

Encyclopedia of Life Sciences

Genetic Education of Primary Care Health Professionals in Britain

Advanced Article A21041

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Abstract

The drive to ensure that primary care health professionals in Britain receive appropriate genetics education has made substantial progress in recent years. The strategic initiatives that have emerged from a strong policy foundation are leading developments in education and raising awareness about the role of genetics in primary care. Although significant challenges remain, there is evidence of an evolution from justification of the place of genetics in mainstream healthcare and education, to an articulation of what genetics should be taught, and, more latterly, to a consideration of strategies in ensuring genetics can be fully integrated into practice.

Keywords: genetics education; primary care; genetics; professional development; genetic competence

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Introduction: Genetics, Education and Primary Care

Advances in genetics are a powerful driving force in changing healthcare and there is widespread acknowledgement that primary care has a significant role to play in ensuring patients benefit from clinical advances (for example, Emery and Hayflick 2001; Department of Health 2003; Smith *et al.* 2006). There is also a strong argument that primary care health professionals (including general practitioners, midwives, community based nurses, practice nurses and health visitors) already play an important role in meeting the current genetic needs of existing patients. Hopkinson reviewed 1823 sets of notes from seven GP practices in London and found a prevalence of genetic disease of 10.4%, a figure he argued to be an underestimate (Hopkinson 2004). New and enhanced roles for primary care are also envisaged; Bennett *et al.* (2007) report on several cancer genetics pilot projects, primarily delivered in a primary care or community setting. See also: Human Genome Project, Caretakers and Gatekeepers, Clinical Genetic Services in the United Kingdom, Genetic Counseling, Genetic Services: Access.

Preparing health professionals appropriately to enable them to adapt to these changes as they integrate genetics into practice presents a considerable challenge. Educators have to recognise the relevance of genetics, within overloaded pre-registration programmes, where the misconception persists that it relates to a small number of highly specialist areas rather than as a fundamental science of health and disease (Guttmacher *et al.* 2007). Practitioners too have to appreciate the relevance and importance of genetics, not only for the benefit of their patients, but also so that they can mentor students and junior staff appropriately. Thus education programmes for different professional groups, including those working in primary care, have to make provision through a

continuum from pre-registration through to advanced levels of practice in the workplace, whilst addressing the challenges associated with limited awareness amongst both educators and practitioners. The policy context for this change, the challenges that need to be addressed, and some of the progress that has been made, will be outlined in this article.

Genetics in UK health policy

In 2003 the UK government published its policy to ensure that the National Health Service (NHS) could realise the potential of genetics in healthcare (Department of Health 2003). One of its key action strands was to 'ensure genetic skills and learning needs are reflected, integrated and delivered within education curricula and training programmes for all healthcare professionals' (Department of Health 2003; p49). As part of its accompanying investment programme, the government established the NHS National Genetics Education and Development Centre (the Centre) in 2004, to drive and coordinate genetic education initiatives such as the development of skills and competence frameworks, and identifying learning needs for different NHS staff groups. Promoting genetics education amongst primary care health professionals was identified as an early priority for the new Centre.

The genetics white paper paid particular attention to primary care, outlining how it was uniquely placed to help patients and families benefit from new genetics knowledge and its applications. Further initiatives announced to support the policy specifically targeted primary care, including funding to create ten posts for GPs with special interest in genetics, and several service development pilots located in primary care.

This publication was swiftly followed by a report that set out a strategic framework to advance the integration of genetics throughout the whole system of health professional education and continuing professional development (Burton 2003). This was in response to the identified need for a more systematic and coordinated approach to new genetics advances, which hitherto had largely been a result of local enthusiasm. The need for a formal programme for genetics education was highlighted, with core competences in genetics being included as a foundational element in all health training programmes.

