

UNCONFIRMED

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 meeting of the Joint Committee on Medical Genetics was held at the Royal College of Physicians on 22nd October 2002 at 11am

Present:

Professor Peter A Farndon	JCMG Chairman, RCP
Dr Stephen Abbs	RCPPath
Dr John Crolla	RCPPath SAC
Dr Sally Davies	Observer (Wales)
Professor Dian Donnai	CMO Advisor
Dr Rob Elles	BSHG
Dr Alan E Fryer	RCP
Professor Neva Haites	BSHG
Dr M Henderson	RCPPath
Dr Shirley Hodgson	BSHG
Ms Dianne Kennard	DH Observer
Mr Alastair Kent	Genetic Interest Group
Dr Helen Kingston	RCP SAC
Dr Ruth Newbury-Ecob	RCP&CH
Dr Anand Saggar	BSHG
Dr Heather Skirton	BSHG
Professor Peter Soothill	RCOG
Dr Virginia Warren	Faculty of Public Health Medicine
Mrs Katie Waters	BSHG

Mrs Alex Martin Committee Administrator

1 **Apologies for absence and welcome to new members**

Apologies for absence were received from:

Dr Naomi Brecker, Dr Paul Brennan, Dr Lorraine Gaunt, Dr Anne Green, Dr Rhydian Hapgood, Dr Helen Hughes, Professor R F Mueller, Dr John Old, Dr Helen Williams, Prof Robin Winter, Mrs Elizabeth Woodeson, Dr Ron Zimmern, Professor Gilmore.

Professor Farndon welcomed Dr Saggar, Ms Kennard, Mrs Waters and Dr Henderson who were all standing in for members who had sent their apologies (Professor Winter, Dr Brecker, Dr Gaunt and Dr Green respectively).

2 To confirm and sign the minutes for the meeting held on 20th May 2002

2.1 Dr Henderson asked that paragraph one in item 3.4 be changed from “Manpower data showed that 24 senior places were required but *no-one* is in training to fill them”, to “but *few are* in training to fill them.”

2.2 With this change noted the minutes were duly signed as a true record.

3 Matters Arising from the Minutes (not itemised elsewhere)

3.1 Patents and genetic testing (Dr N Brecker)

3.1.1 In Dr Brecker’s absence, Ms Kennard reported that there were no further developments particularly over the BRCA1 patent.

3.2 Clinical Governance (Dr H Hughes)

3.2.1 This item was deferred to a future meeting. The chairman of the Clinical Genetics Society Clinical Governance Committee, Dr Hughes, had been reporting on this to JCMG, but as she had relinquished her place on JCMG, the chairman would ask her to send a report on the Clinical Genetics Society proposals.

Action: Professor Farndon

3.3 Genetic Counsellors Registration Board (Dr H Skirton)

3.3.1 Dr Skirton reported that the Registration Board was now fully operational with the first 8 counsellors fully registered. These will go on to supervise new registrants.

3.3.2 Professor Farndon asked how patient referrals would be made to Genetic Counsellors. Dr Skirton said that it was intended that the referrals would still be made through the Consultant Clinical Geneticists in Regional Genetic Centres as per the current practice. Professor Farndon believed that this was not explicitly stated in the original written report and clarification may be helpful as a marker of expected practice. Dr Skirton agreed to raise this with the education group.

Action: Dr Skirton

3.3.3 Professor Farndon informed the Committee that the Association of Genetic Nurse Counsellors had asked him to identify a JCMG representative for the registration panel. After discussion with various members of the Joint Committee, he had proposed Dr Nick Dennis, who had accepted.

3.4 Training posts for genetic counsellors (Dr H Skirton)

3.4.1 Funding for training posts of 2 years duration – open to MSc Counsellors and nurses – had been made available by the Department of Health. A panel was meeting to assess Genetics Centres’ bids for these posts.

3.4.2 In response to a query made at the last meeting regarding recognising those with a science background, Dr Skirton informed the Committee that the Registration Board felt strongly that a Masters degree in genetic counselling should be undertaken, because the Board believed that specific training was required to achieve skills in dealing with patients as well as scientific skills.

