



**Australian
Privacy
Foundation**

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The Healthelink Scheme

Did you know that, if you live in Western Sydney, and your child has attended a doctor or a public hospital recently, your personal data has probably been entered onto a centralised health database? Did you know that data is accessible by people not involved in your child's care? Were you given the chance to 'opt out'? And, if you opted out, did they actually delete the data they collected?

There are some patients for whom the centralised Health-e-Link database may have benefits. However, the scheme will not improve health care for most people. It is primarily for the benefit of administrators and researchers.

The scheme also creates risks, because it puts in one place a large amount of highly sensitive personal data, including both health data and contact information. That information has previously been stored where it belongs – in the many separate records of health care professionals and health care organisations such as clinics and hospitals.

The central records are accessible by a great many people, many of them not health care professionals, and many of them without any relationship to the person concerned. This creates risks of leakage of sensitive data, and of identity fraud.

The risks are greatest for vulnerable members of the community. Many parents may be particularly concerned that data about their children is being placed in a central repository, without parental consent.

A scheme of this kind seriously breaches the public's expectations. It was against the law, so the Department of Health arranged for the State's privacy laws to be relaxed to enable it to proceed.

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. The APF made many submissions opposing the scheme, but political expediency won through.

The APF recommends as follows:

- **inform yourself about this scheme.** Descriptions are available from the Department and hospitals: <http://www.healthelink.nsw.gov.au/>. See also http://www.privacy.org.au/Campaigns/E_Health_Record/HealthElink.html
- if you are concerned about central storage of large quantities of sensitive data about you and your children, **exercise your right to opt out of the scheme.** The Department makes it highly inconvenient to do so. See this page: http://www.healthelink.nsw.gov.au/what_is_healthelink/participation_in_healthelink
- **complain to your local MP, the media, the Department of Health, and the Minister for Health** (Carmel Tebbutt), about centralising highly sensitive personal data without consent

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