Nurse Education and the New Genetics - Preparing the Practitioners of the Future

A Report of an Expert Advisory Panel

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June 1999
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PREFACE AND ACKNOWLEDGEMENTS

In 1995 a group of some of the top genetic and health policy experts in the UK\(^{(1)}\) concluded that “major areas of health service activity will be experiencing the impact of service-ready genomic technologies within the 5 – 10 year time span. This means that those charged with planning for the future – health service providers, commissioners, educators, regulators – need to explore now what the likely practical consequences will be”.

In the meantime, we have seen the arrival of the Human Genetics Advisory Commission, its opening session given prominence by the publicity surrounding the cloning of Dolly the sheep. Genetically modified (GM) foods have further muddied the waters. And professionals and the public alike lack the knowledge to understand the arguments and differentiate myth from reality.

The Human Genome Project – the massive interactive scientific mapping effort – moves inexorably along to completion in the next three years or so; but even then much work will remain to be done to understand the pathogenesis of even common disorders. However, as John Savill, Professor of Medicine at Nottingham has said “awareness of molecular and cell biology have unleashed an investigative approach which, like a mechanised army is systematically crushing ignorance”. In all this, where is nursing education?

The UKCC Education Commission has been urged to include genetics in its thinking about a common core of underpinning skills and competencies – ‘literacies’ – which will equip nurses and midwives to ensure high quality patient care in the future.\(^{(2)}\)

But the future is now! Action is required urgently; and nursing, which has so readily embraced the need for curriculum change in the past, must be proactive again. Midwives, too, must join this search for relevance. Neither, fortunately, have exhibited a symptom so often attributed to medical school curricula – changing them is tantamount to trying to relocate a graveyard!

This report marks the beginning of a process. It is the result of the work of a panel of experts from education, regulatory organisations, government, the voluntary sector and practice settings, who came together under the aegis of the Genomics Policy Unit of the Welsh Institute for Health and Social Care. Patients and Nurses of the future will thank them all for their pioneering thinking. So, now do I!

The key outcome is a recommendation by the Panel for the establishment of a National Collaboration for education of nurses in genetics. WIHSC both endorses this and is willing to bring intellectual leadership to its inception.

Professor Morton Warner
Director

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Summary

Following on from research carried out by the Genomics Policy Unit into the provision of genetics education in pre-registration nursing programmes, an Advisory Panel of nurse experts was convened in November 1998 to consider nurse education and the ‘new genetics’.

The aim of the panel meeting was

• to identify the appropriate place for genetics in future pre-registration nurse education programmes;
• to make recommendations on how genetics education may be developed and delivered to provide a curriculum that is relevant, focused on nursing, and flexible enough to adapt to clinical advances in the fast-moving field of genetics.

The consensus was that nurses were being inadequately prepared in genetics to meet existing or future needs of patients, and that there was an urgent need to address this.

A number of obstacles to the provision of genetics education were outlined:

• The status of science in the nursing curriculum
• Lack of awareness of the growing importance of genetics in health and nursing
• Lack of resources in higher education, including appropriately qualified lecturers
• Deficits in knowledge and skills of qualified nurses, compounded by a poverty of provision for continuing professional education
• Lack of a national strategic framework for education
• Other competing priorities

Recommendations made were that:

1. Stakeholders in nursing education need to recognise the place of genetics in health care
2. Other stakeholders in nursing need to be aware of the growing importance of genetics
3. Nursing needs to develop its own evidence base in genetics
4. Genetics must be placed appropriately within the nursing curriculum
5. Guidelines for a core curriculum are needed
6. The contribution of the Clinical Genetics Service to education should be exploited more fully
7. Effective and relevant teaching resources should be developed
8. The status of science in nurse education must be raised
9. The quality of science teaching in nursing should be reviewed
10. The science literacy of students needs to be addressed
11. The length of the training programme may need to be reassessed as the curriculum attempts to embrace technological advances
12. Post registration education in genetics should also be reviewed
13. Nursing should consider the merits of establishing a national collaboration for education in genetics

The key action point of the panel was support for the establishment of a National Collaboration for the education of nurses in genetics. The function of such a group would be:

• To promote awareness of genetics issues in nursing practice;
• To promote equitable and appropriate provision of genetics education for nurses;
• To act as a resource for educators, offering advice and information.
Introduction

In November 1998, representatives from various fields within nursing met in Cardiff over the course of two days to review the place of genetics in nurse education. Members of the panel were chosen because of their particular expertise in the areas of genetics, education, clinical practice, management and research, or because they represented a particular nursing body - although these categories were not mutually exclusive. They were invited to share their experience, knowledge and uncertainties about the advances in the ‘new genetics’, its likely impact on health care and nursing, and on the preparation of nurses to practice in the new era of ‘genomics based medicine’.

