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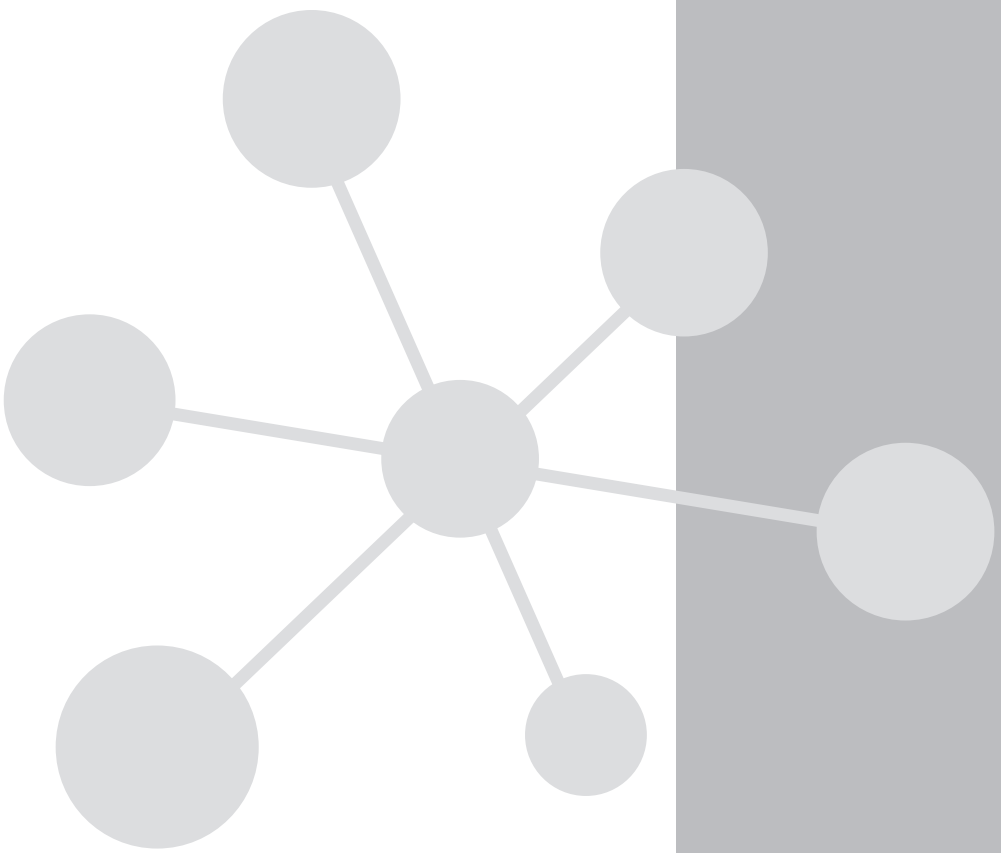
Voluntary Medical and Emergency Information:

Submission to Access Card Consumer and Privacy Taskforce: 20 March 2007



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Submission to Access Card Consumer and Privacy Taskforce

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1. Introduction

1.1 The Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) seeks to promote a just and democratic society by making strategic interventions on public interest issues.

PIAC is an independent, non-profit law and policy organisation that identifies public interest issues and works co-operatively with other organisations to advocate for individuals and groups affected.

In making strategic interventions on public interest issues PIAC seeks to:

- expose unjust or unsafe practices, deficient laws or policies;
- promote accountable, transparent and responsive government;
- encourage, influence and inform public debate;
- promote the development of law—both statutory and common—that reflects the public interest; and
- develop community organisations to pursue the interests of the communities they represent.

Established in July 1982 as an initiative of the Law Foundation of New South Wales, with support from the NSW Legal Aid Commission, PIAC was the first, and remains the only, broadly based public interest legal centre in Australia. Financial support for PIAC comes primarily from the NSW Public Purpose Fund and the Commonwealth and State Community Legal Centre Funding Program. PIAC generates approximately forty per cent of its income from project and case grants, seminars, consultancy fees, donations and recovery of costs in legal actions.

1.2 The Taskforce

PIAC welcomes the opportunity to make a submission to the Access Card Consumer and Privacy Taskforce's second Discussion Paper on voluntary medical and emergency information.

