

# Addressing Genetics Delivering Health

A strategy for advancing the dissemination  
and application of genetics knowledge  
throughout our health professions

Funded by



**Executive Summary**

**Hilary Burton**

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# Summary of Recommendations

## Establishment of a national Steering Group for Genetics Education

- drawn from many organisations with a UK wide role
- providing leadership and vision for the genetics education of health workers
- providing strategic overview of education programme
- collaborating with NCHPEG in the US
- ensuring continuing resources for the programme
- responsible for establishing and steering the Centre for Genetics Education

## Establishment of a Centre for Genetics Education

- coordinating the education programme
- promoting genetics in NHS strategy and motivating its workforce to learn
- pressuring for inclusion of genetics in all relevant curricula
- seeking out new ways to develop genetics competence and share learning
- developing those professionals with a genetics special interest
- commissioning educational programmes using varied electronic resources

## Establishment of a formal Programme for Genetics Education

- reviewing curricula at each stage of education and for each professional group:  
undergraduate and postgraduate medicine; nurse education; pharmacists; dietitians;  
public health professionals; health service managers
- facilitating the inclusion of core competency in genetics as a foundational  
component of all health training and education
- ensuring diverse, responsive, practical and relevant methods of teaching

# Executive Summary

## Introduction

The enormous international investment at the end of the last century in the Human Genome Project (HGP) underlined recognition throughout research and clinical establishments that genetics would transform our understanding of health and disease and, with it, the practice of medicine. As we move into the 21st century this becomes a reality as new technologies are developed that increase our capacity to predict, prevent, diagnose and treat disease.

Until recently, genetics was a relatively small specialty concerned with rare single gene and chromosomal disorders. The findings from the HGP, however, are challenging these boundaries and health professionals throughout the health service will increasingly be confronting new genetics technologies. Accordingly, an understanding of genetics needs to become a fundamental component of the scientific knowledge and practical competence of our healthcare workforce. This role, as key mediators ensuring that the outcomes of research can be realised through health benefits for society has been recognised as an important theme in The Wellcome Trust research programme and within NHS policy.

The identification and characterisation of more single gene disorders in many areas of clinical practice already provide a challenge to clinicians as they respond to concerns from patients about family history and steer them through decision-making about testing and preventive services. Even this aspect of genetics is relatively unfamiliar at present to clinicians, most commonly emerging in the context of antenatal care and general practice. In the future, as genomic medicine becomes a reality, health professionals will be moving into uncharted territory. The identification of common gene variants associated with major chronic disease such as coronary heart disease, asthma, diabetes, psychiatric disease and cancers will lead to opportunities to test for increased disease susceptibility and offer prevention options or lifestyle advice. Furthermore, pharmacogenetic testing will be used to provide individualised treatments and genetic information from cells involved in disease processes will be used to provide greater levels of accuracy of diagnosis, and sometimes for screening.

There is much work still to be done to consolidate the research basis for many of these activities and there is debate about how long this will take. Nevertheless, there is little doubt that over the next decade or so, such possibilities will become a reality. Our capacity to reap the ensuing health benefits for the population will be dependent on having a workforce that can embrace these developments, bringing the full weight of their clinical experience into shaping and absorbing them into their practice. An increasingly knowledgeable public will demand no less.

Achieving this will require our health professionals to be equipped with the necessary educational background. Genetic science has progressed so rapidly during recent years that educational establishments and professionals in practice have not been able to keep up and a widening gap has developed. Change will not be easy. The health care system is immensely complex and the use of new genetic applications will be very pervasive. So targeting any small group of professionals will not be an option. Rather, education in genetics needs to infiltrate the whole system, from undergraduate to continuing professional development and from practitioners in primary and community care to those in specialist practice. A substantial programme will be required.

This document sets out the basis of need and a strategic framework for just such an education programme.

## Project

In 2002 the Department of Health and The Wellcome Trust commissioned the Public Health Genetics Unit (PHGU) to work with key stakeholder groups to develop a strategy for education in genetics for health professionals. This built on a background review commissioned by The Wellcome Trust and undertaken by the PHGU the previous year that had included needs assessment, educational methods, and a survey of current education<sup>1</sup>. The report drew attention to the relative lack of genetics teaching within all areas of professional education. Any positive developments in the field seemed unsystematic and were usually products of local enthusiasm rather than any wider policy. Genetics teachers were scarce and most establishments could not cover the whole breadth from basic science to ethical, legal and social issues (ELSI). Evidence also suggested that educational approaches must be diverse, sustained in the long-term, and responsive to different learners' needs and varying access to resources.

In short, education in genetics for health professionals across the length and breadth of the UK had not kept up with scientific and clinical progress. But reversing this trend would be a difficult and time-consuming process because of the unfamiliarity and breadth of genetics content, the complexity of both educational and health systems and the cumbersome mechanisms to influence them.

