

Joint Committee on Medical Genetics

The Royal College of Physicians
Royal College of Pathologists

The British Society for Human Genetics

The

A summary of the second meeting of the Joint Committee on Medical Genetics held on Thursday 13th May 1999

Present

Professor Peter A Farndon, Chairman RCP; Dr Julie Crow, RCPPath Registrar; Professor Ian Gilmore, RCP Registrar; Professor Andrew Read, BSHG Chairman; Mr John Barber, RCPPath; Dr Angela Brady, RCP trainee representative; Dr Naomi Brecker, NHS Executive observer; Dr Angus Clarke, RCP JCHMT SAC; Dr Jill Clayton-Smith, RCPCH; Professor Dian Donnai, CMO Adviser; Dr Rob Elles, RCPPath; Dr Alan Fryer, RCP; Dr Lorraine Gaunt, BSHG; Mrs Penny Guilbert, BSHG; Dr Helen Hughes, BSHG; Professor Noor Kalsheker, RCPPath; Professor Sue Malcolm, RCPPath; Professor Robert Mueller, RCP; Dr Virginia Warren, FPHM; Ms Hilary Irons, RCP Committee Administrator

Review of genetic services by National Screening Contract Advisory Group

Dr Brecker reported that a strategy meeting had been held to look at genetic services and new developments, including specialist services, biotechnology issues, and likely future developments. It had been attended by Ministers, the CMO, and Chief Executives of Trusts, and there had been recognition of the need to monitor genetics more closely. It was hoped that an action plan, which would involve Chief Executives, would be formulated.

Patents and genetic testing

Dr Elles reported that approval had been given for the Secretary of State to approach Myriad for exploratory talks and the current view was that a national licence would be the best way forward.

DNA services

(a) UK genetic testing network

The British Society for Human Genetics had produced a document describing how a national network for DNA diagnosis of single gene disorders would be beneficial and cost effective. The document had been sent to the Department of Health.

(b) DNA Services for rare single gene disorders

Professor Mueller reported that a questionnaire to ascertain the need for rare disease testing had shown that not all centres wished to perform all the tests. A national service could be achieved by some reorganisation, and an additional cost of

probably half a million pounds per annum. He suggested that it would be appropriate for a molecular geneticist to take this forward. The Scottish genetics centres had declined to take part in the exercise but he would nevertheless try to obtain data.

Members expressed concern about the ability to recover the costs of testing following the abolition of the ECR system on 1st April. Members proposed that a national budget was needed and agreed that the situation was acute as centres would be reluctant to carry out testing in case they were not reimbursed.

The committee heard that the NHSE recognised that there were problems which needed to be addressed urgently. The Chairman stressed that genetic testing for rare disorders required a national approach, and Professor Read agreed to ask the Council of the BSHG to consider reconvening its working party to look at how a national scheme might operate. The Chairman would convey the Joint Committee's anxieties to the NHSE.

Clinical governance

Professor Donnai reported that the working group set up by the Clinical Genetics Society had reviewed the documents issued by the RCP, RCOG, and RCPCH and hoped to produce a document on clinical governance in clinical genetics shortly. The group was also gathering existing guidelines from clinical genetics units.

Genetics knowledge/education of non-genetics professionals

Dr J Clayton-Smith presented the findings of a study of genetic education for non-geneticists provided by members of selected UK genetic departments. It was agreed that data should be obtained from all the centres to confirm the large amount of teaching which the survey had shown.

Advisory Group on Scientific Advances in Genetics

Professor Donnai presented two items discussed at the March meeting of ASAG: (i) haemochromatosis, and (ii) colorectal cancer.

Human Genetics Advisory Committee/Department of Health

Dr Brecker reported that a review of national regulatory bodies, following wide consultation, had been completed. Announcements would be made within the next few weeks.

Workshop on commissioning guidance for genetic services

A report from a workshop which had examined the commissioning of genetic services was presented by Dr Brecker. A paper for consultation would be published in the Autumn. The Chairman requested that the Joint Committee have an opportunity to comment.