The format of the Advisory Panel was designed to promote participation, through a combination of individual presentations and lively debate. The programme was facilitated by Marcus Longley, a healthcare expert from outside the field of nursing.

This report outlines the process of the meeting and summarises the considerations of the panel in discussing the provision for genetics in nurse education. The recommendations put forward to address the deficit in provision are also presented.

Background

The Genomics Policy Unit (GPU) is part of the Welsh Institute for Health and Social Care (WIHSC) at the University of Glamorgan, and has received funding from SmithKline Beecham Pharmaceuticals for a three year programme of research. The overall objective of the GPU is to examine the impact of the new genetics on healthcare in the UK, to help the NHS to make optimal use of the new technology. One of the themes that has been pursued is an assessment of the implications of new genetics for the future provision of education and training for health and social care professionals.

This current advisory panel on nurse education and the new genetics follows on from research which aimed:

- to establish the status of genetics education on pre-registration diploma nursing courses in the UK;

- to assess the attitudes and opinions of those with responsibility for the provision and development of curricula.

This research questioned whether the preparation that nurses currently receive on pre-registration training programmes is sufficient to provide them with the basic genetic literacy needed to respond to developments in genetics as they impact on health care.1
The Advisory Panel was thus convened to discuss the question:

**What is the appropriate place for genetics in the future of pre-registration nurse education?**

**Definitions**

The terms ‘genetics’, ‘new genetics’, and ‘genomics’ are used frequently in discussions about genetics. Some explanation of the origin of the terms is offered here, but it should be noted that as ‘new genetics’ is now 10 years old, the terms ‘genetics’ and ‘new genetics’ are often used interchangeably.

**Genetics**

Genetics is the science of inheritance, essentially studying what happens as a consequence of fertilisation. Traditional investigative techniques studying gene expression in relation to family pedigrees, built on the work of Gregor Mendel. He studied the variation in offspring after cross-pollinating pea plants in his monastery garden in the last century, to elucidate patterns of inheritance. However, much of the work in traditional genetics was accomplished without any real knowledge of the structure and function of the genes themselves.

**‘New genetics’**

The discovery of the structure of DNA, which carries the hereditary information in the form of genes, transformed the study of genetics. ‘New genetics’ builds on the foundation of traditional genetics, utilising molecular techniques to identify the individual genes that make up the human genome, and to study their structure and function. Although DNA structure was elucidated in 1953, it was not until the 1970’s that the discoveries made in molecular biology, allowing the direct analysis of genes, were to pave the way for the genetics revolution. Increasing sophistication and automation of such techniques encouraged scientists to embark on the hitherto unthinkable task of deciphering the ‘blueprint of life’ - the human genome. The Human Genome Project, commenced in 1990, underpins the ‘new genetics’. It is anticipated that the human genome will be sequenced by 2003.

**Genomics**

Genomics was defined by the Welsh Health Planning Forum in 1995 as “the study of the genetic control of body functions, both in health and disease” and they see it as “a step beyond genetics”. Not only does it study the structure and function of genes, but also the control of the genes themselves.
Aim of the Advisory Panel Meeting

The aim of the panel was:

- to identify the appropriate place for genetics in future pre-registration nurse education programmes;
- to make recommendations on how genetics education may be developed and delivered to provide a curriculum that is relevant, focused on nursing, and flexible enough to adapt to clinical advances in the fast-moving field of genetics.

The intention of the panel was thus:

- to share ideas and understanding about the place of genetics in nurse education for the future;
- to identify the optimal place for genetics in pre-registration nurse education;
- to identify obstacles to the development of genetics education;
- to suggest approaches that may overcome such obstacles and be consistent with future strategies for nurse education generally.

Participants

Members of the panel were drawn from a variety of nursing backgrounds, including:

- nurses working in the field of genetics;
- educationists with responsibility for nursing curricula;
- those interested in developments in the provision of care;
- professional groups involved with defining nurse education and practice.