The project aimed to bring together a wide range of health professional groups, experts in genetics and experts in medical education and to explore with them the implications of genetics for practice in each professional group, their requirement for genetics education, the practical ways in which a broad genetics educational programme could be established for all health professions and the structures that would be needed to underpin this.

Such a programme would need to:

- Be based on sound educational theory and practice
- Be supported by the genetics community whose expertise would be needed as genetics became more widespread in the NHS and who would be involved in much of the education
- Have support from the various stakeholders, including the professional associations and Royal Colleges; providers of education; professionals in practice; the public and people with genetic disease
- Tie in with existing educational structures and programmes without overburdening current curricula
- Be far-reaching, adaptable and sustained over many years as the clinical applications of genetics expand and are clarified and new roles develop

## Method

The strategy development process was guided by a small steering group of individuals from the Department of Health and The Wellcome Trust, British Society for Human Genetics, Genetics Interest Group and the deans of UK medical and nursing schools. Educational expertise was provided by the Open University Centre for Education in Medicine.

Central to the process was a series of stakeholder workshops covering the following public and professional sectors: patients and carers, postgraduate medicine, nursing, midwifery and health visiting, primary care, pharmacy practice, dietetic practice and health service managers.

Workshops to which the public was invited were used to allow patients and carers to reflect on their experience of genetic disease and the requirements they had of health professionals.

<sup>1</sup> Burton, H. Education in genetics for health professionals. Report to The Wellcome Trust. Public Health Genetics Unit. July 2002

In professional workshops we brought together a breadth of interest including practitioners, teachers, professional organisations, researchers, and specialists in genetics. Structured discussions were used to obtain views on: the impact of genetics; awareness and readiness of the profession; opportunities and barriers to education. A nominal group process was used to obtain priorities for educational topics and resources required.

Further topics including undergraduate medical education in genetics, the use of UK genetics websites and the role of pharmaceutical companies in genetics education were pursued in depth through reviews, interviews, surveys and visits.

A final workshop was held in May 2003 in which all the material was presented and debate undertaken to provide the outline of the final strategic framework.

## Results

The process provided a wealth of information which is published as separate reports on the PHGU website and summarised as evidence in the strategy document.

Work with the public and patients emphasised the point, accepted by professionals, that an educational programme must have the needs of patients and the public at its heart. As a fundamental principle the process of developing the programme must, itself, be publicly accountable. Education should prepare professionals for a future in which patients are better informed and expect to be partners with professionals in deciding on care. Finally, educational programmes should seek to utilise the power of first-hand accounts from patients.

The importance of genetics was agreed by all professional groups, but getting it onto the educational agenda will be an uphill struggle for all professions because of many competing priorities. This will be compounded by common professional perceptions that genetic disease is rare and that there is little current clinical utility. Whereas for undergraduates there should be a shift towards teaching of genomic medicine – the genetics of individual variation and common diseases - for today's practitioners education must be orientated towards the “here and now” if it is to have any hope of achieving an impact. Priorities for primary care such as cancer genetics, antenatal and neonatal genetic screening programmes were agreed. For professionals in areas such as obstetrics, hospital specialties such as cardiology or neurology, pharmacy practice or those involved in chronic disease care, the content of genetics education would need to be carefully tailored to the particular clinical context.

The formal processes influencing professional education are powerful but can be hard and slow to change. Work must be done to develop and establish an understanding of competencies for all professional areas and levels of practice. This has already been achieved for undergraduate medicine with some effect in influencing the developing programmes. All professions need teaching in basic science, clinical aspects and ethical, legal and social aspects (ELSI) of genetics but it was considered that many higher education establishments will lack teaching capacity, and most will be unable to field the full range to include ELSI aspects. Our review also showed recognition that high quality educational material, such as that which includes first-hand content, or clinical scenarios, is time-consuming to develop. However, there is a broad willingness of institutions to share development and resulting resources.

For those in practice, incentives to genetics learning through such means as the inclusion of standards on genetics in National Service Frameworks and the promotion of education as an integral part of developments of genetics in clinical practice should be exploited. Learning should be made easy by the provision of a wide range of material accessible to people with different learning styles, and by the ready availability through the Internet of information, guidance and education in genetics to support everyday clinical practice.

Members of the final workshop recommended that ownership of the education programme should be consciously sought by involvement at three levels:

- Statutory bodies and professional associations
- Higher education institutions and other education providers and commissioners
- Local level including those in everyday practice

Responsibility for provision of this wide range of education would remain within normal mechanisms and would continue to rest with current educational providers. However, a special programme would be needed to provide the necessary energy to promote genetics in all fields, to undertake the necessary detailed work on educational resources and to coordinate work for maximum effect. Support might be achieved for such a programme from various sectors in the UK including major charities and the pharmaceutical industry and from the experience already gained in the United States.

