

# 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 Monday 20<sup>th</sup> May 2002 at 11 am

### Present

Professor P Farndon	Chairman RCP
Dr S Abbs	RCPPath
Dr N Brecker	DH Observer
Dr P Brennan	RCP(Trainees)
Dr John Crolla	RCPPath SAC
Professor D Donnai	CMO Adviser
Dr F Douglas	Chair Working Party Consent & Confidentiality
Dr R Elles	BSHG
Dr A Fryer	RCP
Dr L Gaunt	BSHG
Dr A Green	RCPPath
Professor N Haites	Chairman British Society for Human Genetics
Dr Shirley Hodgson	BSHG
Dr H Hughes	Observer (Wales)
Mr A Kent	Genetic Interest Group (GIG)
Dr R Newbury-Ecob	RCPCH
Dr J Old	RCPPath
Professor P Soothill	RCOG
Professor R Winter	BSHG
Dr R Zimmern	Observer, Public Health Genetics Unit

### In Attendance

Mrs Alex Martin      Committee Administrator RCP  
Mrs Val Knight Committee Administrator RCP

### 1 Apologies for absence/Welcome/Introduction

Apologies for absence were received from:

Professor Ian Gilmore, Professor R Mueller, Dr H Kingston, Dr Helen Williams, Ms Caroline Browne, Dr S Davies, Dr Heather Skirton, Dr V Warren, Professor Mike Connor, Dr R Hapgood, Mrs E Woodeson

Professor Farndon welcomed Mrs Alex Martin who was replacing Mrs Val Knight as the Committee Administrator, and Dr John Crolla who has been appointed Chair of RCPPath SAC – Professor S Malcolm was thanked for her work for the Joint Committee in this role.

### 2 Minutes of the last meeting – 9 January 2002

The minutes were accepted as a true record.

### **3 Matters Arising from the Minutes**

#### **3.1 Patents & Genetic Testing**

Dr N Brecker, DoH, advised there was no further information to report, either about the challenges from several European countries to the patent, or about Myriad's proposals for BRCA1 testing in the UK. It was advised that no changes should be made to clinical practice at present.

#### **3.2 Clinical Governance**

Deferred to the next meeting.

#### **3.3 Training Needs of Genetic Counsellors**

Dr Heather Skirton, in a written report, confirmed that extra places on the two MSc in Genetic Counselling courses were being supported by the Department of Health.

The Department of Health is considering funding training posts in Regional Genetic Centres that satisfy certain criteria for training. These are two year posts. Regional Genetics Centres have been contacted by Association of Genetic Nurses and Counsellors to determine the number of such training posts which might be possible.

The AGNC Registration Board is ready to assess the first tranche of genetic counsellors for registration.

Professor Haites reported that the Department of Health had facilitated a meeting between AGNC, representatives of the MSc in Genetic Counselling Courses, and representatives from the Joint Committee on Undergraduate and Postgraduate Education, to begin to identify areas of collaboration.

Professor Haites asked the AGNC Registration Board to consider how individuals with a background in genetics but not wishing to take full registration may be recognised.

#### **3.4 Specialist training for clinical scientists: metabolic biochemistry**

##### **ENCLOSURE 1**

Dr Green reported that the Enclosure was the final version of the document. Manpower data showed that 24 senior places were required but few are in training to fill them. The issue had been taken to the Workforce Branch at the Department of Health and feedback was awaited.

Dr Zimmern suggested that a specific paragraph be added with regard to adult disorders. Dr Green pointed out that although Paediatric services were the main focus, there was no intention to have separate adult services. Dr Zimmern asked if there were plans to have adult specialists. It was noted that members believed that Adult Metabolic Medicine had been recognised by the JCHMT for training. Dr Green had been asked to compose a syllabus but no trainers were available. Dr Old asked how this syllabus was envisaged to fit in with the MRCPATH exam and whether it was thought that Part 2 would have to be altered.

Mr Kent reported that patients groups were concerned that there were facilities for adult treatment. Professor Donnai felt that flexibility needed to be used to allow paediatric metabolic specialists to treat adults in a non-paediatric setting. The Joint Committee supported this view.

