

## SCIENCE AND SOCIETY

# Educating health-care professionals about genetics and genomics

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**Abstract** | To biomedical researchers, this is the ‘genome era’. Advances in genetics and genomics such as the sequence of the human genome, the human haplotype map, open access databases, cheaper genotyping and chemical genomics have already transformed basic and translational biomedical research. However, for most clinicians, the genome era has not yet arrived. For genomics to have an effect on clinical practice that is comparable to its impact on research will require advances in the genomic literacy of health-care providers. Here we describe the knowledge, skills and attitudes that genomic medicine will require, and approaches to integrate them into the health-care community.

There is growing evidence that genomics will change irrevocably the practice of medicine, but that change has yet to occur and its precise details are still unclear. We must define the knowledge, skills and attitudes that ‘genomic medicine’ will demand, and develop and implement methods by which the health-care workforce can learn them. If we fail to move the benefits of genomics into patient care as expeditiously as we have into biomedical research, many individuals will suffer avoidable morbidity and premature mortality.

If ever there were an area of medicine that is appropriate for lifelong learning, it is genomics. It is a young and quickly evolving field, so we cannot currently discern either the genomic knowledge or the clinical application of that knowledge that will be commonplace in the working years of today’s students and trainees. Therefore, although one goal of educating health-care professionals in genomics is to provide tools that can be used today, it is perhaps even more important to teach the key underlying concepts and instil an appreciation of the future clinical importance of genomics, so that students will be motivated to be lifelong learners of genetics and genomics.

Although novel, the ability to analyse and compare entire genomes and apply that knowledge to matters of health and disease is a natural extension of genetic medicine and its century-long history. In the clinical setting, genetics and genomics share a focus on probability and risk assessment, and on communicating both of these to health-care professionals and patients in ways that optimize decision making. So, an important goal in educating health-care professionals in genomics is to enable them to understand and utilize genetic-based probability and risk assessment, and to communicate effectively about them.

### Why is genomic medicine important?

Diseases form a spectrum, from ‘simple’ Mendelian diseases with high penetrance to ‘complex’ multifactorial diseases in which genetic factors have a relatively small role. However, genomics knowledge and approaches will soon be important to practitioners dealing with any disease, regardless of where on this spectrum it resides.

Whether in terms of prevention, diagnosis or therapy, health care has historically relied on models that view patients as representative of humanity in general, or at best some sub-category of humanity. However, each patient is an individual

with unique biology, not some biological everyman, which limits the efficacy of such models. Genomics-based knowledge and tools promise the ability to approach each patient as the biological individual he or she is, thereby radically changing our paradigms and improving efficacy.

In terms of prevention, for instance, testing that shows that an individual harbours a pathological mutation in a mismatch repair gene can lead to more aggressive surveillance and earlier surgical intervention to reduce the otherwise increased risk for colorectal cancer<sup>1</sup> — individualized modifications in management that would make neither medical nor economic sense if they were applied to all patients. In terms of diagnosis, use of genetic microarrays is already making inroads in refining the diagnosis of many cancers from a broader histological framework to a more precise molecular framework<sup>2</sup>. In terms of treatment, the ability to test for mutations in genes that encode for enzymes that metabolize specific medicines can already individualize the choice and dosing of medication, for example, mercaptopurine for acute lymphoblastic leukaemia<sup>3</sup> or warfarin for deep venous thrombosis<sup>4</sup>.

### What health-care providers need to know

In an age of competing medical priorities, why should health-care professionals who are already overloaded with information develop core competencies in genetics and genomics? Will genetics and genomics significantly affect their practice? What is the point of preparing for future needs when it is so hard to keep up with current medical advances?

One key role of the primary care provider is to accurately identify those patients who require further investigation (or specialist referral). With advances in genomic medicine, more and more patients will have disorders with a recognizable genetic component that should be managed appropriately. Health-care professionals who are ignorant of the basic concepts of medical genetics put their patients at risk of not receiving the best available care, and therefore also put themselves at risk of a malpractice suit. For instance, although

Mendelian disorders are individually rare, they constitute a significant health-care burden when taken as a whole<sup>5</sup>. Genetic scenarios that non-genetic health-care professionals can encounter in the clinic are shown in BOX 1. Such situations

will increase in frequency as genomic medicine becomes a reality.