Background: Identifying the Challenges

The genetics white paper acknowledged that the challenges faced in producing practitioners who were confident and effective in dealing with genetics within mainstream healthcare were enormous (Department of Health 2003). This view was informed by a body of literature that had articulated the implications of developments in genetics and its impact on healthcare. The implications for education were a particular cause for concern, with studies highlighting deficits in provision and in professional knowledge and skills in genetics, alongside reports of a lack of awareness of its relevance. Although progress is evident, these factors remain a significant challenge.

The deficits in genetics education

The inadequacies of provision for nurse education in genetics in the UK have been documented at pre- and post-registration levels (Kirk 1999; Metcalfe and Burton 2003). In a literature review, Burke and Kirk (2006) found that empirical evidence highlights widespread deficits in knowledge and skills, and low confidence levels, with education provision patchy and insubstantial. A survey reviewing the extent to which pre-registration curricula were equipping UK nurses, midwives and health visitors to demonstrate each of seven nursing competences (Kirk *et al.* 2003b) found that none of these are achieved fully at any of the institutions that responded (n=37; response rate 50.6%) (Kirk and Tonkin 2006).

Genetics competence and confidence is also variable amongst practitioners. A survey of practising nurses (n=198) from a range of healthcare settings including primary care, revealed that the competences are not used equally, nor with equal confidence, or viewed with equal importance (Kirk *et al.* 2007). Midwives have reported low levels of confidence in integrating genetics into practice (Metcalf *et al.* 2007) and Barr and McConkey (2006) found that health visitors had limited confidence in supporting parents in relation to genetic investigations.

A similar picture emerges for medical education and GPs. Emery *et al.* (1999) conducted a systematic review of the literature to explore the role of primary care in genetics services. They identified that although GPs acknowledged their increasing role to play in genetics, they lack confidence because of limited knowledge. In their grounded theory study, Kumar and Gantley (1999) noted the paucity of training in genetics, although this was not considered to be problematic by GPs because of the perceived rarity of genetic conditions in general practice. Elwyn *et al.* (2002) felt that their study echoed these findings, noting a reluctance among GPs in referring patients to cancer services. A review of empirical papers, conducted to explore barriers to genetics service provision by primary care physicians, revealed inadequate knowledge and lack of confidence (Suther and Goodson 2003). In a survey of GPs' attitudes (n=397) towards prenatal screening, Qureshi *et al.* (2006) found a lack of confidence in providing basic advice about screening, with poor awareness of the availability of rapid referral facilities.

As part of a wider European study, Challen *et al.* (2006) found UK genetics education on undergraduate medical curricula to be varied and commented that 'there is a discouraging lack of a competency-based structure; any ongoing education in genetics remains entirely optional' (Challen *et al.* 2006, p258). They concluded by emphasising the need to develop competences in genetics for all aspects of healthcare training.

Building the foundation

Guidelines for education and practice

Good progress has been made in developing guidelines for genetics education for health professional groups. In 2003, an education framework for nursing competences in genetics was published following a process of consensus and consultation (Kirk *et al.* 2003a). An expert panel acknowledged that the potential role for primary care was substantial and recognised the need for additional education and training to support this. The education framework that resulted from this work set out seven core concepts that all nursing professional groups (including midwives and health visitors) should be able to demonstrate on qualifying. Each core concept statement was accompanied by suggested learning outcomes and practice indicators (Kirk *et al.* 2003b).

In partnership with the Centre, the Royal College of General Practitioners issued a curriculum statement on genetics in primary care (Farndon *et al.* 2007). This sets out learning outcomes in a framework of knowledge, skills and attitudes that incorporate primary care management and the underpinning knowledge base. Core skills are also identified, including taking and interpreting a family history and relevant communication and consultation skills. The curriculum statement built on an earlier study to identify genetics learning topics for GP registrars (Burke *et al.* 2005).

The RCGP curriculum statement has been used as the platform for extending the competences expected of GPs with a special interest in genetics (GPwSI Genetics), developed by the GPwSI Genetics themselves, in collaboration with the Centre (NHS National Genetics Education and Development Centre 2007a). It was felt that such a framework would help support the continuum of patient care from the undergraduate medical curriculum to GP registrar and specialist levels.

