Should families own genetic information?

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YES The genetic code is held inside the cells that make up a person's body. The genetic material, cells, and body might be seen to belong to that person, but does the genetic information deduced from this code belong (solely) to the individual? Just because you own a hard disk, does it mean that you own the data on it? Or a DVD, the film?

Information from a particular section of genetic code can allow predictions or conclusions about a person's current or future health. The genetic code is inherited from parents and passed on to offspring. This transmission cannot be entirely avoided or altered. The red hair or blue eyes that a child has inherited from their parent signify a shared section of genetic code. Someone with achondroplasia probably has a mutation in the FGFR3 gene. Can it be said that the person owns this genetic information when it is clear for all to see?

When genetic information is not obvious to the outside world, or may become apparent only in the future, people have a right to expect some privacy, but this is not the same as having sole ownership of the information. The difficulty arises when a genetic test on one person tells us something about the genetic code held by others. How to balance a right to privacy with disclosing risks to others, who may be unaware of their potential genetic inheritance? Should they be told, and does the person valuing his or her privacy have the right to veto this disclosure?

Where genetic information points to an intervention that would decrease the morbidity or mortality from a disease, taking an individual ownership stance could lead to harm in others. Take the following analogy. A company identifies traces of a contaminating, toxic substance in a batch of tinned beans after one woman develops symptoms. The woman owns her contaminated tin but does not own the other tins in the batch, which have the same chance of causing illness in others. The woman is entitled to privacy and patient confidentiality but cannot say that she does not want others informed of the danger; nor can she prevent

disclosure on the basis that she owns the information about the poisoning.

Autonomy versus altruism

This ownership debate arises from a difficulty in practising genetic medicine, which by definition involves families, in a modern medical framework that lays huge emphasis on individual autonomy. Patient confidentiality is, of course, one of the most important cornerstones of medical practice. Patients need to know that doctors will keep their details private. Trust in the relationship and the ability to make autonomous decisions would be diminished if this was not a fundamental concept in medical practice. Nevertheless, confidentiality is rarely seen as absolute, and there are both statutory and professional guidelines on exceptions to the duty of confidentiality.^{1 2}

Genetic medicine has rarely been mentioned as an exception because few highly predictive genetic tests have been available and there are relatively few evidence based interventions. As the evidence base increases (such as for bowel screening in familial bowel cancer; prophylactic surgery in familial endocrine neoplasia), so does the tension between preserving individual confidentiality and communication of genetic risk to others. The Human Genetics Commission's 2002 report suggested that "genetic solidarity" and altruism should be promoted,³ and several authors have challenged the supremacy of individual autonomy in genetic medicine and introduced versions of family rather than individual confidentiality.⁴⁻⁶ For example, the joint account model argues that since genetic information is

shared by more than one person, the conventional model of confidentiality should be

reversed: the genetic information should be available to all "account holders" (family members) unless there are good reasons to do otherwise. These models are useful in encouraging a different perspective towards genetic information and reflect that most individuals availing themselves of genetic medicine do so with some degree of altruism.

Communication of risk

However, when families do not agree, or are unable to contact others at risk, clinicians may be left knowing there are

potential harms to others that might be prevented. Most genetic services have support mechanisms to work with families and their doctors to ensure that people at risk are appropriately informed. Direct communication between the medical professional and family members at risk is successful and acceptable.^{8 9}

Clearly, doctors cannot be expected to trace all relatives in extended families across the world.¹⁰ The challenge is how to deal with the situation when doctors know the identity of people at risk but consent to communicate that risk has not been obtained. There is no UK case law on this subject, but US courts have made opposing decisions, with one concluding that a doctor should have informed relatives despite the insistence of the affected person that he did not.^{11 12} UK professional guidelines tell us that where there is a serious preventable harm confidentiality may be breached,¹ and professionals looking after whole families may feel a moral obligation to inform all the family members who may hold the same genetic information.

In conclusion, this debate is more about privacy than ownership, but if anyone is to own genetic information it has to be all those who have inherited it. More importantly, it must be available to all those who might be at risk. Methods for sharing information need to be sensitive and relevant, but today's increasingly individualistic modern medicine must find ways of facilitating this. It should not be denied because of a narrow view of information ownership.