A major challenge of genomic medicine lies in understanding and communicating disease risk in order to facilitate and support the patient's informed decision making.

An understanding of genetic principles is vital to meet this challenge. The health-care professional who is now competent to deal with the needs of genetic medicine will be well prepared to deal with advances in genomic medicine as they arise.

## Box 1 | Family histories

### Case

John, aged 37, is concerned about his family history of colorectal cancer (CRC) and consults his primary care provider. He has already drafted his family history online using the web site for the **US Surgeon General's Family History Initiative** (shown in the figure). John's sister Anita has CRC, his mother died of ovarian cancer and his maternal grandfather has CRC.

### Genetics issues

The family history tool is a useful first step to enable the patient to collect and structure family information. However, the primary care provider needs to interpret (and often expand on) family history information, no matter how it is gathered. In this example, it is important to know the age of each affected relative at the onset of cancer. The provider should know where to access information that would allow a broad assessment of risk (for example, does John need onward referral to a geneticist, a surgeon, or a gastroenterologist?). Most providers would recognize that John should consider a screening colonoscopy. However, John should also be referred to a specialist with advanced competencies in genetics, because the family history indicates a mismatch repair gene mutation and there is a possibility of screening Anita for this, which would offer John the opportunity for pre-symptomatic testing if such a mutation were found in her.

### Case

Carolyn is 9 weeks pregnant. At her first appointment she tells her obstetrician that her paternal aunt has two sons with a learning disability. A nurse who is a friend of her mother has reassured Carolyn that there would be no risk to her baby because the problem is "on her dad's side."

### Genetics issues

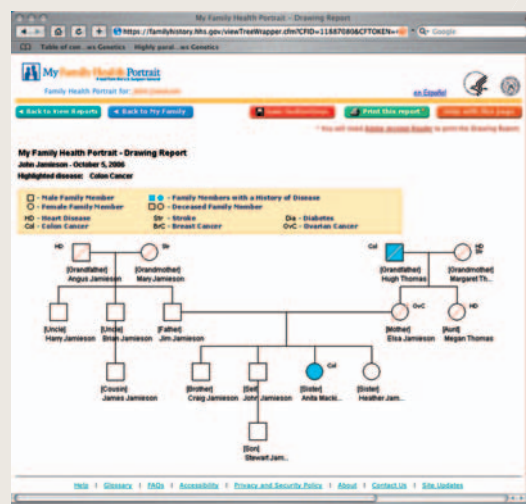
The obstetrician must know what questions to ask Carolyn in order to decide whether this situation needs rapid further investigation. The family friend has a little genetic knowledge and has surmised that Carolyn's cousins might have an X-linked recessive condition that could not be passed through Carolyn's healthy father. However, she has failed to consider a diagnosis of **fragile X syndrome**, which is the most common Mendelian cause of learning disability, or a chromosomal translocation, both of which could have major implications and are plausible here. It is important that the obstetrician clarifies the situation promptly, so that Carolyn can be offered appropriate antenatal testing if the pregnancy is at an increased risk.

### Case

Karen, aged 24, has a family history of **CADASIL** (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy). The condition is due to mutations in the **NOTCH3** gene and can often be detected pre-symptomatically in the third decade of life by identification of distinctive hyperdense regions of white matter in the temporal lobes by magnetic resonance imaging (MRI). During a game of football, Karen sustains a head injury and is briefly disoriented. By the time she reaches the emergency room she feels fine.

### Genetics issues

The emergency room staff need to understand that because of her family history, performing an MRI scan might disclose Karen's genetic status. Obviously, if the scan is necessary for optimum management of the presenting symptom it should be carried out, but alternatives should be considered first, particularly if Karen might be subject to employment or insurance discrimination on the basis of pre-symptomatic genetic status. The physician will have to discuss possible outcomes of the investigation with Karen to allow her to make a fully informed choice about the test.



## Essential knowledge

**Modes of inheritance and the role of family history.** Central to the understanding of genomic medicine is the concept of multifactorial inheritance, but practitioners should be aware that rare Mendelian forms of common diseases exist, and should recognize these. The family history is often the key to determining the mode of inheritance and framing discussion with the patient, and basic health information should be recorded across three generations. Sometimes the pattern of inheritance will be more complex (such as mitochondrial inheritance, genomic imprinting and so on) and the practitioner should have a low threshold for discussion of the case with a genetics specialist (BOX 1).