A list of those who attended is given in Appendix 1. Representatives from three National Boards, UKCC, RCN, and Welsh Office were present, as well as the Chair and the Secretary of the Council of Deans of Schools of Nursing, and the Chair of the Association of Genetic Nurses and Counsellors (AGNC).

The process

A copy of the programme is presented in Appendix 2. Over the course of two days, the panel explored how genetics was likely to change health care and looked at the skills and knowledge that nurses would need for practice in the new era of ‘genomics-based medicine’. Current education practice was reviewed before addressing the question of whether the preparation was sufficient to equip nurses with the basic genetic literacy needed to inform practice as we enter the next millennium.
At the close of the first day, each panel member was asked to identify important gaps in the provision of genetics education. These were categorised and used to inform the discussion of the following day.

The final phase of the programme explored how an appropriate preparation of nurses in genetics might be achieved at pre-registration level. First, other developments in nurse education generally that may have a bearing on genetics education were outlined. Secondly, potential obstacles to reform were examined. Finally practical proposals as to how these may be overcome were considered, so as to prescribe a series of recommendations that were realistic, significant and achievable.

Proposals deemed to be appropriate for further consideration were identified through a process of consensus. Each panel member was asked to submit a proposal for the rest of the panel to decide if it was sufficiently significant and practical to merit further exploration. All recommendations that received more than half of the possible votes were carried forward for discussion in the final session of the programme.

**Reviewing the provision for genetics in pre-registration nurse education**

*The implications of genetics for healthcare*

The implications of advances in genetics for healthcare were discussed. These have been reviewed in a recent publication commissioned by the UKCC. In this report, genetics was identified as potentially “the most powerful example yet” of technological change driving organisational change in the NHS.

It is widely accepted that the Human Genome Project - which aims to have sequenced the entire human genome by 2003 - will have a significant impact on public health and clinical medicine. Fundamental to this impact is the identification of all the major genetic factors associated with human disease. There is growing recognition that most of the common serious diseases have at least some genetic basis - diseases such as diabetes, asthma, osteoporosis, epilepsy, cancer, cardiovascular disease, Alzheimer’s disease, schizophrenia and bipolar affective disorder.

Benefits to health care from advances in genetics may accrue in five key areas:

1. **Classifying diseases**
   The foundation has already been laid for the development of a new taxonomy of disease based on an understanding of the contribution of genetic mechanisms, both to the severity and course of disease. A new classification would incorporate ‘sub-types’ based on genotype, such as is developing for diabetes, breast cancer and Alzheimer’s disease.
2. Gene testing
As more and more genes are identified, both for rare and more common diseases, there will be an increasingly widespread use of gene tests to diagnose and predict disease. Testing of symptomatic patients will facilitate more accurate diagnosis and prognosis. Predictive testing of asymptomatic individuals will help identify the lifetime risk of developing a particular disease.

3. Opportunities for prevention of disease
The new knowledge and understanding of the genetic component of common disorders is likely to transform disease management from a ‘diagnose and treat’ approach to one of ‘predict and prevent’. As the nature of the gene-environment interaction is elucidated, interventions can be targeted to modify risk factors before symptoms emerge. Integrating this into prevention programmes will require patient and provider education, along with the identification of effective compliance programmes.

4. More effective treatments
More effective treatments will be developed through rational drug design. It is also anticipated that population genotyping or profiling will facilitate better targeted treatments, through a more accurate definition of responders and non-responders to specific treatment regimes.

5. New treatments
Ultimately, newer types of treatments, incorporating gene therapy techniques such as gene replacement, gene augmentation and gene correction will become available.

However, these benefits will not come alone. The anticipated increase in demand from the public for genetic information about themselves and their families is unlikely to be met by an already overstretched clinical genetics service. The need for primary care teams to play a key role in the assessment and management of genetic risk, and to act as gatekeepers to specialist genetics services has been identified.

Concerns have also been expressed on issues about genetic testing, particularly third party access to information and the potential for discrimination in employment and insurance. The potential of predictive testing for raising anxieties in otherwise well

Increased understanding of the genetic component of common diseases may lead to:

- A new way of classifying diseases
- The possibility of earlier detection of disease
- Greater opportunities for prevention
- The ability to provide better targeted and more effective treatments
- New types of treatment
people - the ‘worried well’ - and the implications of this for the workload in primary care have been documented.10

Implications for nursing

The advances in new genetics and technology will impact on all areas of nursing, although many non-geneticist professionals still feel that genetics is not relevant to most health care.11 Increasing awareness of the contribution of genotype to disease indicates that this attitude is no longer appropriate - genetics cannot now be viewed in isolation, as a specialist (and optional) subject, to be dealt with only by specialist nurses.

