

Joint Committee on Medical Genetics

The Royal College of Physicians
Pathologists

The British Society for Human Genetics

The Royal College of

RCP 11 St Andrews Place Regents Park London NW1 4LE

A summary of the fourth meeting of the Joint Committee on Medical Genetics held on Tuesday 11th January 2000

Present

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| Professor Peter A Farndon | Chairman RCP |
| Professor Sir George Alberti | PRCP |
| Dr Julie Crow | RCPPath Registrar |
| Professor Andrew Read | BSHG Chairman |
| Mr John Barber | BSHG |
| Dr Angela Brady | RCP trainee representative |
| Dr Naomi Brecker | NHSE Observer |
| Ms Caroline Browne | RCPPath trainee |
| Dr Angus Clarke | RCP JCHMT SAC |
| Dr Jill Clayton-Smith | RCPCH |
| Professor Dian Donnai | CMO Adviser |
| Dr Rob Elles | BSHG |
| Mrs Margaret Fitchett | RCPPath |
| Dr Alan Fryer | RCP |
| Dr Lorraine Gaunt | BSHG |
| Mrs Penny Guilbert | BSHG |
| Dr Helen Hughes | BSHG |
| Professor Noor Kalsheker | RCPPath |
| Mr Alastair Kent | GIG |
| Professor Sue Malcolm | RCPPath |
| Professor Peter Soothill | RCOG |
| Dr Virginia Warren | FPHM |
| Ms Hilary Irons | RCP Committee Administrator |

In Attendance: Dr Fiona Douglas, Professor Neva Haites, and Dr Ron Zimmern

- 1 Apologies: Professor Michael Connor (Scottish Colleges), Dr Dennis Cox (RCGP), Professor Robert Mueller (RCP), Dr Virginia Warren (FPHM), Mr Anthony Taylor (DH Observer), and Professor Ian Gilmore (RCP Registrar).

Dr Angela Brady was relinquishing her position as the RCP trainee representative.

In attendance: Dr Fiona Douglas, Professor Neva Haites, Dr Ron Zimmern.

The Chairman referred to the new developments and initiatives for genetics and commented that he believed the Joint Committee should be actively involved. The main areas were the education of both the general public and health care professionals, maintaining and improving standards of service provision, and manpower planning. The issues of consent and confidentiality had also become most important. The Joint

Committee should set down its views on how best genetic services could be provided in the future.

2 DH/NHSE Review of Genetic Services

This report had been delayed. From April 2000 genetic services would be designated a priority specialty for regional specialist commissioning groups.

The Chairman referred to a letter from Dr Barber pointing out that regional specialist commissioning groups did not have a budget and had no control over fund-holding authorities who commissioned services. DH/NHSE appreciated that this point and there were groups looking at the appropriateness of methods of commissioning. It would be helpful if appropriate benchmarking measures could be established between Regions.

3 Patents and genetic testing

It was understood that Myriad was in the process of licensing to the UK a bio-technique for breast and ovarian cancer. Reliable information was awaited. It was reported that in Holland it may have been agreed that a proportion of the testing could continue in the health laboratories but that unresolved cases would go to Myriad. These developments had been discussed at the BSHG Council meeting and were regarded with extreme concern. There was concern about being able to operate a service as a package and not as disparate items. The Joint Committee's concerns were being reported to the Department of Health.

4 Clinical governance

The Council of the BSHG had accepted the outline document prepared by the Clinical Genetics Society, which was being printed and would be circulated widely. The BSHG would consider how best to proceed but as there were aspects which would affect genetic centres the BSHG would consult the Joint Committee.

A document prepared by GIG on clinical governance from the patient's point of view was received.

The RCPATH had delayed providing general guidance on clinical governance because of the variation between the disciplines, but this likely to be available within the next year.

5 Nuffield Trust Genetics Scenario Project

The Chairman had attended the final workshop. The Nuffield Trust will be launching the report in late spring.