**What genetic tests are indicated and what do the results mean?** Although most current molecular genetic tests aim to identify individuals who carry mutations in Mendelian disorders, such testing is increasingly available for more common diseases with multifactorial causation, such as breast cancer (see the **GeneTests** web site), and is sometimes useful even in the absence of a significant family history. In such cases it is particularly important that the health-care practitioner understands the information in the laboratory report, including its limitations. Is the variant that has been reported pathogenic or not? How much weight should be given to the result?

Pre-symptomatic testing for Mendelian disease should usually be done only in association with genetic counselling. Health-care professionals should always consider whether such tests might give the individual information on their genetic status they did not wish to know (BOX 1). Conversely, molecular genetic tests to confirm a disease in an already symptomatic individual can have a status that is similar to other diagnostic tests, and counselling might be unnecessary. The health-care professional must be clear about the basis on which a genetic test is carried out, and ensure that the patient is fully involved in the decision to test.

As genomic medicine begins to mature, both the general and scientific press frequently

report findings about specific genes that seem to contribute to specific disorders; the practitioner must understand — and be able to explain to patients — which of these reports have clinical significance and which are merely unsubstantiated claims. Moreover, the practitioner must know which genetic tests can make a real difference in patient management. For example, individuals who carry two mutations in the *HFE* gene are predisposed to develop haemochromatosis, but only a minority will develop symptoms of the disease<sup>6</sup>. The health-care provider must be clear, in this and in many other instances, about the distinction between abnormal genotype and abnormal phenotype, and about both the wisdom of ordering a genotypic test and the full implications, or lack thereof, of its results.

**How to calculate risk and the indications for referral to a genetic specialist.** The majority of primary care providers do not see the calculation of genetic risk as part of their role, but they recognize that they have a crucial part in identifying individuals who require referral to genetic services<sup>7</sup>. Although it is unrealistic to expect all health-care professionals to calculate genetic risks, they must understand the features in a medical and family history or a physical examination that indicate that a patient is at a significantly increased risk of a disorder, if they are to manage the patient effectively (BOX 2), which includes making any appropriate referrals (BOX 1). It is also important to the patient that their provider can give appropriate reassurance in cases in which the genetic risk of developing a disease is not elevated.

### Essential skills

**Communicating genetic information and facilitating informed decision making by patients.** As in other areas of medicine, successful communication of genetic information requires the health-care professional to use plain language that is delivered at the appropriate educational level for the patient without patronization. Many tools are available to help the health-care professional convey complex genetic information. Pamphlets on disorders from local genetics referral centres or patient advocacy groups are one important form of information that can be discussed with the patient.

**Managing family dynamics.** Genetics differs from other areas of medicine in that it so often involves families, rather than only

### Box 2 | Assessing risk

#### Case

Alison is 39 and has recently had a mastectomy for breast cancer. There is no other relevant family history. Her sister Mary, aged 35, attends her primary care physician for advice about screening.

#### Genetics issues

The majority of primary care physicians will recognize this scenario, and many will turn to local and national guidelines to define a family history that 'qualifies' the patient for mammography screening. In Scotland, for example, Mary would be offered mammography every 2 years until the age of 40, every year between the ages of 40 and 50, and then every 3 years as part of the national breast screening programme. In England, recent guidelines suggest screening from age 40.

Mutations in the highly penetrant cancer susceptibility genes *BRCA1* and *BRCA2* explain the majority of families in which four or more close relatives are affected by breast cancer. However, these mutations are responsible for only a small minority of families that have a less dramatic family history. It is likely that the increased risk that is seen in close relatives of patients with breast cancer is due to multiple genetic variants, each with limited effect. Mutations in the *ATM* gene, which causes *ataxia telangiectasia* in biallelic carriers, confer a relative risk of 2.37 in monoallelic carriers<sup>26</sup>. The *CHEK2\*1100delC* variant doubles the risk of breast cancer in an unselected group of women, but seems to confer a higher risk to a subset of women with a family history of bilateral breast cancer<sup>27</sup>.