As part of the learning continuum and to take genetics from education into clinical practice, the Centre, in partnership with Skills for Health, has developed nine workforce competences in genetics for non-genetics health workers (Fig 1; NHS National Genetics Education and Development Centre 2007b). These represent steps in the typical patient pathway, although not all competences will be applicable to every role, and more specific detail would need to be identified for particular pathways.

Identifying needs and developing resources

If curriculum guidelines and competence frameworks represent the first steps in developing genetic literacy, conducting a needs analysis of healthcare educators and practitioners is an important next step, so that appropriate resources and practical support can be prioritised, based on evidence rather than assumption. A needs analysis of both nurse educators and nurse clinicians revealed gaps in provision for, and understanding of, issues around genetic testing. Resources to support teaching ranked as most useful were access to genetics service providers and users willing to talk to students, and a library of annotated stories and case studies (Kirk and Tonkin 2006). Nurse clinicians indicated a preference for accessible, interactive learning opportunities, with the line manager playing a key role in providing support through time and funding (Kirk *et al.* 2007). A survey of educational needs of midwives found a similar preference for interactive workshops and lectures, with clinical patient-based case examples (Metcalf *et al.* 2007).

The needs analysis of GPs (Burke *et al.* 2005) enabled GPs to prioritise three key areas for education:

- Identifying and referring patients with genetic disorders;
- Basic knowledge of genetics;
- Genetic testing.

The importance of demonstrating relevance to clinical practice, such as through the use of appropriate case examples was stressed. Similar findings amongst GPs in Australia had been earlier reported by Metcalfe *et al.* (2002).

A common theme that has emerged from these studies is the need for clinically relevant and patient-focused resources. Several authors have reviewed available resources or reported on work to develop these (for example Prows *et al.* 2005; Gresty *et al.* 2007) and there appears to be a willingness to share such resources.

From content to process: Integrating genetics into primary care practice

A clearly described education framework and appropriate resources to support both educators and learners sets the foundation for improvement in genetics competence. The need for a coordinated approach to integrate genetics into clinical practice was recognised with the establishment of the NHS National Genetics Education and Development Centre, and Farndon and Bennett (2008) outline the Centre's strategy to achieve this. In an accompanying paper, Kirk *et al.* (2008) outline the Centre's strategy for nursing.

Learning how to apply newly-acquired competences in primary care practice should also be seen as an integral part of the education process. Gaff *et al.* (2007) describe how they used a systematic approach to this to develop genetic education programmes for GPs in Australia.

Other initiatives are also helping to raise awareness and develop genetics competence. The GPwSI Genetics have been instrumental in establishing the Primary Care Genetics Society to support the educational needs of primary care professionals to help them translate and integrate the continuing

advances in genetics into their practice. They include as one of their objectives, to 'help to improve diagnosis and appropriate referral of people with inherited conditions through to specialist services' (Primary Care Genetics Society 2007).

Moving forward: 'how?' not 'why?'

The literature, whilst reflecting challenges still being addressed in relation to education provision and raising awareness about the relevance of genetics, also indicates a steady progress. There has been a gradual evolution from the need to justify the place of genetics in mainstream healthcare and education, to an articulation of what genetics should be taught, and, more latterly, to a consideration of strategies in ensuring genetics can be fully integrated into practice (Fig. 2).

Conclusions

The slow but steady shift in attitudes, and progress in education developments is heartening. However, although competences and curriculum guidelines have been developed, they are a long way from being fully integrated into pre-registration curricula, or embedded into continuing education programmes. What is important though is the recognition and acceptance that change is necessary and that a strategic approach to this, involving real dialogue between stakeholder groups, where processes can be mapped out and practical support offered, is likely to be the most successful in integrating genetics into primary care practice.

