

There is a responsible role for the pharmacy profession in genetic testing

By Philip Webb

When people think of genetic testing in the medical context, they will most likely associate this with a visit to their general practitioner or a referral by their GP to a hospital. They would expect tests on their DNA to establish whether they are suffering from an inherited disorder or might develop symptoms in the future. Now, all this could be changing because some companies are starting to offer genetic tests outside the usual context of a medical consultation.

The sequencing of the human genome, our knowledge about our genes and new technologies that make the analysis simpler are beginning to open up opportunities for "high street" testing. Some people have already had their genes tested by private companies in the UK and received advice about how they should change their diets or lifestyle with a view to improving their health. Others are sceptical about such testing and see it as commerce taking advantage of people's lack of understanding of what such tests can really do to improve one's health. Some experts believe that our knowledge of the interactions between genes, lifestyle and environment are still in their infancy and it is not appropriate to offer such tests until our understanding is much more advanced.

When genetic testing takes place in the usual medical consultation setting, patients are informed about the tests, their limitations, what the results may tell them and what the implications are of taking such a test for them and other members of their families. This may not happen if people decide to buy genetic tests direct from companies or over the internet and they may not be prepared for the information they receive once the test has been performed.

CONSUMER GROUPS CONCERNED

Some consumer groups are concerned about the possibility of a sudden growth in direct genetic testing, especially where the company carrying out the testing is also associated with the sale of complementary medicines. They believe that some people may be persuaded to take a test and then be told that they need to take a dietary supplement for the rest of their lives.

In "Genes direct", the recent report from the Human Genetics Commission, we have undertaken a thorough review of direct genetic testing and have consulted widely so we have a good understanding of the concerns people have about such testing. The HGC is the Government's independent advisory body that advises ministers on the ethical and social issues relating to human genetics. In our report, we make a number

of recommendations as to how we think the regulation of direct genetic testing can be improved. We have identified some important issues and have suggested a number of things that need to be done to ensure the effective oversight of direct genetic testing.

In reaching our conclusions, we have been careful to ensure that the right of individuals to obtain personal information about their genes is safeguarded, but at the same time, we have made recommendations to protect the more vulnerable members of our society. The HGC is an advisory body and so does not regulate such testing, but we have made a number of suggestions as to how those who are responsible for regulation can improve the current, largely unregulated situation. Our recommendations suggest that stricter controls are necessary, but we do not believe a statutory ban is appropriate.

We believe that the vast majority of predictive genetic tests should be carried out in consultation with medical professionals and a fully funded NHS genetics service will continue to carry out many of these tests. The NHS may also provide access to testing services provided by commercial testing laboratories.

A ROLE FOR PHARMACISTS?

The HGC consultation looked into the role of health professionals in the supply of genetic tests to the public and saw the need for health care professionals to be appropriately trained and able to provide impartial advice, before and after testing.

Many responses to the consultation contained comments on the main professional bodies for medical practitioners (General Medical Council), nurses (Nursing and Midwifery Council) and pharmacists (Royal Pharmaceutical Society). The HGC subsequently had detailed discussions with two groups relevant to direct genetic testing: pharmacists and nutritional therapists. These two groups demonstrated a marked difference in the level of training, accreditation and professional self-regulation.

The consultation highlighted the possible benefits of groups such as pharmacists in offering genetic testing services following self-referral. The HGC therefore paid particular attention to the possible future role of pharmacists. It learnt that the Royal Pharmaceutical Society had started work on the use of genetic information in drug pre-

scribing and that it is considering the requirements for quality assurance, training and patient counselling. The responsible administration of genetics tests by pharmacists may be underpinned by amending the Society's Code of Ethics and Code of Practice.

A key issue highlighted in the consultation was that pharmacists may not have received training in genetics at undergraduate level. As such it will be necessary for pharmacists to cover this as part of their continuing professional development.

The HGC believes that co-operation between pharmacists and GPs is important. It was suggested that pharmacists providing a genetic testing service should inform their local GPs. There is also the issue of adequate facilities, for example, a private consulting room in the pharmacy.

Overall the HGC understands that the role of pharmacies is changing. It is a possibility that in the future, pharmacies will have a skills mix that will allow pharmacists to spend more time consulting with patients and GPs. Indeed, the NHS is already setting up new services in deprived areas to provide care and counselling facilities. The recent changes to allow emergency hormonal contraception to become available over the counter are also relevant because this points to the ability of pharmacies to provide facilities for counselling and dispensing sensitively and privately, allowing a person to bypass normal GP consultations.

CONSUMER EDUCATION IMPORTANT

Strict controls on the advertising of genetic tests direct to the public should be put in place and consumer education is important so that people can make informed decisions about whether or not to have a test. We recommend that the Government makes funds available to help with public education in this area.

Genetic testing will become much more prevalent in future and has the potential to deliver significant health benefits to us all. It is important that direct testing is regulated now in such a way that we can gain the benefits of our new knowledge without allowing the exploitation of the most vulnerable members of our society.

Those involved in genetic testing, therefore, must have appropriate knowledge and experience to ensure that good quality advice is given to consumers or patients.

We expect professional bodies to ensure their members follow a code of conduct and to develop improved professional standards. The industry should also ensure that high standards are maintained to safeguard the public.

Philip Webb is chairman of the Human Genetics Commission working group on genetic testing services supplied direct to the public