Commentary: needs of the living should come first

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If there were any information in my family's medical history that would allow me to find out whether I was likely to get cancer and how I could minimise the risk, I would certainly want to know about it. Clinical red tape about consent and next of kin when a patient is dead seems completely unreasonable when it holds back information that could protect the living.

Certainly you can't have a medical records free for all, and there are issues about confidentiality and respect. Some people have secrets that they want to take to the grave with them, and perhaps AIDS might be an example here. However, selfishly, I am younger and could live for many years if I could get hold of the records. The information might help not only my survival but also the chances of my children or other members of my family.

I appreciate that it must be difficult for hospital staff when recent public inquiries have put the spotlight on using patient information without explicit consent. It is much simpler and less work to refuse a request for information if the guidelines are unclear. If the term next of kin can't be defined accurately, it is difficult to make a decision. If the possible next of kin cannot be found, this makes matters even worse.

The suggestion that hospital departments should be able to breach confidentiality under certain conditions seems sensible. I would like to feel that when my doctors asked for the records of a dead relative whose next of kin was not known, someone at the hospital would be able to take a balanced view and release them because they could help predict disease in family members. Of course, if the relative had expressed her objections before she died, then my case might fall down.

Commentary: the arguments could be extended

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Lucassen and colleagues are right to query whether obtaining consent from next of kin always protects patients' interests. In the example they give, it is quite proper to argue for a more practical approach that balances benefits and harms. However, this particular example leaves other questions unanswered.

Suppose that Ms Cole's aunt is alive but is demented and not competent to consent to any disclosure from her medical records or that she is untraceable. Even if there were no good reason to believe that she would not have objected to such disclosure, it is likely that Ms Cole would be prevented from accessing the information by the hospital, and it is unlikely that the draft mental incapacity bill will help.¹ Or consider that the aunt is a curmudgeonly soul who has fallen out with Ms Cole's mother decades ago. If she expressly objects to the disclosure to Ms Cole, there is probably nothing Ms Cole can do, since it is arguable that the "risk of serious harm or death" referred to in the General Medical Council's confidentiality guidance² may be too speculative or remote to justify disclosure.

Problems with the law

The law of confidentiality is already fraught with inconsistencies and contradictions, as are the ethical grounds for breaching it. The Human Tissue Bill, when enacted, will add further obstacles and complexities for clinical geneticists and will criminalise practices that have been, for many years, considered quite proper and ethical.³

The bill enshrines differences between information from the living and dead, stating that tissue from a living person can be used without consent only for audit, limited forms of education or training, public health monitoring, and quality assurance. For the purposes of "obtaining scientific and medical information about a living or deceased person which may be relevant to any other person (including a future person)," which is

the case here, only the consent of the donor will suffice. Ms Cole would be denied access to tissue that may be critical to her health and wellbeing if her aunt refuses consent, is untraceable, or demented. It is only if the donor is dead that the bill provides for consent by a "qualifying relative." The bill entrenches consent at the expense of beneficence without stipulating what the requirements for consent are in terms of scope and specificity and without providing means to adjudicate between the requirements of different family members.

The requirement for consent lies quite properly at the heart of the new legislation, but equally properly, this is waived for audit, public health monitoring, and education and training because these activities are deemed to be in the public interest, unlikely to harm the donor, and ethically justifiable. So far, neither the GMC nor the BMA has objected to these exceptions. The drafters of the bill, and by implication the GMC and BMA, already concede that obtaining consent is not mandatory in all circumstances. However, by failing to recognise the differences between taking tissue, when consent should be mandatory, and its storage and use, which should be subject to less stringent regulations that take into account the interests of the donor and those of others and of the public, the Bill is ethically flawed. Professional judgment is being devolved to the patient under the guise of increasing patient autonomy. The recommendations suggested by Lucassen and colleagues should apply equally to tissue and information, and these principles should be used to inform amendments to the bill.

Competing interests: None declared.

- 1 United Kingdom Parliament. Mental Incapacity Bill www.parliament.uk/bills/draftbills0203.cfm (accessed 24 Mar 2004).
- 2 General Medical Council. Confidentiality: protecting and providing information. www.gmc-uk.org/standards/secret.htm (accessed 22 Mar 2004).
- 3 United Kingdom Parliament. Human Tissue Bill (amended in standing committee G). www.publications.parliament.uk/pa/cm200304/cmbills/049/2004049.htm (accessed 22 Mar 2004).
- 4 United Kingdom Parliament. Human Tissue Bill (amended in standing committee G): schedule 1, part 1, para 5.