

Joint Committee on Medical Genetics

The Royal College of Physicians

The British Society for Human Genetics

The Royal College of Pathologists

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 Tuesday, 13 January 2004 at 11am

Present:

Dr Heather Skirton JCMG Chair, BSHG

Dr Stephen Abbs	-	RCPPath
Dr Hayley Archer	-	RCP, Trainee representative
Dr Hilary Burton	-	Observer, PHGU
Dr John Crolla	-	RCPPath
Professor Peter Farndon	-	BSHG
Dr Alan E Fryer	-	RCP
Dr Anne Green	-	RCPPath
Dr Alison Hill	-	Observer, DH (in attendance)
Professor Shirley Hodgson	-	BSHG
Dr Tessa Homfray	-	RCP
Ms Dianne Kennard	-	Observer, DH
Dr Helen Kingston	-	RCP, JCHMT SAC Chair
Dr Phil Lee	-	BIMDG (Item 4 only)
Dr Sian Morgan	-	RCPPath, Trainee representative
Professor Julian Sampson	-	Chairman, BSHG
Dr Graham Shortland	-	BIMDG (Item 4 only)
Dr Virginia Warren	-	FPH
Dr Maggie Williams	-	RCPPath, Trainee representative
Mr Philip Masterton-Smith	-	RCP, Chief Executive (Items 1-6)
Mr Simon Land	-	Committee administrator

1. Apologies for absence and welcome to new members

- Apologies were received from Professor Carol Black (RCP, President), Dr Trevor Cole (RCP), Dr Sally Davies (Observer, Wales), Professor Dian Donnai (Advisor to the CMO), Professor Ian Gilmore (RCP, Registrar), Mr Alastair Kent (Genetics Interest Group), Dr Ruth Newbury-Ecob (RCPCH), Professor Peter

Soothill (RCOG), Dr Linda Tyfield (BSHG), Dr Helen Williams (RCPath, Registrar) and Ms Elizabeth Woodeson (Observer, DH).

- Dr Skirton welcomed Professor Sampson and Dr Archer to their first meeting.
- Members expressed great sadness and regret on the death of Professor Robin Winter. All agreed that his contribution to Clinical Genetics in the UK and abroad was inestimable.

2. To confirm and sign the minutes for the meeting held on 21 October 2003

- Following two minor amendments the minutes of the last meeting were confirmed and signed as a true record.

3. Matters arising on the minutes

3.1 Copying of Laboratory Reports

- Concern was expressed that the issue may not be fully covered by the CPA standard G2. It was agreed that Dr Crolla would submit a supplementary paragraph to CPA to add to this. The paragraph would detail that the JCMG and RCPath were aware of the issue and that if other incidents occurred they should be reported. A short article in the BSHG newsletter would also be used to reinforce.

ACTION: Dr Crolla

3.2 Fetal Medicine

- The committee noted the response to the curriculum for the special skills training module in Fetal Medicine. Dr Skirton thanked Dr Kingston for co-ordinating this.

4. Appropriate Services for adults with Inherited Metabolic Diseases

- The committee viewed a presentation on the current services available in the UK (both paediatric and adult IMD) presented by Dr Shortland and Dr Lee from the BIMDG. Members also noted the latest draft of the Vision document.
- After a long discussion, the JCMG strongly recommended a needs assessment with regard to the establishment of an IMD network in the UK. The following actions were agreed to help progress this:
 - Dr Skirton to raise the issue at GENCAG with a view to placing it on the commissioner's agenda.
 - Dr Burton to progress the issue of Public Health support

- Dr Shortland/Lee to ‘flesh out’ the Vision document. It should incorporate a service framework as to what would be needed to set up a network. It should also indicate the demands of the posts to SHOs.
- Professor Farndon to forward the documents that progressed the acceptance and resourcing of genetics as a specialty. This could act as a template for the ‘Vision’ document .
- Need links between the BSHG trainee web pages and the BIMDG.

5. Reports of the work of the JCMG in progress

5.1 Consent & Confidentiality Working Party

- The responses to the external consultation on the document had been circulated to members before the meeting. They were fairly unanimous in stating that the report was excellent. The committee discussed at length the suggested amendments and it was agreed that Professor Farndon would make the necessary revisions and then return the document to members for a final inspection.

ACTION: Professor Farndon

- Once circulated, members would be given 2 weeks to submit their final comments. The document would then be approved for publication under Chairs Action.

ACTION: All

- It was agreed that the report was to be published under the banner of the JCMG. Mr Masterton-Smith suggested that Professor Farndon contact the head of publications at RCP (Diana Beaven) who was highly experienced in this respect.

ACTION: Professor Farndon

- It was agreed that the committee administrator would contact all those who had responded to the consultation in order to thank them for their input.

