



# Australian National Bowel Screening Program

## Automating data capture and transfer to Register

Preventative Health

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# Abstract

- Population screening programs
  - Aim to reduce morbidity and mortality through early detection
- Complete, high quality data is essential for
  - Follow-up of positive test results
  - Evaluation of program impact and cost-effectiveness
  - Building underlying evidence-base for treatment
- The challenge
  - Participant information is spread across a number of locations
  - Information is lost if forms are not completed or are lost in transfer
  - Patient confidentiality and privacy are vital
- In this paper we explore the hypothesis that:
  - Automatic data capture and transfer to screening program register is possible without compromising patient confidentiality or privacy
    - Using Privacy-preserving data linkage techniques

# Background

- **National Bowel Cancer Screening Program (NBCSP)**
  - Central data Register established by Medicare Australia holds
    - Participant personal details
    - Results of Faecal Occult Blood Tests (FOBT)
    - Results of colonoscopies and/or biopsies following positive FOBT
- **Information is transferred to the register**
  - Using paper-based or electronic forms
    - Completed by participant, doctors and specialists
- **Key evaluation findings from NBCSP Pilot evaluation [5]**
  - Concerns over data integrity, especially missing information on follow-up of participants with positive FOBT
  - Missing data issue should be addressed with high priority
- **Concerns would be addressed by automatic data capture and transfer to NBCSP register**
  - If patient confidentiality and privacy requirements can be met

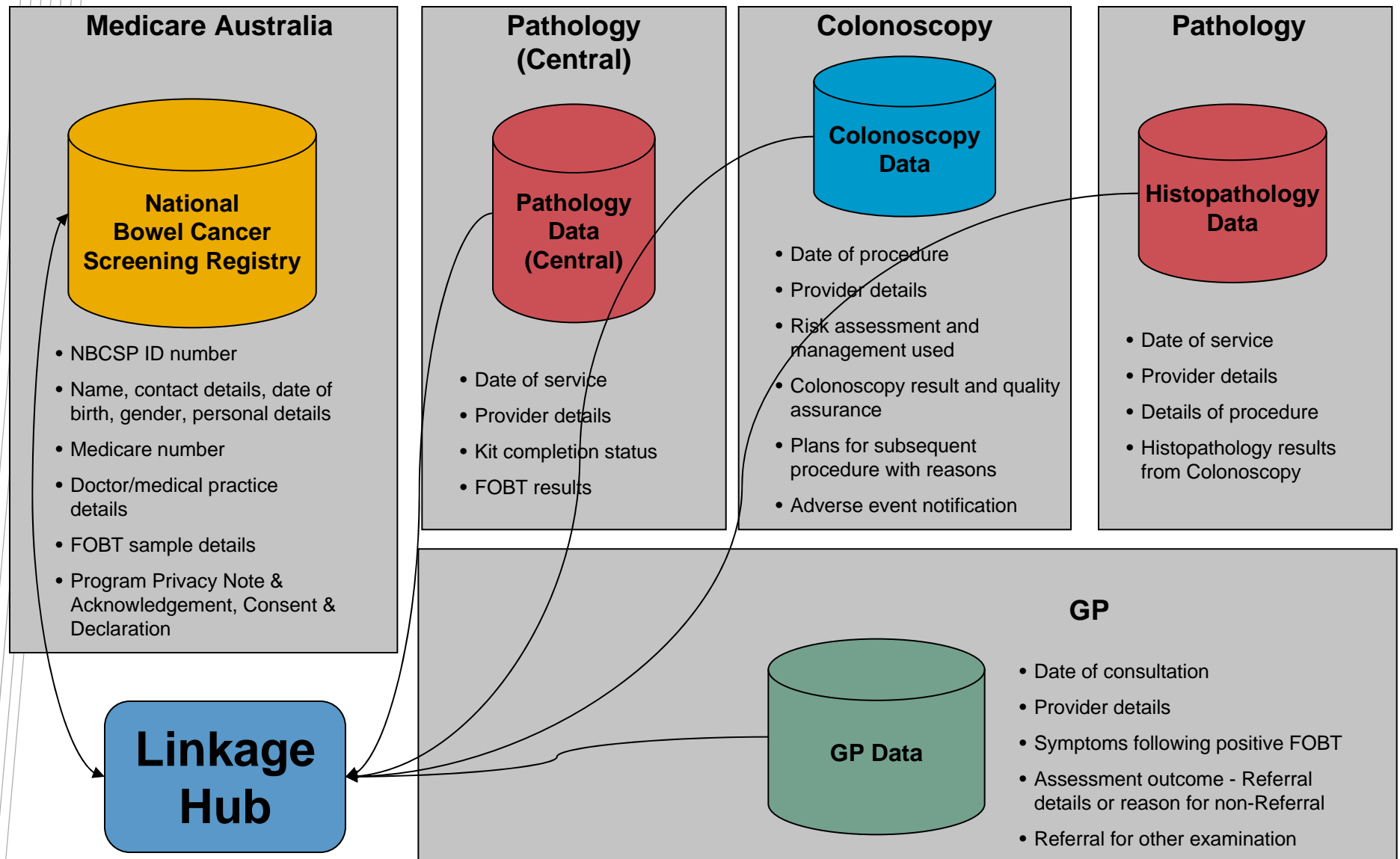
# NBCSP Register – holds participant information

