Role of next of kin in accessing health records of deceased relatives

Anneke M Lucassen, Michael Parker and Robert Wheeler

BMJ 2004;328;952-953
doi:10.1136/bmj.328.7445.952

1 UK Clinical Ethics Network. About the network. www.ethics-network.org.uk/who.htm (accessed 6 Feb 2004).
2 Slowther A, Bunch C, Woolnough B, Hope T. *Clinical ethics support in the UK: a review of the current position and likely development.* London: Nuffield Trust, 2001.
3 UK Clinical Ethics Network. What are clinical ethics committees? www.ethics-network.org.uk/what.htm (accessed 6 Feb 2004).
4 Larcher V, Lask B, McCarthy J. Paediatrics at the cutting edge: do we need ethics committees? *J Med Ethics* 1997;23:245-9.
5 Slowther A, Underwood M. Is there a need for a clinical ethics support service in the UK? *J Med Ethics* 1998;24:207.
6 Joint Commission on Accreditation of Healthcare Organizations. *Comprehensive accreditation manual for hospitals, the official handbook.* Oakbrook Terrace IL: JCAHO, 1996:R1.
7 Ehleben CM, Childs BH, Saltzman SL. What is it exactly that you do? A "snapshot" of an ethicist at work. *HEC Forum* 1998;10(1):71-4.
8 La Puma J, Toulmin SE. Ethics consultants and ethics committees. *Arch Intern Med* 1989;149:1109-12.
9 Ruyter KW. Ethics committees: the national situation in Norway. In: Lebeer G, Moulin M, eds. *Ethical function in hospital ethics committees: Biomed 2 working papers.* Brussels: Brussels University Library, 2000: 91-105.
10 Van der Kloot Meijburg H. Different profiles for the institutional ethics committees in the Netherlands. *HEC Forum* 1994;6:139-57.
11 Fox E, Arnold RM. Evaluating outcomes in ethics consultation research. *J Clin Ethics* 1996;7:127-38.
12 Schneiderman LJ, Gilmer T, Teetzel HD, Duggan DO, Blustein J, Cranford R, et al. Effect of ethics consultations on non-beneficial life-sustaining treatments in the intensive care setting: a randomised controlled trial. *JAMA* 2003;290:1166-72.

(Accepted 9 February 2004)

Role of next of kin in accessing health records of deceased relatives

Anneke M Lucassen, Michael Parker, Robert Wheeler

When potential benefits outweigh harms should clinical geneticists be given access to medical records of dead patients without relatives' consent?

Wessex Clinical Genetics Service, Princess Anne Hospital, Southampton SO16 5YA
Anneke M Lucassen
senior lecturer

Oxford Genetics Knowledge Park, Ethox Centre, University of Oxford, Oxford OX3 7LF
Michael Parker
reader in medical ethics

Southampton University NHS Trust, Southampton SO16 5YB
Robert Wheeler
paediatric surgeon and medical lawyer

Correspondence to: A M Lucassen
annekel@soton.ac.uk

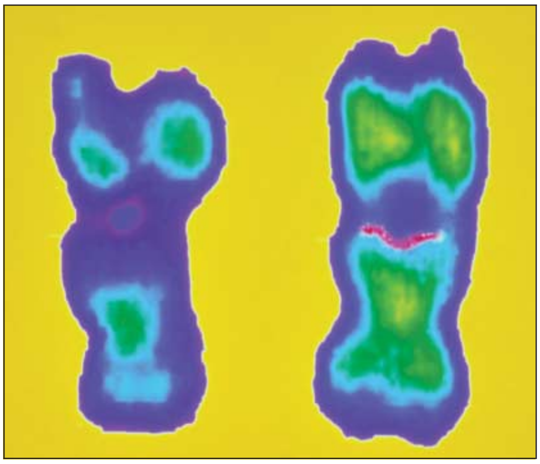
BMJ 2004;328:952–4

Family history is an important tool used by clinical geneticists to assess risk. Patients' recollection of family illnesses can sometimes be inaccurate or lack detail. Information obtained through medical records of the patient's relatives is therefore important. When relatives are alive, the person seeking genetic advice usually asks them for access to their medical records. However, access is more difficult if the relatives are dead. This difficulty is the result of a combination of a lack of clarity in the law and a wariness among hospital departments about releasing information in the light of recent public inquiries and means that hospital departments are often unwilling to allow access to the medical records of deceased patients without consent from their next of kin. We use a fictional case based on real experiences to illustrate the difficulties that this practice can cause in obtaining relevant information for diagnostic and surveillance management of relatives.

Case history

Anne Cole is 38 years old and has a family history of cancer. Her mother died of breast cancer at the age of 42 and her maternal grandmother developed breast cancer in her late 40s. Her maternal aunt died three years ago from an abdominal malignancy, aged 56. Ms Cole wants to know whether she is at increased risk of developing breast cancer and what measures she can take to prevent it or improve her prognosis should she develop it.

The clinical genetics team attempts to confirm the details of Ms Cole's family history through cancer registries, and from pathology reports by accessing hospital records. The maternal aunt is of particular concern, since if her abdominal malignancy was an ovarian carcinoma, the chances of a dominantly inherited predisposing gene mutation such as BRCA1 or 2 are increased.