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See also

Genetic Services: Access, and Public and Professional Understandings of Genetics

Fig 1

UK Workforce Competences for Genetics in Clinical Practice for Non-Genetics Healthcare Staff- The Patient Pathway

Nine workforce competences cover the pathway for a patient with, or at risk of, a genetic disorder

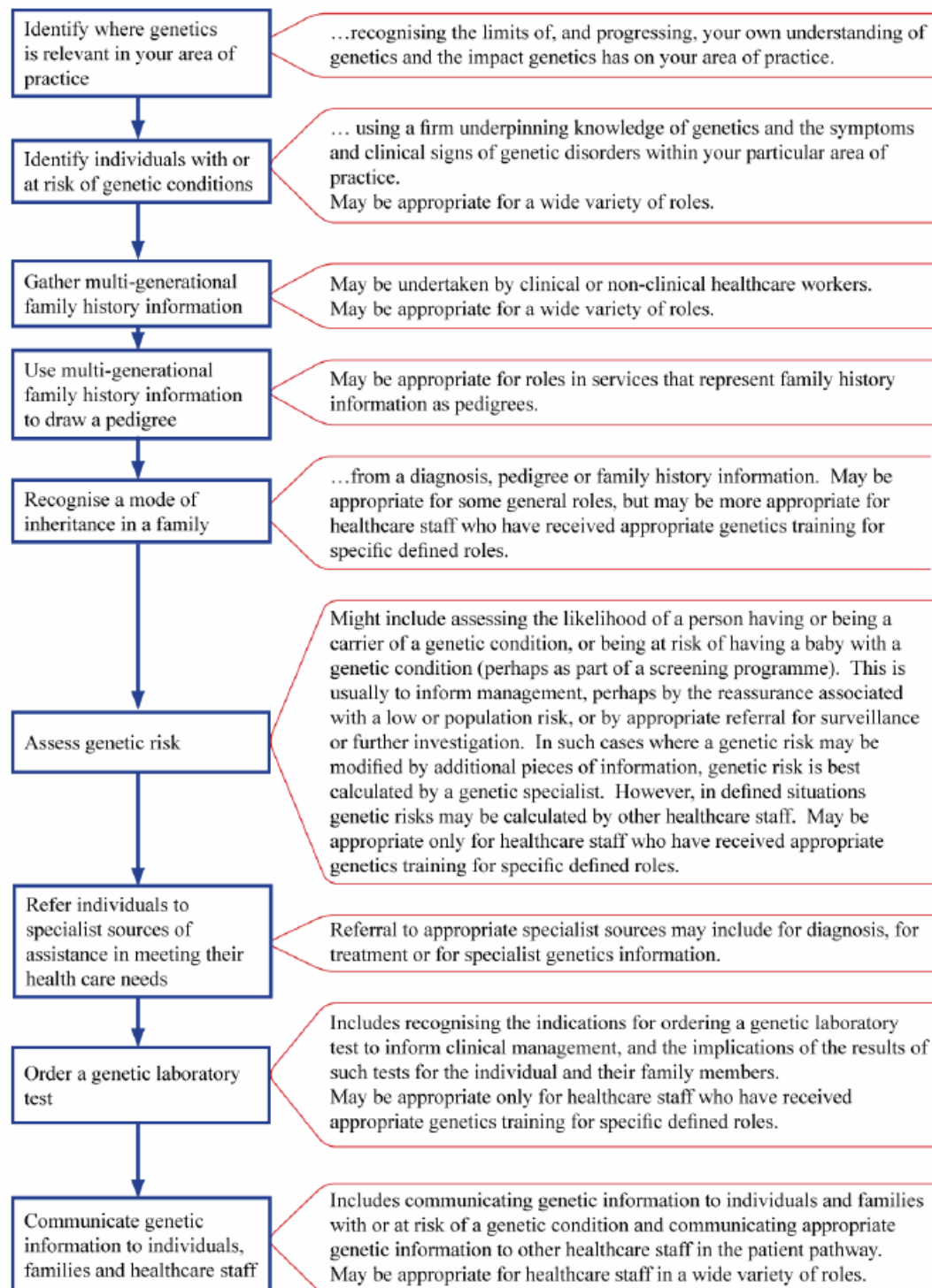


Fig 2