Definition of an increased risk that is sufficient to justify earlier and more frequent mammographic screening might depend on local health-care resources. How will the primary care physician effectively combine family history and perhaps lifestyle factors, such as obesity and smoking, to identify women who are at a sufficiently increased risk to justify more intensive screening? As the differential pathogenicity of the *CHEK2\*1100delC* has shown, an accurate family history is essential for correct interpretation of genomic data. Perhaps the primary care physician of the future will receive a SNP chip printout to factor into an assessment of risk, but the results must be interpreted in light of the family history.

individuals. The patients are often healthy, but concerned about the risk of developing or transmitting a disorder. The patient's perceptions of risk and their attitude towards genetic testing will depend on psychosocial factors such as cultural beliefs, ethnicity and personal experiences of disease in the family. Accurate information for one family member usually relies on sharing of information from other family members, and the concept of ownership of medical information can sometimes be ethically problematic (BOX 3). The primary provider must be able to negotiate this varied and important personal landscape.

#### Are the needs similar everywhere?

Some might assume that genomic medicine, with its heavy use of sometimes expensive technologies and its utility in combating those diseases that are of importance in developed nations, will be of little significance in nations that have fewer resources to invest in health care and a greater interest in infectious and other 'less genetic' diseases. However, this view is short-sighted. As others have shown in detail, the application of genomics will be key to effective prevention and management of many of the most important health-care issues, even in resource-poor nations<sup>8</sup>. For instance, the genomes of both

the malaria parasite<sup>9</sup> and the *Anopheles gambiae* mosquito<sup>10</sup> have been sequenced, and an understanding of the genetic factors that affect host response to malaria and its therapies is growing<sup>11</sup>. Such advances raise hopes that genomic approaches will lead to better treatment and prevention strategies, not only for malaria, but also for other leading causes of morbidity and mortality in resource-poor regions.

Like other aspects of medicine, genomic medicine will certainly be practised in widely disparate health-care settings. This will dictate different applications of genetics and genomics knowledge and tools, but the fundamental educational needs in these fields of health-care professionals will be similar everywhere. Whether one practices within a national health-care system or in a nation in which private payers dominate, the sensitivity of genetic information remains the same, the familial nature of genes is the same and the clinical challenges and opportunities are virtually identical. Whether in a resource-rich or resource-poor area, causation of disease and modes of inheritance are identical.

#### How will health-care professionals learn?

As with all health-related disciplines, education about genetics and genomics encompasses preparation for clinical practice

## Box 3 | Ethical considerations

**Case**

Hannah, aged 39, is terminally ill and in a coma with a cerebellar haemangioblastoma. Twenty years previously she had a retinal bleed that left her blind in her right eye. Her father also died of a recurrent brain tumour. Hannah's 21 year old daughter, Jenny, is approached by a maternal cousin for details of her mother's illness, but refuses to share information as she feels the approach is insensitive and that the family has let her mother down in the past. Jenny has been advised that her mother might have **von Hippel–Lindau disease**, an autosomal dominant cancer predisposition syndrome, and has arranged for a sample of blood from her mother to be sent for mutation analysis.

**Genetics issues**

Do the doctors treating Hannah or Jenny herself have an ethical obligation to share information with other family members who might be at risk? Clearly a trusted genetically competent primary care physician would be well placed to guide Jenny towards information sharing. Professional societies such as the American Society of Human Genetics and the US National Society of Genetic Counselors have published guidelines on patient confidentiality and duty to warn third parties. The practitioner's legal obligations in such cases will vary depending on jurisdiction.

(pre-service education) and education in the practice context itself (continuing education). The conceptual problems are the same in these two contexts, but they pose different practical challenges.

These problems include the still prevailing misconception that genetics is circumscribed by rare single-gene or chromosomal disorders, and is therefore of concern to only a few areas of clinical practice, such as dysmorphology, metabolic disease and prenatal obstetrics. That misconception is itself a manifestation of a more fundamental and deeply entrenched assumption, which is reflected in textbooks and informal discourse, that diseases fall into genetic and non-genetic categories rather than into a continuum of interplay between genetic and non-genetic components.

