

Joint Committee on Medical Genetics

**The Royal College of Physicians
The Royal College of Pathologists**

The British Society for Human Genetics

RCP 11 St Andrews Place, Regents Park, London NW1 4LE

A meeting of the Joint Committee on Medical Genetics was held at the Royal College of Physicians on Thursday 1st May 2003 at 11am

Present:

Dr Heather Skirton	JCMG Chair – BSHG rep
Dr Trevor Cole	RCP
Dr John Crolla	RCPPath
Dr Sally Davies	Welsh Observer
Dr Alan E Fryer	RCP
Dr Anne Green	RCPPath
Professor Neva Haites	BSHG Chair
Dr Shirley Hodgson	BSHG (part of meeting)
Dr Helen Kingston	RCP JCHMT SAC Chair
Dr Ruth Newbury-Ecob	RCPCH
Professor Peter Soothill	RCOG
Dr Linda Tyfield	BSHG
Dr Virginia Warren	Faculty of Public Health Medicine
Mrs Katie Waters	In attendance
Ms Elizabeth Woodeson	Department of Health observer
Professor Carol Black	RCP President (part of meeting)
Mr Philip Masterton Smith	RCP Chief Executive (part of meeting)

1 Apologies for absence and welcome to new members

Apologies were received from Dr Stephen Abbs, Professor Dian Donnai, Professor Peter Farndon, Dr Lorraine Gaunt, Ms Dianne Kennard, Mr Alastair Kent, Dr Sian Morgan, Dr John Old, Dr Maggie Williams, Dr Ron Zimmern and Professor Ian Gilmore.

Dr Skirton welcomed Dr Trevor Cole as the new RCP rep and Dr Linda Tyfield as the new BSHG rep.

2 To confirm and sign the minutes for the meeting held on 14th January 2003

2.1 It was noted that Katie Waters should be listed as attending.

2.2 Professor Soothill noted that item 8.2.3 should read ‘ovarian cancer *implications of breast screening* recommendations’.

2.3 Dr Fryer asked that item 11.1 be changed to “Dr Fryer had suggested the Chair of the WP contact Dr Skirton for discussion about *training for professionals involved in genetic counselling*”.

2.4 A typographical error was noted in item 4.1.3. In sentence 2, ‘for’ should be deleted.

3 Matters Arising from the Minutes (not itemised elsewhere)

3.1 Patents and Genetics Testing (Ms Kennard)

3.1.1 Ms Woodeson said that there was nothing further to report on this item. No further negotiations were in progress.

3.2 Genetic Counsellor’s Registration Board (Dr H Skirton)

3.2.1 A second cohort of experienced registrants is being registered. .

3.3 Training Posts for Genetic Counsellors (Dr H Skirton)

3.3.1 Confirmation of funding of posts had been received from DOH. Approved centres were now able to advertise training posts.

3.4 “Pharmacogenetics: ethical issues”

3.4.1 Dr Fryer had prepared a response to the consultation document and this had been sent to the Nuffield Bioethics Committee on behalf of the JCMG.

3.5 Consultation document, “The supply of genetics tests direct to the public”

3.5.1 Ms Woodeson reported that the responses to this document had been recently published and the Government would consider and respond in due course.

3.6 Specialty Specific Standards for Good Medical Practice

3.6.1 Professor Winter had now stepped down from this Committee as Professor Farndon had taken over as President of the Clinical Genetics Society. However, he had written to Professor Gilmore with suggested amendments. He asked the Registrar to clarify the definition of ‘national comparisons’ but was yet to receive a response. A copy of his letter had been tabled.

3.6.2 The CGS had set up a working party in conjunction with the AGNC to look at clinical standards.

3.6.3 Dr Tyfield is to contact Prof Farndon regarding standards and guidelines for laboratory service that are to be written by the CMGS.

3.7 British Inherited Metabolic Disease Group Workshop

3.7.1 Dr Newbury-Ecob presented a short report on the meeting that was held last October. The main issues identified were:

- Isolation of single consultant services
- Service inequity due to regional variations, geographical factors, funding variation.
- Need for comprehensive multidisciplinary services including dieticians, paediatricians, labs, biochemistry, genetics, screening services etc
- High cost therapies
- National audit required because of small numbers of patients

3.7.2 Graeme Shortland was preparing a document describing the current situation, a draft of which was available. It outlined that there is a lack of appropriate service for adults with metabolic diseases, both in medical management and genetic counselling. Ms Woodeson pointed out that specialist commissioning of services for these groups of patients is now the remit of collaborative groups of PCT's. However, the Committee expresses the opinion that each PCT has so few patients in this group that services are not likely to be prioritised.

