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Department of Health

Addendum to the 2016 National Cancer Screening Register Privacy Impact Assessment

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Verso

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Preface

Operating and administering the National Cancer Screening Register (NCSR) involves the handling of a substantial amount of personal information. A comprehensive Privacy Impact Assessment, analysing the privacy risks and impacts of the NCSR, was undertaken in 2016 (the 2016 PIA). The 2016 PIA assessed the privacy impacts in relation to the NCSR generally, with a focus on establishing the NCSR.

This Addendum and the 2016 PIA should be read together. This Addendum considers they key project and system developments since the 2016 PIA, including implementation of the 2016 PIA recommendations, NCSR implementation and program and system developments, and examines the privacy impacts of information flows not assessed in the 2016 PIA. This Addendum has made a number of recommendations (summarised in section 2 below) to address privacy management risks that have arisen from new information flows.

Overall, this Addendum concludes that the NCSR continues to be privacy positive and that privacy issues, including those with respect to open and transparent management of personal information and quality and security of personal information, are being appropriately managed. This Addendum recommends that the Department continue to adopt a privacy positive approach to any future project developments associated with the NCSR.

Summary

RECOMMENDATION 1

The Department should continue to regularly update and review its privacy governance strategy and related privacy documents to ensure they remain current and to take account of any new technical or system functionality developments.

DEPARTMENT COMMENTS

The Department accepts this recommendation.

The Department will continue to monitor the privacy governance to ensure any privacy impact as a consequence of developments in system functionality is appropriately addressed.

RECOMMENDATION 2

The Department should continue to regularly update and review its security risk strategies to ensure that terms and conditions of use and user authentication, and user access controls are updated to account for any updates or changes to the manner in which information may be accessed.

DEPARTMENT COMMENTS

The Department accepts this recommendation.

The Department will continue to monitor privacy and security risks associated with information handling and ensure any privacy and security risks are appropriately mitigated.

Introduction to the NCSR

Purpose

The NCSR was established to support the delivery of the National Cervical Screening Program (NCSP) and the National Bowel Cancer Screening Program (NBCSP). The NCSR is established pursuant to the *National Cancer Screening Register Act 2016* (Cth). Telstra Health currently operates the NCSR on behalf of the Australian Government Department of Health (the Department).

Functions

The NCSR supports the NCSP and NBCSP by:

- providing the electronic infrastructure for the collection, storage, analysis and reporting of national cervical and bowel cancer screening program data, including cervical and bowel cancer diagnoses;
- issuing invitations and reminders to screen, issuing NBCSP test kits, and facilitating participant follow-ups to progress through the clinical pathways;
- enabling healthcare providers (HCPs), including pathology laboratories and specialists, to submit and access information about a participant's screening and diagnoses of cervical or bowel cancer or their precursors to support clinical decision-making; and
- generating comprehensive information and data to inform cancer screening policy development and to improve cancer screening program quality and service delivery.

Information handling

In order to carry out its functions, the NCSR:

- collects and stores personal information from various sources such as Services Australia (e.g. Medicare enrolment and claims information), pathology laboratories (e.g. screening test results and results from follow-up procedures/investigations), HCPs, including specialists (e.g. diagnoses), and State and Territory health departments (e.g. state/territory cancer databases);
- collects personal information directly from participants, their personal representatives and third parties (with the prior consent of the participant, or as otherwise authorised);
- discloses personal information to HCPs including pathology laboratories and specialists, participant follow-up function (PFUF) officers, NCSR contact centre operators (CCOs), and authorised third parties (such as the Department, the Australian Institute of Health and Welfare and State and Territories); and
- discloses personal information to authentication and verification service providers.

NCSR information can be accessed and updated by participants, HCPs (including pathology laboratories and specialists), and PFUF officers and CCOs (who liaise with participants and their personal representatives in relation to the NBCSP and NCSP). Access to information stored on the NCSR is restricted to users based on their role and function, and is protected by authentication and verification systems. Access is monitored for unauthorised use to ensure personal information is only disclosed for the purposes of the NCSR, as prescribed under the NCSR Act, and in accordance with participants' preferences.

Relevant legislation

The following Commonwealth enactments apply to the handling of information as part of the NCSR:

- the National Cancer Screening Register Act 2016 (Cth) (NCSR Act), which prescribes the manner in which information may be handled as part of the NCSR and the purposes for which that information must be handled as part of the NCSR;
- the Privacy Act 1988 (Cth) (Privacy Act), including the Australian Privacy Principles (APPs) at Schedule 1 of that Act. The Privacy Act and APPs impose general obligations with respect to the handling of personal information (including sensitive information) by the Department (as an APP entity);
- the Healthcare Identifiers Act 2010 (HI Act), which regulates the handling of healthcare identifiers (as that term is defined in the HI Act); and
- the My Health Records Act 2012 (MHR Act), which regulates the inclusion of information on an individual's My Health Record, and prescribes the procedures for integration and opt-out of the My Health Record system.

Privacy compliance analysis

2016 PIA

The 2016 PIA carried out a comprehensive assessment of the privacy impacts associated with establishing and operating the NCSR. The privacy assessment carried out by the 2016 PIA considered:

- the mass migration of cervical cancer screening data from State and Territory operated registers;
- the establishment of the relevant electronic infrastructure to operate and administer the NCSR;
- the collection, use and disclosure of personal information necessary to operate and administer the NCSR;
- the NCSR's integration with other Commonwealth, State and Territory run databases and systems, including Medicare, the National Human Papilloma Virus Register (NHPVR) (now the Australian Immunisation Register) and My Health Record;
- the development of privacy policies, privacy statements, collection notices, governance strategies and communication strategies to enhance transparency in relation to how personal information would be handled as part of the NCSR;
- issues with respect to maintaining the security and accuracy of personal information handled as part of the NCSR; and
- specific privacy implications of, and strategies to manage, the NCSR's opt-out provisions, mandatory reporting provisions, the scale of the NCSR, and the sensitive nature of the information handled by the NCSR.