Four areas where genetics will have an impact on nursing were described:

Nursing practice, particularly in primary care and adult nursing settings, will have to address the ‘genetic concerns’ of a public made increasingly aware - and sometimes unnecessarily alarmed - about genetic issues. Clients with concerns about specific disorders, or about screening or testing options, will have to be helped by knowledgeable practitioners educated about the use and interpretation of genetic tests. It is in the area of genetic testing that nurses will perhaps face the most immediate impact, particularly as options for treatment or management of ‘at risk’ patients lags some way behind the ability to identify such people.

As genetics is further integrated into health care, nurses will have to enhance skills in ascertainment, to collect and record accurate information pertaining to family history. The coordinating function of the nurse will be important in identifying resources and appropriate referral pathways. Equally important will be the role as advocate, acting on behalf of the patient to protect privacy, confidentiality and autonomy in decision-making. Nurses will also participate in the management and new treatments of patients with or at risk of genetic conditions.

Nursing research in genetics will have to address the need for a greater body of nursing knowledge to inform a practice in which genetics is an integral part. The optimal ways to integrate genetics technology into the delivery of nursing care will have to be identified, to reduce any conflict with existing practice or with the values and beliefs of nurses delivering care.
The nursing profession will need to demonstrate leadership in participating in debate over the choices that the application of genetic technology is creating, and in encouraging public involvement in developing policies of concern to society.

Nurse education will have to equip nurses at all levels and in all settings with the knowledge and skills needed as healthcare adopts the changes in practice and organisation brought about by genetics. While knowledge of the science of genetics is needed to underpin practice, awareness of the ethical, legal and social issues for individuals, families and society facing decisions about genetics is equally essential.

The current status of genetics education

The outcome of the survey on provision of genetics education for pre-registration nurses was presented. In 1997 a questionnaire was sent to the managers of branch programmes in all colleges of nursing in the UK that offer pre-registration training at diploma level. The response rate was 84%.

The survey revealed that although genetics is taught on all but two training courses, provision is insubstantial in many cases. Most programmes include ten hours or less of genetics, with nearly one-third of courses providing five hours or less. Courses incorporating Adult Branch are least likely to teach more than ten hours of genetics.

The curriculum emphasis tends to be on ‘traditional’ genetics topics, and teaching is delivered by lecturers with no qualification in genetics on 94% of programmes. There is also little rigorous examination of the subject; 75% of programmes do not assess students compulsorily in genetics and only 13% of programmes indicated that assessment is more substantial than multiple choice questions.

The majority of respondents to the survey (81%) appear to acknowledge the growing importance of genetics in health care and agree that genetics education will become an increasingly important issue for the future of nursing. Although 58% agree that genetics should have a higher profile in professional training, 68% feel that the genetics teaching they are offering is appropriate to meet patients’ needs.

The report concluded that genetics education on pre-registration diploma nursing courses was unlikely to provide basic genetic literacy for the majority of students in the UK. The adequacy of current pre-registration education (and continuing professional education) in genetics was also questioned by Warner et al.. They highlighted that a fundamental understanding of genetics was needed to equip the healthcare professional of the future.

The panel discussed these findings and considered whether there was a need to reform the current provision of genetics education.

Do we need to change the current provision for genetics education?
The panel was unanimous in agreeing that there was a need to review genetics education:

**The consensus was that nurses were not being prepared adequately in genetics to meet existing or future needs of patients, and that there was an urgent need to address this.**

One panellist commented further that genetics education was necessary not only because of its scientific and clinical application, but also because it should inform us about one of the fundamental aspects of personhood and that understanding people is a fundamental core component of nursing. He said “genetics impacts on the whole of human growth and development - this is a bio-psycho-social process”.

**The deficits in provision**

A number of gaps were identified, along with potential obstacles to reform. Whilst individual categories are outlined below, many are inter-related.

- **The status of science within the nursing curriculum**
  Genetics education is widely addressed through the science curriculum, and this is felt to be a key factor in its relatively low profile. The lack of scientific literacy was identified on the part of students both on entry and on exit from training programmes, although it was also acknowledged that this was not unique to nursing. The lack of science literacy on the part of educators is thought to contribute to the low status of science within nursing. Lack of appreciation of the role of science in nursing knowledge and practice, and resistance to science teaching on the nursing curriculum, are felt to be obstacles to overcoming this.

