Australian Health Survey

Privacy Impact Assessment

Executive Summary

This Privacy Impact Assessment is being conducted to assess the possible privacy issues related to the Australian Health Survey. This report details how the Australian Bureau of Statistics (ABS) will conduct the Australian Health Survey and outlines the potential privacy impacts, evaluates the appropriateness of the proposed measures for protecting participants' privacy and provides recommendations for privacy management.

The ABS Health Surveys program was designed to create a national health information source, obtain national benchmarks on a wide range of health issues, and to enable changes in health to be monitored over time or between populations. The Australian Health Survey will expand the existing health survey program to add more detailed information about physical activity and nutrition as well as collect biomedical data on biomedical risk factors of chronic disease and nutrition status.

To date, all information in the ABS Health Surveys program has been collected under the *Census and Statistics Act 1905* (CSA) which imposes strict secrecy provisions on staff and the disclosure of data. However, the new voluntary biomedical component of the survey, involving the collection and subsequent testing of blood and urine samples to produce the biomedical data, does raise some new privacy concerns. The sensitive nature of health information and biomedical samples increases the privacy impact and thus the need for privacy protection measures. The involvement of third party service providers for the pathology testing and reimbursement services, while also obliged to comply with the Privacy Act, could increase the perceived level of risk to respondent privacy.

As these privacy concerns are raised in the voluntary biomedical component of the survey, the ABS anticipates that AHS respondents will weigh up their concerns against the benefits of participating and choose whether or not to provide their blood and urine samples. The benefits to the participants are:

- For individuals – participants will receive their own results and the results of their children, if selected, providing valuable feedback on their health status. This will contribute to raising a participant's awareness of their health and encouraging preventative health care.
- For the community – analysis of blood and urine samples will provide objective information about the health of the nation, vastly improving the quality of the self-reported information.

The Australian Health Survey and all ABS operations will be consistent with the requirements of the *Privacy Act 1988*. The ABS will closely manage the third party providers' protection of respondents' privacy in alignment with the Privacy Act.

The recommendations for effective privacy management related to the implementation of AHS include:

- Managing compliance with privacy laws in third party contracts;
- Excluding data linking of AHS data to other datasets using personal information (such as name and address);
- Minimising the need to collect personal information, and where personal information is required, ensure the respondent provides it directly to the party requiring it; and
- Ensuring respondents provide informed consent to participate in the voluntary biomedical component of the survey and understand the information provided including their privacy protection.

Australian Health Survey - Privacy Impact Assessment

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1 Background

1. The Australian Bureau of Statistics (ABS) is Australia's official statistical organisation. The ABS acknowledges the support of the individuals and organisations who contribute to the ongoing wealth of statistical information about our nation through participation in ABS surveys[1]. ABS core values include maintaining the trust of its data providers, as outlined in the ABS Corporate Plan[2], and thus ABS recognises privacy as a significant consideration in relation to conducting the Australian Health Survey (AHS).
2. This Privacy Impact Assessment (PIA) is being prepared by ABS officers to address privacy issues related to the AHS.
3. This PIA has been prepared on the advice of the Commonwealth Privacy Commissioner.

2 Privacy Impact Assessment

4. The Australian Health Survey has been exposed to a number of audiences in order to obtain comment on its proposed methodologies and their potential privacy impact. There were extensive public consultations in the form of focus groups, public seminars, briefings, media releases and web-based presentations, each method seeking input from the audience on a range of issues. Privacy issues were discussed specifically at the focus groups and details of these discussions can be found in Part **7 - Research into community attitudes**. Further, the biomedical component of the AHS is being submitted to the Department of Health and Ageing Departmental Ethics Committee. As per the NHMRC *National Statement on Ethical Conduct in Human Research* (National Statement) an Ethics Committee considers issues of privacy[3].
5. In addition to outlining the consultation conducted on the privacy issues surrounding the AHS, this PIA identifies and analyses the impact of the personal information flows, which lead to recommendations for minimising the risk of privacy intrusions, and maximising privacy protection.

3 What is the Australian Health Survey?

6. The Australian Health Survey (AHS) is a new ABS household survey that expands on the existing ABS Health Surveys Program. This has been made possible by additional funds provided by the Department of Health and Ageing and the National Heart Foundation of Australia. The AHS will measure health status, health conditions, health risk factors (with particular emphasis on physical activity), health related actions and medications, nutrition, physical measures and facilitate pathology testing of biomarkers (e.g. cholesterol, sodium). Collection of this unique combination of health-related components has not been undertaken in Australia on this scale, however, it has been implemented in other countries in various forms e.g. England, United States of America, Canada and most recently in New Zealand.

[1] 1008.0 ABS Surveys Charter, released 5th March 2010 (see www.abs.gov.au)
[2] *ABS Corporate Plan*, updated 25 July 2008 (see www.abs.gov.au)
[3] National Human Research Medical Council, *National Statement on Ethical Conduct in Human Research* (2007) see http://www.nhmrc.gov.au/publications/synopses/e72syn.htm

7. The existing Health Surveys were designed to obtain national benchmarks on a wide range of health issues and enable changes in population health to be monitored over time. The AHS expands the range of objectives to:

   - provide objective prevalence estimates of certain chronic diseases and conditions and selected biomedical and behavioural risk factors, including physical activity participation and sedentary behaviour, in the population as a whole;
   - enable monitoring and reporting against national food, nutrition and physical activity guidelines and recommendations;
   - underpin the development of new guidelines and recommendations on healthy weight, nutrition and physical activity;
   - inform the development and evaluation of food regulatory standards; and
   - determine how these data vary for different population sub-groups of interest.