3.5 Formation of the Metabolic Biochemistry Network (Doc 02/01) (Dr M Henderson)

3.5.1 Dr Henderson reported that the Metabolic Biochemistry Network was being set up with Dr Anne Green as part-time lead scientist for the next two years.

3.5.2 Dr Henderson informed JCMG that the Metabolic Biochemistry Network was discussing the training of practitioners. He noted the current very serious training issues and the lack of candidates. It was thought that the length of training was putting off some candidates. In response to this, the Metabolic Biochemistry Network was looking at the possibility of changing components of the MRCPPath examination specifically for metabolic disorders.

3.5.3 He also noted that the British Inherited Metabolic Disease Group (BIMDG) had been looking at issues of training and how to take the discipline forward. BIMDG was hosting a high level workshop including Workforce Development Federations in the following week to discuss this.

3.5.4 Dr Newbury-Ecob was asked, at the last meeting, to take these concerns to the Royal College of Paediatrics and Child Health (RCPCH). She reported that she had done this and, as a result, would be attending the BIMDG meeting as the RCPCH representative.

3.6 Biobank UK (Dr R Zimmern)

3.6.1 A report from Dr Zimmern highlighted that bids for the ‘hub and spoke’ centres were currently being sought. He had been asked to chair an advisory panel at Wellcome, to address ethical and governance issues associated with the Biobank project.

4 Reports of the work of the Joint Committee in progress

4.1 Consent & Confidentiality Working Party (Document tabled)

4.1.1 The latest draft of the report on "Consent and Confidentiality in Genetic Practice 2002: Guidelines for Genetics Professionals" was tabled. A long and detailed discussion was held in two parts: to decide the content of the document and the

method of recording consent. JCMG came to the view that many issues regarding ‘genetic tests’ were the same as other medical tests, and on balance felt that as many as possible of the currently accepted procedures should be adopted to reduce the perception that genetic tests were different. The Joint Committee took the view that, for the majority of patients and families, the concepts of altruism and ‘genetic solidarity’ were the guiding principles.

4.1.2 *Content of the report*

4.1.2a It was agreed that Professor Haites would redraft a sentence on the law on consent regarding an adults with incapacity in Scotland.

Action: Professor Haites

4.1.2b Dr Crolla agreed to re-write a paragraph within the section ‘Samples taken at post mortem examination’, taking into account the post-Alder Hey document ‘Human Bodies, Human Choices’

Action: Dr Crolla

4.1.2c Professor Farndon agreed to clarify several issues with the Data Protection Office.

Action: Professor Farndon

4.1.3 *Consent*

JCMG discussed how consent should be documented. The working party had devised model consent forms for genetic practice, but had also noted that for most purposes a contemporaneous record in the patient’s notes of what was discussed is adequate. JCMG wished to discuss how a patient could be given a record of the discussion and the consent which had been granted.

4.1.3.a JCMG noted that there was a perception amongst some patients that genetic tests and treatments were different from other types of medical practice. There was concern that asking a patient to sign an extremely detailed consent form with multiple components would enhance this perception.

4.1.3.b Dr Newbury-Ecob asked for clarification on the role of the Department of Health consent forms. It was noted that form 3 allowed the recording of specific items for which consent was sought and could be used in place of one of the forms recommended by the JCMG working party. Dr Newbury-Ecob had been informed by her Trust that no other forms than the NHS model forms were acceptable. Professor Farndon reported that he had been told that this was likely to be a local interpretation of the guidance and was not a national requirement. (See <http://www.doh.gov.uk/consent/>)

4.1.3.c A carbon copy form in triplicate was suggested so that a copy could be given to the patient. The form would contain a tick box list for the professional to use during discussions and include a statement “If on consideration you wish to

discuss any of these decisions, please contact the Genetics Centre/Counsellor.” JCMG preferred that this should be called a ‘record of discussion’ rather than a ‘consent form’. Dr Newbury-Ecob asked that legal advice be taken on this, as she believed that specific ‘consent’ was required for the storage of samples.

4.2 Training posts for genetic laboratory scientists (Dr S Abbs)

- 4.2.1 Dr Abbs reported that a very positive meeting of the JCMG Working Party was held in June, and had included wide representation from the Department of Health and the Workforce Confederations. The Working Party is producing a document to outline and explain training and manpower needs for genetic laboratory scientists. The document will be circulated to Chief Executives of the Work Force Confederations. Dr Abbs agreed to work with Professor Farndon on taking this forward.