The 2016 PIA is publicly available on the Department's website, and made 28 recommendations, all of which were accepted by the Department. One of those recommendations was for the Department to conduct a future review of the NCSR's privacy compliance. This PIA Addendum has been undertaken to implement that recommendation.

2021 PIA Addendum

The 2021 PIA Addendum should be read with the 2016 PIA and is intended to:

- summarise developments in the national bowel and cervical screening programs and NCSR system developments that have occurred since the 2016 PIA, including the implementation of the recommendations made in the 2016 PIA;
- examine key updates in relation to information handling since the 2016 PIA, and assess the privacy impacts and risks associated with new information flows that have been introduced since the 2016 PIA; and
- make further recommendations with respect to how the Department can continue to manage privacy compliance and enhance the privacy positivity of the NCSR.

This Addendum otherwise proceeds on the basis of the same scope, assumptions and limitations as the 2016 PIA, except where changes have been described in this Addendum.

Materials considered

This Addendum has been prepared having regard to new information since the 2016 PIA was prepared. This information includes:

- the NCSR Privacy Policy;
- the NCSR Data Access and Release Policy;
- the Department's summary of the implementation of the recommendations from the 2016 PIA;
- the PIA review document;
- the NBCSP Participant Details Form; and
- additional information provided by the Department in meetings conducted between August 2019 and May 2021.

Project Description – key developments since the 2016 PIA

The NCSR's collection, storage, use and disclosure of information remains fundamentally the same as that which was considered and assessed in the 2016 PIA. The same stakeholders are involved in the handling of information as part of the NCSR, and the scope and scale of the NCSR from a project perspective remains the same.

- Since the 2016 PIA was conducted, there have been significant program and system developments:
- on 1 December 2017, the NCSR became operational. The State and Territory cervical screening registers were migrated into the NCSR in mid-2018. Bowel cancer screening data was migrated from the NBCSP Register held by Services Australia to the NCSR in November 2019, and the NBCSP commenced operations in November 2019;
- information system products have been developed to support participants, HCPs (including pathology laboratories and specialists), PFUF officers and CCOs to interact with the information stored on the NCSR through online self-service options; and
- the recommendations of the 2016 PIA have been implemented.

Information system product developments

Portals

Between November 2019 and April 2021, the following Portals, which offer end users a self-service alternative to access, update and submit information to the NCSR have now been implemented. The specific information flows associated with each Portal were addressed in the 2016 PIA

Participant Follow-Up Function Portal (PFUF Portal)

The PFUF Portal was made operational in November 2019. The PFUF portal is accessible through the NCSR website, and enables PFUF Officers to perform their obligations under the National Partnership Agreement for the NBCSP ensuring participants with positive bowel screening test results progress through the clinical pathway.

Healthcare Provider Portal (HCP Portal)

The HCP Portal, accessed through the NCSR website or PRODA, became available in December 2020. The HCP Portal enables healthcare providers (GPs, nurses, pathologists, specialists and their delegated administrative staff) to manage their patient's participation in the NBCSP and NCSP, including opting out and deferring their screening; access screening information for participants; and lodge clinical forms relating to both programs electronically.

NCSR Participant Portal (Participant Portal)

The Participant Portal, accessed through the NCSR website or through myGov, was made available in April 2021. The Participant Portal allows participants to view and update their personal details, their preferred method of receiving communication, their HCP details, their personal representative details and to elect to defer or opt out of screening.

Integration with Clinical Information Systems

Also previously assessed in the 2016 PIA, the CIS interface became operational from October 2020. The CIS is a third party system which enables HCPs to access the NCSR through the practice's existing software. HCPs may access participant information through the CIS interface where information from the NCSR may be stored (depending on the particular practice management system software with which the CIS is integrated). The CIS differs from the NCSR Portals in that it involves the third party storage of participant information, rather than enabling third party access (through portal functionality) to particular information.

Integrated authentication services

With the implementation of portals and the CIS interface, additional authentication and verification services have been integrated with the NCSR. For participants registering to access the Participant Portal, personal information will be authorised through myGov. For HCPs registering to access the HCP portal, personal information will be authorised through Provider Digital Access (PRODA). In both cases, documents will be verified by the Document Verification Service (DVS).

Future planned implementation

Developments, which are yet to be implemented, but were previously assessed in the 2016 PIA include: integration with My Health Record and the collection of Human Papilloma Virus (HPV) vaccination information from the Australian Immunisation Register (AIR) (previously the NHPVR).

Bowel and cancer screening program developments

Since the 2016 PIA, program developments have resulted in additional information flows. These relate to the bowel cancer screening pathway, and reporting and ongoing access to NCSR information across both programs.

New flows in relation to the bowel screening pathway are between:

- a HCP, the NCSR and the Contracted Pathologist, when a HCP issues a bowel screening kit to an eligible person through the alternative kit distribution pathway (alternative to figure 5 of the 2016 PIA);
- the Contracted Pathologist, the NCSR and Unsolicited Screener, when a person provides a completed bowel screening test, using someone else's kit, before their eligibility for participation in the program has been determined (alternative to figure 7 of the 2016 PIA);
- the Contracted Pathologist, the NCSR and HCP, when a participant nominates a clinic as their HCP (additional to figure 7 of the 2016 PIA);
- the Contracted Pathologist, NCSR, PFUFs and participants, where a participant has identified a hospital as their HCP (additional to figure 7 of the 2016 PIA);
- pathology laboratories, the NCSR, HCPs, PFUFs and CCOs in administering the NBCSP by using collected participant histopathology information (e.g. colonoscopy results) for the purpose of clinical decision-making and facilitating participant follow-up through the clinical pathway (extension of figure 9 of the 2016 PIA regarding use of data); and
- pathology laboratories, the NCSR and participants, through the collection and use of histopathology results (e.g. from colonoscopies) for all age-eligible individuals to assess eligibility for screening and to notify individuals when and why they are not required to screen when they reach their due date (extension of figure 9 of the 2016 PIA regarding expanded collection of histopathology data).