Public Health Genetics Unit

Dr Virginia Warren tabled a paper outlining the aims of the PHGU and its current initiatives.

Nuffield Trust Genetics Scenario Project: Dr Warren commented on the seven stakeholder groups, explaining that each group would include a nominee from GIG which would organise an eighth workshop. The Nuffield Trust would aim to publish a report early next year.

Summer school for policy makers in 2000: Dr Warren reported that this was aimed at policy makers, for example senior executives and people working in primary care and cancer care. A detailed paper was available.

Development of a communications function: Dr Warren said that the PHGN would be pleased to undertake any work from the Joint Committee.

Royal College of General Practitioners Primary Care Genetics web discussion forum
(<http://www.rcgp.org.uk/forums/genetics/wwwboard.htm>)

The Chairman drew members' attention to a web discussion forum hosted by RCGP.

Services for adults with inherited metabolic disorders

Professor Kalsheker tabled a paper listing four key issues, and commented that they mirrored the previous discussions on dealing with rare disorders and the question of where testing should be done. The Committee asked Professor Kalsheker, Dr Clayton-Smith and Dr Warren to identify the problems before deciding how the committee should become involved.

Accreditation proposals for non-medical genetic counsellors in (a) specialist genetic centres and (b) future community liaison posts

Mrs Guilbert presented a position statement from the Association of Genetic Nurses and Counsellors (AGNC) for the development of the profession of genetic counselling. Members expressed their support for the proposals and made the following comments: (a) it would be helpful to include the mechanism for registration; (b) the status of those already practising should be considered; (c) the two years professional clinical experience be regarded by Trusts and purchasers as a two year probationary period. Mrs Guilbert advised that manpower issues should be considered in the context of professions supplementary to medicine. The Chairman suggested that this point (and that a national manpower plan for genetics should be drawn up) will be conveyed to the Department of Health.

Career structure and prospects for academic medical genetics

The Chairman said that he had concerns about the present status of academic medical genetics. He had discussed these with Professor John Saville, Chairman of the Society for Medical Sciences, who is reviewing academic medicine. The chairman had asked Professor Connor if he would prepare a paper on academic medical genetics in the UK for the Joint Committee.

Royal College of Physicians Job Plans for Consultant Clinical Geneticists

The RCP was shortly to publish specimen consultant job plans in a College document "Consultant Physicians Working for Patients".

Manpower and training

RCPATH SAC: Professor Malcolm had nothing to report.

JCHMT SAC in clinical genetics: Dr A Clarke reported that the curriculum had been revised slightly. It was hoped that every training centre would be visited over the next year. The role of educational supervisor had been defined and a sub-group was working on appraisals and assessments. For manpower purposes the length of training was regarded as four to five years.

Course on management for clinical geneticists in training: Dr Brady gave a report on the first course which had been held in Edinburgh for 36 trainees. The aim had been to provide confidence in day to day management issues, and the planning and development of services.

Publications received

- (a) Learning to manage health information: a theme for clinical education. NHS Executive (www.enablingpp.exec.nhs.uk)
- (b) Confidentiality guidelines: Genetic Interest Group
- (c) Genetic Guidelines: United Kingdom Haemophilia Centre Directors Organisation.
The Chairman commented that this was an excellent document and he would enquire whether a summary was available which could be circulated to members.
- (d) Physicians maintaining good medical practice: clinical governance and self-regulation (February 1999) Royal College of Physicians

Professor Malcolm asked for comments on the guidelines on the retention of tissues at post mortem which were being prepared by RCPATH. The general view of members was that the guidelines should be more positive in relation to retaining tissue for genetic purposes.

Any other business

The Chairman had been contacted by the National Horizon Scanning Unit, which would feed information into NICE. He asked members for their views on any technologies which should be included.

Dates of future meetings

Wednesday 22nd September 1999

Tuesday 11th January 2000