## Strategic Framework

The need for a strategic and wholesale approach to genetics education was strongly supported by all professional groups and, through the project, commitment was achieved to work together on a programme.

Based on the workshop and review findings and further discussion within PHGU and with experts in professional education, we make recommendations for the establishment and development of such a programme and its major elements.

**We recommend** the establishment of:

- (a) A national **Steering Group** for Genetics Education
- (b) A **Centre** for Genetics Education and
- (c) A formal **Programme** for Genetics Education

### Establishment of a national Steering Group for Genetics Education

The establishment of a national Steering Group will be essential for championing the cause of genetics education amongst all professional staff and for bringing together all those with an interest in the development and/or provision of genetics education. With a membership drawn from many organisations with a UK wide role and, crucially, from the public and patients, it will:

- Provide leadership and vision for the genetics education of health workers
- Ensure continuing resources for the Programme
- Maintain a strategic overview of the education Programme
- Be responsible for establishing and steering the Centre for Genetics Education
- Collaborate with NCHPEG in the US

## **Establishment of a Centre for Genetics Education**

A Centre for Genetics Education should be established that will have a remit to develop the UK Genetics Education Programme. The Centre should be developed as an enterprise of an established parent organisation such as a higher education institute, NHS trust, charitable or private organisation or a genetics knowledge park. Its eventual structure will need to take account of the needs of the UK as a whole.

It would have demonstrable expertise in:

- The education of health professionals
- The full breadth of genetics, including science, clinical aspects and ethical, legal and social aspects
- Networking with a wide range of partners
- Communication
- Database management, website development and management, and information technology

## **Establishment of a formal Programme for Genetics Education**

We recommend that the components of the Programme for genetics education should include:

***Leadership and coordination*** The Centre should achieve leadership and coordination for genetics education through its role as a focus for development that promotes and maintains an overview of initiatives and promulgates good practice.

***Raising awareness and motivation to learn in practising professionals*** The Centre should pursue a programme to raise awareness of genetics amongst health professionals in three main ways: using formal opportunities; by building on needs arising through clinical practice; and by promoting its own work

***Pursuing formal opportunities to promote genetics education in health service provision*** The Centre should pursue formal opportunities to promote genetics education within the NHS by identifying, promoting and coordinating involvement in national policy work and by promoting and contributing to the integration of genetics education as part of service developments

***Promoting the development of leaders and facilitators with a special interest in genetics*** The Centre should promote the development of professionals with a special interest in genetics and support an educational role through formation of a network.

***Developing core competencies in genetics*** The Centre should work with statutory and professional bodies and educational establishments to ensure that:

- Genetics education is embedded in general education at undergraduate, professional, specialist and continuing development levels as appropriate for that profession
- Consideration is given to training and accrediting physicians, nurse and others with a special interest in genetics.

***Development of educational programmes*** A rolling programme of educational resource development should be implemented covering each professional group and all levels based on an understanding of needs and priorities. Each area would need input from a range of experts and, importantly, the public and patients with genetic disease.

**Facilitation and sharing of resources** The Centre should promote and facilitate the sharing and dissemination of educational resources through the development of a database and information service

**The development of electronic resources to provide clinical support and information**

A major programme should be developed to provide access to authoritative information, clinical support and educational resources via the Internet. This should include further development and functional linking of the NeLH genetics site, BSHG and regional genetics centre websites and provision of links to specific educational material.

## **Implementing the Genetics Education Programme**

The resources to set up such a Programme would be substantial. Success will only be achieved by the establishment of a significant presence and the completion of highly regarded work. Resources to set up and run the Centre alone will be in the order of £750K annually and further funds will be needed to develop educational materials and to pump-prime other developments such as intensive “training the trainer” programmes.

All in all, we estimate that an annual budget of around £2 million will be required. Ideally the commitment for this work should come from a range of bodies including the Department of Health and major research organisations and charities, as well as the private sector. In supporting this work they would take their share of responsibility for the preparation of the NHS workforce in genetics, an outcome that is much in their interests. They will also ensure the best possible chance that the ensuing educational developments will be rapid, high quality and achieve maximum coverage.

## **Conclusion**

We believe that the time has now come to implement our recommendations and, for this, the announcements in the Genetics White Paper provide a very welcome catalyst. We should move forward in a partnership that acknowledges the interests of the many organisations in this process, from the researchers keen to see the translation of their work into health benefits to those involved in the delivery of health services, and from public health specialists to the private sector.

In 2001 the Secretary of State announced a new ambition for Britain: to put us at the leading edge of advances in genetic technologies and to develop in the UK a modern genetics health service unrivalled in the world. A competent workforce will be fundamental to achieving that vision.