[head] A quick guide to confidentiality and genetic testing

[sf] Dr Pallavi Bradshaw advises on managing patient records, communications and confidentiality

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In recent years the advances in genetic science has been coupled with an increasing appetite by patients to explore this area of medicine, often outside the normal framework of the NHS.

Whilst genetic testing is now seen as commonplace for certain diseases such as breast and colon cancer, progress in predictive testing for other debilitating and life threatening conditions like Batten’s disease has led to greater availability and demand.

The relatively straightforward and non-invasive tests belie the ethical complexity that the process entails from consent to confidentiality, and the keeping and sharing of this sensitive information.

**The patient’s diagnosis**

Despite specialist genetic services providing testing and counselling, you are likely to be given information which could have potential significance not only for your patient but also third parties.

You are a source of vital information during the referral and follow up process. Care should be taken when discussing family histories with genetic services especially when you could be privy to medical information regarding other family members who may also be patients.

Confidential information which may be relevant should only be passed on with the express consent of the patient(s).There is also potential for inadvertent breaches of confidentiality once information is received by the practice, in the same way that there is during the referral process.

**The patient’s family**

Whether a particular test is positive or negative you may be involved in ongoing counselling and treatment for a particular patient. Increasingly, the issue of incidental findings such as non-paternity is creating ethical and social dilemmas for GPs and patients.

You must always consider his or her duty to family members upon whom the test may impact. Other family members may not even be aware that a test had been carried out or appreciate the implications for them. It is usual for genetic clinics to co-ordinate family tracing; you may be a conduit to approach these other family members in the first instance to advise them of the need of testing or counselling.

There are several issues which must be addressed in the first instance, including the confidentiality of the index patient. Consent to disclose results and relevant information to family members should be sought.

If consent is not provided or is withheld you should discuss the risks to the third party with the specialist and consider the General Medical Council’s (GMC) guidance ‘Confidentiality’ paragraphs 67-69 and the recently published guidelines on consent and confidentiality from the joint committee of the Royal Colleges of Physicians and Pathologists and the British Society for Human Genetics.1 Both documents state that genetic information pertinent to another person should be provided if failure to disclose could leave that person at risk of serious harm or death.

An unmonitored or untreated inherited condition may meet this public interest criterion for disclosure without specific consent. If you consider it necessary to breach confidentiality you should warn the patient why you consider it necessary and let them know when the disclosure is made.

In situations where a patient is in unable to give consent on the basis of incompetence, information should only be disclosed if it is deemed in their best interests. There may be rare circumstances when medical information of patients lacking capacity is shared to assist in risk assessment for other family members.

The control of sensitive information will be harder with shared electronic record management systems, but the principle that all relevant information should be recorded in the notes remains, whether it relates to genetics or some other health related condition. Summarised information may not require specific familial identities to be recorded. .

**The patient’s records**

Any clinic letters or discussions with secondary care should be noted within the patient’s medical record. Given that the information and results should have been relayed to the tested patient already by the clinic there should be no concern about holding this information within the GP record.

Where information is obtained which is directly relevant to another person it would be appropriate for that to be recorded in the record of that third party. Whether information about the index patient is needed in full in the new record is a matter of judgement. Clinicians may consider summarised information to suffice. Needless to say, those affected should have been told the information before it is saved in their respective records.

**The patient’s data rights**

Patients requesting access to their records would be entitled to genetic information contained within them as per the Data Protection Act 1998. As it would be reasonable to assume that the patient was aware of all the information including information about family members, third party confidentiality would not be breached. In rare situations where the patient is not aware of sensitive information about family members which is contained within the record, you should consider whether this information should have been disclosed to the patient or if not, why not.

If there is a specific reason to withhold that information (for example, it is likely to cause serious harm to the mental or physical health of the data subject or third party) then it should be redacted and an explanation as to why it has not been disclosed provided.

Due diligence would be expected when any requests for medical information are requested by third parties (such as insurance companies). It may be wise in some instances to redact the identity of a patient’s relatives referred to unless that information is directly relevant to the information being sought.

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**References**

**1** General Medical Council. *Confidentiality*. 2006.

NHS Genetics Education. *Consent and confidentiality in clinical genetic practice: Guidance on genetic testing and sharing genetic information*. September 2011.