Dr Brecker advised that the Workforce Advisory Group at DoH was currently taking advice on the numbers of posts required. Dr Brecker agreed to approach Guy Cross to ensure that the paper by Dr Green had been received and to pass on the Joint Committee's concerns.

**Action: Dr Brecker**

It was agreed that the Joint Committee would send its concerns to the British Inherited Metabolic Disease Group, chaired by Graham Shortland in Cardiff, seeking to produce a national overview of metabolic biochemistry. Dr Newbury-Ecob agreed to take these issues to the Royal College of Paediatrics and Child Health.

**Action: Dr Newbury Ecob**

It was agreed that Professor Farndon would write to GENCAG highlighting that provision needed to be made for adults with metabolic disease.

**Action: Professor Farndon**

## **4 Reports of the work of the Joint Committee in progress**

### **4.1 Consent & Confidentiality Working Party**

#### **ENCLOSURE 2**

Professor Farndon thanked the Human Genetics Commission for pre-publication access to their report on Personal Genetic Data which was to be published the following day.

The Joint Committee felt it was more appropriate to look at our working party's document in conjunction with the Human Genetics Commission Report, "Inside Information: Balancing Interests in the use of personal genetic data".

The Joint Committee found both documents compatible; it was agreed that the legal outlines in our own working party document could be replaced by a reference to the HGC document which discussed these in detail. The Joint Committee asked that our own document clearly present recommendations for practice.

Dr Newbury-Ecob asked whether the examples of consent forms in our working party document were now obsolete in view of the new Department of Health forms. Dr Brecker did not believe that this was the case.

The Joint Committee discussed the levels of consent needed with regards to unexpected outcomes and how complicated the consent form to cover these should be. It was felt that a simple form confirming that a patient knows what test is being undertaken and that the sample will be stored for future use was required. The Joint Committee was divided as to whether consent should be sought by a specific form to allow the passing on of information to a General Practitioner. Dr Zimmern suggested that consent for genetic diagnosis should be no different from consent for other diagnostic testing. If the problem was that of sample storage, an information sheet on data protection should be produced for the patient.

The Joint Committee concluded that

- The consent form should be simplified
- A front sheet summarising the key points listed under essential and desirable should be added to the document
- Guidelines for when written consent (as opposed to oral consent) is required should be made explicit
- The document be modified to take into account the Human Genetic Commission's recommendations

- Current good practice should be highlighted and illustrated in this document.

It was agreed that Dr Haites, Dr Brennan and Dr Newbury-Ecob would work with Dr Douglas to encompass these issues.

**ACTION: Professor Haites, Drs Brennan, Newbury-Ecob and Douglas**

Professor Donnai agreed to send her adapted versions of consent forms to Dr Douglas.

**ACTION: Professor Donnai**

Dr Brecker reported that the Department of Health may be able to offer financial assistance to the Joint Committee in producing and distributing the document.

#### **4.2 Training posts for genetic laboratory scientists**

Dr Abbs reported on the setting up of this working party, which aims to identify areas of concern over manpower numbers and training of staff for genetics laboratories. The first meeting was set for the end of June after which a time scale for its report would be known.

Dr Brecker stressed that if this work was to inform the Green Paper it would need to be submitted to the Department of Health within a couple of months, even if the final report was not ready.

The specific issues to be discussed were the availability of trainer time, the lack of Grade A trainees, the immediate need for metabolic biochemistry posts and how the doubling of numbers of scientists in genetic laboratories as envisaged by the Secretary of State would be achieved.

Although there were concerns about training and recruitment for A Grade posts, Dr Gaunt and Dr Crolla raised concerns about recruitment and retention to the B Grade posts, especially the lack of support for B Grade training. It was noted that service pressures were so severe that it was proving difficult to undertake CPD during the working day. Dr Crolla suggested that an aim would be to have equivalent educational support to that for specialist clinical registrars, with their protected time for educational activities.