Dr Abbs reported that the Working Party was still investigating the number of trainee and trainer posts required for general laboratory staffing.

Action: Dr Abbs and Professor Farndon

- 4.2.2 Dr Abbs told the Committee of a 2 year pilot study on on-line learning being run by Pat Harvey in London. It was hoped that this project would help to overcome the issues of the lack of trainer posts. All London trusts had signed up to it. There were to be 6 Bio-medical modules and Dr Abbs had been asked to set up a section on ‘Detecting Nucleic Acids’. If the pilot were successful, further genetics modules would be written. It was thought that the London Knowledge Park might wish to take this forward.
- 4.2.3 The Heads of Cytogenetics Laboratories had recently met to discuss training in A grade posts. They were hoping to work with the Clinical Molecular Genetics Society to achieve a unified approach.

4.3 Genetics Education: Medical Undergraduates (Professor Haites) Doc 02/02

- 4.3.2 The final report was welcomed by the JCMG. Professor Haites proposed working with Dr Hilary Burton from the Public Health Genetics Unit to mount a workshop to consider the suggested curriculum and to share good practice. The Open University would facilitate this group. The Committee agreed with this proposal.

4.4 Guidance on Genetics for Ethical Committees

- 4.4.1 Professor Terry Stacey had welcomed the guidance document and planned to circulate the Guidance to Ethical Committees.

4.5 Ante-natal report

- 4.5.1 Professor Soothill reported that the recommendations of the working party had been incorporated into some antenatal booking records, including those of the West Midlands.

5 Public Health Genetics Unit (Dr R Zimmern)

5.1 Patents project

- 5.1.1 Stage 1 of the report had been completed and delivered to the Department of Health. It included a report on the law as it stands. Six areas had been identified requiring further work; these would be addressed by a working group next February.

5.2 “Education in Genetics for Health Professionals”, report from Wellcome and PHGU. (Previously circulated)

- 5.2.1 The report, compiled by Dr Hilary Burton, mapped current provision, and was welcomed by the JCMG. Further funding had been received for the second stage, the development of a national strategy. six stakeholder workshops and a strategy workshop would be held. It was important that the other Royal Colleges were involved, and their representatives on JCMG agreed to take this forward. Dr Hilary Burton would contact them directly.

6 National Genetics Commissioning Advisory Group (Dr N Brecker)

6.1 Cancer Genetics

- 6.1.1 Ms Kennard reported that Macmillan would be co-ordinating further work on the document from DoH and Macmillan Cancer Relief proposing the future shape of cancer genetics services in England. (The document was discussed by JCMG at the January 2002 meeting). Further information is awaited.

6.2 Contract Currencies

- 6.2.1 Professor Farndon had written to Sir John Pattison at the Information Authority to ask if it were possible for their experience with other specialties to be utilised. Ms Kennard had no further information on this but would take it forward.

6.3 “Specialised Pathology Services (all ages) Definition No 25” (Doc 02/03)

- 6.3.1 This document had been circulated for the Committee’s information.

6.3.2 Although peri-natal pathology was mentioned in the definition, Mr Kent noted that the importance of this very specialised service was given insufficient attention. Professor Soothill and Dr Newbury-Ecob both stated that their respective colleges were highly supportive of the need to improve the availability of the perinatal pathology services. Professor Farndon agreed to raise this with GenCAG.

6.4 Document for Primary Care Trusts to raise awareness of genetic service issues.

6.4.1 This GenCAG document had been circulated to Regional Specialised Commissioning Groups so that they could add local information before cascading the document out to Primary Care Trusts. Professor Farndon thanked JCMG members for identifying future scientific developments which were likely to impact on commissioning, so that these could be brought to the attention of PCTs. These had been forwarded to GenCAG and included in the document.

6.5 Pre-implantation Genetic Diagnosis Guidance

6.5.1 Ms Kennard reported that this guidance had been sent out.

6.6 Commissioning

6.6.1 Professor Farndon reported that he had received a letter from a regional centre regarding the fact that they were finding it difficult to place outreach posts in primary care despite funding being made available, as, they believe, genetics is near the bottom of the agendas of Primary Care Trusts. Members of JCMG agreed that they envisaged problems arising. Ms Kennard hoped that the document 'Shifting the balance of Power' should resolve some of these issues but agreed that clear leadership in commissioning is needed. The Joint Committee again raised concerns over screening programmes being commissioned by PCTs but needing to be implemented over a Strategic Health Authority's boundaries.

