

Short Communication

Economics of Genetics from a Health Commissioning Point of View

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Clinical Genetics is evolving from a relatively minor specialty to a discipline which will eventually affect every branch of medicine and surgery. From a commissioning, as opposed to a clinical or academic point of view, the major practical impact of DNA technology to date has been that it has led to acceptance of the inherited nature of many diseases which were previously thought to occur by chance, or to have an environmental aetiology — particularly certain cancers. This has led to a requirement for screening programmes for affected family members which did not exist before. Secondly, it has enabled individuals with a family history of conditions in which genetic defects have been identified to be informed as to whether they either carry an abnormal gene or do not carry it. This has created a great demand for genetic counselling from both patients and their relatives. As far as the future is concerned commissioners also need to know whether there will be an increasing demand for laboratory DNA testing to determine how individuals will respond to drugs in relatively common conditions and/or whether they are at particular risk from certain environmental factors, including smoking, etc. which could have a major impact on both pharmacology and health promotion programmes.

Those who plan or commission health services, including health insurance companies,

now need to take a view on what importance should be attached to this new specialty. It is evident from experience over the past few years that the numbers of new referrals to Clinical Genetics departments are increasing, as are the numbers of DNA tests, and that as a result there is increasing demand from the profession for new appointments (both for medically qualified geneticists and genetic counsellors with specific training) and more extensive laboratory facilities.

What is not clear is whether these will in time result in a decrease in demand for other services, particularly major surgery, radiotherapy, medical oncology and/or palliative care, among family members of affected individuals, or whether General medical or Surgical physicians should provide genetic counselling themselves, rather than send patients with familial conditions to specialist genetic departments. There is also a danger that the service will be developed mainly to meet the demands of worried families who learn from the media that specific genes have now been identified for particular conditions but who do not realise that gene identification is far outstripping the introduction of effective remedies. Experience from Breast and Cervical cancer screening programmes has demonstrated that such programmes can give rise to considerable fear and despondency or even surgery among people found subsequently not to have any serious disease. Finally, we seem to be entering various ethical minefields as regards stigmatisation of patients for insurance and employment purposes, pre-natal testing, and the rights of other family members not to know they are at risk of certain conditions if they so wish are concerned. Can we guarantee that the

provision of accurate genetic information will always be of benefit to individuals or families? It would be very unfortunate if a “media explosion” in any of these areas led to the same outcry as has occurred recently in relation to genetically modified foods.

To summarise, there are planning and monitoring issues which should be tackled now before we repeat all the mistakes which have occurred in other screening programmes, namely:

1. Some were oversold to the public as regards their sensitivity, specificity, and reliability — resulting in litigation later on.
2. The costs involved in providing a reliable, permanent, well-motivated service were underestimated.
3. Programme evaluation was not properly considered at the outset, producing ongoing controversy over cost effectiveness which could not then be scientifically demonstrated.
4. Many screening programmes caused considerable stress among members of the public which could have been avoided.

There is an additional problem as far as Health Service commissioners are concerned in that financial investment in genetic services is demanded now even though the clinical and/or financial return on this investment may not be realised for many years to come. Politically, it is always easier for commissioners to take money from programmes such as these to fund more immediate demands from surgeons who have long waiting lists today. Secondly, there is a misconception that geneticists only provide advice to other clinicians, and that this is less important than other specialties which actually treat people themselves. It is also quite a complex discipline for the non-specialist commissioner to understand.

To solve these problems, what we need is more cost-benefit analysis on one hand and for geneticists to clarify the service aspects of what

they do more clearly as far as Health Commissioners are concerned. The cost-benefit analysis needs to look beyond the cost of treatment to the health service and the benefit to the patient and consider as well cost to the patient and benefit to the NHS. How many patients, for example, need to have lengthy counselling (with the need to take time off work and pay travelling expenses together with the associated anxiety that this may cause), only to find that they do not have the gene concerned when a DNA test is finally carried out? On the patient benefit side, how often do they decide to act differently after being counselled from how they would have acted before particular genes were discovered, and to what extent does this benefit them? Do they live longer? Do they have more symptom-free months or years of life? Does knowing more about their condition reduce stress and anxiety — both in patients found to have defective genes and those found to have normal genes? As far as benefit to the NHS is concerned, do patients found to have defective genes early in life consume less resources over many years than they would if the relevant genes had not been discovered? Can clinical geneticists provide more accurate and useful information to patients than surgeons can, given that they are the specialists in this field, and if so could we transfer resources from surgical outpatient clinics to clinical genetics? Are fewer affected children born as an indirect result of the development of this specialty?

The four relevant headings from an economic point of view are ‘Benefit to the patient (and to their relatives)’, ‘Benefit to the NHS’, ‘Cost to the patient’, and ‘Cost to the NHS’. These considerations will enable the Business case for Clinical genetics to be established in terms which commissioners understand, and my expectation is that the case for investment in these services will be strong.