ACTION: Committee administrator

5.2 Training posts for genetic laboratory scientists

- Dr Abbs reported that funding had been agreed for 10 grade A training posts. This would be for 4 years (2 years Grade A + 2 years towards registration). It was hoped that by funding the posts for 4 years would set a precedent and ease disparities in funding length across Federations.
- Dr Abbs stated that the CMGS Executive had discussed the appointment of a National Training Co-ordinator. The committee were asked to consider whether this should constitute one or two posts (i.e. one post for each discipline). The

committee was unanimous in supporting one role as this would provide one point of contact and serve to bring the disciplines closer together.

- The National Metabolic Biochemists Network has been funded by the DOH for 3 Trainer posts (or equivalent) and 8 Higher Specialist Training posts (Grade B Clinical Scientists).
- Dr Abbs tabled the notes of the Training Workshop Group for information. The committee noted the following points:
 - Agreed to extend funding from two to four year training programme. Will fund intake for 04/05 then review timescales and funding for full commitment of 90 trainees.
 - Trainees agreed for 2004/5: 8 molecular genetics, 15-20 cytogenetics (ACC to assess capacity and confirm final figure) for 4 year training.
 - Agreed phasing in trainer posts, initially 3 WTEs for molecular genetics and 3 WTEs for cytogenetics, each post to be on a 3-year contract.
 - Professional bodies to take forward in collaboration with Heads of Labs: by end of February to agree roles, devise job specifications, agree location of posts and %WTE. Further posts to be discussed at later meetings.
 - Recruitment and funding to be routed through WDCs. WDCs to advise on mechanisms for employing nationally-focussed trainers as currently support similar placements.

5.3 UK Haemophilia Centres Genetics Working Party

- Dr Fryer reported that more news would be available following the next meeting on the 1st March 2004.

5.4 Genetic Counsellor Training Post Panel

- Dr Skirton reminded the committee of the 27 month DH funding aimed at increasing the number of genetic counsellors. Of the 23 approved training posts, 13 were currently in place with 6 pending appointment and a further 4 to be advertised in the next financial year.
- Professor Sampson asked whether the panel dealt with individuals who were funded by charities. The committee was concerned that these counsellors (also Research and MacMillan nurses) were not audited and it was not clear as to who they were responsible. It was agreed that there was a need for broad guidelines to be produced to replace the ad hoc procedures that exist at the moment.

- Professor Farndon reported that the CGS/AGNC were due to set up a Working Party to look at multi-disciplinary teams. It was agreed that the above issue would be incorporated into its remit in order to clarify the situation.

ACTION: Professor Farndon

6. GPwSIs

- Dr Warren and Dr Cole had attended the half-day workshop during which attendees had “brainstormed” on the specifications of a GPwSI in Genetics. It had focused on the competencies needed, activities, experience, maintenance of skills and the administrative structure that would be required. Dr Burton stated that a GPwSI in Genetics is very much more a leadership/educator role than that in other specialties. It was agreed that it would be a huge role to support GPwSIs and that it was critical to develop this support system as early as possible.
- Dr Hill informed the committee that the framework for GPwSI in Genetics was required by the end of the financial year to then invite bids. It was agreed that Dr Hill would forward the draft framework to members who would feedback within 2 weeks. A link to the GPwSI web page would accompany this.

ACTION: All

- After consultation the document would be signed off by both the RCP and RCGP before being forwarded to the National Steering Group.

7. NICE

7.1 NICE Familial Breast Cancer Guideline Development

- Professor Hodgson stated that the guidelines were due to be published in February 2004 and that she would speak to it at the next meeting.

7.2 Research and Development Strategy Consultation Document

- The Chairman reminded members that the document had been previously circulated by e-mail. It was noted that Mr Kent had already responded to the Chairman. It was agreed that one member from each body would be required to review the document and deliver comments back to the Chairman by 10th February 2004.

ACTION: Dr Homfray (RCP), Dr Sampson (BSHG) and Dr Warren (FPH)

8. Curriculum for non-genetic SpRs

8.1 Genetic Education: Needs and Evaluation (GENE)

- Professor Farndon reported that the results from the pilot would be available shortly. A curriculum would also be available in the future and the next meeting would focus on the education initiative for delivery.

8.2 Multi-disciplinary course in formal genetics

- Dr Skirton reported that at present only the ACC from the 4 constituent groups had responded to her letter regarding this issue.

9. Genetics Commissioning Advisory Group

9.1 Update

- Ms Kennard stated that the last meeting had discussed National Screening Initiatives. A working group had been set up between genetics and screening to discuss links with a view to getting screening onto the commissioners agenda.

9.2 UK Genetics Testing Group

- Professor Farndon detailed that the committee had reviewed and discussed the 80 gene dossiers submitted. The names of the tests will appear on the NHS website and act as a flag to commissioners that they need to fund/supply the tests. It was thought that in future the website will need to offer information on where the tests are (geographically) completed.
- Professor Farndon reported that the Steering Group was setting up professional panels to “future gaze” as regards new tests. It was noted that it would be important to have JCMG representation on these.