Perhaps the most important and difficult task is to implement educational programmes that address those misconceptions and flawed assumptions, and convey to students and clinicians alike that genetics is qualitatively different from all other topics because it underlies all of pathophysiology, and is therefore the fundamental science of health and disease<sup>12,13</sup>. That recognition must become pervasive if genetics is to achieve its potential in education and practice, and it argues implicitly against educational approaches that treat genetics solely as a medical specialty akin to all others.

Practical challenges for genetics education derive from these conceptual issues, and range from institutional matters such as the structure and sequence of the pre-service curriculum to the time constraints that are inherent in a busy clinical practice,

in which the health-care provider is compelled to seek only those educational opportunities that address the immediate needs of his or her patients. Any attempts to improve the quality and quantity of genetics that is taught to health-care professionals will need to combine new conceptual views of genetics with mechanisms that address those practical matters.

**Deficiencies in current education**

Although medical schools continue to increase genetics content of the undergraduate curriculum, studies in the United States and the European Union alike show that current educational approaches do not prepare students to practise in a health-care environment that will be increasingly influenced by genetics and genomics<sup>14,15,16,17,18,19,20</sup>. A literature review by Suther and Goodson<sup>14</sup>, for example, identified a lack of knowledge about genetics — and a related lack of confidence in addressing genetics issues in the clinical setting — as hindering the "...provision of genetic services by primary care physicians." In a knowledge survey of practising psychiatrists, largely from the United States and Canada, Finn and colleagues<sup>15</sup> found that, although psychiatrists recognize the growing clinical importance of genetics and believe they should discuss such information with patients and families, "...fewer than 25% felt prepared or competent to do so." They also noted that published studies have found similar deficiencies in genetics knowledge among "internists and primary care physicians." Baars *et al.* also found knowledge gaps among both medical students<sup>16</sup> and practising physicians<sup>17</sup> in the Netherlands,

findings that were confirmed and extended by later studies in The Netherlands, Sweden, France, Germany and the United Kingdom under the auspices of the **GenEd Project**<sup>18</sup>, and in reports from the British Royal Society (BRS)<sup>19</sup> and from the Wellcome Trust and the UK Department of Health<sup>20</sup>.

The BRS study, which assessed the future of personalized medicine, found that "...education in genetics at undergraduate, postgraduate, and continuing medical education levels has trailed behind the enormous scientific and technical advances in this field."<sup>19</sup> The report from the Wellcome Trust and the UK Department of Health found similar deficiencies, and called for a coordinated national effort in genetics education for health-care professionals in the United Kingdom, a recommendation that has found fruition in the recently established **National Genetics Education and Development Centre** in Birmingham, England.

However, deficiencies in genetics knowledge among medical personnel are not limited to students and practitioners. Billings *et al.*<sup>21</sup> found that a lack of genetics knowledge among senior medical officers in major health plans in the United States is likely to be an impediment to the integration and reimbursement of genetics services. In an editorial that addressed the future of genetic medicine in the United States, Korf<sup>22</sup> called for "collaborative models" between genetics professionals and "...payers to establish mechanisms for reimbursement..." to redress the sorts of impediments that Billings *et al.* identified.

**Providers' attitudes toward genetics**

Existing perceptions of genetics and deficiencies in genetics knowledge influence the attitudes of primary providers about the role of genetics in practice. Indeed, both anecdotal evidence and the literature confirm that most providers view genetics as peripheral to everyday clinical concerns. Many attitudes can be summarized as follows: "The Human Genome Project is interesting, and I know that it will change health care dramatically some day. But unless it will change my practice tomorrow in a concrete way, I really don't have time to deal with it. What will genetics and genomics do for me now, and how will they improve patient outcomes?" As Suther and Goodson<sup>14</sup> point out, this attitude might reflect health-care provider's "...uncertainty about the clinical utility of specific (genetic) technologies."

Similarly, as the [American Academy of Family Physicians](#) was contemplating its year-long focus on genomics for 2005, surveys of the academy's members showed that genetics and genomics were not high on the list of most important topics for continuing medical education (N. Kahn, personal communication). Nonetheless, virtually every topic that did make the list included relevant genetics content. These data reveal a perception that genetics is not a relevant topic by itself and, further, that the most important clinical issues are unrelated to genetics.