PIAC values the informed and independent contribution to the debate made so far by Professor Fels and his colleagues in regard to the Federal Government's Access Card proposal.

2. Current debate regarding health and emergency information

The question of whether health and emergency information should be contained on the chip of the proposed Access Card has generated considerable public debate, some of which has been specifically discussed in the Taskforce Discussion Paper. PIAC believes that the expert opinion expressed in the media around core concerns to do with the storage of health and emergency information need due consideration.

Many of the issues outlined in the Discussion Paper have important implications for the dimensions of the card and chip, and what each will be used for. Once again, PIAC takes the opportunity to highlight the importance of working through these issues before any legislation is passed through parliament and before any of the commercial tenders are finalised. The protection of personal information should be a key feature of any legislative proposal.

2.1 Ownership of the card

The Discussion Paper outlines the following:

> There is no doubt that the access card provides a series of opportunities for consumers, who are, under the legislation, the personal owners of the card in any event, to decide on the use of the card for a range of purposes and services of their own choosing.1

As outlined above, the Human Services (Enhanced Service Delivery) Bill 2006 (the Bill) (now withdrawn) provides that 'you own your access card'.[2] The Government has made much publicly about the concept of the cardholder 'owning' the access card that is issued to them, and how this is a defining feature of the proposal. PIAC submits that, once all factors are considered, this concept has limited meaning.

The Bill sets out the limits on 'ownership' of the card including that it does not:

- include the usual right to deal with property by selling it or otherwise disposing of it; or
- include ownership of the intellectual property or information on the surface or chip on the card.[3]

However, effort is made to emphasise that ownership of the card means more than owning the piece of plastic. As the Explanatory Memorandum to the Bill states '[t]he card consists of more than just the physical card'.[4] It is not at all clear what the purpose is of this statement as the Explanatory Memorandum immediately goes on to state:

> It also includes information that is stored in the chip of the card. It is not intended that ownership of the physical card also vests ownership rights in the information on the chip of the card. For this reason subclause 175(3) clarifies that ownership of the physical card itself does not give the holder ownership of the information in the Commonwealth's area in the chip in their access card that they do not otherwise have.[5]

So, effectively, 'ownership' means that people will own the physical piece of plastic, the physical chip, and their name and address details, as well as information that they already previously 'owned'. As stated above, 'ownership' of the card appears to be a relatively meaningless concept and it is arguable that it is simply being included by Government in the package in an attempt to distinguish the current proposal from the previous Australia Card proposal of the 1980s.

Some limited space on the chip on the card is allocated to enable the cardholder to 'customise their card to include additional information.[6] In PIAC's view this does not change the limited meaning of 'owning' the card. It simply means that the card holder will be able to store some information on the card of their own choosing. As the Discussion Paper outlines, in order for the information held in the personal area of the card to be of benefit to the card hold, this information must be accessible and, as such, not secure against disclosure.

> Against this enhanced range of consumer choice, cardholders need to be conscious of and balance the potential loss of privacy which is inherent in storage of personal data (some of it highly sensitive) which can, potentially, be read by third parties.[7]

There is a very real possibility that the emphasis being placed by Government on the 'ownership' of the card will cloud the fact that in order to be in any way beneficial for the card holder, the personal

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1 Access Card Consumer and Privacy Taskforce, *Discussion Paper Number 2: Voluntary Medical and Emergency Information* (2007) 14

2 Human Services (Enhanced Service Delivery) Bill 2007 (Cth), cl 37.

3 Human Services (Enhanced Service Delivery) Bill 2007 (Cth), cll 38, 39

4 Explanatory Memorandum, Human Services (Enhanced Service Delivery) Bill 2007 (Cth) 40.

5 Ibid.

6 Ibid, 36.

7 Access Card Consumer and Privacy Taskforce, above n1 at 14.

information held on the chip must be readily accessible and therefore no longer private, despite being of a highly sensitive nature.