3.7.3 Carol Black is meeting with Liam Donaldson and Nigel Crisp next week, and agreed to raise this issue. It was felt that this was not the only group of patients affected by a rare condition that may be disadvantaged by the current system of service funding. It was agreed that Dr Newbury Ecob and Dr Green would draft a document and statement to Carol Black before her meeting with Liam Donaldson next week. Professor Black would report the outcome of the meeting to Dr Skirton.

Action: Dr Newbury-Ecob, Dr Green and Professor Black

3.7.4 It was agreed that Dr Skirton would write a letter of support to Graeme Shortland supporting content of his document on behalf of JCMG and copy it to Dr Green, Dr Newbury-Ecob, Professor Black and David Hall.

Action: Dr Skirton

3.7.5 Dr Warren would raise awareness of the issues through Faculty of Public Health Medicine.

Action: Dr Warren

3.7.6 Genetic centres could alert their relevant Strategic Health Authorities if services not adequate.

3.8 Referrals to genetic services

3.8.1 Dr Cole commented that referrals to genetic services that were not made to a named consultant were being discussed by CGS. Dr Skirton clarified that the sentence corrected in the previous minutes (Item 2.1) was altered to reflect the fact that referrals may not always be made to a named consultant but that it was

felt all referrals should be made through regional genetic centres rather than to practitioners working independently.

4 Reports of the work of the Joint Committee in progress

4.1 Consent & Confidentiality Working Party (Dr Skirton)

4.1.1 The final report was not yet available. Professor Farndon had sent a message stating that some rewriting was necessary after advice obtained about Data Protection.

4.2 Training posts for genetic laboratory scientists (Dr Abbs)

4.2.1 Dr Abbs had sent his apologies but had emailed an update of the progress made as follows.

4.2.2 The Online Learning project was going well. The introductory module on Genetics, written mostly by Helen Middleton-Price with additions by Professor Nick Saunders (from Public Health Laboratories) was currently being piloted over an 8 week period by 6 students. Professor Sue Malcolm was acting as an independent reviewer of the course, and Daniel Kelberman, a post-doc research fellow in the Centre for Cardiovascular Genetics at UCL was the tutor for the course. Once the pilot course was completed the Working Party would be critically reviewing comments from the students, Professor Malcolm and Daniel Kelberman, regarding the usefulness and effectiveness of this approach to training. If the comments were positive, they hoped to develop further modules with the aim of making them available for training purposes in Genetics laboratories, and they were already investigating possibilities for doing this. They hoped to be able to demonstrate the course at the BSHG meeting later this year.

4.2.3 Dr Abbs and Dr Green had done more work documenting the serious situation regarding recruitment and retention of laboratory scientists. Scientists were currently funding and facilitating their own training due to lack of resources in the laboratories. It was thought that the changes to working conditions following Agenda for Change would make the situation worse. Discussion followed on a strategy to bring the situation to the attention of relevant bodies. It was felt that the WDCs and the Knowledge Parks could be approached initially.

4.2.4 It was agreed that Dr Skirton should write to Dr Abbs to find out if document was ready for circulation to members JCMG.

Action: Dr Skirton

4.2.5 When the document was ready, it was suggested that Dr Abbs send it to all WDCs, Ms Woodeson and Sue Hill (Chief Scientist) with a covering letter from Dr Skirton.

Action: Dr Abbs and Dr Skirton

4.2.6 There was a suggestion that the WDCs were merging with Strategic Health Authorities. Ms Woodeson agreed to check and let Dr Skirton know.

Action: Ms Woodeson

4.2.7 Dr Skirton would write to Professor Steve Humphries and Helen Middleton-Price to ask that the issue be raised at the next combined Knowledge Parks meeting.

Action: Dr Skirton

4.3 Genetics Education: Medical Undergraduates (Professor Haites)

4.3.2 Professor Haites reported that the JCMG had previously asked her to convene a group to examine the core curriculum related to genetics for undergraduate medical students. The content of the core curriculum for medical graduates who may wish to become general practitioners had been agreed and was posted on the BSHG website. A survey of the topics that were included in the proposed core curriculum and were currently taught in medical schools was being undertaken by means of a questionnaire completed by medical students. Professor Haites would report on this at next meeting.

4.3.3 Hilary Burton has had funding to research education in genetics for non-specialist health professionals and will present an evaluation of the project in May 2003 in Cambridge.

4.4 UK Haemophilia Centres Genetics Working Party (Dr A Fryer)

4.4.1 Dr Fryer reported on the last Working Party meeting. Issues being addressed included the interface between lab and clinical services, management of prenatal diagnosis, data handling and education for professionals on genetic issues. Dr Skirton attended the last meeting and was contributing to a draft document on genetics education and preparation for competent practice in genetic counselling for families affected by haemophilia.

