

**House of Representatives Standing Committee on
Legal and Constitutional Affairs**

Inquiry into the Privacy Amendment (Private Sector) Bill 2000

Submission by

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Introduction

The Breast Cancer Action Group is an advocacy group for women with breast cancer. It has some 500 members, mainly in Victoria and is a key member of the Breast Cancer Network Australia which has some 42 group and 4500 individual members throughout Australia. The Breast Cancer Network Australia is the national peak body for breast cancer consumers.

The Breast Cancer Action Group was formed in 1994 and since this time has been actively involved in the development and implementation of many improvements in services to women, both nationally and at the state level

Its aims are

- ◆ To encourage those with experience of breast cancer to contribute to all levels of decision-making about this disease
- ◆ To promote and contribute to research into the cause, prevention and optimal treatments of breast cancer
- ◆ To improve the experience of those undergoing treatment for breast cancer
- ◆ To work towards ensuring access to the highest quality treatment services for people with breast cancer, regardless of their geographical location, social and/ or economic status or stage of disease
- ◆ To provide a forum for women and men to share their experiences of breast cancer.

The Group endeavours to encourage women to take responsibility for their own health care decision-making. To do this effectively, women need access to good quality information about the disease of breast cancer, the various treatment options and how this might impact on their own individual situations. Women with breast cancer need to understand not only the medical 'facts' of their disease, but the clinicians' logical progression of thoughts in recommending what is often differing courses of treatment over time. The clinical record thus becomes the cornerstone of informed and participatory decision making for both the practitioner and the patient. Access to records which are accurate, and comprehensive is imperative for effective medical care and informed consent

This submission attempts to provide the committee members with an understanding of the situation in which women with breast cancer often find themselves and hence to illuminate the needs for effective access to medical records and measures which protect the privacy of these records..

It argues that health records should be treated differently from other records and should be considered separately in another Act which covers both access to, and privacy of, medical records.

A scenario -

A 50 year old woman, “Elisabeth”, presents to her GP with breast lumps. After a clinical examination she is referred for a mammogram and ultrasound. These procedures were carried out in a public and private organization respectively. The results indicated the need for further investigation and the woman was referred to a private breast surgeon for a fine needle biopsy. These tests are equivocal and the lumps are then excised in the day-care center of a major private hospital. Pathology testing reveals invasive ductal carcinoma - breast cancer. Breast conserving surgery is performed within days at another private hospital. Elisabeth then 6 weeks radiation therapy at a public facility. She also is referred to a medical oncologist to consider chemotherapy. The attending oncologists work at both public and private hospitals, yet the patient visits her in totally separate locations. Elisabeth is unsure whether she is classified as a public or private patient in the different hospitals in which she is treated.

Two years later there is a recurrence of her breast cancer. Elisabeth has a mastectomy performed by the original surgeon. She is referred to a medical oncologist for chemotherapy and a psychologist for her anxiety. She also attends a large department store for prosthetic fittings. The store requires customer details. As Elisabeth’s mother died of breast cancer and another one of her two sisters has also been diagnosed with breast cancer, she decides to enroll in a research program about the genetics of breast cancer and undergoes numerous blood and pathology and psychology tests.

During these 2 years this woman has attended and encountered -

- 2 GPs
- 1 breast surgeon
- 2 medical oncologists
- 1 radiation oncologists
- 1 general surgeon (ear, nose and throat specialist)
- 9 radiation therapists
- 1 physiotherapist
- 2 breast care nurses
- 1 psychiatrist or psychologist
- 1 geneticist
- 2 genetic counselors
- 4 sales/fitting staff
- pathology nurses
- ward nurses
- receptionists

This scenario is commonplace for many women diagnosed with breast cancer. Modern medicine with its specializations precludes single, comprehensive care from one practitioner or institution. Indeed, overseas research shows that treatment by multi-

disciplinary teams results in longer survival and it is likely that there will be increased treatment by such teams in Australia

The result? Medical records are bulging, and for Elisabeth, are maintained in at least 17 separate locations, comprising both public and private organizations. She assumes that many are computerized, but knows that some are handwritten, and a few reside on audiotape.

What assurances does she have that -

1. all of these records are 'complete and accurate'
2. they have not 'fallen into the wrong hands'
3. if necessary, she can directly access those records she wishes to see
4. having undergone genetic testing, this data will not be procured or sold to other bodies/organizations
5. the 'codes of practice' governing the various organizations are consistent, whether this be in the private or public sector of her dealings with the medical establishment
6. if necessary, there is recourse for complaint that does not depend on the 'goodwill' of specific parties
7. that the force of law applies equally across all jurisdictions, whether they be in the public or private sector

To any woman, who requires longterm monitoring and care, the proposed Privacy Amendment Act [2000] does not provide her with the assurances she is seeking. If anything, they compound existing problems.