2.2 Emergency medical information

As is outlined in the Discussion Paper, in his address to the Australian Medical Association (AMA) National Conference on 27 May 2006, the then Minister for Human Services, Hon Joe Hockey MP stated:

> Importantly for the medical profession, there will also be space available for cardholders to voluntarily include vital personal information that could be used in medical emergency such as, next of kin, doctor details, allergies, drug alerts, chronic illnesses, organ donor status and childhood immunisation information. This information may save lives.[8]

While it is true that emergency access to medical information may, for some people, be the difference between life and death, it is critical that the very fact of the card's existence and that it may contain relevant medical information does not cause delay. It is vital that the possible emergency benefits of the Access Card not be oversold to the public. On the face of its, the Human Services Access Card does not fulfil the same purpose as existing medical emergency information communication systems, such as Medic Alert, Medic Tag, SOS Talisman or Vial for Life.[9]

While the Taskforce correctly draws out the similarities with the MedicAlert system, it is important to note the differences:[10]

- MedicAlert is an internationally recognised system that operates globally, which means that in an emergency in another country having a MedicAlert number can still ensure access to important medical information.

- MedicAlert operates through the member wearing a bracelet or necklace bearing a token engraved with the MedicAlert symbol, a 24-hour telephone number indicating the country and STD code, emergency information about the wearer such as major health conditions or allergies, and the wearer's membership number.

These differences are significant when one considers that a person may be seeking to rely on the system in a medical emergency:

- The Human Services Access Card chip containing emergency medical information will be completely unhelpful in a medical emergency in another country as the only way to access the information will be through having a compatible smartcard reader.

- The Human Services Access Card will not provide immediate information such as major health conditions or allergies on its face. Rather the person administering emergency medical care will have to access the information through a compatible smartcard reader. While this may cause only a short delay in Australia, it could be a delay that is critical.

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8 Ibid, 3

9 *Australian Adverse Drug Reactions Bulletin* (2006) Therapeutic Good Administration <http://www.tga.gov.au/adr/aadrb/aadr0604.htm> at 18 March 2007.

10 This submission focuses on the MedicAlert system rather than any other of the emergency medical information systems as the MedicAlert system has a system for obtaining medical practitioner verification of the medical information and information about the MedicAlert system is readily available.

- The Human Services Access Card is not likely to be worn on the body and so, in an emergency, the health care provider will need to spend time trying to locate the card on the off-chance that the card contains emergency medical information. While it is possible, as the Taskforce has indicated, to include on the surface of the card a symbol to indicate that emergency medical information is stored on the chip, this does not avoid the potential problem of time being wasted looking for the card itself only to find that the card does not carry the indicative symbol.

The very existence of the option to have emergency medical information on the chip could be counterproductive to emergency treatment. A person who currently uses MedicAlert could see the Human Services Access Card option as the equivalent of MedicAlert and opt to cease their membership of MedicAlert, relying instead on the Access Card. Given the differences and ramifications of those differences identified above, the person could be worse off in a medical emergency.

2.3 Risk of discrimination

There is also the possibility that information about medical conditions contained on the card chip may facilitate discrimination against the card holder on the prohibited ground of disability. As the Discussion Paper outlines:

> There are a number of other conditions which have been suggested regularly for inclusion in the first tier of the record, namely blood type and HIV/Hepatitis C status. The Taskforce would reject both of these examples.
>
> There is no need for emergency/health personnel to know of a person's HIV/HCV status since it is expected that they will be applying universal precautions to deal with blood spills and possible contamination and because knowledge of HIV/HCV status leads frequently to the individual concerned being treated in an improperly discriminatory fashion and of the risk of having their privacy compromised.[11]

It is important to emphasise that discrimination occurs on the basis of a wide range of disabilities, including many that are treatable medical conditions, not only the examples outlined above. For example, discrimination is often experienced by people who have a mental illness.

Again, even fairly rudimentary analysis of the risks of adverse outcomes in terms of discrimination indicates that it is dangerous to promote as a benefit of the card the fact of having a sector on the chip for personal use. Where emergency medical information, such as conditions that require particular emergency treatment and serious drug reactions, can more readily be accessed through an existing emergency medical information system, there is little or no justification for creating the risk of disclosure of excessive amounts of information about a person's medical history and conditions.