8. The survey contains two parts: a self-report questionnaire and a voluntary biomedical component. Respondents will be invited to participate in the voluntary component of the survey for which they will attend a pathology collection centre to provide a small sample of blood and urine, with results from these tests transferred to the ABS (with consent) for integration with survey results.

9. The ABS has selected Sonic Healthcare, via a competitive tender process, to provide a national pathology service to:

   - collect blood and urine samples at collection centres or via home visits where necessary;
   - test biomedical samples;
   - distribute the test results report to participants and their doctor (if nominated);
   - scrutinise test results for clinically significant results; and
   - contact participants or their nominated doctor if medical follow-up is recommended (i.e. to fulfil the required legal duty of care).

10. Two 'waves' of the survey are being planned. The first will involve a sample of 26,000 households from the general population. The second wave will be aimed specifically at Aboriginal and Torres Strait Islander peoples. For both waves, information will be collected about children (from parents) and directly from adults in a self-reported face-to-face interview conducted by ABS staff. In the biomedical component of the survey, for the general wave, children from 5 years will be invited to give a urine sample and children from 12 years will be invited to give blood and urine samples. Consent for participation in the biomedical component will be gained from respondents or from a parent/guardian of respondents for children under 16 years of age. For the Indigenous wave, only respondents 18 years and over will be invited to participate in the biomedical component.

11. The primary objectives of collecting biomedical data from the Australian population are to measure the:

   - prevalence of indicators of chronic disease (e.g. cardiovascular disease, chronic kidney disease, liver disease and Type 2 diabetes)
   - levels of nutrients associated with biomedical risk factors for which food consumption data may be inaccurate (e.g. sodium and potassium)
   - levels of nutrients for which food composition data may be inaccurate or food is not the only source (e.g. vitamin D)

- levels of nutrients subject to a fortification program (i.e. folic acid and iodine)
- prevalence of some nutrient deficiencies (e.g. iron and vitamin B12 in the elderly).

12. Participants can receive a copy of their test results directly from the pathology provider undertaking the tests for the ABS. Participants may also choose to have a copy of their results sent to their nominated doctor.

13. Participants of the biomedical component will be eligible for a $50 reimbursement to off-set costs incurred in attending a pathology collection centre such as travel, parking and childcare. A reimbursement will not be available if the participant receives a home visit.

4 How will the AHS differ from other ABS surveys?

14. The AHS will be the first national full-scale survey conducted by the ABS where respondents will be asked to provide biomedical samples.

15. The biomedical collection will involve a participant voluntarily attending a pathology collection centre to provide blood and urine samples. The biomedical collection cannot be conducted under the *Census and Statistics Act 1905* (CSA), rather it will be an optional collection within the scope of the *National Statement on Ethical Conduct in Human Research*.

16. The protocols for the biomedical collection will be agreed between ABS and Sonic Healthcare and approved by the Department of Health and Ageing Departmental Ethics Committee.

17. The pathology provider (Sonic Healthcare) must uphold a duty-of-care to the participant in the event that clinically significant results are found and thus the participant may not remain anonymous to the pathology provider. Normally in ABS household surveys respondents do not have to give their real name and may remain anonymous to the ABS interviewer.

18. ABS will request written consent from participants to receive a copy of their pathology test results. Although the biomedical collection is not conducted under the *Census and Statistics Act 1905*, when the ABS receives a copy of the pathology test data, the secrecy of this information is protected under the *Census and Statistics Act 1905* (see *Diagram 3*). That Act does not allow for the release of any data that could identify any individual or household. ABS will link the household survey data and biomedical data by way of the AHS Reference Number not names or other personal information.

19. The need for respondents to travel to provide biomedical samples raises additional burden not normally incurred in an ABS survey. The ABS Surveys Charter[4] is clear that ABS legislation underpins the policy that ABS does not provide payment to respondents for providing statistical information. However, the collection of biomedical samples cannot be regarded as statistical collection. Sonic Healthcare will collect the samples and resulting biomedical data outside ABS legislation and thus it is possible and appropriate for ABS to reimburse respondents for their costs such as travel.

20. De-identified leftover biomedical samples are to be stored for the period of the survey to mitigate against the risk that data quality issues arise and re-testing is required to check the accuracy of results. Samples will be destroyed at the completion of the processing of the survey once a review of the results has been completed.

[4] 1008.0 ABS Surveys Charter, released 5th March 2010 (see www.abs.gov.au)