9.3 Contract Currencies

- Ms Kennard reported that the NHS was moving towards a single pricing system, therefore it was important to standardise the contract currencies used for Molecular Genetics and Cytogenetics. To address this, Molecular Genetics was piloting a scheme that just included Workload Units and Cytogenetics had agreed to redefine its scheme.

10. Genetics Branch, Department of Health

- The committee noted a report on the progress on implementation of commitments in the genetics White Paper. Ms Kennard further updated members on the following issues:

- The tenders received for the Genetic Education and Development Centre had been to expectation.
- Pharmacogenetics bids have been received (25)

11. National Genetic Reference Laboratories

- Dr Crolla referred members to the reports (previously circulated by e-mail) from the respective heads of the Manchester and Salisbury laboratories. He stated that the remit of each laboratory was very different and that updates on all ongoing issues could be found on the website.

12. Manpower and Training

12.1 RCPATH SAC

- Dr Crolla reported that 28 Clinical Scientists had been registered by the Health Professions Council (HPC) under the new registration process. The committee thanked Dr Old for his work in this area.
- Dr Morgan and Dr Williams updated the committee with regard to trainee issues. They reported that the SAC had seen the results of a trainee questionnaire at its last meeting. As a result the following issues had arisen:
 - Training records are not being used hence will be revised
 - Past examination papers will be placed on the website
 - A dedicated Genetics web page is required
- A workshop had been held at York in September 2003 to inform trainees of the mentoring scheme. The data collected will be progressed by Dr Abbs and Dr Crolla and forwarded to the DH.

12.2 JCHMT SAC in Clinical Genetics

- Dr Kingston agreed to update the committee at the next meeting.

12.3 Manpower

- Dr Kingston stated that there would be no new funded posts for next year. It was estimated that 12 new CCSTs would come through in each of the next two years, with 17 completions in 2007.
- Dr Green welcomed the Association of Clinical Scientists decision to recognise Metabolic Biochemistry as a sub-specialty. It was agreed that this would help with recruitment.

13. Antenatal screening – working standards

- Professor Farndon reported that the UK Genetic Testing Network Steering Group had written to Martin Whittle (Department of Fetal Medicine, Birmingham Women's Hospital) with regard to the issue. GENCAG had also set up a small meeting to discuss the issue on the 28th January 2004.

14. Conference programme 2005

- Members noted the details of the JCMG submission.

15. Consultant Physicians Working with Patients 3rd Edition

- Members noted the letter from Dr Mary Armitage to Dr Skirton asking for an update to be produced. Dr Sally Davies had been asked for input on workforce and manpower issues. Professor Farndon stated that there were implications for manpower issues from this document and that significant input from the CGS was required. Dr Skirton apologised that this had not already happened. It was agreed that the means of dissemination from RCP to the committee on such documents should be reviewed. In the interim, Dr Skirton agreed to forward the template to Professor Farndon so that the issue could be discussed at the forthcoming CGS Away Day.
- Professor Sampson asked that the CGS also included reference to clinical academic issues in their discussions.

16. For information

- The committee noted that Dr Peter Lunt had been nominated by the JCMG to be part of the DH panel to consider applications for the NHS Genetics Education and Development Centre.
- The committee noted that Dr Alan Fryer had been nominated by the JCMG as the RCP representative on the RCPath SAC.

17. Any other business

17.1 ABN/CGS Report – Genetic Services for Neurological Disorders

- The committee noted the report (previously circulated by e-mail) and it was agreed that the item should be discussed at the next meeting. Dr Skirton agreed to approach a representative of each college to review the document for issues of relevance to the committee.

17.2 Human Tissue Bill

- The JCMG has serious concerns about some aspects of the Bill and these had been expressed to Prof Gilmore. Dr Skirton informed members that the comments had been forwarded via Professor Gilmore to Professor Underwood who issued the RCPATH response to the Bill. It was agreed that members should contact the committee administrator if they wished to have a copy of the response, but it was felt the response had not addressed all of the specific issues raised by the JCMG. .

ACTION: All

- Dr Crolla raised concerns that DNA genetics was not mentioned in the Bill. There was discussion over the difficulty in understanding the Bill. It was noted that Ron Zimmern (ex committee observer) had expressed concerns about the Bill and had translated it into a more readable format. It was therefore agreed that Dr Crolla would contact Dr Zimmern to explore ways of taking the Committee's concerns further. .

ACTION: Dr Crolla

17.3 PHGU Steering Group

- Dr Burton informed the committee that a PHGU steering group focusing on Genetics Education in the UK was due to meet in February. Its remit would be the strategic overview of education and the establishing of resources.

18. Dates of the next meetings

- Thursday 20 May 2004
- Tuesday 19 October 2004