

b) Innovation group met 09/05/2011

Discussed the requirement for a formal national agreement on ethical approval for non-interventional research projects, allowing collective sign off using a host/lead Trust for research ethics approval.

Discussed Stratified Medicine Programme:

Clinical Sites approved: Cambridge, Cardiff, Marsden, Edinburgh, Glasgow, Manchester (Lung only) and possibly one other. Laboratory sites short listed: Cambridge, Marsden, Birmingham, Cardiff, Nottingham, Edinburgh, only 3 will be chosen following site visits.

The 6 clinical sites will feed into the 3 labs sites. NICE is to be involved in Diagnostics evaluation as well as Pathways.

Key performance indicators published by Royal College Pathologists.

Action: AD to use document to define standards for genetics. Paper will be produced for next meeting

David Nicholson to review innovation in NHS - report to be published in November.

c) Commissioning

This group has not met yet but the terms of reference have been agreed. Agreed that Genetic services should be commissioned as part of a clinical care pathway and should not be commissioned in isolation. A specific working group will be set up to complete this task. The group will address the following questions and provide advice on what could be done to ensure equity of access to quality NHS genetics testing services over the medium to long term. The group should also identify the priorities for genetic commissioning.

1. Are current and proposed commissioning processes fit to meet the future demand for laboratory and clinical genetic services?
2. What further changes are needed to realise the full potential of the Pathology Services reconfiguration with regard to the provision of NHS genetic testing services?
3. What help will GP consortia need to commission genetic services in the most effective and efficient way?
4. What are the inconsistencies in genetic test service provision in clinical pathways in genetic and non genetic specialties and how should they be addressed?
5. Is there any potential benefit in an agreed set of national standards and introducing a tariff for the commissioning of genetic tests? If yes, who is best placed to develop and maintain this work.

d) Bioinformatics

Bioinformatics Institute:

Workstream will look at the environment of the Institute, will this be virtual or Brick? What will be the remit of the Institute? Will the institute be involved in looking at databases and their use in delivering clinical need? Will the institute be involved in setting standards, including for training and other issues? Should the remit be limited to biomedical informatics?

There is a lot of work going on nationally; this all needs to be brought together. There is also a transitional use of Genetic data as a tool for diagnostics, tied into stratified medicine and other areas this also needs to be considered. A Bioinformatics paper is currently being written to go to HGSG in June; the Technology Strategy Board (TSB) is also involved in writing this paper. To inform this paper TSB holding 2 innovation events (24/05, 09/06), AD attended the former.

Action: AD to email DM and Eddy Maher to see if they have seen report going to HGSG.

(ii) Developing Datasets for Genetic Medicine

Workshop to take place 17th June 2011 (Co-ordinated by Andrew Devereaux, UKGTN and DH Genetics Unit), paper has been circulated on developing datasets for Genetic Medicine and has been forwarded to Eddy Maher and Dom McMullan. The workshop is being held in order to obtain a wider consensus of the Dataset standardisation outputs for Genetic services, for submission to the DH for further development, and sign off by UKGTN Steering Group in September, this piece of work to also feed into the above paper.

Action AD to email DM and Eddy Maher to see if they can attend.

(iii) BSHG

Met 25/05/2011. See report from DM in item 11.

(iv) UKGTN (Did not attend)

AD invited to attend next meeting of UKGTN Clinical and Scientific Advisory Group on 29/09/2011

(v) ACS General Meeting (17/03/2011)

Met on 17/03/2011. New competencies for trainee assessments are now on website and trainees will be assessed against these from March.

Command paper on regulation of healthcare workforce was discussed. There will be no extension of statutory regulation. Professions will need to risk assess duties of the workforce and make a decision on whether workforce is of significant clinical risk to patients, which in turn will determine whether workforce needs:

- 1) State registration/ Statutory regulation – significant risk imposed
- 2) Professional Regulation – Moderate risk imposed
- 3) No registration or regulation – minimal risk imposed

We need to decide as a profession to pursue with CHRE (Council for Health Regulation Excellence) if we want genetic technologists to be registered. We would have to perform a risk assessment and show they present a moderate risk. New titles under MSC will not come under Statutory Regulation – HPC Statement. Although healthcare scientists coming through MSC will be able to register with HPC as a clinical scientist through route 2.