5 Identification of Personal Information flows

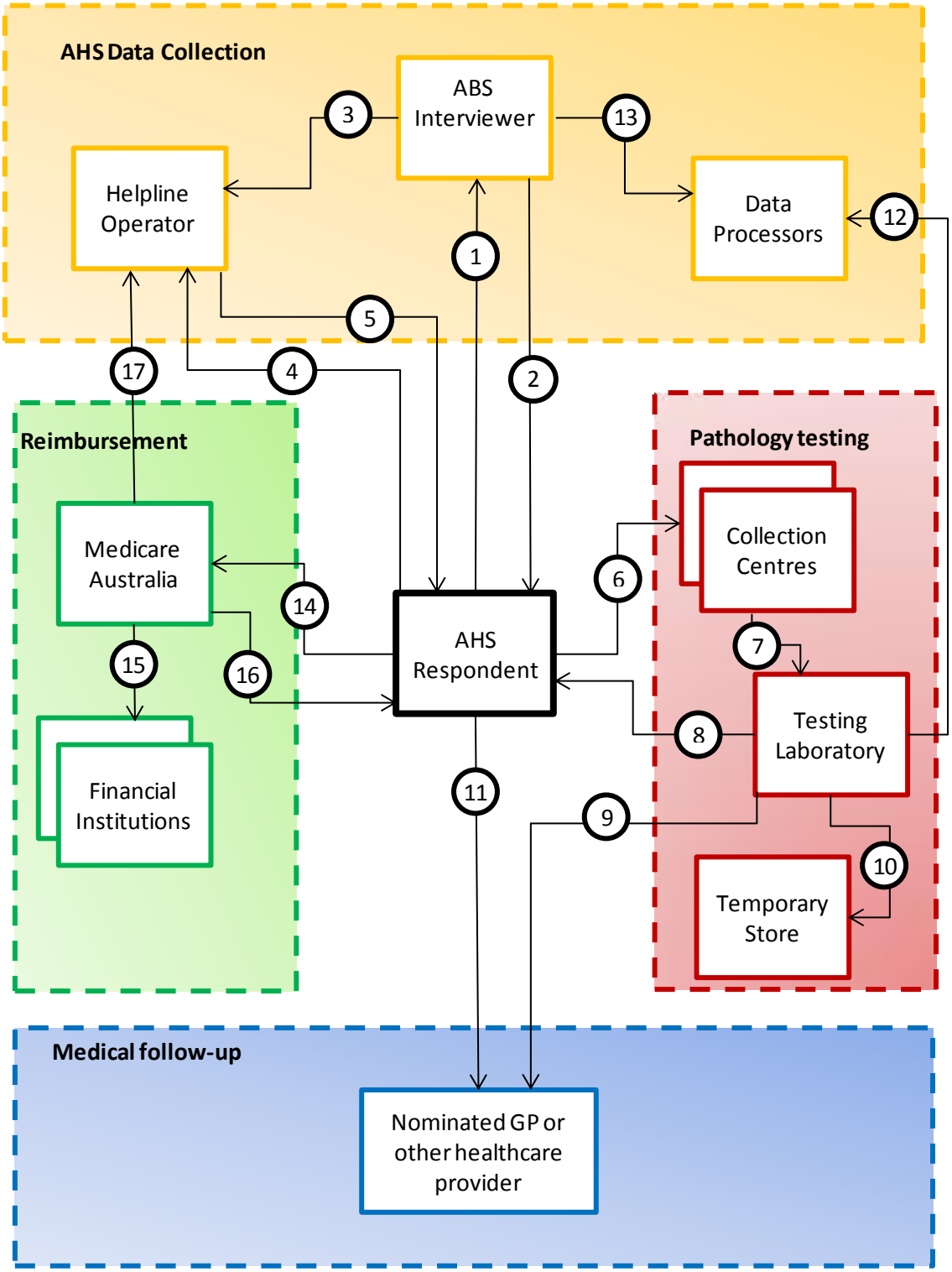
21. The conduct of the voluntary biomedical component of the AHS requires the collection of personal information by three parties:

    - ABS – responsible for the conduct of the survey including the collection, processing and dissemination of the data;
    - Sonic Healthcare – the contracted pathology service provider; and
    - Medicare Australia – the Commonwealth agency providing reimbursement services.

22. The participant is also encouraged to nominate a doctor who would receive a copy of the participant's pathology test results. This doctor would be contacted by the pathologist in the event of clinically significant results (i.e. high health risk) being found. In this situation, communications between the pathologist and the doctor will occur in a clinical setting and assist the pathologist in determining the appropriate advice to give the participant about their results.

23. *Diagram 1* shows the information flows between parties and the AHS respondent for the biomedical component, with data items exchanged detailed in *Diagram 2*.