6 Genetics knowledge/education of non-genetics professionals

A small survey by Dr Clayton-Smith's working group for the Joint Committee had documented that a great deal of teaching was being provided for obstetricians, midwives, paediatricians and, to a lesser extent, general practitioners. The Joint Committee had agreed that more comprehensive information was required but as they had learnt that the Public Health Genetics Unit had already distributed a questionnaire they were anxious to avoid duplication. Dr Zimmern confirmed that the Public Health Genetics Unit was more concerned about the training of managers and health authorities. However, he felt that there would be some information of interest to the Joint Committee which they would be pleased to make available.

Dr Clayton-Smith said that the working group was now involved in determining the core competencies required by different groups of medical professionals.

Members were aware that various bodies were working in this area and wished to avoid duplication. A widely held view outside the speciality was that geneticists should be providing the education and therefore it would be appropriate for the Joint Committee to continue with its investigations and take a lead in formulating views. The Human Genetics Commission will be looking at education and so the Chairman will convey the Joint Committee's interest to the Commission.

7 Review of undergraduate medical training in genetics

A report was published by the RCP in 1990 on the Teaching of Genetics to Medical Students. An update in 1997 but not published because of rapid changes at that time in courses. The Chairman had asked Professor Haites to repeat the survey for the Joint Committee.

8 Genetics proforma for antenatal care

It was noted that there was insufficient information about proformas currently in use, and that, as such a wide range of professional groups were involved, any proforma would have to be at a very basic level. Such a development for antenatal clinic use may be possible as a proforma was being used to enable patients with a family history of cancer to document their family history.

9 Services for adults with inherited metabolic disorders

It was noted that metabolic medicine was not a separate specialty but both the RCP and the RCPATH had accepted that it was a sub-specialty. The RCPATH was reviewing its stance but a firm decision had not yet been made. The Joint Committee's working group was continuing with their enquiries.

10 Accreditation proposals for non-medical genetic counsellors

The membership of the Association of Genetic Nurses and Counsellors (AGNC) had given its mandate to the accreditation proposals and AGNC was exploring the issues to agree an implementation plan for the future.

11 DNA Services

(a) **UK specialist genetic testing network for molecular diagnosis**

The BSHG was anxious to introduce this scheme but felt it might be best to wait for the Working Group on Laboratory Services for Genetics (chaired by Professor Martin Bobrow) to report. It was thought that the BSHG could act as referees for a pilot scheme.

Dr Brecker tabled a briefing paper on the establishment, terms of reference, and ongoing work of this DH Working Group.

(b) **DNA Services for rare single gene disorders**

Discussion was deferred.

(c) **Review of operation of OAT system**

Dr Elles had not repeated the survey he had carried out for the first quarter for the Joint Committee but had reviewed the service managed from his own centre. The OAT agreement established on activity for 1997/98 was not covering this year's activities predicting a shortfall in income by the end of the year of about 30%. Dr Elles was asked to repeat the national survey.

Members reported similar problems from genetics units around the country. Dr Brecker would report these to Professor Martin Bobrow's group who wanted to hear of such problems because it was not a consistent picture. Dr Zimmern said that he had received various interpretations of how the system should work and there needed to be definitive advice from DH/NHSE. The Joint Committee's concerns were being relayed to DH/NHSE.

12 Human Genetics Commission/Department of Health/NHS Executive

The origin and role of the Human Genetics Commission were discussed. The Commission would take on the work previously undertaken by the advisory committees and would complete any projects already started. With regard to work on genetic testing and the insurance industry, it was hoped that first submissions from the insurance companies would have been received by April.

The importance now given to genetics within the Department of Health and by Health Ministers was noted. There were two high level Departmental groups for genetics, a steering and an implementation group. The NSHE was making a bid to the Treasury for extra funding for the next three years which would include genetics.

GIG wished to draw the Joint Committee's attention to the lack of GIG representation in the membership of the Human Genetics Commission, despite there being representatives from the British Association of Disabled People and the Consumer Association. Members of GIG were surprised that no-one was representing genetic disorders which they felt was a major omission. Members of the Joint Committee supported their objection and the Chairman undertook to convey this view.

13 Public Health Genetics Unit

The Unit had been set up with five years funding because of the gap in or lack of information and knowledge within health authorities. The first task was to set up a public health genetics network and website, and the Nuffield project was part of the initial stage. The Unit was trying to obtain information about commissioning services but so far the data were not good.