On the other hand, Suther and Goodson<sup>14</sup> and Fry *et al.*<sup>7</sup> also describe a lack of confidence among primary providers that results from a self-perceived lack of knowledge about genetics. Therefore, it might be that health-care providers' attitudes are compounded of: a misperception about the reach of genetics; a lack of self confidence in one's knowledge; and scepticism about the utility of current genetic applications.

Whatever the underlying cause, anecdotal and published data make it clear that educational initiatives for prospective and practising primary care providers must situate genetics in a practical clinical context. A case in point is the aforementioned 2005 focus on genomics by the American Academy of Family Physicians: the academy organized the programme around clinical issues that are familiar to family practitioners, and the resulting web site has drawn roughly 16,000 unique visitors in little more than a year (N. Kahn, personal communication).

### Pre-service education

Among the most helpful improvements in pre-service education would be the inclusion of clinical examples to illustrate the fundamental principles of genetics as they relate to common diseases — those maladies that will occupy most of the students' time once they are in practice. Furthermore, those examples and principles should be manifest not only in genetics courses or in courses in which genetics is integrated into other basic sciences, but also in courses that address specific organ systems and related disease processes.

However, even if excellent genetics content is included in the basic sciences, it must be applied to real patients in the clinical years of pre-service education. Those who teach genetics in medical schools report that clinical experiences for medical students often fail to bridge

“...educational initiatives for prospective and practising primary care providers must situate genetics in a practical clinical context.”

the gap between basic science courses and clinical perspectives. Addressing this deficiency is a considerable challenge, because it requires clinical preceptors who “think genetically”<sup>12,23</sup>, and can elaborate for students the genetics-based lessons in diverse clinical cases.

Those who direct postgraduate training in primary care specialties should also attempt to bring genetics perspectives to residency programmes and fellowships. A recent report<sup>24</sup> that addresses physician training in genetics provides a number of concrete suggestions for building bridges between genetics and other specialties, including the establishment of “...joint residency programs that combine medical genetics with another major discipline...” and development of “...subspecialty fellowships [that are open to] individuals trained outside of genetics.” The report notes that joint residency programmes already exist for “...genetics and pediatrics, internal medicine, and maternal-fetal medicine.”<sup>24</sup> It also suggests that joint fellowship programmes could “...qualify a geneticist to counsel cancer patients, but not to treat their cancer [and] an oncologist to counsel cancer patients but not to provide care for other types of genetic disorders.”<sup>24</sup> Of course, in genetics, as in other areas of medicine, the same programme can often meet many of the educational needs of both medical students and residents. For instance, [Genetics in Primary Care](#),<sup>25</sup> a case-based programme that was developed by the American Academy of Family Physicians and the Society of Teachers of Family Medicine, is intended for the education of medical students and residents alike.

One can make a number of cogent arguments to show that integration of genetics into the curricula of schools for health-care professionals is vital today if we are to have a workforce of health-care professionals who are able to provide optimal clinical care in the future. However, such arguments do not always succeed in determining curricula; because examinations for licensure and certification are important determinants of the content for pre-service education, such examinations

should have substantial inclusion of genetics-related questions.

So, pre-service education in genetics should combine content that reflects the pervasive role of this discipline in health and disease, with clinical instruction that makes explicit connections between teaching content and applications to patients. Such an approach would, one hopes, produce clinicians who ask themselves not, “Is this disease genetic?” but rather, “What roles do genetic factors have in the expression of this disease in this patient at this moment?”

### Continuing education

Practising clinicians receive continuing education through various formal and informal mechanisms, including continuing-education courses, experiences with their patients and their own investigations of questions that relate to patient management. Irrespective of the mechanism, however, continuing education should equip primary care clinicians to provide some genetic services on their own, while providing clear guidance for referral to genetics specialists when warranted.

Educators can take advantage of a number of converging factors to promote continuing education and the integration of genetics into practice. For example, the growing interest among clinicians and health plans in electronic data-management systems can help to deliver genetics content at the point of care, especially as common standards emerge for electronic medical records. That has important implications for improved applications of family history, which is central to genetically based care today.