Action: AD to email HoDs and Council re GT registration when information available

(vi) Academy of Healthcare Scientists

Met on 01/04/2011 to set strategy. Steve Barnett, CEO of the AHCS which is funded by DH, presented functions AHCS might be involved in:

- 1) Maintenance and promotion of curricula
- 2) CPD and monitoring quality of training facilities
- 3) Accreditation of Providers of training and quality of Courses
- 4) Assessing equivalence in training
- 5) Standards for voluntary regulation

Act in a supporting capacity, provide a strong coherent voice for HCS's in new architecture, provide professions with higher profile in HEE and support wider Healthcare initiatives.

AHCS Board: Steve Barnett (CEO), Sue Hill (CSO), Keith Ison (MSC Team), Chris Gibson (IPEM), Iain Chambers (IPEM), David Bennet (MSC Team), Joanna Sheldon (ACB). SHA Lead scientists will act in an advisory capacity to the Board.

Action: AD to invite Steve Barnett to next Council meeting to discuss nomination for membership from Joint Professional Body

(vii) RCOG Green Top Guideline

This guideline will impact on Genetic Services.

Action: Council members to discuss with local obstetricians and feed back to Council.

(viii) OECD Questionnaire for the QA in Molecular Genetic Testing

Annual questionnaire completed, ACC took part this year as Microarray analysis included in questionnaire.

(ix) IVDD Steering Group meeting

Minutes of meeting on 04/04/2011 sent for information

(x) JCMG

See report from Jonathan Waters under item 11.

(xi) Professional Societies Meeting (13/04/2011)

Attended this meeting, very poor attendance. Discussed financial Issues facing laboratories as result of NHS funding cuts, merging professional bodies and closer collaboration between professional bodies in back office functions.

(xii) Future of ACC/CMGS

There is a joint website set up by David Gokhale and paid for by CMGS www.geneticlabs.org.uk

It was agreed that the website would have FAQs to inform the membership and allow them to raise concerns. The future composition of the new executive committee will be placed on the website, this still needs to be done.

The information leaflet in delegate packs at Spring conference was emailed to entire membership. SMC informed by e-mail (05/05/11) that it was not possible to conduct the ballot before July since the rules provide for members to be 6 months in arrears from the 2nd Jan of any given year. SMC will contact Dina for printed labels at the end of June for July ballot. The ballot will begin around the 7th July and close on the 31st August. Once we go to ballot, membership should be frozen. The two exec committees will be meeting again to discuss further structure and constitution and mechanics of setting up a new society on 13th June in Liverpool. SMC has written to the FSA to ask for clarification on dissolution of a society and ensure we are doing it properly. An important point to remember if we achieve our 75% yes and CMGS don't achieve theirs, we shall still have to dissolve the society, there will be no going back, therefore both ballots should be carried out around the same time. SMC will do his best to advise on ACC constitution and rules surrounding balloting members and KO will have to ensure all financial matters are carried out appropriately and are correct to satisfy the registrar of friendly societies.

Action: SMC to check with BSHG to see if we can transfer ACC members to BSHG and on to new body.

5 **Treasurer's report**

Report compiled by KO and circulated.

(i) Current financial position

Expenditure for current year to 15th May 2011 amounts to £8080. Income for this year is likely to be derived from two key sources: -

a) membership fees - last years income received £9195 (December 2010) as an indicator to likely income for 2011.

b) Spring Conference joint ACC/CMGS meeting - Durham 2011.

John Wolstenholme (JW) has maintained administration of the ACC Spring Conference current account to enable simple integration with the course organisers. JW reports that a profit was obtained from this meeting, the final balance to be confirmed on consolidation of the Spring Conference accounts.

c) No further income is likely to be received in relation to training and assessment fees and expenses. The current and deposit accounts have sufficient reserves to cover a likely shortfall in this financial year. The training and assessment fee line of expenditure will be monitored closely over the remaining year and Council advised of its impact on the ACC's current assets.

(ii) Submission of final accounts year end 2010.

The final accounts for 2010 have been signed off, and the Friendly Society returns have been completed by the Auditors for submission to the Friendly Society. I would like to thank JW for completing this work and for continuing to administer the Spring Conference Current account for the Durham Spring meeting.

(iii) Joint ACC/CMGS Spring Conference 2012 - Birmingham

Following discussions with Sian Ellard (CMGS Treasurer), it has been decided that the ACC and CMGS will work together in running the accounts for this meeting. The ACC Spring Conference Account will be used for income and expenditure and the profit/loss will be shared between the two Societies. The ACC treasurer will act as lead for this account administration. The Birmingham team have been advised of this arrangement.