  A further factor identified is that teaching genetics within the science component of the curriculum could limit its focus and lead to ‘isolation’ of the subject. Other important aspects, such as ethics and psychological and social issues, might not then be addressed adequately.

- **Lack of awareness of the growing importance of genetics**
  This was identified as a key ‘gap’ in education in two respects. First, it is thought that at organisation level (i.e. statutory and professional bodies, academics and the NHS), there is a lack of awareness of the implications of the rapid developments in clinical genetics, and a lack of appreciation of how these will affect health care. Secondly, there is a lack of awareness about the nature of genetics and clinical genetics services. That it is multidisciplinary, and of relevance for all branches of nursing, does not appear to be widely recognised.
• **The expertise of teachers**
Genetics is a rapidly developing field of health care, and although clinical advances have implications for all aspects of medicine, medical genetics itself is a clinical speciality of which most nurses will have had little clinical experience. The subject speciality is also a complex one, incorporating biology, psychology, social sciences and ethics, as well as requiring an understanding of the clinical implications for nursing practice, particularly in relation to counselling and supporting decision-making.

The panel identified that the availability of appropriately qualified teachers with both subject knowledge and relevant clinical experience is low, and a lack of opportunity to remain abreast of developments may further diminish expertise.

• **Lack of resources**
Not unrelated to the previous point, the panel highlighted the availability of, and access to resources as key gaps in education provision. There is little nursing literature in the UK that focuses on genetics, and there is a lack of an appropriate infrastructure for dissemination of relevant information. Further, it is felt a critical mass of literature might be necessary to convince policy makers that genetics is a serious contender for a place in pre-registration nursing programmes.

• **Competing priorities**
Competition for curriculum space is thought to be a major obstacle. There are many expansions of the scope of practice as new care technologies impact on nursing, all of which have to compete for space alongside key skills in a content-driven curriculum.

Other competing priorities were linked to EU harmonisation issues, the demands of purchasing consortia, and employers’ expectations of newly-qualified staff.

• **Lack of a national strategic framework**
One issue highlighted is the lack of informed guidelines regarding the content and level of genetics teaching.

It was also agreed that there is insufficient focus on joint planning by education providers and purchasers. The need for a constructive, planned programme, elements of which are linked to a ‘benchmarked system’ of clinical evidence and outcomes was indicated.

• **Deficits in nursing skills**
Some specific deficits in nursing skills were identified in relation to genetics. Many nurses lack ‘genetic awareness’ and so are unobservant of family history, are unaware of the referral pathways to the clinical genetics service, and do not always appreciate that genetic testing and prenatal diagnosis are options available by a process of informed decision-making. If nurses are to be prepared to meet future demands in health care, they need also to be effective in communicating genetic information, particularly in terms of risk, to patients identified as being susceptible to specific common diseases.
• **Theory-practice gap**
There are a number of issues related to genetics that contribute to the wider debate of the theory-practice gap. First the general deficit in genetics knowledge and awareness limits the ability to apply theory to the clinical environment. This situation is further exacerbated by lack of relevant expertise in teachers who have difficulty in ‘making links’ to practice. There is also a dearth of nurses outside of the specialist field who are able to act as suitable role models for student nurses. Exposure to good practice is seen as an essential accompaniment to theory in the curriculum.

• **Continuing professional education**
Appropriate and relevant education in genetics at pre-registration level can form a firm foundation on which to build further knowledge and skills involving genetics. At present this assumption cannot be made, and there is a need to address the deficit in genetics knowledge of qualified nurses.

**Recommendations**

Practical suggestions as to how these obstacles may be overcome were considered, taking into account future strategies for nurse education generally. The main recommendations are outlined below:

1. **Stakeholders in nursing education need to recognise the place of genetics in health care**
Greater awareness must be promoted amongst providers and purchasers of nurse education of the growing importance of genetics in health care and its relevance to nursing practice.

2. **Other stakeholders in nursing need to demonstrate greater awareness of the growing importance of genetics**
The statutory bodies, UKCC and professional organisations will need to give further recognition to the relevance of genetics education in nursing.

3. **Nursing needs to develop its own evidence base in genetics**
A broader evidence base for the role of nursing in genetics should be promoted through nursing journals.

4. **Genetics must be placed appropriately within the nursing curriculum**
Genetics should be recognised as a cross-curricular subject in nurse education programmes.