#### **4.3 Genetics Education: Medical Undergraduates**

Professor Haites reported that a document on a core curriculum in medical genetics for medical undergraduates was being finalised. It would be circulated to consultant clinical geneticists known to be interested, medical schools and the Joint Committee. It was hoped that medical students would report whether their existing courses covered all aspects of the proposed core curriculum, this could also inform the Green Paper. The core curriculum had been devised as to be that which every medical practitioner should know. Professor Donnai was interested to know whether there would be any difference in this core knowledge between those who trained in traditional and problem based learning environments.

#### **4.4 Guidance on Genetics for Ethical Committees**

#### **ENCLOSURE 3**

Dr Cyril Chapman had incorporated all points raised in previous Joint Committee meetings. Prof Donnai asked if the report could be amended to include research subjects with learning difficulties. Mr Kent observed that People First had shown that people with learning difficulties were capable of making complicated decisions, and recommended their website ([www.peoplefirst.org.uk](http://www.peoplefirst.org.uk)) for evidence of good practice.

Mr Alistair Kent reported that GIG will be producing a document following its workshop "Issues relating to undertaking research in rare genetic disorders – ethics committees and confidentiality".

The Joint Committee agreed that the guidance would be submitted to Professor Terry Stacey at the Central Office for Research Ethics Committees.

**Action: Prof Farndon**

#### **4.5 Contract Currencies**

#### **ENCLOSURE 4**

Several laboratories and clinical units have been using the contract currencies on a trial basis to assess the practicality of collecting them. This had been led by the professionals. It was agreed that a commissioner's perspective should be brought to the use of the currencies, as there were professional concerns as to how they would be used, and from where the funding would come for implementation of the IT resources required for their uniform collection throughout the United Kingdom. Dr Brecker agreed that this would be discussed at the next GenCAG meeting on 1 July.

**Action: Dr Brecker**

Arising from the last GenCAG meeting, Professor Farndon met James Bradley from the Information Authority to discuss the use of contract currencies, and whether work in other specialties may be helpful in genetics. Many of the issues surrounding workload, movement of samples and payment applied to other pathology specialties, as did some of the work in other clinical specialties. Professor Farndon would write to Sir John Pattison to ask whether the Information Authority may be asked to undertake work in genetics.

### **5 Public Health Genetics Unit**

Dr R Zimmern reported:

#### **(a) Patents project**

This project had been funded by the Department of Health to review the legal situation and potential effects on the National Health Service of gene patenting. The interim report is likely to be circulated at the end of June. Phase 2 will address specific issues with the view to offering advice to the Department of Health. A meeting will be held in 2003 with invited participants to discuss the results. The activity is being led by two lawyers, Professor Bill Cornish and Dr Margaret Llewelyn.

#### **(b) Education project**

The report of the first phase, identifying current scope and provision of genetics education for health professionals has been submitted to the Department of Health and Wellcome Trust. A proposal has been requested for funding for phase 2, which is planned to produce an overarching educational strategy. The process will include workshops.

**(c)** The Public Health Genetics Unit are mounting a genetic epidemiology course in July with an international faculty.

**(d)** The PHGU has been asked to be involved in a neurological genetics joint working group of the Clinical Genetics Society and the Neurology Society. This group is considering the organisation and function of neuro-genetics clinics,

possibly as a prototype for the organisation of specialist clinics. Dr Zimmern will report at the next meeting.

## **6 National Genetics Commissioning Advisory Group**

### **6.1 Cancer Genetics**

Dr Brecker thanked all who had responded to the draft document on the organisation of cancer genetics services from the Department of Health and Macmillan Cancer Relief, following discussion at the last Joint Committee meeting. These comments had been included in a re-draft; Macmillan was intending to produce a publication setting good practice markers. The DH/Macmillan steering group were meeting to discuss workforce planning and undertake an evaluation of the implications of the structure and the resources required. Work was continuing to ensure that the work of organisations such as NICE was considered.