2.4 Costs and difficulties of using the Access Card as an emergency medical information system

The Taskforce in considering the use of the cardholder's area of the chip to hold emergency medical information noted that it 'understands that the Australian Government itself has no interest in running such a project'.[12] This suggests that any emergency medical information system would be developed and implemented by a private sector agency (whether for profit or non-profit). The options for entering data onto the chip appear to be either:

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11 Ibid 6

12 Ibid 13.

- entry by the card holder's general practitioner; or
- entry by a third-party (private) provider.

In either case, there is likely to be an additional cost, either to the Australian taxpayer or to the card holder, because of the cost of having card-writing facilities and the cost of the time taken to actually enter and update the data. The cost of entering data onto the card would not be a one-off cost as it will be important to ensure the data is updated to reflect any changes to the cardholder's medical information for emergency purposes.

PIAC notes that the Department of Human Services in its supplementary submission to the Senate Finance and Public Administration Committee's Inquiry into the Human Services (Enhanced Service Delivery) Bill 2007 (the DHS Supplementary Submission) indicated that providing card terminals to medical and allied health professionals with a capacity to access photo data on the chip would add at least $700 million to the cost of the scheme (taking the cost from $1.1 billion to $1.8 billion).[13]

There are no details available as to the cost of providing card terminals to medical practitioners with the capacity to write data to the chip. The DHS Supplementary Submission illustrates the way in which a medical practitioner would use the Access Card. That information indicates that all that the medical practitioner would be able to do is view relevant and up-to-date information and record that information in the practitioner's own practice management system.[14] Given the additional $700 million it would cost to upgrade the card terminals to have photo-display capacity, it is likely that the cost of providing card interface technology with data-entry capacity would be significant.

In addition to the cost of having the relevant technology available to all medical practitioners, there is also the time-cost burden of entering data as well as the administrative burden. The DHS Supplementary Submission indicates that adding photographic reader capacity to doctors' surgeries 'adds an unnecessary layer of red tape' and seems to indicate that having photographic reader capacity would require an additional terminal as the current proposal relies on 'leveraging' 'the installed infrastructure of bank, acquirer and merchant owned Point of Sale terminals.[15] This suggests that adding card-writing capacity could result in even more administrative problems and even, potentially, an additional terminal. The DHS Supplementary Submission notes that aside from the additional $700 million cost of upgrading terminals, doing so 'is unlikely to be technically viable or logistically feasible'.[16]

The DHS Supplementary Submission also notes that having multiple terminals for different purposes 'would eliminate one of the benefits' of the scheme and the Department 'would expect a strong negative reaction from the medical … sector because of the proliferation of readers, the reduced space for business and the cost and complexity of systems'.[17] In addition, the DHS Supplementary Submission indicates that not all medical practitioners have the technology available or are willing to upgrade their information technology systems.[18]

So, in the event that the entry of emergency medical information were to rely on medical practitioners, it seems likely, on the evidence of the Department of Human Services, that there would be uneven access to this purported benefit of the card as well as significant costs and possible resistance from medical practitioners.

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13 Department of Human Services, *Supplementary Submission to the Senate Inquiry into the Human Services (Enhanced Service Delivery) Bill 2007* (2007) 11.

14 Ibid 5.

15 Ibid 10.

16 Ibid 11.

17 Ibid 12.

18 Ibid 12.

The fact that the Government is not interested in running this aspect of the access card project inevitably means that there will be costs to the cardholder of obtaining the potential benefit of having emergency medical information stored on the personal area of the chip of their access card.

Without an indication of what these costs are likely to be, it is difficult to fully assess whether or not this is even a viable option. However, a simple mathematical exercise using the current levels of usage of MedicAlert (as reported by MedicAlert[19]) and the cost of providing photographic readers, indicate that the cost of obtaining the purported benefit is likely to be in the order of $3,500 per person ($700 million divided by 200,000). This compares with the current cost of accessing MedicAlert, which is significantly less than $100 to join and get registered and be supplied with the bracelet or necklace, and then an annual fee of less than $20.

