

# INFORMATION MANAGEMENT IN FAMILIAL CANCER

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## Abstract

The diagnosis of a familial predisposition to develop cancer carries major implications for both the affected person and their well but worried relatives. But familial cancer can almost never be diagnosed on the basis of one person's experience; it is the shared cancer experience among relatives that enables the diagnosis to be made. Once this diagnosis has been made, it carries medical implications for the unaffected members of the family. Obtaining information about affected members of the extended family and sharing the collated information with unaffected relatives are major functions of familial cancer services. Managing this information flow raises a number of ethical, legal and practical issues, however Australia is fortunate in generally having a workable framework of legislation that permits this information flow. Managing information flow across a large family requires the resources of a familial cancer clinic, however the principles can and must be applied by all healthcare professionals in everyday clinical practice.

When a patient is seen by a healthcare professional, it is usually a one-on-one relationship. There are, of course, social factors that may be crucial in the management of the case and relatives or friends may attend the appointment. However, those factors revolve around the needs and capabilities of the patient in the room and the patient can readily provide consent for access to records and contact with other doctors.

Familial cancer is different. It is rarely possible to make a diagnosis of familial cancer solely on the basis of the patient's experience. The cancers that occur in most familial cancer syndromes are no different to the cancers found in other settings. For this reason, the key to the diagnosis of familial cancer is the pattern of cancer diagnoses seen among affected relatives. These relatives are usually not present in the clinic and may have died. This immediately raises the question as to how this information should be obtained, recorded and validated. Is the patient allowed to pass on information about these relatives? Can this information be recorded? Can this information be used when counselling another member of the family?

Once a diagnosis of familial cancer has been made using information about affected relatives, it carries significant implications for unaffected members of the family. They may be at increased risk of developing cancer and targeted prevention or surveillance programs may be warranted. These relatives are usually not clients of the clinic and may not even know of the family's history of cancer. Should at-risk relatives be advised of this medical information? Who should notify them? Would such a notification represent a breach of the privacy of the patient or of the relative being notified?

The management of familial cancer requires care in the collection of information from and dissemination of information to relatives. The legal and ethical framework for this information management is becoming clearer and it usually does not constitute a barrier to the

effective care of the family as a whole. However, it is essential that all professionals involved in cancer care are aware of the benefits and potential risks of using family information.

## Gathering information from relatives

It is accepted that the collection of private medical information about relatives is necessary for good clinical practice and that the information constitutes part of the medical history that the patient provides to the professional. In fact, it may be medico-legally negligent if a professional fails to solicit, document and correctly interpret this information. However, it has taken a long time to have this practice accepted under law. Under the *Federal Privacy Act (1988)*, the collection of private information about potentially identifiable relatives was prohibited unless they provided consent. But obtaining such consent would be both unworkable and could represent a breach of the patient's privacy. After a successful appeal by ACHA Health (a private healthcare provider in South Australia) and the Human Genetics Society of Australia, a specific provision (Public Interest Determination 9A) was made in 2003, which allows healthcare providers to collect and record information about relatives from the patient without the relatives' consent, provided this information is relevant for the care of the patient.<sup>1</sup> (The federal legislation only applies to private sector organisations; most public sector health facilities fall under state privacy laws which, in general, reflect the federal law).

This provision is sufficient to record family information provided by the patient, including identifying information such as name and date of birth, to reduce the risk of errors and facilitate confirmation of reported diagnoses (see below). However, this provision does not allow the professional to release this information to another relative or health provider. At this point, the professional only has legal sanction to collect and use this information for the management of the patient's care.

It is not uncommon for reported diagnoses of cancer to

be incorrect. This does not reflect a lack of care on the part of the patient; it is simply that medical information is not always reliably shared within families. Studies have shown that up to 20% of the reported cancer diagnoses in relatives are inaccurate.<sup>2</sup> The risk assessment provided by the professional to a patient is critically dependent on the accuracy of the reported family history and so it is necessary that cancer diagnoses be confirmed. In some states there is provision under State legislation for approved professionals to obtain details of cancer diagnoses directly from the State's Cancer Registry, without having consent from the relative. In other states this is not allowed and the relative must be contacted and asked to provide written consent.

A relative cannot be contacted directly by the professional regarding the release of this information, as such an intrusion is not sanctioned under the federal privacy legislation. Relatives need to be approached through the patient and asked to provide written consent for the professional to access the relative's medical records. The patient may indicate that they do not want to approach certain relatives and consequently the matter cannot be taken further. In the case of deceased relatives, which is a common issue, it is necessary to seek consent from the executor of the deceased relative's estate or from the next of kin. Such consent is sufficient to release medical information in most jurisdictions, but not in Queensland; in that state, the release of medical information about a deceased person is viewed under State law as a freedom of information request and is subject to the constraints of that legislation.

In our experience, 90% of the requests for access that are made are granted. It is rare for us to be advised that a request has been explicitly denied (<1% of requests) and we do not know why the remaining relatives do not provide consent. However, it is important to note that there is no right under federal law for a patient to gain access to a relative's records. In its exhaustive and highly commended review of genetics and privacy, the Australian Law Reform Commission proposed that a person be able to access appropriate elements of a close relative's medical record without consent if there was a clear medical benefit from doing so.<sup>3</sup> However, the Federal Government rejected this proposal. This is an important point because, as detailed below, there is now provision under federal law for a healthcare professional to disclose information to relatives without consent. But there is no provision to obtain information from relatives without consent.