Improved access to the internet in the clinical setting also provides opportunities for practitioners to consult up-to-date genetics information for guidance. Organizations such as the [American College of Medical Genetics](#) and the US-based [National Coalition for Health Professional Education in Genetics](#) (NCHPEG) are developing point-of-care, electronic decision-support systems for primary care providers. These systems incorporate basic educational materials, sometimes combined with clinical guidelines, including recommendations for referral to genetics specialists when appropriate.

However, access to the internet is not universal and alternative effective educational strategies must be developed. Some health-care professionals lack the skills

## Box 4 | Recommendations for integrating genetics into education

- Integrate genetics across the pre-service curriculum
- Increase the amount of content that is related to genetics and common diseases, as opposed to rare Mendelian diseases
- Build bridges between basic sciences and clinical instruction
- Ensure that instruction is case-based and reflects practical examples that demonstrate that genetics matters on a daily basis and can improve patient outcomes
- Develop continuing-education programmes in conjunction with representatives of the target audience

and confidence to use web-based teaching, whereas others might simply be unable to access the web because of a lack of local computer resources. Cascading of genetic education by teaching teachers — for example, residency directors — and empowering them to teach the same materials has been considered as an appropriate way to ensure wide dissemination of genetic knowledge. Whether this is an appropriate model for dissemination of often highly complex information is debatable, and any such programme would need to have a stringent quality-control mechanism in place. Along with reviews in medical journals, there are excellent textbooks that contain the core knowledge that is required, many of which are frequently updated to reflect the latest advances in the field.

The number of continuing education programmes in genetics has increased in the United States and elsewhere during the past 5 years, which is partly a result of the attention that the Human Genome Project has received in the professional literature and the lay press. Examples of

recent programmes include: the year-long 2005 Annual Clinical Focus on Genomics, developed by the American Academy of Family Physicians in conjunction with numerous public and private partners; programmes for dentists and dental hygienists, physician assistants, and speech, language, and hearing professionals, developed by NCHPEG in conjunction with the associated professional societies; programmes for practising nurses, developed by organizations such as the **International Society of Nurses in Genetics** and the Foundation for Blood Research, and by the University of Cincinnati and Duke University; and **Genetics in Your Practice**, developed by the March of Dimes.

Recommendations about genetics education for health-care professionals are given in BOX 4, and a list of resources to help with the development of educational programmes is shown in BOX 5.

### Conclusion

Knowledge that inheritance affects health is not new. It has long been known that family history can be a major risk factor

for many diseases, whether monogenic or complex in their etiology. However, new genomics-based knowledge and approaches promise the ability to go beyond the generalized guidelines that are given on the basis of family history to more specific and productive interventions that can be made with a knowledge of an individual's genetic makeup. Informed and effective health-care professionals will use these approaches to treat patients as individuals, rather than representatives of categories of humanity. Educating both those in practice and those in training about key concepts of genomics and, importantly, engaging them in the design of how this knowledge will be applied most effectively will rapidly bring the era of genomic medicine to patient care, resulting in improved health.

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## Box 5 | A sampling of resources for genetics education for health-care professionals

From the US-based National Coalition for Health Professional Education in Genetics (NCHPEG):

- Core Competencies in Genetics Essential for All Health Care Professionals (2001 and 2005)
- Core Principles in Genetics (2004)
- Genetics and Common Disorders: Implications for Primary Care and Public Health Providers (2005)
- Genetics, Race, and Health Care: What We Know and What It Means for Your Practice (2006)
- Psychiatric Genetics: A Program for Genetic Counselors (2002)
- Family history newsletter (ongoing)
- Genetics Resources On the Web (GROW) — a targeted search engine
- Genetics in Dentistry (2004)
- Genetics for Speech-Language Therapists and Audiologists (2006)

From other sources:

- **Genetics in Clinical Practice: A Team Approach** (developed by the US Centers for Disease Control and Prevention and Dartmouth College of Medicine)
- GeneTests and GeneClinics
- National Genetics Education and Development Centre (UK National Health Service)

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#### Competing interests statement

The authors declare no competing financial interests.

#### DATABASES

The following terms in this article are linked online to:

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ataxia telangiectasia | CADASIL | fragile X syndrome | von Hippel–Lindau disease

#### FURTHER INFORMATION

American Academy of Family Physicians:

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GenEd Project:

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Genetics: <http://www.nchpeg.org>

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