The Faculty of Public Health Medicine had sanctioned the seconding of public health specialist registrars to regional genetics units for a period of time during their last year of training. Professor Read pointed out that this development was not generally known within the regional clinical genetics units.

Summer school: work was progressing well in developing curricula for managers, non-executive directors, public health doctors, general practitioners, and they were now seeking funding for this.

Nuffield project: to look at the impact of genetics on health services and potential for disease prevention over the next fifteen years. There had been eight different stakeholder groups culminating in a workshop. Consideration was being given to the following policy

areas: national framework; education and training strategy; policy for a scientific base; commercial considerations and links with industry; information about confidentiality; issue of affordability and keeping profession within the NHS. A copy would be submitted to the Joint Committee but it would also be in the public domain.

14 Information from Genetics Interest Group

Documents from GIG on clinical governance and “Getting involved in Research - a guide for individuals, families, and the groups that support them” were discussed.

This year was GIG’s tenth anniversary and they were planning to mark the occasion in some way, possibly with a conference in Autumn.

15 Confidentiality and Consent

Several letters had been received from laboratory and clinical services from which it was evident that there was wide variation in the way Trusts dealt with the medical records of family members, results of genetic tests, and consent procedures for storage of patient DNA.

Dr Douglas detailed issues affecting the confidentiality of medical information, covering points relating to relevant law, accurate information, rights of an individual versus duty of care to family, rights of the dead, and DNA samples. Members agreed that a national policy was needed with regard to the access of information and the use of samples/tissues for both living and dead people, and that there would need to be a clear differentiation between service and research requirements.

The Chairman commented that there seemed to be a need for a forum which related specifically to genetics which would attempt to rationalise practices and he felt that it would be desirable for the people who were working in the field of genetics to put forward their views. He proposed that Dr Douglas should head a working group of the Joint Committee and invited the submission of names for consideration.

16 Matters referred from the Royal College of Physicians

16.1 **“Consultant Physicians Working for Patients”**

The RCP were to issue a revised version of this document. Changes had been made to the job description for consultant clinical geneticists, particularly to illustrate the mixture of clinical and teaching work.

16.2 **Assessment of Consultant Numbers**

The RCP had requested an assessment of the numbers of consultants required in clinical genetics to achieve the standards in the above document. Members discussed the clinical workload relative to population. It was noted that approximately 30-40% of consultant posts in clinical genetics combined academic with clinical work.

16.3 **College Journal**

The Joint Committee had been invited to submit articles on genetic issues for publication in the Journal.

17 "Genetic Research and You": leaflet from Consumers for Ethics in Research

The Joint Committee was concerned that the leaflet presented only a negative viewpoint.

In discussion, it was noted that it was important for the speciality to communicate with such authoring groups to offer advice and information and to challenge inaccuracy or distortion. The current document appeared to have been distributed already, and may have been referred to by some research committees.

18 Workforce and Training

(a) **RCPATH SAC**

Professor Malcolm was now the workforce representative, and sought the Joint Committee's view on ADHs for trainees in Pathology. It was agreed that this would depend on individual jobs and circumstances, and if there was no on-call then there should be no ADHs.

(b) **Clinical Genetics - SWAG specialty review 1999**

Dr Hughes reported that SWAG recommendations were based on a rigid formula, and a reduction of 8 NTN's had been planned for 2000/2001, and 14 further reductions for 2001/02, with no reductions in 2002/03. This was against a background of the specialty requiring consultant expansion.

The Chairman reported that he had been drawing the attention of appropriate national authorities to the inconsistency of the SWAG formula reducing trainee numbers at a time when planning procedures were identifying the need to increase consultant clinical geneticist posts.

Dr Hughes wished to pass on her SWAG liaison role to Professor Mueller, and she was thanked for her previous work.

(c) **JCHMT SAC in Clinical Genetics**

A new curriculum had been produced and approved.

Dr Brady raised four main concerns of SpRs: the definition of work covered by clinical genetics; extending the training period whilst seeking a consultant job; expansion of consultant numbers; the reduction in NTNs.

19 **Publications received**

Consultation document from the Human Fertilisation Authority on Pre-implantation Genetic Diagnosis.

20 **Dates of future meetings**

Wednesdays 24th May and 27th September 2000