It was noted that NICE were consulting on the scope for guidance for females at risk for familial breast cancer (Chairman Professor Gareth Evans). Because of the extensive consultation undertaken by NICE in drawing up guidance, it was unlikely that this document would be available before December 2003.

Professor Haites informed the Joint Committee that she had been approached on behalf of NICE to be a member of the Committee considering the guidelines. The Joint Committee noted that it would have expected that NICE would have contacted either the Royal College of Physicians or the Joint Committee for further professional input but this had not been received. It appears that the organisation setting up the Committee on behalf of NICE had taken advice from an individual in Oncology rather than contact the Joint Committee or the RCP.

Professor Farndon would try and ascertain the mechanism which had been employed.

It was thought that the NICE document was likely to parallel the Scottish Intercollegiate guidelines – those on colorectal cancer have already been published, and those on ovarian and breast cancer are expected.

### **6.2 Commissioning Genetics Services**

Dr Brecker reported that there was ministerial commitment to review commissioning procedures following the implementation of 'Shifting the Balance of Power'. Julia Stalibrass, who was setting up the review process, was fully aware of the problems. Consultation would be undertaken with the English Health and Social Care Strategic Authorities, GenCAG and the Regional Specialties Commissioning Groups. Dr Brecker asked that comments from the genetics community be routed through the Regional Specialties Commissioning Groups.

The challenges of commissioning genetic services were recognised at the Department of Health. Dr Zimmern noted that the commissioning problems were those of all developing services and stressed that the review should consider the processes for capital and revenue development in an integrated and co-ordinated manner.

### **6.3 UK Genetics Testing Network (see also item 10)**

At the last GENCAG meeting, Lynda Tyfield (President of the Clinical Molecular Genetics Society) presented work on a structure for the genetics testing network. A view from the Commissioners was also presented. GenGAG agreed that further work was needed to address accountability and management.

Dr Brecker acknowledged the professional frustration over the length of time it was taking to set up the network. GenCAG had asked that a meeting of Heads of Laboratories, Members of GenCAG together with Clinical Geneticists, consumers and members of the DoH Genetics Unit be held to examine what was required from the network. This meeting is on 18 June 2002 in London. The Joint Committee again stressed that the uncertainty over future funding mechanisms was a major difficulty in setting up the network and urged Commissioners to develop a workable proposal to achieve stability of funding.

Professor Donnai asked that clinical need be considered in the provision and organisation of tests within the network, and that it would be very advantageous to include patients and clinicians in the discussions. Dr Green asked that when arrangements for the genetic testing network are being considered, the relationship with the metabolic network be included .

Dr Zimmern pointed out that such organisation and funding issues were affecting the USA, Canada and New Zealand as well as the UK. These countries had undertaken reports and evaluations, and he recommended that these documents be consulted during any deliberations.

Professor Haites pointed out that the development of the network was likely to require the skills and time of laboratory and clinical scientists, for which no funding for others to take over their clinical work was available.

#### **6.4 National Reference Laboratories**

Manchester and Salisbury are the two National Genetics Reference Laboratories.

They had been consulting colleagues around the country, and it was hoped that by the time of the next Joint Committee meeting their work programmes would be available.

#### **6.5 Knowledge Parks**

Final work plans were being discussed. Dr Peter Greenaway would write a summary of what each Knowledge Park had been commissioned to do, and these again hopefully would be circulated before the next meeting.

#### **6.6 Green Paper**

The Green Paper will be a consultation document. Its prime scope is preparing the NHS for the future to enable it to deliver genetic advances in patient care. The Green Paper will include exploration of ethical and societal issues, education and training, particularly consulting on how best to achieve a knowledgeable NHS work force. It was hoped that the Green Paper would be published later this year, but ministerial decisions on its content have not yet been made.

### **7 Human Genetics Commission**

#### **7.1 Human Genetics Commission Personal Genetic Information Report:**

<http://www.hgc.gov.uk/papers/hgc02-p3.pdf>

Working Group Update January 2002 ENCLOSURE 5

The main recommendations from this report had already been considered under an earlier item on Consent and Confidentiality.

