

# Community views on the collection and use of identifiable data for health research – is it an invasion of privacy?

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## Background

- The Western Australian Birth Defects Registry (WABDR) historically relies on voluntary notification of cases from the health system (with or without patient consent).
- High ascertainment rates are essential for validity and reliability of the data and public health research.
- Identifiable case data are required (e.g. to ensure identity of each case and to link cases to other datasets for public health research).
- Private medical practitioners are the only source of around 30% of cases, but the introduction of Australian data protection legislation now queries the tenability of them providing data without patient consent.
- Requiring informed consent may result in selection bias and lower ascertainment rates.
- Statutory notification was proposed as a solution to maintaining the case ascertainment rate and data quality.
- Before this could be legislated, it was required that consumers and the community support statutory notification, but consumer representatives could not reach consensus on this issue.

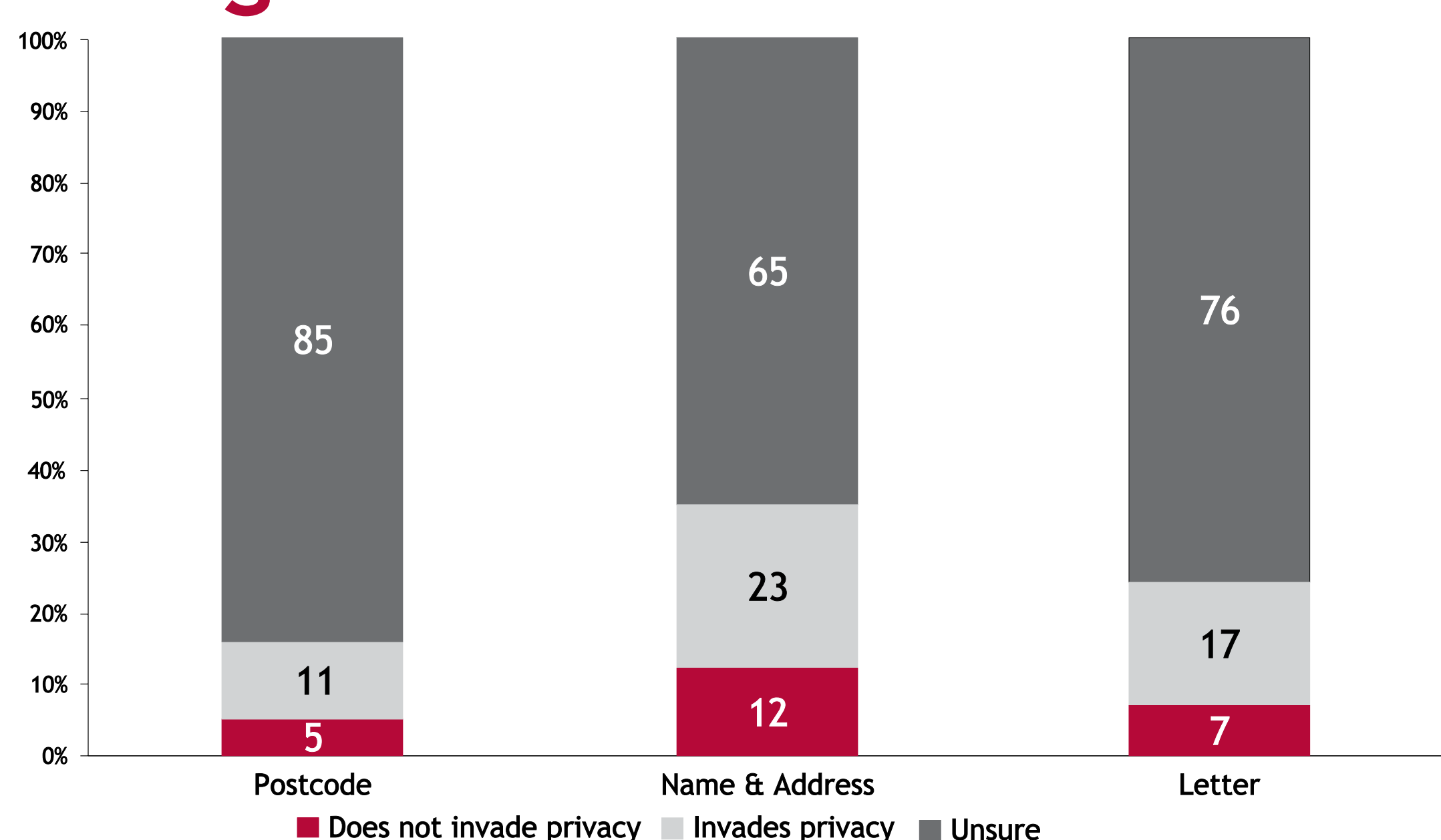
## Objectives

- Investigate community views on the statutory collection of identifiable data by the WABDR.
- Explore the extent to which the use of such data is perceived to be an invasion of privacy, when balanced against the community benefit of three public health scenarios.

## Method

- Cross sectional, Computer Assisted Telephone Interviewing (CATI) in August 2006.
- 600 adults recruited randomly from the electronic version of the Western Australian telephone directory.
- Data weighted prior to analysis to ensure sample was representative of population in terms of age, sex and geographic area.

## Key findings



79% support statutory notification of cases to WABDR  
Similar trends in UK Cancer Registry study (Barrett et al, BMJ, 2006)

## Public health scenarios

Data	Public Good	Privacy
Postcode	To research if birth defects are related to living around polluted areas	Invasion?
Name & Address	To accurately monitor the total number of cases of birth defects in Western Australia	Invasion?
Receiving letter to participate in University research	To do research with people who had a particular type of birth defect	Invasion?

Data provided by ‘your doctor’ to the WABDR

Data to be ‘held confidentially and under strict security’

Replicates a study on the UK Cancer Registry (Barrett et al, BMJ, 2006)

## Impact of findings

- Contributed to achievement of consumer consensus on support for statutory notification.
- Statutory notification proposal more likely to get political/legislative support.
- Private medical practitioners more likely to continue providing case information.
- WABDR maintains high ascertainment rate.
- High quality of public health research is maintained.
- Cannot assume the public will always place personal privacy above the societal benefit of health research.