

23 April 2008

RCGP EVIDENCE

House of Lords Science and Technology Committee call for evidence: Genomic Medicine

1. The College welcomes the opportunity to respond to the House of Lords Science and Technology Committee's call for evidence on Genomic Medicine.
2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the 'voice' of GPs on issues concerned with education, training, research, and clinical standards. Founded in 1952, the RCGP has over 33,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.
3. We consider the questions raised by the committee to be timely and relevant. We believe that genomic medicine must be developed in such a way that places the patient first, giving particular consideration to issues of patient consent. It is also essential that such technology is developed in consultation with a wide range of healthcare organisations to ensure that it is applied to clinical practice effectively and appropriately.

Policy Framework

4. We would advise that any policy framework should be developed in collaboration with relevant expertise groups, including the Manchester National Centre for Primary Care Research and Development.

Research and Scientific Development

5. Funding should be available for applied health services research and not be restricted to laboratory-based research. Research priorities should include clinical studies at the level of the individual patient, taking into account patient perceptions of the value and the best use of data.

Data Use and Interpretation

6. The principles of managing the use of information in a health care setting should be those of patient-centred ethical practice. There should be safeguards on individual data. GPs will need to be careful in the future when filling in Personal Medical Reports about what genomic information is provided to insurance companies as this may impact on insurance loading.
7. There is a clear need to adapt GP systems to allow the future recording of genome data. As GPs will have a responsibility to store genome data on their IT systems, there will need to be a dialogue between primary care IT experts and the IT software industry to determine how such information can be stored and accessed.
8. It may well be possible in the future for completely anonymised genetic data to be linked with anonymised medical records and utilised for research. While the general public appear to have little or no objection to totally anonymised clinical data being used for research purposes, whether this is true for genetic data is unclear.
9. When patient consent is sought for the use of non-anonymised genomic material for research purposes, it is difficult - indeed probably impossible - to ensure that all potential uses can be foreseen at the time of consent.

10. It is likely that in the future, obtaining consent for genetic testing - whether for clinical care or for research - will increasingly fall to general practitioners. This has implications for training, in particular ensuring that GPs have the necessary expertise and feel confident in their ability to undertake such tasks.
11. The storage of genetic information on databases poses the risk of violation of individual privacy and confidentiality. We would caution against interfacing such databases with the NHS spine as this could increase the risk.

Translation

12. The translation to clinical practice should include consultation with the royal colleges at every step. This is because it is likely to be primary care services which are in the best position to use data for prevention, shared decision making and effective referral.
13. Re 'future-proof' technologies: In such a fast moving field, virtually any technology invested in will inevitably become obsolete at some point in the future. However, a moratorium on investment is not advisable. This is because it would be difficult for healthcare or research organisations to suddenly rejoin the world of modern genetics having stood still for a number of years. Developments in this technology are incremental, and therefore ongoing investment is needed to maintain and update workforce skills, experience and expertise.

The Use of Genomic Medicine in a Healthcare Setting

14. We anticipate that genomic medicine will have a major impact on healthcare, and we are already seeing this with sub classification of diseases e.g. Diabetes (MODY). General Practice must accept this and be aware of the changing classification of disease and the potential interventions that may differ depending on disease state. As with all developments in medical technology, training will need to follow the emerging evidence base, and GPs will have to feel confident to give patients the relevant advice.¹
15. In order to disseminate expertise on this rapidly developing technology, it may be necessary to provide community based genetics advisory services. Involving close collaboration between regional genetics departments and primary care, they will act as a centre where local primary care physicians can access help and information when faced with clinical problems or issues associated with the ethical, legal and social aspects of genome based medicine.
16. The application of genome technologies in medicine may have many benefits, but it must not be assumed that all persons would wish to submit themselves for genetic testing. If a person is found to have a high risk of a condition, there will be instances where this is likely to be shared by relatives. While some relatives might wish to be tested, others may not, particularly if they believe that there is little they can do to alter the situation.
17. GPs regularly advise their patients to eat a balanced diet, take exercise, not to smoke and limit their alcohol consumption. Giving patients inappropriately negative impressions of their health status can lead to anxiety, depression and the restriction of activities that they might otherwise engage in. This situation could arise with the provision of genetic information to patients.
18. Genetic testing can, of course, throw up ethical debates about the benefits to society versus the rights of the individual. A member of the College reported being engaged in such a debate about genetic testing for Huntington's Chorea and the implications for other family members.

Additional points and recommendations:

Prioritising diagnostic technologies for evaluation

19. One of the difficulties faced by organisations, such as the National Institute for Health and Clinical Excellence (NICE), is the need to find a means to prioritise diagnostic technologies for rapid evaluation. A College member has recently developed prioritisation criterion for use by organisations.² The criterion includes questions relating to the nature of the disease being tested (e.g. is the condition an important problem in terms of prevalence and incidence or morbidity and

¹ A chapter on Genetics is now part of the RCGP curriculum

² BMJ 2008;336:683 (29 March)

mortality?), questions relating to the diagnostic technology involved (e.g. has the safety and analytical validity been established?) and questions relating to the impact of the diagnostic technology (e.g. could greater diagnostic precision using the technology lead to better targeted treatment delivery?).