Professor Farndon confirmed that he had sent information to the Human Genetics Commission Working Group on Personal Genetic Information of the main points from our Consent and Confidentiality working party.

## **7.2 Work plan of the Human Genetics Commission**

Professor Farndon confirmed that he had written to Baroness Kennedy with the Joint Committee's comments on the future work plan of the Human Genetics Commission. These were outlined in the last minutes of the Joint Committee.

## **7.3 HGC Newsletter**

**ENCLOSURE 6**

JCMG noted the contents of the latest HGC newsletter.

## **8 Antenatal sub-group meeting of the UK national screening committee**

A written report had been received from Dr Frances Flinter, JCMG representative on the Antenatal Sub-group.

### **8.1 Cystic Fibrosis**

Cystic fibrosis carrier testing in the general population would not be offered until more work had been completed to consider the complex issues involved.

Professor Donnai reported that she had been invited to be on a steering group of stakeholders involved in screening for cystic fibrosis, and she would report back to the Joint Committee.

**Action: Professor Donnai**

The Joint Committee discussed several issues arising from screening for cystic fibrosis. Mr Kent suggested a wider debate about the issue of whether or not to inform parents where a child had been found to be a carrier in the neonatal screening programme. It was also noted that some antenatal clinics may be using molecular tests which screen for 5 mutations, whereas the new neonatal screening programme could detect 31 mutations. Occasionally, therefore, a child will be diagnosed postnatally whose parents were reassured that they were not carriers prenatally.

### **8.2 Royal College of Paediatrics and Child Health Report: The future of Paediatric Pathology Services**

Dr Flinter had commented that this excellent report did not mention "genetics". An opportunity to stress the storage of samples for future molecular studies would have been helpful in section 8 under "Application of Paediatric Pathology".

Dr Newbury-Ecob agreed to report the Joint Committee's discussion to a meeting at the Royal College of Paediatrics and Child Health a few days later, and report back to the Joint Committee if there were any specific genetic issues.

**Action : Dr Newbury-Ecob**

### **8.3 Down Syndrome Screening Programme**

Dr Flinter reported the work being undertaken, including the screening committee being appraised of the introduction of QFPCR and the feasibility of including ultrasound screening for the presence of the nasal bone. A national leaflet for guidance on Down syndrome screening is planned to be available by mid 2003.

Professor Soothill raised concerns that there was the potential for confusion in antenatal services and stressed that perhaps rather than increasing the numbers of tests performed, it was important that the tests were performed early. The requirement of a dating scan before screening needed to be emphasised. Dr Gaunt informed the Joint Committee that the Association of Clinical Cytogeneticists had similar concerns and would be replying to the National Screening Committee. She undertook to send a copy of the response to the Joint Committee.

**Action: Dr Gaunt**

#### **8.4 Haemoglobinopathy screening programme**

Alison Streetly is taking the lead, aiming to introduce a National Haemoglobinopathy Screening Programme. It has been suggested that in very low prevalence areas Regional Genetics Services provide the counselling service following a positive screening test. In high risk areas, specifically trained counsellors are already providing this service.

The Joint Committee felt that this was an appropriate strategy as the numbers referred to Regional Genetics Services were likely to be small.

#### **8.5 Wales Antenatal Screening Project**

A copy of the report had been received for interest.

#### **8.6 The Joint Committee on Medical Genetics Report on “Suggestions for Antenatal Genetic History Taking**

Our own working party report had been discussed at the Antenatal Sub Group of the UK National Screening Committee and welcomed.

### **9 Matters from the Royal College of Physicians**

#### **9.1 Good Medical Practice for Physicians**

It was noted that Specialty Specific Guidance for clinical geneticists had been drawn up by Professor Winter through the Joint Committee on Medical Genetics and submitted to the GMC Standards Committee via the Royal College of Physicians.

#### **9.2 Consultant appraisal in the NHS: guidance for appraisees and appraisers.**

This College Guidance document is now available. It includes a stipulation that an ‘appraiser must be medically qualified’.