Diagram 1 The Biomedical Process

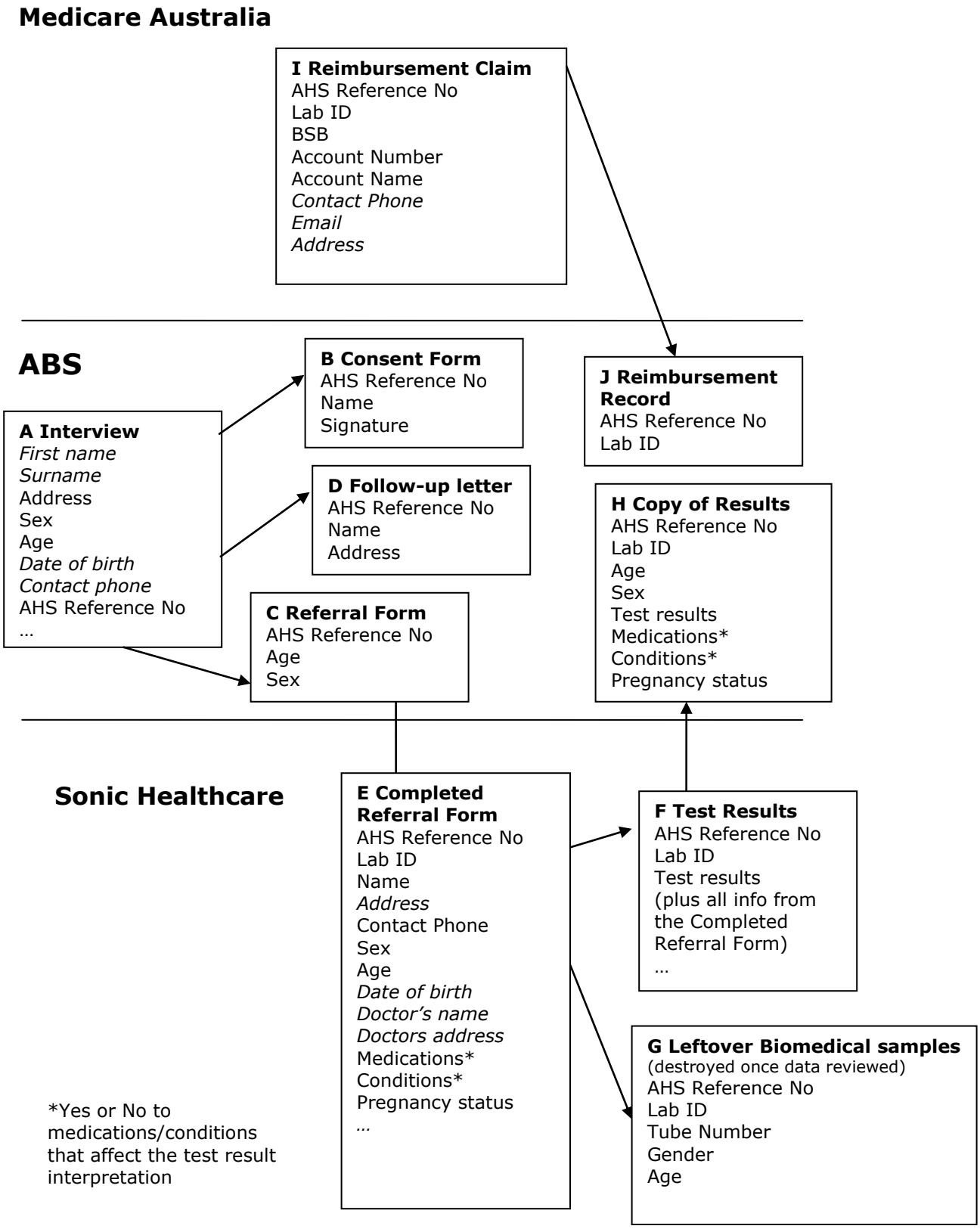


1. The ABS interviewer undertakes a computer assisted interview with the AHS respondent. The respondent does not have to give their name or date of birth. If the respondent agrees to participate in the voluntary biomedical component they must provide a signed consent form to the interviewer or mail back the consent form to the ABS. (See A, B in Diagram 2)

2. The ABS provides a pathology referral form to the respondent with only the participant's AHS reference number, age and sex completed. (See C in Diagram 2)
3. The AHS reference number, consent status, age, sex and contact details of the respondent is provided to the AHS Helpline operators to assist in answering enquiries and conducting follow-up procedures.
4. If during any stage of the process the respondent has questions or wishes to opt in or out of the biomedical component they may call the AHS Helpline. ABS staff may need to log the call to take the necessary action, in which case, the respondent will need to identify themselves via their AHS reference number, name, address or phone number given to the ABS interviewer.
5. If the respondent indicates they may participate in the biomedical collection and a consent form has not been received, or a consent form has been provided but the respondent has not provided biomedical samples, a reminder letter will be sent (or a phone call in some cases). (See D in Diagram 2)
6. The respondent completes the referral form and provides it to the pathology collector at the time of sample collection. (See E in Diagram 2)
7. Vials and specimen jars are labelled and transported to a central processing laboratory where the referral form data is entered, samples are tested and the results analysed by a pathologist.
8. Normal results are sent to the participant by mail. In the case of clinically significant results, the participant will be contacted first by phone if they have not nominated a doctor or their doctor is unavailable. This would be followed by a registered letter containing their results and advice to seek medical advice as soon as possible.
9. Where the participant has nominated a doctor, normal results will be sent by mail or electronically. If doctors already receive results electronically from Sonic Healthcare for other referred patients, they will receive the results electronically for AHS participants. The nominated doctor may also be phoned about a participant's results where they are clinically significant in order to discuss how best to advise the patient of their results and next action.
10. De-identified leftover samples are stored for the period of the survey in order to mitigate the risk that any data quality issues are found and re-testing is required in order to investigate the extent and cause of any problems. They will only be used for the purpose of the Australian Health Survey. (See G in Diagram 2)
11. The participant may choose to consult their nominated doctor or another healthcare provider about their AHS test results.
12. A copy of the pathology test results, as well as information related to the tests e.g. whether medications are taken for certain conditions, is provided to the ABS identified only by the AHS reference number and Laboratory ID. Age and sex data items are also transferred in order to check that the biomedical data is an appropriate match with the interview data. (See H in Diagram 2)
13. Address information associated with the self-reported interview data is removed and then provided to ABS data processing staff to process the interview data and match with any biomedical results for the same AHS reference number.
14. The respondent may claim their reimbursement payment which is authorised by Medicare Australia confirming the validity of their AHS reference number and Laboratory ID only, via a secure webpage provided by Sonic Healthcare. (See I in Diagram 2)
15. Medicare Australia creates a payment transaction to the bank account as advised by the respondent.
16. Where requested, Medicare Australia will send a remittance advice via mail or e-mail to the AHS respondent.

17. Medicare Australia regularly notifies ABS of the AHS reference numbers and Laboratory IDs for which reimbursements have been paid.

Diagram 2 Detail of personal information flows



6 Comparative experience overseas

24. Similar health surveys involving the collection of biomedical samples have been conducted in the United States of America (USA), Canada, England and New Zealand. Unlike the AHS, those studies have involved the long-term storage of biomedical samples for future testing. No long term storage of samples is planned for the AHS.

25. While the AHS will only test for markers of chronic disease and nutrition status, other countries such as the USA and Canada also test for pregnancy, sexually transmitted diseases, exposure to environmental toxins and some DNA testing. In those countries positive or high readings for some of these tests results are reportable to governmental authorities. This is the not the case with the AHS.

7 Research into community attitudes

26. The ABS has researched community attitudes by conducting focus group testing and cognitive interviews.

27. The ABS conducted 16 focus groups between February and August 2010 with a total of 128 participants. Four focus groups were in Canberra, two in Moss Vale, one in Braidwood, two in Melbourne and seven in Albury. The focus groups were asked if they had any concerns about:

    - the ABS storing (for the life of the survey) their personal information on the consent form?
    - the pathology service provider having access to their personal information?
    - the purpose for which the ABS needs their personal information?