2.5 Privacy concerns

Any system of recording emergency medical information on the chip involves the potential disclosure of that information through the data on the chip being accessed. While such disclosure is necessary if emergency medical care is to be tailored to the person's medical needs, any disclosure beyond that is of concern. Finding the balance between ease of access for emergency medical personnel and appropriate protection of sensitive personal information is vital.

In addition, a scheme relying on either public sector or private sector data entry (other than by the card holder's medical practitioner) necessarily also involves disclosure to the person entering the data. It is important that the privacy implications of such a scheme be fully considered and that consumers be made aware of the extent of disclosure of that information before they elect to use the chip in this way.

2.6 Conclusion on emergency medical information

Given all of these considerations, it is PIAC's view that promoting a scheme of using the chip to hold emergency medical information may be counter to the public interest due to cost to consumers and potential adverse impact on emergency medical responses.

3. Recommendations - Discussion Paper 2

PIAC's position on the range of recommendations outlined in the Discussion Paper is outlined below.

Recommendation 1: That the Taskforce's preferred two-tier model be considered as a standard should the inclusion of voluntary emergency and health information be available to the individual for inclusion on their access card chip.

Recommendation 2: That consultations be undertaken with the relevant medical and emergency service authorities to draw up an agreed definition of what should be regarded as "absolutely necessary" medical data to be included in the first tier of the proposed model.

If the potential for the use of the chip to store emergency medical information remains, PIAC supports both of these recommendations.

[19] *Australian MedicAlert Foundation* (2007) MedicAlert <http://www.medicalert.com.au> at 18 March 2007.

Recommendation 3: That no voluntary medical information be entered into any part of the access card without verification of the accuracy of that information by an approved medical or other practitioner.

PIAC supports this proposal but we have concerns about how information might be updated on the card in an appropriate and timely manner, and the implications that this might have for ongoing treatment.

Recommendation 4: That the medico-legal issues arising from persons acting in good faith on the medical data contained in an access card be addressed and clarified in future legislation related to the operation of the access card chip.

PIAC supports this recommendation, and is pleased that implementation of the Bill that was before the Senate will be delayed and amended and will presumably resolve some of the important issues referred to above.

Recommendation 5: The Australian Government, in its information campaign, restate its policy that the access card will not be used to store electronic health records or link to existing electronic health records.

PIAC supports this recommendation. However, this should go further and recommend that the Australian Government make it clear, in its information campaign, that it will not be funding use of the card as a storage facility for emergency medical information and that the cost will be borne by cardholders.

Recommendation 6: At the point of registration, card applicants could be given the chance to give informed consent to some flagging in either or both of the customer-controlled section of the chip, or the register itself to any record which is held in relation to their organ donor status by Medicare Australia.

PIAC supports this recommendation.

Recommendation 7: That direct linkages between the access card customer controlled part of the chip and services which provide direct assistance or instruction about the provision of emergency medical services (such as advanced directives or MedicAlert-type schemes) be accepted as the customer's choice and control, in terms of usage of the access card.

PIAC believes that this recommendation needs to be developed further below it can be supported.

Recommendation 8: That the Office of the Privacy Commissioner be actively engaged in any development of policy in relation to the voluntary medical and emergency information.

PIAC supports this recommendation.

Recommendation 9: Once decisions about the inclusion of medical and health data have been made, the Australian Government must consider the question of whether such a scheme should be administered in the public sector or by some private sector operator chosen in an open tender process.

PIAC supports this observation but is disappointed that the recommendation above does not indicate what view the Taskforce has in relation to whether the private or public sector should manage the inclusion of medical and health data.

PIAC would be more supportive of this recommendation if it dealt with not only the nature of the entity, but also the cost of the scheme and privacy protections. However, any support for public sector involvement is conditional on the role of the public sector being simply to facilitate entry of verified data onto the chip rather than adding any medical information to the registration or any other government database.

4. Conclusion

PIAC holds some grave concerns about the Access Card and the range of proposals that accompany it. PIAC is pleased to see that the Government plans to delay the implementation of legislation accompanying the proposal in order to incorporate the intended 'second tranche' of legislative proposals. PIAC hopes that the legislation to accompanying the medical and safety information initiatives will be included in the new legislation.


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