5. **Guidelines for a core curriculum are needed**
A core curriculum in genetics should be developed and guidelines disseminated on a national scale.
6. The contribution of the Clinical Genetics Service to education should be exploited more fully
More effective and planned utilisation of the Clinical Genetics Service as a resource should be made, including a review of the lecturer-practitioner role for specialist genetics nurses.

7. Effective and relevant teaching resources should be developed
There is a need to develop a resource for teaching genetics to nurses that provides material that is focused on the knowledge and skills necessary for clinical effectiveness in nursing practice.

8. The status of science in nurse education must be raised
The role of science in nursing is currently undervalued, and by association, so is genetics. Consideration should be given to the formation of a ‘science group’ in nursing to promote awareness of the fundamental role science plays in nursing.

9. The quality of science teaching in nursing should be reviewed
The science literacy of nurses teachers should be reviewed, and practical support offered to overcome any deficits.

10. The science literacy of students needs to be addressed
The needs of students to receive support in science and numeracy has to be acknowledged and addressed.

11. The length of the training programme may need to be reassessed as the curriculum attempts to embrace technological advances
Consideration needs to be given to how other competing advances, such as in care technologies, information technology, and expansions in the scope of practice, are to be assimilated into the nurse education without adjusting the length of the training programme.

12. Post registration education in genetics should also be reviewed
Whilst the remit of the panel was to review pre-registration education, there was a general agreement that this could not considered in isolation from post-registration education. The need to review post-registration education is also considered to be urgent.

13. Nursing should consider the merits of establishing a national collaboration for education in genetics
The establishment of a national collaborative body, with the support of purchasers and providers of education, could serve to promote awareness of genetics, and to act as a resource for genetics teaching.
Each recommendation was reviewed both separately and in the context of the other recommendations. A key action point of the ensuing discussion was the support for the establishment of a National Collaboration for the education of nurses in genetics. It is felt that this would be the most effective and appropriate vehicle for addressing many of the individual recommendations made.

The Collaboration would consist of a Steering Group, drawn from experts in the field of genetics and education, with representatives from the statutory bodies, UKCC and RCN, and other interested organisations such as the Health Education Authority. Membership would be open to all colleges and NHS departments with responsibility for the education of nurses.

A similar move was made in 1997 in the US with the establishment of the National Coalition for Health Professional Education in Genetics, of which American Nurses Association is a member. The goal of the coalition is to provide an organised, systematic and national approach to the provision of genetic education for all healthcare professionals.12

**The function of a national collaboration in the UK** would be:

- to promote awareness of the relevance and growing importance of genetics in nursing practice and health care;
- to promote the equitable provision across the UK of courses that are current and relevant to nurses;
- to act as a resource offering advice and information for those with responsibility for developing and delivering genetics education for nurses at pre-registration and post-registration levels.

The function of a National Collaboration for education of nurses in genetics:

- **To promote awareness of genetics issues in nursing practice;**
- **To promote equitable and appropriate provision of genetics education for nurses;**
- **To act as a resource for educators, offering advice and information.**

*It would aim to achieve this* by:
• developing and issuing guidelines for a ‘core curriculum’ of genetics (to be adopted at the discretion of individual education establishments);

• developing and maintaining a resource package, including clinical case studies, advice on text books, and key journal articles;

• developing a national network and database for peer support and information exchange, and to disseminate ‘best’ practice;

• developing and maintaining a Web site, so that the above information is available electronically, with links to other national and international sites;

• promoting regular contact with statutory bodies, NHS managers and educators via feedback from Steering Group members, and local and national seminar programmes.

The importance of viewing genetics in conjunction with other developments in nurse education was stressed, such as the potential changes in the entry gates, increases in graduate numbers and reformation of the initial preparation of nurses. The need for close links with statutory and professional bodies would be crucial in this respect.

**Moving forward**

There was considerable enthusiasm amongst most of those participating to be involved in establishing the Collaboration, and WIHSC is happy to facilitate this process. Successful implementation of the venture will rely on identifying an appropriate Chair for the Steering Group, an ‘Information Officer’ particularly to develop and maintain a Web site, and on attracting sources of funding.

WIHSC has agreed to convene an inaugural meeting, open to all with an interest in nurse education. The meeting could serve to assess support for the recommendation and identify the appropriate way forward. In weighing up the appropriateness of this approach, it may be of worth to reflect on a recent comment about the development of the coalition for genetics education in the USA:13

> “Professional nursing societies that adopt such a proactive role in preparing for the future are exhibiting visionary leadership and a willingness to invest in the future.”