The process of obtaining this consent must be documented, with records of who was approached and retention of a hard copy of the signed consent form. This creates significant data management issues for busy clinical services. However, once consent has been obtained, the professional can contact other healthcare providers such as hospitals, clinicians, pathology and laboratories to obtain the information pertinent to the primary purpose of the patient's consultation ie. assessment of the risk of familial cancer. It is not appropriate to obtain other information that does not relate to this primary purpose.

## Disseminating information to relatives

Once a diagnosis of familial cancer has been made, and the appropriate risk minimisation strategy formulated, this is very significant information for the unaffected relatives, some of whom may still be children. This raises the issue of whether medical information should be provided to relatives, especially if they are not clients of the professional involved. This matter is usually discussed in the context of a familial mutation being identified in the family and of the process for notifying relatives that genetic testing is available to clarify their risk of cancer. However, the same principles apply to simply informing relatives that there is a risk of familial cancer, even if the causative mutation has not been found.

In the first instance, the professional must advise the patient that the diagnosis of familial cancer carries implications for relatives and they should seek medical advice. The fact that this advice has been given must be documented, as there is already clear evidence in case law that failure to provide such advice would be deemed negligent.<sup>4</sup> Many clinical services also provide patients with multiple copies of a form letter, which provides the key information and contact details for the service, and recommend that these be distributed to relatives.

Leaving the notification of relatives in the hands of the patient has a number of advantages. It is cheap, the privacy of the family is assured and the patient can plan the best approach to a relative, including the possibility that the relative not be advised. However, this approach also raises problems. Firstly, it is not very effective. In our experience, only 20% of the eligible relatives actually seek information or genetic testing if risk notification is left in the hands of the patient. Secondly, many patients find the responsibility of informing relatives burdensome. This may be because they have significant issues of their own to address, such as their own illness, or because they do not have a good relationship with some relatives.

We have trialled writing to all eligible relatives, with the contact details being provided by the patient.<sup>5</sup> In this way, the patient retains control over the communication to relatives, but is spared the responsibility for the communication. This process has resulted in a doubling of the proportion of eligible relatives seeking advice. The letter sent to relatives must be carefully worded to provide sufficient information, while not breaching the privacy of the patient. We do not chase up non-responders because each person has a right not to pursue further information. In the context of a familial cancer service, in which family information has already been collected to assist in making the diagnosis, the additional steps necessary to advise relatives in this way require few resources. However, this approach would be much more demanding in other clinical settings.

The success of this approach begs the question as to why it is not more successful. Why do 60% of eligible relatives who have been informed of the cancer risk and the availability of useful interventions, not seek further information to protect their own health? It is likely that there are issues of fear and complacency, but the short answer is that we do not know. We have found that men in families at risk of breast/ovarian cancer are less

likely to respond, even though we do not specify the cancer risk in our letters.<sup>6</sup> Clearly the 'bush radio' is working and these men are hearing about the specifics of the cancer risk from other family members. The 'bush radio' mechanism may also account for our observation that relatives living close to the patient are more likely to respond. These observations suggest that a combination of formal notification and informal encouragement may be the most effective strategy for spreading information. But we do not know why some people choose not to act on that information.

These processes for informing relatives are carried out with the patient's consent. But what if the patient declines to provide this information to relatives? To take an extreme but actual example: "I hate my brother and do not want to tell him anything that might save his life". This would be very confronting for any health professional and it is fortunate that such responses are rare. Sometimes the rationale is different, however the outcome is the same: "My brother would be too frightened by this information to have a colonoscopy, and so I won't tell him". Prevention is better than cure and genetic counsellors usually discuss the familial implications of a diagnosis or testing as part of the initial consultation. In effect, a genetic test is done on the family as a whole (albeit using one person's DNA) for the benefit of the family as a whole. Genes are not owned by an individual but are shared within a family, with relatives the patient may not even like.<sup>7</sup> The familial implications of a test result are an explicit component of the formal consent process that must be completed prior to genetic testing. In practice, the patient is an autonomous individual and genetic testing could not be withheld on the basis that the patient would not share an important result with relatives. However, familial cancer clinics seek to address and resolve this issue before testing is initiated.

Nonetheless, there are situations in which a patient refuses to share medically significant information with at-risk relatives. In its report, the Australian Law Reform Commission recommended that the *Federal Privacy Act* be amended to allow health professionals to breach a patient's privacy and notify relatives without their consent in certain circumstances. The necessary amendment to the *Privacy Act* was passed late last year. The Human Genetics Advisory Committee of the

National Health and Medical Research Council is developing guidelines for the implementation of this amendment and they will be ready in 2008. In brief, a health professional will be permitted to notify a relative of the patient of significant medical information if this is necessary to reduce the risk of serious medical harm to the relative. It is important to note that this privilege is permissive not mandatory ie. clinicians are not obliged to notify relatives. In addition, the privilege should only be exercised when extensive attempts to obtain consent to notify have failed.

## Conclusion

The genes that we share with our relatives are cords that bind us, for good and ill, to the medical fortunes of our extended families. Recognising the significance of these ties can pave the way for the effective management of a familial risk of cancer. The key to such an approach is information sharing - knowing what diseases the family as a whole has had and sharing this collated information with unaffected family members who have the most to gain from preventative and surveillance strategies. Most families are keen to share this information and Australia now has a framework for collecting and utilising this information effectively. It is now up to all healthcare professionals to play their part and to seek, document and use family history information in their daily practice.

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