW's service and breast cancer outcomes
- contributing to breast cancer research.

De-identification means that all identifying personal details are removed from the health information that is used.

To evaluate and improve the effectiveness of the BreastScreen NSW Program, information held in the BreastScreen NSW database is routinely matched to other relevant databases, such as the NSW Cancer Registries.

If my screening episode results in a diagnosis of cancer, in what other ways is my information used?

Most women who have a mammogram through BreastScreen NSW will receive a normal result letter. Less than 10% of women will be asked to return for further tests (assessment). Most women (about 9 out of 10) who need assessment will be reassured that they do not have breast cancer.

If you are diagnosed with cancer, your treating health service and pathology laboratories are required by law to notify your cancer diagnosis to the NSW Cancer Registry, in accordance with the Public Health Act 2010 (NSW). The NSW Cancer Registry is not provided with any information directly from BreastScreen NSW.

Consent for women with a disability

Some women with a physical or intellectual disability are willing to undergo screening, but may be unable to sign the consent section. It is important that a woman with a disability is given the opportunity to make an informed decision, to the best of her ability, about having a screening mammogram. If the woman is unable to formally indicate her decision by signing the consent statement, BreastScreen NSW staff will be guided by her willingness to proceed and obtain a signature from her guardian or another person responsible. This will be noted in her records.

Information for Women with Breast Implants

Please ensure you read the brochure "Information for women with breast implants" before you sign the consent. Please note the following:

- you may require additional images to be taken using different techniques
- the breast implant may make it more difficult to see possible breast cancers
- minimal compression is used for women with breast implants, and while unlikely, it is possible that compression may:
  - Cause or worsen existing damage to implants
  - Cause possible changes in the shape or texture of the breast
- BreastScreen NSW does not assess the condition of implants. Please discuss any concerns about your implants with your doctor.

By signing the consent statement, I agree to the following:

- To have a screening mammogram
- That I understand that there is a small chance that screening mammography might not find an existing cancer
- That I have read this information sheet, and the information sheet for women with implants (if appropriate)
- That BreastScreen NSW can use the information I have provided to contact me for follow up, including invitations to my next screening
- That BreastScreen NSW can contact other providers for previous mammograms to compare with current mammograms
- That BreastScreen NSW can send the results of the screening mammogram to my Doctor if I complete the contact details on the registration form
- That BreastScreen NSW can use and store my information in the ways outlined in this information sheet

Please complete the details below or affix label here

First Name:

Surname:

Date of Birth:

Patient ID:

- That if I require further treatment or tests elsewhere that relates to this visit, BreastScreen NSW may obtain copies of my results
- That I can withdraw consent for a screening mammogram at any time before or during the procedure
- That I can request to be excluded from the program at any time and will no longer receive reminders to attend.

CONSENT STATEMENT

If you have any questions, please ask one of the staff before you sign.

I have read and understand the information provided to me by BreastScreen NSW. I have had the opportunity to ask questions and being satisfied with the responses received, I give my consent to having a screening mammogram.

Signed _____ ***Dated*** _____

Guardian / Person Responsible / Interpreter _____ ***Dated*** _____

Consent Withdrawn

Client Signature _____ Date ___/___/_____

Appendix 10 – Documents consulted for PIA

Documents consulted include:

Overarching guidance on PIAs and APPs

- Commonwealth Statistical Data Integration Risk Assessment Guidelines
- Office of the Australian Information Commissioner, Australian Privacy Principles guidelines
- Office of the Australian Information Commissioner, Guide to undertaking privacy impact assessments

Relevant legislation

- Commonwealth
  - *Privacy Act 1988*
  - *Census and Statistics Act 1905*
  - *Australian Bureau of Statistics Act 1975*
  - *National Cancer Screening Register Act 2016*
  - *Archives Act 1983*
- State
  - *Health Administration Act 1982 (NSW)*
  - *Health Records and Information Privacy Act 2002 (NSW)*
  - *Health Administration Regulation 2015* (NSW)
  - *Public Health Act 2010 (NSW)*
  - *Privacy and Personal Information Protection Act 1998 (NSW)*
  - *Cancer Institute (NSW) Act 2003*
  - *Privacy and Personal Information Protection Regulation 2019 (NSW)*

Office of the Australian Information Commissioner, Community Attitudes to Privacy Survey 2020

Australian Bureau of Statistics, A guide for using statistics for evidence based policy (2010).

Information on Institute data and processes

- NSW Health data governance framework
- NSW Health Privacy Manual for Health Information
- NSW Health Privacy Management Plan
- Research protocol used by the Institute for this linkage
- BreastScreen NSW fact sheet
- NSW Pap Test Register fact sheet
- NSW Government Privacy Leaflet for Patients

Other PIAs:

- Privacy Impact Update (PIA) for the Multi-Agency Data Integration Project (MADIP), MADIP, 2019.
- 2019 MADIP Consultation Report (for PIA Update), MADIP, 2019.
- Independent Privacy Impact Assessment (PIA) for the Multi-Agency Data Integration Project (MADIP), MADIP, 2018.
- Independent Privacy Impact Assessment (PIA) on the National Health Survey (NHS) Linkage Project, ABS, 2018.
- Privacy Impact Assessment Report: Vulnerable and Disadvantaged Children Research Project, Minter Ellison, 2017.

Appendix 11 – Stakeholders consulted for this project

Organisations

Australian Bureau of Statistics (Health Statistics, Data Integration, Policy and Legislation areas)
Cancer Institute of NSW
NSW Population and Health Services Research Ethics Committee (PHSREC)
Aboriginal Health and Medical Research Council of NSW Human Research Committee (AH&MRC)
NSW Ministry of Health
Commonwealth Department of Health
Privcore