5 Representation of JCMG on GenCAG by JCMG Chairman

5.1 As each member of GenCAG now represents an organisation on that committee, Ms Woodeson announced that Dr Skirton (as Chair of JCMG) would represent JCMG.

5.2 Ms Woodeson announced that Marcia Fry, the previous Chair of GenCAG, had left her post and a successor has not yet been appointed. Ms Woodeson would, therefore, Chair the next meeting of GenCAG.

5.3 Dr Newbury-Ecob commented that the new arrangements for GenCAG membership might mean genetic services are not represented regionally. Professor Haites would raise this issue with BSHG.

Action: Professor Haites

6 Federation CPD representative (Doc 03/06)

- 6.1 Dr Sally Davies had been asked by Professor Farndon to be Federation CPD representative last year and agreed to continue in that capacity. Dr Skirton would write to Ian Starke to inform him of this.

Action: Dr Skirton

7 NICE Familial Breast cancer Guideline Development – consent to use information from deceased relatives.

- 7.1 A consensus meeting of a wide range of professionals was held last week. Public comment will be sought in June, and the final document published Feb/Mar 2004.

- 7.2 Dr Evans had written to Dr Skirton asking about consent for use of genetic information from deceased persons for the benefit of their relatives. After discussion it was agreed that Dr Skirton would write stating that this is common practice and it would be untenable to discontinue this practice, as it would seriously disadvantage living persons.

Action: Dr Skirton

8 Caldicott Guidelines (Dr Crolla)

- 8.1 Dr Crolla had received a letter from a non-genetic specialist questioning his laboratory's practice of informing the genetic service of abnormal results on patients who may be referred to genetic services at a later date. The question was raised as to whether this contravened 'Caldicott guidelines'. The Committee discussed this practice. Opinion varied as to whether this practice was always advisable, as some members thought it might place some moral obligation on the recipient of the report copy to take action, but the nature of appropriate action could be unclear.

- 8.2 Dr Skirton had sought advice from Dr Mike Pearson, RCP Caldicott advisor. There are no actual 'Caldicott guidelines', but the Caldicott Guardian in each Trust must implement the Data Protection Act, the Health and Social Services bill, European privacy ruling and common law on confidentiality.

- 8.3 Professor Black agreed that this was an issue raised wherever there were secondary users of patient data and was being addressed in a wider sphere than the College. Guidelines were expected to be formulated within the next year, and must be developed with input from the public. Dr Pearson felt in the interim that practitioners should continue with current practice, as long as this was sensible and could be shown to be in the interest of the patient.

- 8.4 It was agreed that Professor Black would investigate how the JCMG might contribute to wider discussion and feedback to Dr Skirton.

Action: Professor Black

9 Public Health Genetics Unit (Dr Zimmern)

9.1 Patents Project

9.1.1 Dr Zimmern had sent his apologies but had tabled the following report. A meeting of invited experts was convened at Hinxton to consider a final draft of the report by the Project team. Many insights were gained. A number of the participants and others subsequently submitted written comments. These have now all been incorporated in the final report, which is in the stage of final edit by Professor Cornish and Dr Llewelyn. It would be available for distribution in the next couple of weeks.

9.2 “Education in Genetics for Health Professionals” report

9.2.1 Dr Burton has almost completed the set of meetings with the different professional groups. A visit to the USA (which included Dr Alison Hill from the Department of Health and Dr Jon Emery from the University Department of General Practice in Cambridge) was made earlier this year. A final meeting to go over and synthesise all the material and learning will take place later this month. A final report will follow. The Department of Health and the Wellcome Trust have been intimately involved in all stages of the project.

9.3 Public Health Genetics Network

9.3.1 The changes in the job content of individual members consequent to STBOP required us to stand down the Network about 15 months ago. It was agreed by the Executive of the Network that a proposal should be made to the Council of the BSHG to set up a Society for Genetics and Public Policy under its aegis. The BSHG's response, while sympathetic to the proposal, stated that it was premature to incorporate within the BSHG a Society that was not yet in existence. Council suggested the Society should be established independently of the BSHG in the first place but that it would be happy to reconsider the issue of affiliation in due course. It was necessary for the Society to have a clear identity and momentum of its own, and for its members feel that its incorporation within the BSHG would confer advantages.

10 National Genetics Commissioning Advisory Group

10.1 UK Genetic Testing Network Steering Group Terms of Reference

10.1.1 The UKGTN was now operating. The network team, based at Bexley PCT, was now fully staffed and making progress. The application pack to join the network had been sent to laboratories.

10.1.2 The UKGTN were going to produce a list of ‘core’ tests, which should influence which tests are purchased by PCT’s as part of genetic services.