CUSTOM MEDICAL STOCK/SPL

Having only one BRCA1 gene on chromosome 17 (shown in red) increases the risk of breast or ovarian cancer

The cancer registry confirms the diagnosis in Ms Cole's mother but has no details on her aunt. The hospital's histopathology department has details on the aunt but refuses to disclose them until it has received a signed consent form from her next of kin authorising such access. Ms Cole does not know who is the next of kin of her aunt. She knows her aunt had a husband and three children but is not in touch with them, does not know their address, and feels it would be inappropriate for her to contact any one of them to seek consent. She asks the genetics department whether such information could be accessed without having to involve a third, possibly unrelated, person, who might find such an approach upsetting.

What is meant by next of kin?

The term next of kin, as used in everyday language, has no single definition. Although a dictionary might define next of kin as the nearest blood relative, many married people would regard their spouse as their next of kin. Others might wish to nominate a trusted close friend as next of kin.

These differences are further complicated by the fact that next of kin has no legal standing in relation to medical management. Although the term was originally an entity of Roman law devised to apportion property between male relatives of a family, it became irrelevant in Britain after the Administration of Estates Act 1925, which established a different convention for transferring property after death.

Since then, next of kin has often continued to be incorrectly treated in the medical setting as if it were a legal entity. Hospital records, for example, invariably document the name of the patient's next of kin. Although the term can have a role in the allocation of property rights,[1] those identified as having such rights do not thereby acquire rights in relation to medical decisions. It is, for example, well established that in the case of incapacitated patients, someone identified as next of kin in relation to property has no legal right to consent to or refuse treatment on behalf of the patient.[2] Unless a person has clearly nominated who qualifies for the role, there is no clear hierarchy that determines which of several close relatives is the next of kin.

An alternative approach

The approach adopted by hospital departments derives from the belief that information about a patient should be shared with third parties only if there is appropriate consent. This places a great deal of weight on consent. An alternative approach would be to consider that, in the above case, access to the health records of the deceased is a justifiable breach of confidentiality. Acceptable breaches of confidentiality in the case of living patients are already recognised in several well defined areas of medical practice.[3] In some situations there is a statutory duty to disclose—for example, in the case of notifiable diseases, prescription of drugs of dependence, and abortion. The General Medical Council also requires doctors to inform the vehicle licensing body if a patient continues to drive against medical advice.[4]

The GMC's guidance also describes several situations in which the doctor may breach confidentiality. One such situation is where by breaching confidentiality the doctor can prevent death or serious harm to an identifiable third party: "Disclosure of personal information without consent may be justified where failure to do so may expose . . . others to risk of death or serious harm."[4]

This possibility is also recognised in the more specialised professional guidance.[5 6] GMC guidelines referring specifically to the duty of confidentiality after death state that the "extent to which confidential information may be disclosed after a patient's death will depend on . . . the intended use to which the information will be put . . . and the benefit to the patient's . . . family."

This suggests that genetics teams would, at least in some cases, be able to argue that the information has the potential to prevent harm and that the avoidance of such harms outweighs the (dead) patients' privacy interest. In practice, this is the stance taken by most UK cancer registries, which do not require consent from next of kin before disclosing cancer diagnoses for genetic counselling.

In the case history above, the information requested concerns the precise nature of the abdominal malignancy of Ms Cole's aunt. The benefit of this information is that it would give Ms Cole a clearer idea of her risk of cancer and thus a clearer idea of what surveillance or prophylactic options would be appropriate. The risk of harm (to the memory of the aunt) is that information held within the histology report might be particularly sensitive—for example, if the malignancy was AIDS related and the aunt had not wanted her family to know about this.

Summary points

Genetics counselling often requires access to medical records of relatives

Many hospitals will not give access to records of dead patients without consent from next of kin

The definition of next of kin is unclear and confers no rights regarding medical management

Access to records should be given without consent unless it is against the deceased person's interests

Recommendations

Clearly, clinicians will have to assess the harms and benefits of each case to decide an appropriate course of action. This is a balancing exercise with which most clinicians will be familiar. We believe, however, that in many cases, if not most, the balance ought to fall in favour of disclosure. We support recent recommendations that doctors should be able to access information about a dead person if it is important for the prediction of disease in family members; there is no good reason to believe that the person had or would have objected to such access; accessing the information is not against the person's interests; and the policy is openly disclosed.[7]

We thank the Southampton Hospital clinical ethics group, Fiona Douglas, Ian Ellis, and members of the Genethics Group for discussing the issues with us.

Contributors and sources: AML is a clincial geneticist with particular interest in ethicolegal issues. She encounters such cases with increasing frequency (40 such cases in the past 18 months locally, and has anecdotal evidence from colleagues that this is a nationwide issue). This article arose from discussions locally (Southampton hospital ethics group) and nationally (Cancer genetic group meeting 2003 and genethics club) together with MP and RW, who have established expertise in ethical and legal issues of such cases.

Competing interests: None declared.

1 D'Eye *v* Avery [2001] WTLR 227.
2 Re T [1992] 9 BMLR 46(CA) Ld Donaldson@50.
3 W V Egdell [1990] 1 All ER 835 LJ Bingham@848.
4 General Medical Council. Confidentiality: protecting and providing information. www.gmc-uk.org/standards/secret.htm (accessed 8 Mar 2004).
5 Committee on the Ethics of Gene Therapy. *Report of the committee on the ethics of gene therapy: recommendations* [Clothier report]. London: Stationery Office, 1992. (Cm 1788.)
6 Human Genetics Commission. *Inside information: balancing interests in the use of personal genetic data.* London: HGC, 2002. www.hgc.gov.uk/insideinformation/index.htm (accessed 8 Mar 2004).
7 Savulescu J, Skene L. Who has the right to access medical information from a deceased person? Ethical and legal perspectives. *J Law Med* 2000;8:81-7.

(Accepted 17 February 2004)