Comments on some of the principles underlying this Amendment Act

1. Division between private and public records and privacy requirements.

The arbitrary division of records and privacy legislative requirements is inappropriate. As illustrated in the scenario, the 'demarcation zones' between the public and private sector of health care is meaningless. for the consumer .Elisabeth is often not even aware which sector is providing the service. Consumers generally have to deal with both systems on a regular basis. To have different rules and regulations defined for the two systems not only creates a legal and bureaucratic nightmare, but obviates/undermines the stated purpose of the bill to provide consistency and uniformity across the nation.

2. Accuracy, comprehensiveness of records.

It is difficult for any consumer who is being treated by so many different groups to determine whether the records kept are factually correct and do not contain information which might adversely affect the treatment decisions which are being made. With so many different practitioners involved over so many different organizations it is almost inevitable that some of her records will not be accurate or

complete. However tracking down these records and checking their accuracy is almost impossible.

3. Access to records

The right of patients to access their medical records has been a constant refrain from many quarters over the last decade. The philosophical, moral and, in some countries, the legal imperatives have been well documented. Yet, what has possibly not been so well enunciated is the overwhelming evidence which supports the notion that patient access to their clinical record ultimately improves the quality of medical record-keeping and thus ensures a better health outcome. Medical practitioners in the past, particularly those who fear complaints, have been loathe to provide access to medical records of the individual. Yet even here, the evidence would seem to confound this fear. ¹ The Good European Health Record standards best sums up the grounds for patient access - "Morally speaking, it is a violation of the autonomy of patients to deny them access to their health care record. The principle of transparency and accuracy are impossible to maintain without patient access".²

However, this principle of 'transparency and accuracy' will be severely curtailed without adequate systems and mechanisms for enforcement, review, and general protection of patient rights. The very fact that the proposed bill includes 12 exemptions under which practitioners may refuse access, represents a severe erosion of this tenet of 'transparency and accuracy'. Once again, history would seem to indicate that the more exemptions listed, the greater the chance that this will be interpreted as favouring refusal of access. [see Australian Law Reform Commission's report on FOI, 1997]

The exemptions themselves are unacceptable when viewed from the perspective of Elisabeth. Her request for some pathology reports may be interpreted as revealing "the intentions of the organization in relation to negotiations with the individual in such a way as to prejudice those negotiations' or worse, as simply 'frivolous and vexatious', when all Elisabeth requires is personal documentation of a particular result she may have forgotten about. The only recourse which the bill provides Elisabeth with is 'mutually agreed intermediaries', taking such a claim through a health industry body.

Because of the power imbalances between a consumer and medical bodies, it has always been almost impossible for consumers to deal effectively with the profession as a whole. The need for alternatives to the health system regulating its own affairs in relation to complaints by consumers has been shown by the development of

¹ Senate Community Affairs References Committee - *Report on access to medical records, June 1997*, at 7.7

² Good European Health Record - *Ethical and legal requirements: Deliverable 8, 19th October, 1993*, p.33

bodies such as the Victorian Health Complaints Commission and the equivalents in different states and territories.

It is difficult to justify current provisions of the bill which appear to discriminate in favour of 'governing bodies' in the private health-care system. If Elisabeth were to demand to see her records from a public hospital authority she would not be in this predicament. Such anomalies do nothing except obfuscate the presumed objectives of the bill; that is, creating equality and uniformity between the public and private sectors

Conclusions.

'Health information is about our internal selves and is intrinsically personal to us'.³ People such as Elisabeth who undergo the trauma of a life threatening illness, the confusion of diagnosis, treatment and management, need to be assured that the current bill under discussion does everything it can to facilitate their recovery whilst ensuring their privacy as individuals and consumers.

The current bill, fails to address the full complexity of the health care system. with its intermingling of both the private and public sectors; the continuing escalation of 'outsourcing' by the public sector; the inherent confusion that many patients experience as a result. Nor does the bill adequately address the need for external bodies to adjudicate and to have the full force of a legal mandate to ensure that the information privacy of the consumer is maintained. Ideally what is required is separate legislation that recognizes these anomalies and the special place that health has in the community.

It would be a tragedy if this opportunity to enact landmark legislation were lost simply because the issues appeared to be easily diluted into the amorphous categories of 'public' and 'private' sector. We must not allow this to happen. Rather these questions should be removed to a separate Act which can deal comprehensively with these complex issues in a way which empowers consumers to work with medical professionals to ensure that records are accessible when needed, are accurate and comprehensive and that the privacy of records is adequately protected.

³ privacy Branch - 'Background paper; application of the National Principles for the Fair Handling of personal information to personal health information', 25th May 1999, p.5