7 Genetics Unit, Department of Health (Dr N Brecker)

7.1 UK Genetics Testing Network

7.1.1 The UK Genetics Testing Network Steering Group held its first meeting in September. Terms of Reference, job descriptions for the lead scientist and commissioner, and a work programme were agreed.

7.2 National Reference Laboratories

7.2.1 Ms Kennard confirmed that contracts had been signed and the recruitment process had started. JCMG asked that the programmes of work of the Reference Laboratories be presented as soon as they are available.

7.3 Knowledge Parks

- 7.3.1 Further details of the organisation and work programmes are available on the Department of Health website; www.doh.gov.uk/research

7.4 Green Paper

- 7.4.1 Ms Kennard reported that this paper should be completed within the next few months. One of its main aims is to stimulate discussion on genetics knowledge and technology in the context of the NHS.

8 Human Genetics Commission

8.1 Consultation document, “The supply of genetics tests direct to the public” <http://www.hgc.gov.uk/testingconsultation/> (Doc 02/04)

- 8.1.1 Professor Farndon was due to attend a working party meeting on the 4th November and asked for comments on the specific questions to be emailed to him.

Action: All members and Professor Farndon

- 8.1.2 A general discussion was held on the concept of ‘over the counter testing’ and genetic tests. It was thought that people had access to so many medicines and cholesterol, pregnancy and faecal blood testing over the counter that it was difficult to argue that genetic tests should be any different. However it was agreed that it was important to ensure that that 'customer' had access to a full information and interpretive service from the test provider. A professional body might want to regulate how an individual professional could be involved in testing, for example what training and accountability might be necessary.

8.2 Call from the Human Genetic Commission for new members (Doc 02/05)

- 8.2.1 Professor Farndon noted Doc 02/05 in which the HGC asked for those interested in becoming members to contact Dina Markey at the HGC for further information.

9 UK Haemophilia Centres Genetics Working Party (Dr A Fryer) (Doc 02/06)

- 9.1 Dr Fryer discussed document 02/06. He reported that there had been a convergence of practice in haemophilia and genetics services with regard to counselling issues and laboratory practices.

- 9.2 Dr Newbury-Ecob asked whether there was clarity over funding issues. Dr Fryer reported that current commissioning mechanisms between Regional Genetics and Haemophilia Services should continue at present until further guidance was available.

9.3 Professor Farndon thanked Dr Fryer for having been the JCMG representative on this working group and for his continuing work on it.

10. Matters from the Royal College of Physicians

10.1 Good Medical Practice for Physicians

10.1.1 Revalidation – The GMC had accepted that appraisals could form the basis for revalidation but that more work on the sections on Probity, Working with Colleagues and Working with Patients was being undertaken.

10.1.2 RCP Specialty Specific Guidance (Doc 02/07) – The CGS had written the specialty specific guidance, which JCMG accepted. It was suggested that an additional standard regarding having regular laboratory meetings was added and JCMG agreed to this.

Action: Professor Farndon

10.2 Health Committee Report on NICE

10.2.1 To note that this report can be found at:

<http://www.publications.parliament.uk/pa/cm200102/cmselect/cmhealth/515/51502.htm>

10.3 RCP College conference programme 2004(Doc 02/08)

10.3.1 It was agreed that Cancer Genetics would be an appropriate and timely subject for a conference but that the outcomes of the NICE reports should be released first.

Action: Professor Farndon

10.4 RCP College lectureships 2004 – Croonian, Fitzpatrick, Harveian, Lilly, Samuel Gee Lectures (Doc 02/09)

10.4.1 Dame Onora O’Neill was recommended as a possible lecturer on Trust and Confidentiality.

Action: Professor Farndon

10.5 Request by RCP Committee on Ethical Issues in Medicine for items of business

10.5.1 No ethical issues were identified.

10.6 Request by RCP Ethnic Monitoring Committee for a review of ethnic minority health issues

10.6.1 Professor Farndon agreed to respond to this request to confirm that local genetics units were sensitive to the specific needs of their local communities regarding genetics.