**Conclusion**
If, as we enter the next millennium, the nursing profession is to define its own role and scope of practice as genetics is integrated into care in different health settings, we have to demonstrate the ability to embrace change and exhibit a willingness to invest in the future. The recommendations of this panel should be considered carefully. The proposal to establish a national collaboration to help achieve the recommendations indicate that this is not simply an academic exercise, but stems from an enthusiasm for nursing, fundamental to which is a belief in what nurses may achieve when provided with the opportunity and support to be pro-active in shaping the future for nursing and genetics.
References


## APPENDIX 1

### The Members of the Advisory Panel

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<td>Ms Judith Allen</td>
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<td>Assistant Director WIHSC and Head of GPU, University of Glamorgan</td>
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<td>Ms Sally McGregor</td>
<td>Postgraduate Research Student, WIHSC, University of Glamorgan</td>
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<td>Mrs Eileen Martin</td>
<td>Secretary and Treasurer, Council of Deans, University of Central Lancashire</td>
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<td>Professor Donna Mead</td>
<td>Head of School of Nursing and Midwifery, University of Glamorgan</td>
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<td>Mr Thomas Moore</td>
<td>Director of Professional Services, WNB</td>
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<td>Mrs Christine Patch</td>
<td>Association of Genetic Nurses and Counsellors</td>
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<td>Mrs Jean Sait</td>
<td>Director of Patient Care, Dyfed-Powys Health Authority</td>
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<td>Mrs Heather Skirton</td>
<td>Chair, Association of Genetic Nurses and Counsellors</td>
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<td>Mrs June Smail</td>
<td>UKCC</td>
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<td>Mrs Meryl Thomas</td>
<td>Director of Midwifery Education and Practice, ENB</td>
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<td>Professor Colin Torrance</td>
<td>Director of Nursing and Midwifery Research, University of Glamorgan</td>
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<tr>
<td>Mrs Janet Vickers</td>
<td>Divisional Leader, Applied Biological Sciences, St Bartholomew/City University School of Nursing</td>
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APPENDIX 2: THE PROGRAMME

Advisory Panel on Nurse Education and the New Genetics

What is the appropriate place for genetics in the future of pre-registration nurse education?

Thursday 12th November

11.30 Welcome and Introduction
12.30 LUNCH

13.15 Genetics and the Future of Health Care
   How is genetics going to change health care?
   How may genetics impact on nursing?
   The genetics revolution - media hype, millennium bug, and the next nursing bandwagon?
   [Short contributions from Marcus Longley, Maggie Kirk, Peter Birchenall]

14.30 Genetics and the Future of Nursing Practice
   What skills and knowledge will nurses need for practice?
   The specialist role
   Meeting patients’ needs
   The role as health educator
   What will commissioners be looking for?
   [Short contributions from Heather Skirton, Gill Donovan, Sally McGregor and Jean Sait]

15.15 TEA

15.30 Genetics and the Future of Nurse Education - current practice and status
   Preparing the specialist practitioner - building on the foundations
   Pre-registration genetics education - An example of current practice
   The status of genetics in pre-registration education
   Do we need to change current practice?
   What are the gaps in practice?
   [Short contributions from Chris Patch, Janet Vickers, Maggie Kirk, Meryl Thomas]

17.00 SUMMARY AND CLOSE

18.30 DINNER

20.30 Does genetics merit a special place in the nursing curriculum?
   Discussion led by Donna Mead
Friday 13th November

09.00 Recap

09.15 Nurse Education and Genetics - the issues for the future
What else is happening in nurse education in the next 5-10 years that may have a bearing on genetics education?
The view from education
Welsh Office view
The Professional groups (UKCC, RCN)
[Short contributions from Tony Butterworth, Phil Johnson, June Smail, Judith Allen]

10.30 COFFEE

10.45 Genetics and Nurse Education - obstacles to reform
What are the competing priorities?
Genetics in the science curriculum
Resources - can we support a national framework?
[Short contributions from Eileen Martin, Colin Torrance, Peter Bentley and Beatrice Grant]

12.30 LUNCH

13.15 Preparing for the Future
Summarising the issues and the gaps
Recommendations
Taking forward our shared understanding

15.15 SUMMARY AND CLOSE