- NBCSP-generated
  - ID number
- From Medicare Australia data holdings
  - Name, contact details, date of birth, gender, Medicare number
- From Participant Details Form
  - Further contact details, doctor/medical practice details, FOBT sample details, other personal details,
  - Program Privacy Note & Acknowledgement, Consent & Declaration
- Assessment Form – Referred for colonoscopy/Not referred for colonoscopy following a positive FOBT result;
- Colonoscopy Report;
- Procedure Report – Adverse Outcomes; and
- Histopathology Report
  - Screening history
  - Results of FOBT tests
  - Results of colonoscopies or biopsies after a positive FOBT

# Potential to automate most of the data capture

- The first parts of the process remain the same:
  - NBCSP-generated
    - ID number
  - From Medicare Australia data holdings
    - Name, contact details, date of birth, gender, Medicare number
  - From Participant Details Form
    - Further contact details, doctor/medical practice details, FOBT sample details, other personal details,
    - Acknowledgement and Consent to participate in the NBCSP including acknowledgement of Privacy Note
- The remaining data items are already collected in healthcare facility systems. These could be automatically extracted and transferred to the NBCSP Register
  - Using Privacy-preserving data linkage techniques

# Example scenario for NBCSP



# Example scenario for Linkage Hub

- **Periodically (eg daily/weekly)- each facility automatically**
  - Extracts patient identifying details for all patients with FOBT, colonoscopy & related procedures occurring during that period
  - Transforms the details to “encrypted” format in a pre-specified way
  - Sends the encrypted details to the Linkage Hub
    - A special type of encryption is used so that the encrypted patient details cannot be decrypted and read
- **At the same time, Medicare Australia automatically**
  - Applies the same encryption to the participant details from the NBCSP Register and sends the encrypted participant details to the Linkage Hub
- **Then, the Linkage Hub automatically**
  - Compares the sets of encrypted details to find the “matches” – participants in the NBCSP with new relevant information available
    - This is an example of Privacy-preserving data linkage
  - Sends the encrypted details for each “match” to the corresponding facility
- **Each facility automatically**
  - Sends the new information corresponding to only those matching participants to the Register – using the encrypted details to label them
    - Note that consent for such transfer for participants only is given on the participant details form
- **Then, Medicare Australia automatically**
  - Receives the new information, labelled with the encrypted participant details, and records it in the Register

# Example location of Linkage Hub

- Medicare Australia already hosting Register
- Australian Institute of Health and Welfare (AIHW)
  - NBCSP Privacy Note advises that participants' names & addresses already provided to AIHW for matching to cancer registry data
    - Provision of data to AIHW is subject to the secrecy provisions of the Australian Institute of Health and Welfare Act 1987
    - The disclosure of this information to AIHW and state/territory governments is authorised by a service arrangement under subsection 7(2) of the Medicare Australia Act 1973
  - AIHW could potentially encrypt the details itself, reducing the number of steps in the example scenario on the previous slide
    - In this case, the NBCSP Privacy Note may need to be redrafted to include the purpose of collecting data and transferring it to the Register

# Privacy-preserving data linkage - overview

- Finding “matches” between sets of names and addresses without revealing any identifying information
  - Early systems were likely to miss matches where there were misprints, different address formats etc
    - Proposed for use in epidemiology in 1995 and cancer registries in 1996
    - Practical improvements for clinical care in 2001
    - Theoretical improvements in 2003, 2004 – systems impractical
  - Currently much attention on efficient and effective protocols
    - Performance improving to levels considered acceptable
- See [3, 7, 10, 11]

# Summary

- Complete, high quality NBCSP register data is essential
  - For follow-up of positive tests, evaluation and evidence-base
- Much of this data is already captured anyway
  - In healthcare facilities' databases
- Clear opportunity for automatic completion and transfer
  - More complete, high quality data (even richer data)
  - Reduced compliance burden on doctors and specialists
- We have provided an example scenario
  - Participant details form remains
  - AIHW establishes a linkage hub
  - Data extraction and transfers are automated
  - Privacy-preserving data linkage protocols avoid the need for any party to reveal identifying information to any other party

# References

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# Thank you

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