Reporting and ongoing access

New flows in relation to reporting and ongoing access (both the NBCSP and NCSP) are between:

- the NCSR and Services Australia to assess whether a person is eligible for a program;
- a participant, MHR and the NCSR, when a participant requests to withdraw consent to collect, use and disclose their NCSR information with MHR.
- a participant and/or their personal representative and the NCSR, when advising of updates to their clinical pathway;
- a participant and the NCSR, when advising that they have nominated a personal representative, and the NCSR and that representative, when providing confirmation of the nomination;
- a PFUF Officer or CCO and someone not verified as a personal representative through inbound or outbound enquiries or updates about a participant, or a PFUF Officer or CCO with a HCP to confirm whether a participant is in their care; and
- the NCSR and individuals using the NCSR website, when submitting personal contact information, issues, and questions to the NCSR.

Implementation of recommendations from the 2016 PIA

The Department has implemented the recommendations from the 2016 PIA to enhance the privacy positivity of the NCSR, NBCSP and NCSP (2016 Recommendations).

Specifically, the Department has:

- introduced privacy notices and policies about how information will be handled as part of the NCSR, including the NCSR's privacy policy, collection notices.[1] Supporting privacy communication materials have also been introduced to ensure that individuals are able to easily access information about how they can update their details and preferred method of communication, manage their participation in the programs and what's recorded in the NCSR, and provide formal feedback or make a complaint to Telstra Health (as the operator of the NCSR) and/or the Department.[2] Communication materials have also been developed for HCPs to assist them to communicate advantages and disadvantages of opting-out of the NCSR with their patients;[3]
- developed and implemented the National Cancer Screening Register Rules, which have been in effect since November 2017. The Rules address the handling of information in relation to individuals who are not participants, including those who have opted out;[4]
- collaborated with participating States and Territories to achieve consistency and compliance in information handling as part of the NCSR. This has included developing and implementing a privacy governance strategy through the participating States and Territories Memorandum of Understanding;[5]
- developed a data access and release policy to address the disclosure of information from the NCSR for research, in accordance with relevant guidelines and legislation[6];
- managed privacy and security risks associated with information handling, by requiring Telstra Health staff to undergo Privacy and Information Security Training, implementing terms and conditions for access to the NCSR for participants, HCPs and other end users, and the ongoing use of security and access controls for those able to access information on the NCSR.[7] Appropriate data migration and cleansing strategies were also developed and tested prior to the migration of the NBCSP register and State and Territory based Cervical Screening Registers to the NCSR;[8]
- taken steps to integrate the NCSR with My Health Record. The Australian Digital Health Agency (as the operator of My Health Record) has granted authorisation for the NCSR to integrate with My Health Record;[9] and
- conducted a privacy review of the operation of the NCSR.[10]

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[1] Recommendations 1, 5, 18, 27 of the 2016 PIA.
[2] Recommendations 3, 4, 13, 24, 25 and 29 of the 2016 PIA. The Department seeks independent expert advice when developing communication materials for Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds to ensure that communications are culturally sensitive - see: Recommendation 28 of the 2016 PIA.
[3] Recommendation 26 of the 2016 PIA.
[4] Recommendation 6 of the 2016 PIA.
[5] Recommendations 2 and 23 of the 2016 PIA.
[6] Recommendation 22 of the 2016 PIA
[7] Recommendations 7, 8, 9, 10, 20 and 21 of the 2016 PIA.
[8] Recommendations 15, 16 and 17 of the 2016 PIA.
[9] Recommendation 19 of the 2016 PIA.
[10] Recommendation 14 of the 2016 PIA.

Information flows

This PIA considers the additional information flows that have been introduced, and that were not considered in, the 2016 PIA.[11]

Information system developments (portals, CIS interface and associated authentication services)

Introduction of Portals

Since the 2016 PIA, the key updates to information flows associated with participant screening are the introduction of various portals through which participants, HCPs, and PFUF officers (who are State and Territory based) can access and update information held on the NCSR. These are:

- PFUF Portal: The PFUF Portal is used by PFUF officers to access and update the NCSR. The PFUF Portal and was made operational in 2019. PFUF officers are able to access NCSR information through the PFUF Portal in accordance with the National Partnership Agreement for the NBCSP. PFUF officer access to the PFUF Portal is subject to user access controls and PFUF officers are required to agree to terms of use before gaining access to the PFUF Portal.
- HCP Portal: The HCP Portal is used by HCPs to access and update the NCSR. The HCP Portal was made operational in December 2020 and is able to be accessed via the NCSR website or PRODA. HCPs are able to access and update NCSR information through the HCP Portal for the purposes of managing their patient's cancer screening. HCP users are required to agree to terms of use before gaining access to the HCP Portal. HCPs are also directed to the NCSR's privacy statement and a collection notice in relation to their own personal information at the time of their authentication for access to the HCP Portal.
- Participant Portal: The Participant Portal is used by participants to access and update their own information on the NCSR. The Participant Portal is accessible through the NCSR website and through myGov (if enabled by the participant). The Participant Portal allows participants to view and manage their screening preferences (including electing to defer screening or to opt out of screening) personal contact details, preferred method of receiving communication in relation to screening, their nominated HCP details, and their personal and/or nominated representative details. Participants are directed to the NCSR's privacy statement and a collection notice in relation to the collection, use and disclosure of their personal information for the purposes of the NCSR at the time of their authentication for access to the Participant Portal.

The information handling associated with each of the Portals was assessed in the 2016 PIA.