#### **9.3 Director of Continuing Professional Development**

Professor Parveen Kumar completes her term of Office in July. Details of the vacancy will be in the College Commentary in June and posted on the RCP website.

#### **9.4 Medical Education Standards Board**

The consultation paper on postgraduate education and training was now closed. The College had submitted numerous comments.

## **9.5 NICE: Safety and Efficacy of New Interventional Procedures**

The consultation document was noted, but JCMG had not identified any interventional procedures in genetics which needed to be included.

## **9.6 Department of Health Consultation Document: Timing and Selection of Topics for Appraisal by NICE**

<http://www.doh.gov.uk/nice/consultation2002>

ENCLOSURE 7

The proposals in Enclosure 7 were noted.

## **10 Genetic Testing Network – L2L Proposal**

**ENCLOSURES 8 and 9**

Enclosure 8 was a proposal from the Northern Genetics Knowledge Park. A Company would be developed to explore ways in which genetic services can be improved by partnership between the NHS Genetic Services and the private sector. The first phase would be to develop a “clearing house” service in conjunction with the Clinical Molecular Genetics Society and its constituent laboratories to act as a single co-ordinating centre for access to the UK genetic testing network. This would facilitate sample exchange between laboratories, invoicing and payment collection.

Enclosure 9 was the response from the Genetics Unit at the Department of Health which had highlighted some concerns.

The Chair had received additional information from Professor John Burn, one of the proposers of the service.

JCMG considered the proposal and supporting papers.

Professor Haites reported that the British Society for Human Genetics wished to support proposals to aid the development of the genetic testing network, but that it had some residual concerns about the current proposal, and were awaiting further clarification and development of the proposal.

Professor Donnai was concerned that the proposal was too laboratory based with insufficient emphasis on patient needs. There were also concerns about the cost of the scheme, and Dr Zimmern wondered why the additional funding requested could not be used effectively in the existing laboratories to perform the administrative task which was a mainstay of the proposal (of exchanging samples and handling invoicing and payment).

Mr Kent was concerned that although such a proposal would be welcomed in consolidating and providing efficiency for existing tests, that its cost could reduce the residual capacity in the laboratory testing system.

A major concern of the Joint Committee was the funding not only of this proposal but of the genetic testing network in general. L2L was intending to invoice Primary Care Trusts directly, but there was concern that Trusts would not agree to pay for the tests in addition to their regional services, resulting in continuing destabilisation of funding.

Professor Haites felt that the clarification of the role of the reference laboratories and L2L – if any – would be helpful. Dr Brecker commented that quality and best practice procedures were part of the remit of the reference laboratories, and not specifically the functions outlined on L2L.

Dr Elles confirmed the support of the Clinical Molecular Genetics Society which was particularly interested to see whether L2L would be a means of ensuring that payment followed the provision of genetic tests.

The Joint Committee asked the Chair to report the points raised in its discussion to Professor John Burn at the Northern Genetics Knowledge Park and to Mrs Liz Woodeson at the Department of Health.

## **11 Manpower and Training**

### **(a) RCPATH SAC**

A report would be available at the next meeting as Dr Crolla had only recently taken up the role.

### **(b) JCHMT SAC in Clinical Genetics**

Dr Kingston sent a written report

- 1 A new assessment document has been circulated to Regional Specialty Advisers and will be piloted during this year's RITAs. Comments about its utility would be welcomed by the SAC.
- 2 The genetics SAC is involved in the JCHMTs pilots of various methods of assessment. These include mini-CEX, 360<sup>o</sup> assessment, knowledge based assessments and case note and clinic letter reviews. It was noted that some of these assessments are already in use in clinical genetics.
- 3 Funding has been approved for 8 new SpR posts. It was understood that regional centres should now apply for these posts, subject to their having educational approval for additional training slots.
- 4 The Joint Committee shared Dr Brennan's concern that many trainees entering clinical genetics are from a Paediatric background whilst the referral patterns to clinical genetics units are increasingly those for adult disorders. The Clinical Genetics Society is undertaking an initiative to bring clinical genetics to the attention of trainees with backgrounds in adult medicine and cancer.