28. Participants recognised the importance in being aware of personal health and general awareness of risk factors relating to chronic health conditions. The only privacy concern raised during the focus groups was whether or not DNA testing would be conducted.

29. The ABS also conducted 12 cognitive interviews over the period from July to August 2010 to explore community attitudes about the AHS.

30. Cognitive interviewing techniques were used to test the understanding of the consent materials provided to respondents in order to gain 'informed' consent. In these interviews, respondents were asked whether they had any concerns with the pathology company collecting their personal information to use to send them their results. All 12 of participants said that they would not have any concerns. ABS updated the consent information materials to simplify and aid understanding based on feedback from the respondents.

8 Legislative privacy protection and policies

31. Limits on the management of AHS data by ABS are imposed by two laws: the *Census and Statistics Act 1905* and the *Privacy Act 1988* as outlined below. Compliance by other parties providing services for the AHS with the privacy laws are outlined in Part 9.

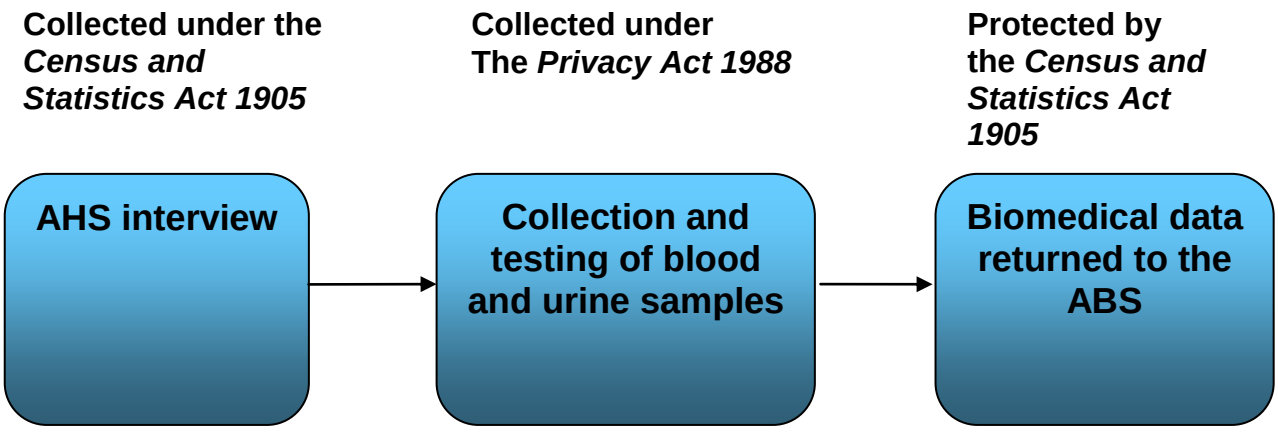
32. To date, all information in the ABS Health Surveys program has been collected under the *Census and Statistics Act 1905* (CSA) which imposes additional strict secrecy provisions on staff and the disclosure of data.

33. The ABS maintains an enviable reputation for the preservation of the confidentiality of reported information and for the protection of its statistical data holdings from unauthorised release.[5]

Census and Statistics Act 1905 (CSA)

34. While the biomedical samples collected by the pathology provider will not be collected under the CSA, the results from the tests on these samples will be received by the ABS under the authority of the CSA. Thus, the secrecy of all information held by the ABS is protected by the CSA. See *Diagram 3* below.

Diagram 3



35. The CSA provides the Australian Statistician with the authority to conduct statistical collections, and when necessary, to direct a person to provide statistical information. Any information collected under the CSA is protected by the strict secrecy provisions (s19) of the Act. The Act requires that the ABS publish statistical information in a manner not likely to enable the identification of a person, business or organisation.

36. While there are some limited provisions in the CSA for the release of non-personal information which may be identifiable, no such provisions exist for personal or domestic data. Thus the ABS will never release any information collected by ABS as part of the AHS in a manner that is likely to identify an AHS participant.

37. ABS officers are required to sign an undertaking of fidelity and secrecy which is set out in a Schedule to the *Statistics Regulations* (Regulation 4). This binds them to comply with the disclosure limitations of the CSA and *Statistics Determination 1983.* A breach of the CSA secrecy provision is a criminal offence carrying a penalty of up to 2 years imprisonment and/or a fine of up to $13,200. Such a prosecution has not occurred in the 100 years since the CSA was enacted.

38. The Australian Statistician's statutory independence prevents political interference in disclosure practices. In the event that any attempt was made to use other powers to obtain identifiable personal information, ABS has always been, and remains, committed to defending its secrecy provisions in the courts.

ABS Policies and Procedures

39. The ABS's use of AHS data will be governed by its standard policies and procedures for personal information. These policies and procedures are designed to ensure identifiable personal

[5] ABS Annual Report 2008-09, p. 100

information is not disclosed. These procedures are enacted when releasing data in tables, where confidentiality procedures are applied to any cell in a table that contain only a very small number of contributors. In this case the procedures may include deliberate perturbation (alteration) of the data, cell suppression and/or collapsing cells into more aggregate tables. The ABS regularly reviews the effectiveness of these procedures to ensure privacy protection is assured.

40. The ABS intends to release AHS data in tables, Confidentialised Unit Record Files (CURFs) and user driven table generation software (Survey Table Builder). Tables are used for aggregated data, whereas CURFs are used for the release of individual records which have been produced in such a way that no participant is identifiable. The Survey Table Builder is designed to provide access to data, which is then converted to tables and automatically confidentialised.