Integration with CIS interface

The CIS interface, which has been operational since October 2020, allows HCPs to access the NCSR through their existing practice software. This information handling involves:

- disclosure of participants' personal information by the NCSR to HCPs; and
- collection, use and storage of participants' personal information by HCPs.

Approved HCPs are able to gain access to the NCSR using the CIS interface once the clinic has been registered as an organisation in PRODA and the HCP Portal. Using their existing practice software to access the NCSR through the CIS interface, registered HCPs are able to check

[11] Each activity described in this section refers to a stage of the screening pathways as assessed in the 2016 PIA at 5.5 (NBCSP) and 5.6 (NCSP).

patient screening information and program status, update patient details, manage their patient's participation in the bowel and cervical screening programs and create and send program forms for the bowel and cervical programs.

The information handling associated with the CIS interface was assessed in the 2016 PIA.

Integration of authentication services

Since the 2016 PIA, the NCSR has also integrated a number of additional service providers to authenticate and verify participant and HCP details when registering to access the participant and HCP portals respectively. These services comprise PRODA, myGov and DVS.

- Information in relation to participants and HCPs will be disclosed by the NCSR to these authentication services for the purposes of verifying the relevant identity information provided.
- PRODA, myGov and DVS are all operated by or on behalf of other Commonwealth government entities.

It is only personal information of participants and HCPs (including HCP officers or employees) that may be disclosed for the purposes of verification. No new handling of healthcare identifier information for the purposes of authentication has been introduced since the 2016 PIA.

Additional NBCSP information flows

Since the 2016 PIA, the following new information flows are occurring and relate to the NBCSP only.

Alternative kit distribution

Since the 2016 PIA, the NBCSP has piloted an alternative kit distribution through HCPs (initially targeting Indigenous Australians). In this scenario, HCPs can order bowel screening kits and provide them to their patients (who are participants or eligible persons) in person (as an alternative to individuals receiving test kits via mail). Specifically:

- the HCP discloses personal information to the NCSR to indicate kit issuance, including preferences for how the participant will be managed (e.g. where to direct correspondence, handling of replacement kits and how to manage notification for next screening round) throughout the screening pathway;
- the NCSR collects and uses this personal information to flag that the individual has been issued a bowel screening kit (so they are not sent an invitation or kit by post); and
- Information in relation to that individual will be handled by their HCP, the NCSR and Contracted Pathologists (if applicable) in the same way as other NCSR participants or as per the preferences for how the participant will be managed, as noted by the HCP).

Unsolicited screening

Unsolicited screening occurs when individuals that have not been invited to participate in the NBCSP, and whose eligibility to participate in the NBCSP has not been assessed, have gained access to an iFOBT test kit and have subsequently provided the completed iFOBT test kit to a Contracted Pathologist. Information handling in relation to unsolicited screeners involves:

- collection by Contracted Pathologists and the NCSR of personal information voluntarily provided by an unsolicited screener that has completed an iFOBT test kit and provided the iFOBT test kit to a Contracted Pathologist. At the time of submitting the completed iFOBT test kit, unsolicited screeners voluntarily provide their personal details in the Participant Details Form for the purposes of screening and receiving their test results;
- the Contracted Pathologist discloses an unsolicited screener's personal information to the NCSR to confirm whether the unsolicited screener is eligible to participate in the NBCSP;

- if the unsolicited screener is eligible for the program, the Contracted Pathologist discloses their test results to the NCSR; and
- if the unsolicited screener is ineligible for the program, the results are not disclosed to the NCSR. If the screening test was positive, the Contracted Pathologist will send the result to the Unsolicited Screener.

Collection and use of histopathology results (NBCSP)

The 2016 PIA assessed the collection of histopathology results for participants following a positive screening test result (figure 9). The new flows relate to:

- the access and use of histopathology information from the NCSR by HCPs and PFUFs to ensure participants with a positive screening (iFOBT) result continue through the clinical pathway; and
- the expanded collection and use of histopathology results to manage screening of individuals that are eligible to participate in the NBCSP. The information handling associated with the use of histopathology results involves the personal information (including sensitive information) that may relate to individuals who are *eligible* to participate in a NBCSP screening round but are excluded due to a procedure/investigation or cancer diagnosis that make a screening test unnecessary at that time.

Information handling in relation to the collection and use of histopathology information involves the following:

- the NCSR collects histopathology results from pathology laboratories and HCPs for individuals in the age-eligible cohort for the NBCSP who have not opted out. This includes individuals who have not completed any screening before and those who are outside of a screening round. These histopathology results are collected by the NCSR directly from the pathology laboratories and HCPs and the individuals to whom the information relates are not notified of the collection of their information by the NCSR prior to the time of collection. Individuals are notified of their histopathology results (and any diagnosis) by their HCP or Specialist;
- the NCSR uses the individual's results to determine whether the individual will require a screening test in their next screening round. Specifically:
    - where the individual's histopathology result is positive (that is, positive for a risk of bowel cancer), the NCSR will update the individual's participant record to include a flag that the individual will be excluded from further preliminary screening in the form of iFOBT or a colonoscopy because the individual has recently been screened and are under care. The NCSR will notify the individual that they are excluded from screening due to their positive result, when their next screening due date is reached; and
    - where the individual's histopathology result is negative, and the procedure type was a colonoscopy (that is, negative for risk of bowel cancer), the NCSR will update the individual's participant record to include a flag that the individual is not required to be invited to screen for the remainder of the screening "round" because of their negative result. The NCSR will notify the individual that they are not required to screen in this round due to their negative results when their next screening date is reached.