### **(c) Manpower in Clinical Genetics**

The Chair has asked Dr Sally Davies to report on manpower issues during Professor Mueller's illness, but she was unable to attend this meeting.

## **12 Genetics reports sent to pathology laboratories for distribution**

**ENCLOSURE 10**

The British Society for Human Genetics had written to the Joint Committee highlighting the potential adverse consequences of genetic reports being transcribed by local pathology laboratories for onward distribution to their clinicians.

The Joint Committee discussed a statement from the British Society for Human Genetics and strongly supported this. The Joint Committee was strongly opposed to the practice of rewriting reports.

Dr Green highlighted that re-writing specialist reports was not specific to genetics. She recommended that the RCPATH and the CPA together would be best placed to make recommendations that the practice was stopped.

Dr Gaunt explained that this appeared to be due more to pathology laboratories documenting an audit trail rather than “double billing” for tests. She had already discussed this with the CPA, but they had felt that they were unable to become involved.

Dr Elles pointed out that re-writing tests results is against clinical governance guidelines and that there were documented cases of transcription errors.

The Joint Committee asked that a statement be made on their behalf to the Royal College of Pathologists and the Pathology Alliance that genetic reports should not be transcribed.

The Chairman undertook to discuss this with the Registrar at the RCPATH who was unable to be present at this meeting.

**Action: Prof Farndon**

### **13 National screening committee workshop to develop set of principles for generic genetic issues to be considered when setting up or evaluating new screening programmes**

**ENCLOSURE 11**

The National Screening Committee had asked for nominations for this workshop, but several Joint Committee members were already attending.

### **14 Biobank UK**

**ENCLOSURE 12:**

<http://www.genewatch.org/HumanGen/Publications/Reports/BioRport.pdf>  
<http://www.genewatch.org/HumanGen/Publications/Leaflets/BioLeaf.pdf>

Dr Zimmern, as a member of the protocol development committee, reported that Biobank was receiving joint funding from the MRC, Wellcome and the Department of Health.

The plan was that there would be a hub and 5 spokes. Calls for interested medical schools to recruit 100,000 people to join the project were shortly to be made.

A draft document on the ethical and legal framework was being produced after a recent meeting and would be available on the Wellcome and MRC websites.

The concerns of Genewatch UK (Enclosure 12) about Biobank were noted by the Joint Committee. Genewatch had produced a set of questions which they recommended that people approached to donate samples should ask.

### **15 Genetics testing on the High Street**

**ENCLOSURE 13**

<http://www.genewatch.org/HumanGen/Sciona/ScionaBrief.rtf>

Dr Warren discussed the report by Genewatch UK on the testing to be offered by Sciona and Body Shop on polymorphisms in genes involved in metabolism, to give people advice about diet and lifestyle.

Dr Brecker reported that the Genetics Services Sub Group of the Human Genetics Commission was looking at the Sciona proposal for this service in the light of the previous guidance from the Advisory Committee on Genetic Testing. The Sub Group will review the guidance and advice and whether regulation was likely to be required.

### **16 Retained Organs Commission Consultation**

<http://www.nhs.uk/retainedorgans/consultationfeb02.pdf>

This consultation document was on unclaimed and unidentifiable organs and tissue and a possible regulatory framework.

Mr Kent reported that there was concern by members of GIG over the potential for over regulation. Families had usually given permission for tissues and organs to be examined in the hope that they would prove useful for clinical purposes, teaching and research. The families were very concerned that any legislation would acknowledge this. The GIG were preparing a document.

Dr John Crolla had written a document for the RCPATH on the genetic issues of consent for post mortem examination. He agreed to consider the consultation document and formulate a response on behalf of the Joint Committee if appropriate.

**Action: Mr Kent and Dr Crolla**

### **17 Any other business**

None

### **18 Dates of Future Meetings**

The date of the next meeting was changed to 22 October 2002 at 11.00 am at the Royal College of Physicians to avoid a clash with the British Human Genetics Conference.