41. Existing procedures designed to protect the confidentiality of the individual records of persons and organisation included in the microdata files released by the ABS are described in the ABS brochure *CURF*[6] and include:

- Removing name and address and *any other information* that might uniquely identify an individual
- Changing a small number of values, particularly unusual values, and removing very unusual records
- Controlling the detail available for all records
- Controlling the modes of access to restrict access to more detailed data. There is a hierarchy of modes:
    - CD-ROM supplied to clients
    - Internet access, under ABS supervision, to an ABS Remote Access Data Laboratory (RADL)
    - Analysis on ABS premises under ABS supervision (ABS Site Data Laboratory (ABSDL).
- Placing restrictions on how the data are used (e.g. that it may not be linked to other data sources), supported by legal undertakings (backed up by the sample penalties and sanctions as they apply to ABS officers (CSA s.19(2)))

42. ABS is proactive in seeking to ensure compliance with legislative requirements and internal administrative practices. Security measures meet the highest standards. Steps taken include a very active internal and external audit program both of internal ABS processes and of external users/uses.

Privacy Act 1988 (PA)

43. The ABS, as a Commonwealth agency, is subject to the Information Privacy Principles (IPPs) in s.14 of the PA. Organisations contracted to provide services to the Commonwealth are also subject to comply with the IPPs.

44. This section goes to the issue of compliance by the ABS with the Information Privacy Principles (IPPs). Compliance with the IPPs is a necessary, but not necessarily sufficient, condition of satisfying privacy concerns. The analysis of compliance with the principles is contained in Table 1.

45. Overall, the analysis shows that the ABS will be able to comply with the Information Privacy Principles of the Privacy Act in its implementation of the AHS by working within its established

[6] Available on the ABS web site.

policies and procedures. Some additional steps will be required in relation to ensuring privacy is appropriately managed by third party providers in line with the IPPs and NPPs of the Privacy Act.

46. A relevant consideration in this assessment is the ABS's 'track record' of privacy compliance.

47. See Part 5 for the details of the personal information that is referred to in Table 1 below.

Table 1: Compliance with Information Privacy Principles (IPP[7]s) (s14 Privacy Act 1988)

IPP	Summary	How ABS will comply for the Australian Health Survey
IPP1	**Manner and purpose of collection** The information must be necessary for the agency's work, and collected fairly and lawfully.	The personal information collected is linked directly to the purpose of the AHS, that is, the collection of health statistics for the Australian population. Personal information for the biomedical component is collected fairly and lawfully as it is collected voluntarily from the respondent supported by an informed consent process. Compulsory elements of the household interview are collected lawfully under the authority of the CSA. The respondent's legal obligation to provide information is clearly outlined in the ABS Surveys Charter[8] as well as being the subject of a FAQ on the Office of the Privacy Commissioners web site[9]. All personal information collected by the ABS and its contract providers will be collected directly from the survey respondent.
IPP2	**Solicitation of personal information from individual** An agency must take steps (usually through an IPP notice) to tell individuals: • Why they are collecting personal information • What laws give them authority to collect it; and • Who they usually disclose it to.	The ABS will provide respondents with a general brochure and biomedical information sheet detailing the purpose of the information collection and will note that the ABS is obliged under the CSA not to release personal information. All data released about the survey will be confidentialised. Consent forms and claim forms for the reimbursement will also include a privacy notice outlining any disclosure and privacy protection.
IPP3	**Solicitation of personal information generally** An agency must take reasonable steps to ensure the personal information it collects is: • Relevant • Up-to-date and complete • Not collected in an	The ABS will provide respondents with an AHS telephone helpline so they can notify ABS if their contact details have changed. The ABS will collect the information from the individuals in the privacy of the respondent's home or a place of the respondent's choosing. The ABS will ensure that personal information collected from respondents in pathology collection centres is done in a manner that

[7] IPPs taken from The Checklist in the *Privacy Impact Assessment Guide* Revised May 2010
[8] See www.abs.gov.au – Survey Participant Information
[9] See http://www.privacy.gov.au/faq/individuals/q16 viewed December 2010.

	unreasonably intrusive way.	considers the respondent's privacy.
IPP4	**Storage and security of personal information** Personal information must be stored securely to prevent its loss or misuse	The ABS has very strict controls over access to information both during and after the conducting of the survey, and keeps the controls constantly under review. Security of ABS systems has been assessed during design of the systems by IT security and compliance is checked as part of the standard IT change management arrangements. The ABS will put provisions into its contract with the pathology service provider to ensure that the contractor follows adequate privacy provisions including compliance with NPPs 7-10. The secrecy provisions applying to the ABS mean that not even contractors and consultants engaged by the ABS (i.e. the pathology provider) are allowed to see identifiable personal information provided to the ABS. ABS will ensure that the transfer of pathology results from the pathology provider to the ABS will be done in a secure manner.
IPP 5	**Information related to records kept by a record-keeper** A record-keeper must take reasonable steps to allow a person to find out: • If the record-keeper has possession or control of personal information • The nature of that information • The purpose that information is used for • The steps to take to get access to their record. The record-keeper must maintain a record of the: • Nature of the records kept • Purpose of each type of record • Classes of individual about whom records are kept • Period each type of record is kept • Persons that may have access to the records and when • How an individual can access their records. The record-keeper must make sure that: • This information is	The ABS complies with this Principle through its privacy policy and statements, including privacy FAQs on its website[10], and the statement which appears in the annual Personal Information Digest. Individuals will know the personal information the ABS has about them as they will be directly and voluntarily giving the ABS this information. In relation to their pathology test results, respondents will be made aware that if they give the contact details of their General Practitioner (GP), their GP will be sent a copy of their results. ABS systems that contain personal information have security functions that limit access only to those ABS officers who need to know, as defined by the system owner. Audit history is also available to be able to see what data has been accessed and by whom.