Use of supplemented HCP information (NBCSP)

The NCSR will use supplemented HCP information where a participant has nominated a medical clinic as their HCP for the purposes of bowel cancer screening, but has not identified a specific medical practitioner. Specifically:

- where a participant has nominated a medical clinic but has not specified a particular medical practitioner:
    - the Contracted Pathologist collects the personal information, including nominated HCP, from the Participant Details Form and discloses this to the NCSR;
    - the Contracted Pathologist records the principal doctor at the medical practice as the participant's HCP in the NCSR and sends the test results to the principal doctor at the medical clinic as well as the participant; and
    - the supplemented HCP information will be used for next actions as per the normal clinical pathway.
- where a participant has nominated a hospital but has not specified a particular medical practitioner:
    - the Contracted Pathologist discloses the participant's details and their iFOBT results to the NCSR. This disclosure will be accompanied by a flag that this participant has no nominated HCP which will trigger a manual follow-up by a PFUF officer;
    - the Contracted Pathologist will send the results to the participant;
    - a PFUF officer will contact the participant and request that they nominate a HCP that is not a hospital. The PFUF officer will update the participant's HCP information on the NCSR accordingly; and
    - the NCSR sends follow-up correspondence to the HCP based on manually retrieved details or advice provided to the PFUF officer.

Additional information flows relating to reporting and ongoing access

Since the 2016 PIA, the following additional information flows have been identified in relation to reporting and ongoing access.

Assessing participant eligibility (both programs)

The 2016 PIA, detailed the NCSR's collection of Medicare enrolment data and Medicare claims data from DHS (now Services Australia) to identify eligible persons to be invited to screen. The additional information flow refers to the NCSR needing to look up individual's eligibility to remain in the program. This is done by:

- the NCSR disclosing details of an individual to Services Australia to validate that individual's eligibility to participate in the program.
- Services Australia discloses the individual's Medicare enrolment data and Medicare claims data to the NCSR. The NCSR collects and uses this information to determine whether the individual is eligible to be a participant in either screening program (e.g. if MBS item says a person has had a hysterectomy or recently undergone colonoscopy they would be excluded

Opt-out from NCSR and My Health Record integration

Participants are able to advise My Health Record, through the My Health Record National Consumer Portal, that they withdraw consent for their NCSR program details to be shared with My Health Record. When this occurs:

- the NCSR will perform a consent status check on the My Health Record system to check whether the participant has provided consent for their NCSR details to be shared with their MHR. NCSR will not push any data to My Health Record if the Participant has opted off or has not indicated their consent to share information with My Health Record.

- My Health Record will also perform a consent status check and will not accept NCSR data if the Participant has opted off or has not indicated consent to share their information with My Health Record.

Updating participant contact information

Since the NCSR has become operational, there are now additional interactions that occur between the NCSR and participants and their representatives which relate to updating the participant's contact details. This includes:

- Participants and/or their personal representatives advising the NCSR of the participant's clinical details;
- Participants advising the NCSR of the contact details of their nominated personal representative;
- the NCSR verifying a nominated personal representative (which will include the collection, by consent, of that nominated personal representative's contact information);
- Contact between a PFUF Officer or CCO and an unverified representative; and
- individuals submitting personal contact information, issues and questions through the NCSR website.

Compliance analysis of information flows

This section of the Addendum considers the compliance of additional information flows that have been introduced since the 2016 PIA with the relevant provisions in the NCSR Act and the Privacy Act. Overall, all information flows relating to the collection, use, disclosure and recording of personal information for the purposes of the NCSR are authorised pursuant to the NCSR Act and accordingly comply with the Privacy Act.

We confirm that we do not consider that APP 2, APP 7, APP 8 and APP 9 are relevant to the additional information flows.12 Compliance with these APPs has accordingly not been assessed as part of this Addendum.

Information system product developments

Portals and integration with CIS interface

The use of portals and the CIS interface involves information flows between participants, PFUF officers, HCPs and the NCSR. The relevant information handling associated with the Portals is authorised by the NCSR Act as follows:

- the disclosure of personal information by the NCSR on the Portals is authorised by sections 12(1)(i) and (j) and 17(3)(a) of the NCSR Act. The disclosure is for the purposes of providing an individual access to information relating to the individual about screening and diagnoses and providing HCPs access to information about screening and diagnoses for the purposes of providing healthcare to the individual. The disclosure, being authorised by the NCSR Act, complies with APP 6 (use and disclosure of personal information).
- the collection of personal information by the NCSR through the Portals is authorised by section 17(1) of the NCSR Act because the collection is for the purposes of including information in the NCSR. To the extent that this collection involves the collection of any

[12] APP 2 relates to anonymity and pseudonymity; APP 7 relates to direct marketing; APP 8 relates to cross-border disclosure of personal information and APP 9 relates to adoption, use or disclosure of government related identifiers and does not apply to the Department as an agency.

sensitive information, that sensitive information is authorised by the NCSR Act, and accordingly complies with APP 3 (collection of personal information).[13]

- the collection and use of participant personal information on the NCSR by HCPs is authorised by section 17(3)(b) of the NCSR Act because the information is either related to the participant's screening or diagnosis or collected for the purposes of providing healthcare to the participant in relation to the designated cancer. The collection and use, being authorised by the NCSR Act, complies with APP 3[14] and APP 6.
- participants and HCPs are directed to the NCSR's privacy statement and a collection notice in relation to the collection, use and disclosure of their personal information by the NCSR at the time of their authentication for access to the relevant Portals, achieving compliance with APP 5 (notification of collection of personal information).

Integration of authentication services

The use of authentication service providers to authenticate and verify participant and HCP details involves information flows between the NCSR and the authentication service providers. Section 17(1) of the NCSR Act authorises the use of personal information for authentication and verification by authentication service providers, as the information will be used for the purposes of including the information on the NCSR. This use of personal information, being authorised by the NCSR Act, complies with APP 6.

