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**Response to NEHTA Document
Privacy Blueprint for the Individual Electronic Health Record (IEHR)**

Cancer Voices Australia (CVA) believes that the development of the privacy principles for embodiment within the proposed IEHR is proceeding well.

NEHTA is engaging in an inclusive cross community consultative process at all stages of its development and implementation. This to consumers is most welcome.

It is essential that all concerns and view points whether of an individual or cross community nature are handled such that they can be fully understood and properly dealt with. A totally inclusive examination and broad agreement will make a significant contribution to what is being proposed.

The document makes reference to the three workshops at Brisbane, Alice Springs and Canberra in June 2008. However, in spite of undertaking to provide a record of these events, this has not occurred.

We believe that there continues to be a fragmentation of community awareness of input into what is a very complex range of issues.

This surely means that the cross community contribution cannot be based on full knowledge of the diverse range of opinions which have emerged at the workshops thus reducing the potential benefits particularly to the vast range of contributors that could not be directly represented.

This principle seemed to be well accepted by the NEHTA management who participated including the recording of proceedings. Reference was made to past deficiencies in NEHTA's consultative techniques. We strongly suggest that the quality and adequacy of the consultative processes and ultimate governance mechanisms of widely embracing coverage will be vital to achieving success in operating a comprehensive national eHealth system.

We, in Cancer Voices recognise that such an end result will be very much to the benefit of health consumers. We offer the following detail comment on the privacy blue print.

- (a) We regard the ownership of data held in an IEHR to belong to the individual to whom it refers. We would expect that service providers would keep their

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own records and Breen vs. Williams principles P16 would continue to apply to them.

- (b) We note that NEHTA has opted for the “opt in” method of joining the system. We think this issue needs more consideration before favouring it rather than an “opt out” approach, and strictly enforced and independently audited, as is proposed. We believe that service providers will assist a speedy uptake regime. This latter result will be important.
- (c) As strongly recommended during the Brisbane workshop we favour a bottom up approach so as to quickly garner the many good projects which are now coming into operation. It is vital however that a set of fundamental interoperability standards be quickly established and adopted by all public and private hospitals and other major service providers.

Even now it would appear that some problems are arising from inadequate attention to and/or understanding of the “break of gauge” principle with some projects currently in vogue. By this we mean that hospitals are being encouraged to develop their own eHealth systems without national direction and guidance on standards to enable interoperability between other treatment centres.

- (d) We propose that the Australian Law Reform Commission publicly comment on the final NEHTA Privacy Blue Print before its promulgation.
- (e) We consider the commercial medical record proposals emerging from Google, Microsoft, IBM and others to be in the nature of personal health diaries and as such unlikely to offer the systemic coverage and interoperability benefits which consumers require.

Use of them should be left to the personal choice of each individual.
- (f) We consider that an effective eHealth system as visualised will assist the very much needed and overdue reform plan the responsibility for which rests with NHHAC.
- (g) The proposed data content of the IEHR presents a satisfactory agenda for on going community wide consideration.
- (h) We support the concept wherever practical of building upon the existing Medicare (and possibly the private health funds) data bases as a means of speeding up the development process and avoidance of duplicating effort and cost.
- (i) We fully support the use of secure, de-identified data to aid in improvements to population health and research into improved treatments and prevention.

- (j) We recommend in depth study of existing worldwide eHealth system techniques in search of success stories relevant to our circumstances so as to avoid any unnecessary costs of “reinventing the wheel”.
- (k) The sensitive label issue will require further consideration and update of pending overseas developments.
- (l) The blueprint identifies a number of issues requiring further study. Please keep CVA advised and involved in their progress.

In conclusion, the Privacy Blueprint marks a significant step forward in the target establishment of an effective National eHealth System. This venture continues to have our support.

Cancer Voices Australia is the national consumer organisation representing Australians affected by cancer. It aims to ensure the voices of people affected by cancer are heard at a national level.

Yours sincerely

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