[10] www.abs.gov.au – see Survey Participant Information

	made for public inspection • A copy of this record is given to the Privacy Commissioner in June each year.	
IPP6	**Access** Individuals can have **access to records,** unless the record keeper is **required** or **authorised** to refuse access under any Commonwealth law.	Individuals will have knowledge of the personal information the ABS has of them as they will be directly and voluntarily giving the ABS this information. Respondents are made aware on the pathology referral form that they will be sent a copy of their pathology test results.
IPP7	**Alteration of records** A **record-keeper** must take **reasonable steps** to ensure that the record is accurate relevant, up-to-date, and not misleading. The **record-keeper** can, on request, attach a statement from the individual correcting, deleting or adding to the record.	Respondents will be notified of the mechanisms to update their personal contact details for the purposes of follow-up. Updating of the collected information will not be relevant as ABS is interested in point–in-time information for statistical purposes.
IPP 8	**Record-keepers obligation to check accuracy etc of personal information before use** **Record-keepers** must take **reasonable steps** to ensure information is accurate, current and complete before using it.	The pathology service provider is obliged to verify the identity of the participant in order to be able to consult with their nominated doctor and/or contact them in future about any clinically significant test results. Other personal information collected by the ABS largely relies on the respondents as it does not undertake any verification, other than tests for internal consistency and integrity. In the context of a population survey this is reasonable, and no further steps are likely to be considered necessary, provided the information continues to only be used for the purposes of the AHS.
IPP 9	**Personal information to be used only for relevant purposes** A **record-keeper** must only use information for a relevant purpose	All personal information is only used for the purpose of collecting and publishing data for the AHS.
IPP 10	**Limits on use of personal information** A **record-keeper** can generally only use the information for another purpose in special circumstances, including with consent and for health and safety or law enforcement reasons.	The personal information in the form of test results is only received by the ABS from the pathology service provider with written consent from the participant. The pathology service contract will state that the provider may not use the personal information (including biomedical samples) for any purpose unrelated to the reason for which the sample was originally collected.
IPP 11	**Disclosure** A **record-keeper** can generally only disclose information in special circumstances	Disclosure will only occur within the terms of the CSA as described above. That is, a respondent's identifiable information may only be released to that respondent. This is consistent with (b) and (d) of IPP 11.1.

9 Compliance with privacy laws by other parties involved in the AHS

Sonic Healthcare Pty Ltd

48. ABS has selected Sonic Healthcare Pty Ltd, via a competitive tender process, to provide a national pathology service for the AHS.

49. AHS participants will be asked to give the pathology service provider their name, address and phone number so that they can:

    - send the participant a copy of their results, and
    - contact the participant if clinically significant results are found.

50. The pathology service provider will also collect the participant's date of birth (as per Industry standards) in order to determine the appropriate age specific reporting range against which to report some test results.

51. The ABS will proactively seek compliance by the contractor with the relevant privacy laws by making the compliance part of the Contract between the pathology service provider and the ABS.

52. The ABS will stipulate in the contract that the contractor only provide the AHS reference number and a unique Laboratory ID to the ABS as the only means of identifying the participant's test results. Identifying information, such as name and address, is not required by ABS as test result data will be linked with other AHS data via the AHS reference number.

53. Under the Privacy Act, agencies must ensure that a **contracted service provider** in a Commonwealth contract does not breach the IPPs (s95B).

54. **Contracted service providers** must also comply with the **NPPs**, unless the contract states otherwise.

55. **Four NPPs** have no IPP **equivalents** (below). Agencies should:

    - Include these four NPP provisions when contracting services.
    - Ensure that any personal information collected under a Commonwealth contract is not used *or* disclosed for direct marketing unless the contract requires it (s16F of the Privacy Act).
    - The analysis of compliance with the principles is contained in Table 2.

Table 2: Compliance with National Privacy Principles (NPPs)
NB: organisation is the contract service provider

NPP	Summary	How ABS/Pathology Centres will comply for AHS
NPP 7	**Identifiers** An **organisation,** must not: • Adopt as its own **identifier** of an individual, an identifier assigned by an agency • Use or disclose an agency identifier unless necessary to fulfil an agency obligation, or for **law enforcement and similar purposes**	The unique identifier, which will be on the referral form that the pathology centre receives, will only be used for the purpose of the AHS. The pathology service provider is unable to use it for any other business with the respondent (that is not related to the survey) and is not to disclose it to anyone but the ABS. Medicare numbers will not be used in anyway for the AHS.

NPP 8	**Anonymity** Where possible, organisations must allow individuals to do business without having to identify themselves.	It is not possible for participants to remain anonymous during the biomedical collection component of the AHS. The pathology service provider must uphold a legal duty of care to the participant which they are at risk of not being able to do if they are not able to identify the participant and verify their identity just prior to the samples being collected. In the event that clinically significant results are found during pathology testing, the participant will be contacted and advised to see their doctor
NPP 9	**Transborder data flows**	The organisation will not be required to send personal information to a foreign country.
NPP 10	**Sensitive Information** An **organisation** must not collect **sensitive information** about an individual unless: • The individual has **consented** • The collection is **required by law** • The collection is **necessary to prevent or lessen a serious an imminent threat to the life or health of an individual,** where the individual is **physically or legally incapable of given consent** or **cannot** communicate **consent** • If the information is collected in the **course of the activities** of non-profit organisations[11], provided the conditions in NPP 10.1 (d)(i) and (ii) are met • The collection is **necessary for the establishment, exercise or defence of a legal or equitable claim** • **NPP 10.2 to 10.4** conditions are satisfied.	The biomedical information that is collected by the organisation will be only done with the respondent's consent. ABS is responsible for obtaining written consent to participate from the participants. Pathology referral forms will only be provided to participants once a signed consent from is received by the ABS. The pathology service provider is unable to provide referral forms (requesting the collection of biomedical samples) to any person.