NBCSP developments

Alternative kit distribution

The alternative kit distribution pathway involves information flows between the HCP, NCSR and Contracted Pathologist. The collection of personal information by the NCSR from HCPs and Contracted Pathologists is authorised by 17(1)(a) of the NCSR Act because the collection is for the purpose of including the information in the NCSR. To the extent that this collection involves the collection of any sensitive information, that sensitive information is authorised by the NCSR Act, and accordingly complies with APP 3.[15]

Unsolicited screening

Unsolicited screening involves information flows between an unsolicited screener, Contracted Pathologist and the NCSR. All information flows are authorised because:

- the unsolicited screener consents to the disclosure of personal information through their signed Participant Details Form, thus authorising the subsequent use and disclosure of the personal information for the purposes of APP 6;
- section 10 of the NCSR Act does not prohibit the inclusion of information on the NCSR where the participant is not yet eligible; and
- the disclosure of personal information by the Contracted Pathologist to the NCSR is authorised by section 12(1)(a) and 17(1)(a) of the NCSR Act because the disclosure is for the purpose of including information in the NCSR and establishing and keeping an electronic database of records relating to screening.

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[13] Specifically, we consider that any collection of sensitive information would be authorised by APP 3.3 (where the sensitive information is collected with the consent of the individual) and/or APP 3.4(a) (because the sensitive information would be collected under an Australian law, being the NCSR Act).
[14] To the extent that the collection involves sensitive information.
[15] Specifically, we consider that any collection of sensitive information would be authorised by APP 3.3 (where the sensitive information is collected with the consent of the individual) and/or APP 3.4(a) (because the sensitive information would be collected under an Australian law, being the NCSR Act).

To the extent that APP 4 (dealing with unsolicited personal information) is engaged by the provision of unsolicited personal information from unsolicited screeners, we consider that compliance with this APP is achieved on the basis that the information provided is reasonably necessary for, or directly related to, the Department's functions or activities in operating and administering the NCSR.

Collection and use of histopathology results

The collection and use of histopathology results involves information flows between the participant, specialist, pathology lab, HCP and the NCSR. All information flows are authorised because:

- the information flows that relate to the NCSR, HCPs or pathology labs collecting, recording and disclosing information are authorised by sections 12(1)(a) and 17(1)(a) of the NCSR Act as this information is collected, recorded and disclosed for the purpose of including that information in the NCSR and establishing and keeping an electronic database of records relating to screening and diagnoses;
- the information flows that relate to the use and collection of information on the NCSR by HCPs and pathology labs are authorised by section 17(3)(b) of the NCSR Act because these entities are healthcare providers and the information is about screening or diagnosis associated with a designated cancer in relation to an individual or the information is used for the purposes of providing healthcare to the individual in relation to the designated cancer;
- the use by the NCSR of histopathology results that are on the NCSR to determine whether the individual will require a screening test is authorised by sections 12(1)(a) and 17(3)(a) of the NCSR Act because the information is used for the purposes of keeping an electronic database of records relating to screening; and
- the authorisation of these information flows under the relevant provisions of the NCSR Act achieves compliance with APP 3, APP 5 and APP 6.

Use of supplemented HCP information

The use of supplemented HCP information involves information flows between the participant, contracted pathologist, the NCSR and the HCP. All information flows are authorised because:

- the collection, recording and disclosure of information by the Contracted Pathologist is authorised by sections 12(1)(a) and 17(1)(a) of the NCSR Act because this information is collected, recorded and disclosed for the purpose of including the information in the NCSR and establishing and keeping and electronic database of records relating to screening;
- the use of the supplemented HCP information by the NCSR is authorised by sections 12(1)(f) and (g) and 17(3)(a) of the NCSR Act because the use relates to the purpose of advising the participant or their HCP about when the individual is due to undergo screening; and
- the authorisation of these information flows under the relevant provisions of the NCSR Act accordingly achieves compliance with APP 3, APP 5 and APP 6.

Reporting and ongoing access

Assessing participant eligibility

Assessing a participant's eligibility involves information flows between Services Australia and the NCSR. All information flows are authorised by sections 12(1)(d) and 17(1) of the NCSR Act because the flows relate to the disclosure of information for the purposes of including information in the NCSR and providing an individual with an invitation to undergo screening. Consistent with the conclusion reached in the 2016 PIA, we consider that privacy compliance is achieved.

Opt-out from NCSR and My Health Record integration

The process of a participant withdrawing consent for their NCSR program details to be shared with My Health Record involve information flows between the participant and My Health Record. The collection, use and disclosure of My Health Record users' personal information through the My Health record system is regulated by Part 4, Division 2 of the MHR Act, and is subject to the My Health Record user's personal access controls. The handling of the a participant's personal information in opting out from NCSR and My Health Record integration will be consented to by the participant as they will need to initiate the opt out process, which will subsequently be regulated by the MHR Act. We accordingly consider that compliance with APP 3 (to the extent that it may be engaged) and APP 6 will be achieved.

Updating participant contact information

The process of updating participant contact information can involve a number of information flows between the participant, their personal representative, unverified representatives and the NCSR. All information flows are authorised because:

- the information flows that relate to the collection and recording of information provided by participants, personal representatives or unverified representatives to the NCSR are authorised by section 17(1) of the NCSR Act because this information is collected and recorded for the purposes of including the information in the NCSR;
- the use of information on the NCSR by the NCSR to identify the participant's HCP and the disclosure of information to the HCP is authorised by sections 12(1)(g) and 17(3)(a) of the NCSR Act because this information is used for the purpose of advising a participant's HCP when the participant is due to undergo screening;
- information about the collection, use and disclosure of information submitted by an individual to the NCSR website is addressed by the Privacy Notice attached to the online submission form, and the use of the information to contact the individual is accordingly carried out with the consent of the person, achieving compliance with APP 3, 5 and 6; and
- the collection, use and disclosure of a participant's personal information by a personal representative is authorised by the consent of the participant provided in the form used to nominate their representative, achieving compliance with APP 3, 5 and 6.

Analysis of privacy impacts

Open transparent management of personal information (APP1)

The object of APP 1 is to ensure that APP entities manage personal information in an open and transparent way (see APP 1.1).

