



**Australian  
Privacy  
Foundation**

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21 November 2008

Mr Bruce J Carter  
National President  
Heart Foundation  
c/- Ferrier Hodgson, Adelaide

cc. Ms Karen Curtis, Australian Privacy Commissioner  
Ms Marie Shroff, New Zealand Privacy Commissioner  
Mr Gordon Renouf, Australian Consumers Association

Dear Mr Carter

### **Heart Foundation 2008 'Survey'**

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. A brief backgrounder is attached.

I refer to the 'Heart Foundation 2008 Survey', a document apparently being mailed to a large number of recipients during November 2008. A copy has been brought to this organisation's attention.

The document, and the 'survey' of which it forms a part, involve some of the most serious breaches of privacy, and some of the most seriously misleading communication, that have come to this organisation's attention during its 20-year existence.

1. The survey design is completely obscure. No information is provided about its aims, the population, the sampling-frame, or the sample.
2. The questionnaire is presented as a 'survey', and the context is presented initially as "research into the causes, prevention and treatment of [heart] disease", and later as to "give us a better idea of people's awareness and experiences of cardiovascular disease".  
As is apparent from a careful examination of the document, however, the aims are neither of these. The purpose is to collect personal data in order to assist in fund-raising.
3. The letter and the form both carry the recipient's name and address. No indication is provided of the source of that information, although the reference-number may provide some indication.
4. The small print at the end of the form discloses that your organisation is "working with Acxiom". This is seriously inadequate disclosure, because few recipients would be aware that this company is the world's largest consumer profile database operator, and that it is domiciled in a 'privacy haven' (Arkansas, which has little in the way of privacy law, and which is a State of the U.S.A., which has seriously deficient privacy laws).
5. The small print at the end of the form discloses that "working with Acxiom" results in "great savings to The Heart Foundation ...". It is reasonable to infer that Acxiom will be extracting some advantage from the arrangement. The advantage does not appear to be sponsorship (because the only mention of the company is in the fine print). Further, "Acxiom may provide your details to other responsible organisations who may like to contact you ...".

It therefore appears that the personal data disclosed by participants to, ostensibly, the Heart Foundation is in fact being disclosed to Acxiom. Your organisation has committed one of the most blatant misrepresentations that the APF has ever seen in consumer marketing documents.

6. At the very end of the small print, a tick-box is provided, preceded by the text "Please tick here if you would prefer not to be contacted in this way".

This is not consent, but assumed consent with the possibility of opting-out (provided that the recipient reads through the entire document, including the small print at the very end).

It would appear that your organisation, Acxiom, and perhaps other organisations who pay for Acxiom's services, are attempting to achieve consent to the collection, use, disclosure, and further use of the personal data in the form. That may be tenable in the permissive context in which U.S. corporations work, but it is a gross misrepresentation and abuse of the law in Australia and New Zealand.

The recipient who drew this matter to the APF's attention commenced filling in the questionnaire on the assumption that the Heart Foundation is a credible non-government organisation gathering donations to support research and education in the area of heart disease.

As it gradually became apparent what the document actually was, the considerable goodwill that your organisation enjoyed progressively dissolved, and the anger grew. The Heart Foundation has been deleted from that person's list of charities.

The recipient who provided the copy to us will be only one of many people whose support your organisation will lose as a result of this grossly misconceived activity. If you and your Board wish to recover your organisation's good name, the APF sees no option other than the cessation of the activity.

Failing that, the APF requests that you correct the litany of privacy blunders in the design of the activity, including outright breaches of the law, and confirm to the APF the changes that are being made.

Further, the APF requests that you communicate to Acxiom that they are not to use any personal data that they may have acquired as a result of this, any prior, and any similar, activities; and that they are to delete that data, on the grounds that it was acquired through misrepresentation, and quite probably by illegal behaviour. Would you please confirm to the APF that this has been done.

A copy of this letter has been sent to the Australian and New Zealand Privacy Commissioners, at this stage for information only, but also as advance warning that formal complaints will be submitted in the event that your Board fails to ensure that the many problems with the activity are addressed.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Roger Clarke', written over a faint rectangular stamp or box.

Roger Clarke  
Chair, for the Australian Privacy Foundation  
(02) 6288 6916 chair@privacy.org.au

## Australian Privacy Foundation

### Background Information

The Australian Privacy Foundation (APF) is the primary national association dedicated to protecting the privacy rights of Australians. The Foundation aims to focus public attention on emerging issues that pose a threat to the freedom and privacy of Australians. The Foundation has led the fight to defend the right of individuals to control their personal information and to be free of excessive intrusions.

The APF's primary activity is analysis of the privacy impact of systems and proposals for new systems. It makes frequent submissions to parliamentary committees and government agencies. It publishes information on privacy laws and privacy issues. It provides continual background briefings to the media on privacy-related matters.

Where possible, the APF cooperates with and supports privacy oversight agencies, but it is entirely independent of the agencies that administer privacy legislation, and regrettably often finds it necessary to be critical of their performance.

When necessary, the APF conducts campaigns for or against specific proposals. It works with civil liberties councils, consumer organisations, professional associations and other community groups as appropriate to the circumstances. The Privacy Foundation is also an active participant in Privacy International, the world-wide privacy protection network.

The APF's Board comprises professionals who bring to their work deep experience in privacy, information technology and the law.

The following pages provide access to information about the APF:

- papers and submissions <http://www.privacy.org.au/Papers/>
- resources <http://www.privacy.org.au/Resources/>
- media <http://www.privacy.org.au/Media/>
- Board-members <http://www.privacy.org.au/About/Contacts.html>

The following pages outline several campaigns:

- the Australia Card (1985-87)  
<http://www.privacy.org.au/About/Formation.html>
- the Medicare Smart Card (2004-06)  
[http://www.privacy.org.au/Campaigns/ID\\_cards/MedicareSmartcard.html](http://www.privacy.org.au/Campaigns/ID_cards/MedicareSmartcard.html)
- the Human Services Card (2005-06)  
[http://www.privacy.org.au/Campaigns/ID\\_cards/HSCard.html](http://www.privacy.org.au/Campaigns/ID_cards/HSCard.html)
- the Australia Card Mark II (2005-06)  
[http://www.privacy.org.au/Campaigns/ID\\_cards/NatIDScheme.html](http://www.privacy.org.au/Campaigns/ID_cards/NatIDScheme.html)
- the 'Access Card' (2006-07)  
[http://www.privacy.org.au/Campaigns/ID\\_cards/HSAC.html](http://www.privacy.org.au/Campaigns/ID_cards/HSAC.html)