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References are in the full version on bmj.com

Mother (centre) and one child (top) in this family have ectrodactyly, ectrodermal dysplasia and clefting (EEC) syndrome

We all share our genetic make up with relatives, and **Anneke Lucassen** argues that we should also share ownership of the results of DNA analysis. **Angus Clarke** believes, however, that in most cases the knowledge can be considered private

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NO Although genes will often be shared within a family, most specific items of genetic information will have been generated by examining or testing an individual. Such information will, inevitably, belong more strongly to that person than to his or her relatives. To claim that the information belongs to the family is to miss the point. In current practice, to make that claim asks the question that the test would usually be setting out to answer: is mutation M that is found in person P also present in relative, R? If it is present in R, then P and R share the particular genetic variant; otherwise they do not.

There are occasions when genetic information does belong intrinsically to the family. For example, in a genetic linkage study looking at the pattern of sharing of DNA sequences among family members, the results are meaningful only when the family is viewed as a unit. Genetic linkage studies can still be useful in a research setting but are now unusual in clinical practice, as most diagnostic genetic tests seek to identify mutations in known genes. I concede that this type of genetic information does in some sense belong to the family when it has formed part of a diagnostic test in a service setting, but that is a small concession. Furthermore, only the person for whom the result has been generated should be given the result—the others have no particular claim to be told the implications for that one person

of their collective pattern of results. Except for the person being tested, the linkage analysis is unlikely to generate any very important information.

Duty of disclosure

Those who argue that genetic information belongs to the family because their genes are shared are guilty of the naturalistic fallacy—that “is” implies “ought.” I am not seeking to deny that family members have mutual obligations and should be prepared to share important medical information with their relatives, including genetic test results, as they usually do.

Two particular problems arise: firstly, when an individual fails to pass potentially important information to his relatives, such as the fact that he or his child has a serious genetic condition that may be present in other family members; and, secondly, when someone forbids health professionals to release or use genetic test results to provide more accurate or relevant medical advice to her relatives. These are very different types of information.

The first issue relates to the tension between the wish of some people to keep secret some of their medical history and their simultaneous obligation to disclose it to others, when it may be important for those others to find out about it. This is not specific to genetic issues but applies to sexually transmitted diseases, some other infectious diseases, and certain other environmental hazards such as chemical or radioactive contamination. Affected people are obliged to disclose such risks as soon as they realise that they may be a danger to others. If they fail to perform this duty, health professionals may have a duty to warn others instead. In many jurisdictions, legislation forces doctors to disclose information concerning some infectious diseases and also, in relation to driving, personal information about epilepsy and other potential problems.

Are genetic disorders sufficiently similar to infectious diseases—gonorrhoea, syphilis, HIV—that doctors have a similar duty to enforce disclosure by patients or clients to other members of their family? I would

argue that they are not, even when we agree that disclosure would be highly desirable. The harm done by a failure to disclose will usually not entail an immediate and grave form of damage. While effective therapies are not available for most genetic conditions, the preventable harm to be avoided will often be the birth of a child with some physical or mental impairment or disease. Like the UK courts, I think there are many reasons to resist the recognition of “wrongful life” suits of this sort, including the implied disrespect for those affected by the condition in question.

The second contested area is rather different. Here, information has effectively passed through a family so that interested relatives know to approach their local clinical genetics service because of a particular disease or condition that has affected one or more family members. What has failed

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to pass through the family is the precise information about the mutation(s) causing the disease. Should the individual who has been tested first be able to forbid

the laboratory from using its knowledge of the mutation(s) when testing other members of the same family? This would be an absurdity, forcing laboratories to issue incorrect reports out of some formulaic or bureaucratic sense of respect for privacy, when the relevant personal information is already known by all concerned. The genetic privacy has already been lost, and to treat the precise nature of the mutation as equally personal will be most unhelpful, potentially resulting in the needless repetition of expensive laboratory analyses.

In conclusion, I suggest that genetic information should be regarded as private and personal; to treat it as if it were owned in common by a body as vague and ill defined as “the family” is flawed. In the case of known disease causing mutations, however, the genetic information can be argued to belong to the laboratory or the health service that generates it and not to either the individual or the family.

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