APP 1.2 provides that an APP entity must take such steps as are reasonable in the circumstances to implement practices, procedures and systems relating to the entity's functions or activities that:

- will ensure that the entity complies with the APPs and any applicable registered APP codes that bind the entity; and
- will enable the entity to deal with inquiries or complaints from individuals about the entity's compliance with the APPs or a binding registered code.

APP 1.3 provides that an APP entity must have a clearly expressed and up-to-date policy (an "APP privacy policy") about the management of personal information by the entity. The policy must contain information about certain matters relating to how and why an entity handles personal information.

The Agency has a comprehensive privacy policy that complies with relevant legislation and regulations, which is available on its website

As considered in the 2016 PIA, the scale and nature of the NCSR, the amount of personal information handled and the number of stakeholders means that administering the NCSR requires careful and transparent management of how the NCSR handles personal information. In order to maintain compliance with APP 1, the NCSR should continue to ensure that personal information is managed in an open and transparent way. This involves ensuring that participants, prospective participants and other individuals whose information may be handled as part of the NCSR are able to easily access information that explains how their personal information may be collected, used, disclosed and stored as part of the NCSR.

Since the 2016 PIA, the NCSR has created a publicly accessible privacy statement, privacy governance strategy, complaints management framework, data access and release policy and communications policy. These documents assist the NCSR to meet its obligations under APP 1 and to maintain the overall privacy positivity of the NCSR. We recommend that the Department continue to adopt a privacy positive approach in operating and administering the NCSR by regularly reviewing and updating its privacy policies and materials, particularly to take account of any new technical or project developments.

RECOMMENDATION 1

The Department should continue to regularly update and review its privacy governance strategy and related privacy documents to ensure they remain current and to take account of any new technical or system functionality developments.

Access to, and quality and correction of, personal information (APP10, APP12, APP13)

APP 10 requires that APP entities must take such steps (if any) as are reasonable in the circumstances to ensure that personal information that the entity collects, uses and discloses is accurate, up to date and complete.[16] APP 12 broadly requires that APP entities must provide individuals with access to personal information it holds, and APP 13 requires APP entities to take reasonable steps (if any) to correct information as requested by an individual.

APP 10

We have considered whether the process of supplementing HCP information may raise issues in relation to the quality of personal information. However, the practice of supplementing HCP data does not compromise the quality of participant's personal information because:

- the HCP listed on the participant's NCSR record remains accurate; and
- subsequent correspondence to the participant from the NCSR will include information about how the participant can update their personal details, including the details of their HCP.

We also confirm our view that the NCSR's procedures for interactions with unverified representatives to update participant contact details reflects appropriate steps being taken to ensure that participants' personal information is accurate, up to date and complete.

On the basis that the processes currently adopted with respect to supplemented HCP information and unverified personal representatives, as described in section 4 and section 5 of this

[16] APP 10.1 relates to personal information the entity collects; APP 10.2 relates to personal information the entity uses and discloses.

Addendum, remain as is we do not make any specific recommendations to further enhance compliance with APP 10.

APP 12 and APP 13

The use of supplemented HCP information and the use of personal representatives requires consideration of compliance with APP 12 and APP 13. We consider that compliance with APP 12 and APP 13 is achieved in circumstances where participants will:

- remain informed and updated of changes to their personal information, including by personal representatives;
- will be able to update their personal information through the Participant Portal or by contacting the NCSR Contact Centre; and
- will be provided with the opportunity to correct or update their HCP information at the appropriate juncture where supplemented HCP information is used.

Security of personal information (APP11)

APP 11 relevantly requires the Department, as an APP entity holding personal information, to take such steps as are reasonable in the circumstances to protect the information from:

- misuse, interference and loss; and
- unauthorised access, modification or disclosure.

Security of personal information was analysed comprehensively with respect to the NCSR in general in the 2016 PIA, based on the information flows that were assessed in that PIA.[17] We confirm that the additional information flows and project developments considered in this Addendum continue to achieve compliance with APP 11 through the use of strategies to mitigate the risk of unauthorised or improper access to information on the NCSR, including:

- access and authentication requirements for external users accessing information held on the NCSR through the various Portals;
- CIS integration is subject to verification by Telstra Health, and this verification requires integrating parties to adhere to the NCSR's software security standards;
- users who have direct access to the NCSR are required to agree to terms and conditions of use of the NCSR prior to being able to access information held on the NCSR;
- ongoing use of role based access controls which appropriately limit authorisations to amend information on the NCSR (for example, participants and personal representatives will not be able to amend participants' clinical information);
- information in the NCSR continues to be protected with appropriate security standards to prevent easy identification of personal information through an unauthorised access point; and
- the relevant recommendations in the 2016 PIA with respect to security of personal information have been adopted and implemented by the Department.[18]

Overall, we consider that the Department is taking appropriate steps to manage the security of personal information handled as part of the NCSR. We recommend that the Department continue to periodically revisit its security risk mitigation strategies to ensure that the strategies (including, for example, terms and conditions of access) accurately reflect the technical aspects of the NCSR at any given time.

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[17] See: section 6.8 of the 2016 PIA.
[18] Recommendations 7, 8, 9 and 10 in the 2016 PIA (at page 107).

RECOMMENDATION 2

The Department should continue to regularly update and review its security risk strategies to ensure that terms and conditions of use and user authentication, and user access controls are updated to account for any updates or changes to the manner in which information may be accessed.

