

# Public Perceptions on Secondary use of health information / biological samples for research and planning

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# Bottom Line

- Public are largely unaware of the extent of linkage of health information
  - Generally onboard once explained
  - Greater confidence in use of their data/samples by:
    - Government
    - Public health
    - Academic researchers
  - Lesser trust in:
    - Public interest groups
    - Private sector
- Assumption that information will be used for public benefit.
  - Importance of being able to return results

- Particularly sensitive issues
  - Private sector and commercial uses
    - Public's interest is not first and foremost
    - Potential to manipulate the data
  - Linkage of health and non-health information
    - Income, education, social services use, justice system
    - Potential for stigmatization and discrimination
- White-coat syndrome around biological samples: High trust around
  - Confidentiality
  - Use in the public interest

# Policy Implications – Public wants:

- Greater transparency about use
  - Factual, not hard sell
    - Benefits, risks, safeguards to mitigate risks
  - Where to get details
    - Generally
    - Registry of studies using these data sets
  - e.g. with renewal of health insurance card
- The option to opt-out of some types of uses, even if data are de-identified
- Public input into projects involving:
  - Commercial uses
  - Linkage of health and non-health information
  - e.g. panels of affected individuals
- Systems that allow for evidence to action (return of results)