Medicare Australia

56. Medicare Australia will be providing the payments for claims for the reimbursement for participating in the voluntary biomedical component of the AHS. Participants will be invited to call the AHS Reimbursement telephone line, operated by Medicare Australia, to organise the payment of the reimbursement. The participants will need to provide bank account details to enable Medicare Australia to provide a direct deposit payment to them.

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57. In assessing the best avenue to make payments to respondents, it was decided that it was not in the best interests of the ABS or the community to administer this function internally. This was because internal administration does not represent the most effective, efficient and ethical use of Commonwealth resources, additionally it is not the core business of the ABS.

58. Consideration was made on a number of possible alternatives including in-house, private sector providers and the Commonwealth. The most effective, efficient and low risk option is to engage a Commonwealth service delivery agency that has relevant experience in disbursing payments.

59. Medicare Australia was approached to provide these disbursement services on the ABS' behalf - having the relevant experience as a service delivery agency in its own right and as a disbursement service provider on a number of Commonwealth Government programs, including Green Loans and the LPG Vehicle Scheme.

60. In addition, as a Commonwealth Agency, Medicare Australia operate and are bound by the Financial Management and Accountability Act and the Privacy Act, thereby ensuring that the service provision and data is handled appropriately and according to how ABS would have had to handle the information if the reimbursement service was not outsourced.

10 Privacy Impact analysis

61. The ABS is strongly committed to meeting its statutory obligations for privacy. There are some privacy concerns that are not fully dealt with by the relevant legislation and these concerns are analysed in this section.

62. The AHS has a privacy impact in that respondents cannot remain completely anonymous if they participate in the biomedical component of the AHS. They are asked for contact details separately by both the ABS, to conduct follow-up procedures, and by the pathology service provider in order to fulfil a legal duty of care.

63. AHS respondents, more so than other survey respondents, may have a need to identify themselves to the ABS and third party service providers in order to enquire about the status of their pathology tests and/or their reimbursement claim.

64. As these privacy concerns are raised in the voluntary component, ABS anticipates that AHS respondents will weigh up their concerns against the benefits of participating and choose whether or not to provide their blood and urine samples. The benefits to the participants include:

- For individuals – participants will receive their own results and the results of their children, if any, providing valuable feedback on their health status. This will contribute to raising a participant's awareness of their health and encouraging preventative health care.
- For the community – analysis of blood and urine samples will provide objective information about the health of the nation, vastly improving the quality of the self-reported information.

65. The biomedical collection will highlight how these data vary for different population groups of interest, allowing health inequalities to be addressed and measure changes in health status over time. Objective national prevalence estimates of biomedical risk factors and some chronic diseases and conditions, including high cholesterol and high blood sugar levels, will allow better informed policy decisions to allocate health services for Australians into the future. ABS anticipates a 60% response rate for the biomedical component (based on international studies). Even with this relatively low response rate, ABS still anticipates a significant return on investment for the biomedical data collection.

66. The standard ABS survey complaint-handling mechanism outlined in the ABS Surveys Charter will be used for the AHS. As outlined in paragraph 45 complaints about alleged breaches of the IPPs can also be made to the Federal Privacy Commissioner.

67. All the ABS systems for handling personal information have audit functions to support investigation of alleged unauthorised access.

68. The personal information that is collected will be de-identified once the collection is complete. Once the data is processed the separately stored personal identifiers are destroyed. This short term retention of personal identifiers reduces the value of the data to unauthorised users and thus the long term risk exposure to privacy risk around unauthorised access is also reduced.

69. ABS dissemination policy is to publish compilations and analyses of its statistics collected under the Act, or abstracts of these where doing so serves a public good, or where the resulting products satisfy identified client needs. Therefore all data of acceptable quality that fulfils the objectives of the survey will be published and will be available to researchers either free of charge on the ABS website or at a reasonable price (for CURF access). This includes the biomedical data obtained from the biomedical collection. Any use of the personal information collected would be unauthorised and therefore unethical and thus not valuable to other researchers who require ethical approval to conduct research and publish their research results.

70. The AHS only obtains personal information with the informed consent of the individual – there is no intrusion or surveillance. As indicated by focus group tests, the exclusion of DNA testing from the AHS pathology testing aligns with community values about privacy.

11 Privacy Management/Recommendations

71. As the ABS is contracting a Pathology Service Provider to collect health information from blood and urine samples, the following steps are recommended to ensure respondent privacy is protected:

    a) Make explicit the need for compliance with the four NPPs, outlined in Table 2 above, in the contract between the ABS and the service provider;
    b) Require the Pathology Service Provider (under the contract) to complete Module F – Compliance Checklist for Organisations[12] and update this PIA to include it.

72. ABS will not link data (via identifiers such as name and address) from the AHS project with any other datasets as there is insufficient time to assess any additional privacy concerns that could be raised from such a proposal.

73. Personal information collected for the biomedical process is limited to the minimum amount required. Where personal identifying information is required by a third party, it is to be provided to the third party directly by the participant.

74. ABS will test the communication material developed to recruit volunteers for the biomedical component of the survey and to gain informed consent.

[12] Office of the Privacy Commissioner (OFPC), *Privacy Impact Assessment Guide*¸ Revised May 2010