10.7 General Practitioners with a Special Interest.

10.7.1 The RCP Medical Specialties Board had noted that guidelines were being developed at the Department of Health for General Practitioners who wished to develop a specialty interest. Ten specialties were included, but genetics was not.

11 Manpower and Training

11.1 RCPATH SAC (Dr J Crolla)

11.1.1 Dr Crolla reported that the Association of Clinical Embryologists had approached the RCPATH about the possibility of joining the College. It was proposed that, if accepted, training would be under the remit of the Genetics SAC.

11.1.2 Professor Sue Malcolm and Dr John Old were continuing to work towards standardisation of the evaluation of the MRCPATH examination across genetics disciplines to ensure consistency. There were still concerns that only a small number of candidates proceeded to the Part 2 examination.

11.1.3 Dr Crolla reported that the Genetics SAC had been invited to take part in a one-day workshop about professional standards in March 2003. He would report back.

Action: Dr Crolla

11.1.4 A presentation had been given to the Executive Committee of the RCPATH regarding issues affecting Genetics. These included technological innovation, the NHS, consent and confidentiality, continuing professional development and pathology laboratory accreditation. The Genetics SAC also discussed the role of the RCPATH in encouraging Clinical Scientists and how the RCPATH could help them. They highlighted the pressing issue of post-registration training.

11.2 JCHMT SAC in Clinical Genetics (Dr H Kingston)

11.2.1 Dr Kingston reported that eight new SpR training posts have now been distributed. There will be one new post by conversion in Newcastle.

11.2.2 It was envisaged that there would be twelve new SpR posts next year.

11.2.3 It was noted that it remained to be seen whether recruitment would be a problem. Entry requirements had been broadened in an attempt to deal with this.

11.2.4 The new curriculum had been forwarded to the STA and had been formally approved. The JCHMT was now working on methods of appraisal and assessment

and would be piloting schemes in January next year. The immediate next step would be to redefine trainees' logbooks.

- 11.2.5 Dr Kingston reported that the document, 'Unfinished Business – Proposals for reform of the Senior House Officer grade' was now available from <http://www.doh.gov.uk/shoconsult/shoreport.pdf>. A five-year basic training programme before SpR posts was being proposed. The Genetics SAC had submitted a response but would be pleased to receive comments from JCMG members.

Action: Members

11.3 Manpower in Clinical Genetics (Dr S Davies)

- 11.3.1 Dr Davies reported that England, Scotland, Wales and Northern Ireland were now considered separately in the calculations for SpR posts. This may make the co-ordination of the numbers of training posts in clinical genetics for the UK more difficult.
- 11.3.2 Dr Davies had attended the Advisory Committee on CPD at the RCP which is looking at improving the online system of recognising CPD events. She agreed to keep the JCMG informed.

12 Genetics reports sent to pathology laboratories for distribution

- 12.1 It was agreed to defer this item as Dr Green had sent her apologies.

13 Retained Organs Commission Consultation (Mr Kent and Dr Crolla)

- 13.1 Dr Crolla summarised the consultation document. The main issue for genetics services is one of consent not retention.

14 Chairman Elect and future organisation of Joint Committee.

- 14.1 Professor Farndon informed the Committee that this was his last meeting as chairman as his term of office (which had been extended at the request of the JCMG) had come to an end. The BSHG would now be taking over the organisation and costs of running the Committee although the RCP had agreed to continue to administer the Committee at cost for the BSHG. Dr Skirton would be the next Chairman.
- 14.2 Professor Farndon expressed his thanks to all Committee members and working parties and especially to his secretary, Margaret Lynock, for all the support she had given on Committee issues.

14.3 Dr Helen Hughes had relinquished her place on the Joint Committee and Dr Sally Davies would now be the Wales representative.

14.3 The RCP would be seeking nominations for two clinical geneticists to replace Professor Mueller and Professor Farndon whose terms were ending.

15 Any other business

15.1 There was no further business to report

16 Dates of future meetings

16.1 The dates for next year have been set as January 14th, April 29th and October 21st 2003 at the Royal College of Physicians.