Glossary

Term	Meaning
2016 PIA	Privacy Impact Assessment completed by Clayton Utz in 2016 in relation to the NCSR.
Australian Institute of Health and Welfare	Australian Government agency responsible for cancer screening program monitoring and reporting.
AIR	Australian Immunisation Register, managed by Services Australia.
APP	Australian Privacy Principle.
Authentication service providers	Collectively refers to the Document Verification Service (DVS), GoFax, Address Standardisation and Geocoding Solution, Provider Digital Access (PRODA) and myGov, which authenticate or verify an individual's details when registering to use the NCSR portals.
CCO/Contact Centre Operator	An NCSR employed Contact Centre Operator who is responsible for inbound and outbound enquiries related to the NCSP and NBCSP.
CIS/Clinical Information System	The CIS interface integrates the NCSR with a HCP's practice management software to enable exchange of NCSR data.
Contracted Pathologist	Refers specifically to the pathology provider contracted by the Department to supply and analyse iFOBT test kits under the NBCSP.
Department of Health/ Department	Refers to the Australian Government Department of Health. Responsible for the NCSR and delivering the NBCSP and the NCSP with state and territory health departments.
DVS	Document Verification Service - secure online national documentation verification system, used to verify identity documents that have been provided as part of an individual's registration to access the NCSR.
Eligible Person	An individual who is eligible for the NBCSP or the NCSP but who has not yet participated in the program. **Newly Eligible Persons** are individuals identified from Medicare enrolment data that have reached an age-qualifying birthday and will receive an invitation for a screening round unless excluded, or as otherwise determined by the Department.
End Users	All users of the NCSR either directly or indirectly including eligible persons/participants, Department of Health personnel (program managers), State and Territory personnel (including program managers and PFUF officers) and healthcare professionals (including GPs, pathologists and specialists).
HCP/Healthcare Provider	Healthcare provider – may refer to an individual healthcare provider (e.g. GP, nurse, pathologist, specialist) or a healthcare provider organisation (e.g. clinic, hospital).

Term	Meaning
HCP/Healthcare provider (supplemented)	A HCP/healthcare provider (supplemented) arises where a participant names a medical clinic (that is, a healthcare provider organisation), but not a specific medical practitioner or specialist and the Contracted Pathologist records the principal doctor at that medical practice on the participant's NCSR record as their healthcare provider (supplemented).
HCP Portal	Portal for healthcare providers to access the NCSR. The HCP Portal allows HCPs to access and submit screening data electronically.
HPV	Human Papilloma Virus, which may put a person at risk of developing HPV-associated cervical cancer if persistent infection occurs.
iFOBT	Immunochemical Faecal Occult Blood Test, a diagnostic test used to detect tiny traces of blood in a person's faeces that may be a sign of bowel cancer.
Individual	A member of the public who may, or may not, be considered a participant or eligible person for the NBCSP or NCSP.
MHR Act	*My Health Record Act 2021* (Cth)
MHR/My Health Record	My Health Record – managed by the Australian Digital Health Agency.
MHR/My Health Record user	A user of the My Health Record system, as established under the MHR Act
myGov	Secure way for individuals to access government services online in one place. The NCSR is one of many government services that can be linked to a person's myGov account.
NBCSP	National Bowel Cancer Screening Program
NCSP	National Cervical Screening Program
NCSR	National Cancer Screening Register
NCSR Act	*National Cancer Screening Register Act 2016* (Cth)
NCSR Privacy Policy	Privacy Statement publicly available on the NCSR website at: https://www.ncsr.gov.au/content/ncsr/en/privacy-statement.html
Nominated HCP	Refers to a healthcare provider listed by a participant in the NCSR in their participant information. Can refer to either an individual healthcare professional or a healthcare provider organisation.
Participant	An individual who is eligible for the NBCSP or the NCSP, who has elected to participate in at least one screening round by undertaking a screening test, or was screened whilst attending a HCP or whose invitation to screen has been brought forward by a HCP for either program.

Term	Meaning
Participant Follow-Up Function (PFUF) officers	PFUF officers **(PFUFs)** are employed by state and territory governments in relation to the NBCSP. PFUFs contact participants after a positive iFOBT test result where there's no record, within the set timeframe, of a follow-up with a GP or a colonoscopy in the NCSR. PFUFs encourage participants to schedule appointments, while also answering any questions about the next steps in the screening pathway.
Participant Portal	Portal through which Participants may access and update their information on the NCSR.
Pathology Laboratories/Labs	Refers to any pathology laboratory that tests a sample of relevance to the NCSP or NBCSP. For example specimens from a colposcopy, colonoscopy or a cervical screening test.
Personal Representative	A person who has been nominated by a participant to manage their affairs in relation to the NBCSP and/or NCSP within the NCSR. A personal representative may also be a parent or guardian if the individual is incapable of managing their health affairs, or a trustee of an estate of the individual if they are under a legal disability, or a person who holds an enduring power of attorney granted by the individual (the latter categories may also be referred to as Authorised Representatives, which refers to people empowered, by law, to act on behalf of an individual). A Personal Representative is not recognised in the NCSR until their documentation has been verified.
Privacy Act	*Privacy Act 1988* (Cth).
PRODA	Provider Digital Access authentication system, operated by Services Australia.
Services Australia	Australian Government Department responsible for delivering social, health and child support government payments and services (including Medicare and the Australian Immunisation Register). Formerly known as the Department of Human Services (DHS) and referred as such in the 2016 PIA.
Specialist	A healthcare provider that specialises in a particular area, such as a colorectal surgeon, gastroenterologist, gynaecologist or oncologist.
States and Territories	Refers to State and Territory government departments with responsibility for the NCSP and/or NBCSP.
Telstra Health/Contracted Service Provider	A standalone business unit of Telstra Corporation and the Contracted Service Provider for the operation of the NCSR in accordance with a services agreement with the Department of Health.
Unsolicited Screener	An individual who completes and submits to the Contracted Pathologist, another person's iFOBT test kit and Participant Details Form, before their eligibility for the NBCSP has been assessed.

Term	Meaning
Unverified Representative	A person who is not a personal representative of a participant but has contacted, or is contacted by, a CCO or PFUF officer trying to get hold of a participant.

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All information in this publication is correct as at December 2021