10.2 Cancer Genetics

10.2.1 The Department of Health were continuing to work with Macmillan to produce a document on principles and provision of care in cancer genetics.

10.3 Contract Currencies

10.3.1 The contract currencies for molecular, cytogenetics and clinical genetics had been produced. There was uncertainty as to when they would be in use. Ms Woodeson agreed to enquire about the mechanism for introducing them into use.

Action: Ms Woodeson

10.4 Ms Woodeson reported that there had been no meeting of GenCAG since the last JCMG meeting so there was nothing further to report.

11 Genetics Unit, Department of Health (Ms Kennard)

11.1 National Reference Laboratories

11.1.1 Dr Crolla reported that the reference lab website would go live in the second week of May. It was being co-ordinated through Manchester department.

11.1.2 The main issues are being addressed by the Salisbury lab were technologies, reagents and resources. An evaluation of robotics was also ongoing.

11.2 Green Paper

11.2.1 It had been announced that the expected Green Paper would now be a White Paper. The Paper had been completed and would be presented to parliament by the Secretary of State.

12 Human Genetics Commission

12.1 The Genes Direct document had been circulated. The next major piece of work to be undertaken was on reproductive choices. The timescale for this project was going to be several years, and a scoping group had been set up. Ms Woodeson encouraged JCMG members to be involved in contributing to the discussions. This could be done through the website.

13 Matters from the Royal College of Physicians

13.1 Medical Specialties Board – Committee action plan for 2003/2004

13.1.1 The RCP had asked all committees to complete an action plan of activities for the following year. The Committee discussed the content of the Annual action plan,

which would be prepared by Dr Skirton. Members were asked to comment when circulated by email prior to submission.

Action: Dr Skirton and Committee

14 Manpower and Training

14.1 RCPATH SAC (Dr J Crolla)

14.1.1 Dr Crolla told the Committee that the SAC had not met since the last JCMG meeting and there was therefore nothing to report

14.2 JCHMT SAC in Clinical Genetics (Dr H Kingston)

14.2.1 The new curriculum had been circulated to Regional Specialty Advisors titled 'Higher Medical Training for Medical Genetics' from January 2003. Methods of training assessment were being piloted and a training portfolio was being prepared.

14.2.2 Concern about the scarcity of medical trainees in cancer genetics was expressed. Dr Kingston explained strategies to recruit doctors into genetics at an earlier stage were being considered, and it was believed that using a competency based system would enhance flexibility.

14.3 Manpower in Clinical Genetics

14.3.1 Dr Kingston reported that clinical genetics has 10 new NTN's this year (for England) and there are good numbers of quality applicants for specialist registrar posts. Dr Davies noted that they would not now meet the doubling of numbers in the expected time but she had heard that the situation was the same for other specialties.

15 Genetics reports sent to pathology laboratories for distribution

15.1 The issue of reports being copied, sometimes inaccurately, was raised. It was agreed that the JCMG condemned this practice, as it may adversely affect patient care. The practice may also affect accreditation of a laboratory. It was felt that reports should always be sent to referring clinicians, and if a laboratory that has handled the sample needs to send a report as part of the processing system, the original report could be attached to a blank report slip generated by the handling laboratory. Dr Skirton agreed to write to the Royal Colleges asking them to address the issue.

Action: Dr Skirton

16 ESHG initiative re establishment of medical genetics as a specialty throughout Europe

16.1 In general it is felt to be a positive thing for other EU countries to develop genetics as a specialty, but there may be restrictions in specialists from other

countries practising in genetics in UK as general training may not be equivalent. No further action will be taken at this time.

17 New Membership

17.1 Dr Skirton sought to clarify outstanding memberships issues. New members still being sought to represent : RCP (Scotland), RCP trainee, RCGP.

18 Any other business

18.1 Dr Warren told the JCMG that the Medicines Control Agency (now Medicines and Healthcare Devices Agency) had suggested that different fees be charged by the agency for drug trials sponsored by pharmaceutical companies and those run by academic departments. Dr Warren has also suggested that the lower fee be charged to pharmaceutical companies where trials for drugs for treatment of rare conditions are involved.

18.2 Dr Skirton tabled a request from Professor Pounder for ideas and strategies for a new College Working Party on Continuity of Care for Medical In-Patients. Ideas were to be sent directly to Professor Pounder.

18.3 Dr Skirton had been asked to contribute visual aids for the RCPATH Annual Report and asked that, if anyone had any suitable photographs or graphics, they send them to her.

18.4 Dr Skirton thanked Alex Martin for her assistance in the administration of the JCMG and wished her well in her new post.

19 Dates of future meetings

21st October 2003