(iv) Requests from the Auditors - conflict of interest statements and financial risk assessment.

The auditors have requested that we provide signed statements from each Council member declaring either that:-

a) there is no conflict of interest between their duties whilst serving as a Council member, and other activities they are engaged in, or

b) to declare potential conflicts of interest in order that they may be independently assessed.

The Treasurer will circulate a proforma for each member of Council to sign and return in order that these may be forwarded to the auditors.

The auditors have asked for a financial risk assessment to be provided. This will be undertaken and submitted in due course.

Action: SM to ask KO for balance of accounts and circulate to Council.

SM to ask KO for risk assessment to auditors for circulation.

SM to ask CMGS to put some money in account towards conference.

6 **Genetics Education & Training Board**

Report prepared by GL and circulated. Report from meeting held on 29/03/2011

Anneke Seller and Gareth Cross have joined the GETB, and thanks were expressed to the retiring members with particular note being made to those who in their positions as national trainers had made a significant contribution to the profession(s) over the years.

(i)MSC

MSC and Accredited Specialist Expertise (ASE): request from Sue Hill for information as to what education/qualifications are available to our organisation which may be counted as training at a more advance level of practice. This is to help the MSC identify the programmes that are already available and which might be kite-marked through a national quality assurance system to ensure that standards of Accredited Specialist Expertise are achieved, identified and become recognised as transferable qualifications that employers can accept. **DB VD and GL will respond by 27th June deadline.**

National School of Genetics

GETB contributed to a learning guide which will replace the training manuals.

Merger of GETB and HCS School curriculum Advisory Group.

Support for the proposal by Val Davison for the merger of these two groups was given due to the significant overlap of both the work and the membership of these two bodies. DB/GL will look at remit of this new group to present at next meeting (19th July).

(ii) Pre-MSC training

Administrative support for the outstanding assessments of both Genetic Technologists and A grade clinical scientist trainees is now under the National School. This has now been undertaken by sarah.miller@westmidlands.nhs.uk and all electronic files and the training database is held in Birmingham. Guidance for GT final assessments (2009 scheme) is now available and is on the ACC website.

A request for help to run the FRCPATH revision courses/virtual study group has been circulated around the professions but with minimal response. The outgoing national trainers are willing to provide information and a detailed SOP regarding the running of this and another trawl around the professions will be made.

(iii) Regulation

The latest discussion appears to be that regulation is likely to be undertaken by the professions, (rather than a statutory registration) but the outcome is still very uncertain. Sue Hill is undertaking a risk/benefit assessment to inform the discussions.

7 Professional Standards Committee

Prepared by Carolyn Campbell and NB. Presented by NB.

(i) Constitutional BPGs

Postnatal BPGs – Reviews complete – to be sent to HODs when review of general guidelines complete as documents need to be seen together.

General BPGs – Review underway.

Array BPGs – comments back with authors of guidelines for generation of final draft.

QFPCR BPGs – comments back with authors of guidelines for generation of final draft.

CC to send out questionnaire to Heads of Department regarding authorisation of reports.

(ii) Oncology BPGs

CML / MPNs – final version circulated May, for ratification June.

ALL - final version circulated May, for ratification June.

AML / MDS - pending

Solid tumours – revised version edited by David Betts. For re-circulation June.

8 Membership Liaison Committee

Report prepared by CK and circulated.

The MLC had a stand with the trade exhibitors at the ACC Spring Conference manned by Chris Kettle and Simon Cammack (co-opted GT representative). It was helpful to have a conference liaison representative from the organising lab to co-ordinate this. Visitors to the MLC stand was very good. The prize of a DAB radio provided by Leica Microsystems was a good way to get feedback from the membership/potential members. Forty eight comments slips were returned. Ten people would be interested in helping the MLC in future events, seven people would possibly be interested and thirty one would not be. Comments were left by eight people. Five of these comments dealt with the issue of direct emailing the membership and suggesting that regular emails would be well received, especially updating the membership with matters arising from the council meetings. One suggestion was for a regular MLC article in the BSHG - We are looking into this. Another comment highlighted the need for a membership liaison committee role in the ACC/CMGS, once merged.

The final comment enquired as to whether the FRCpath study groups would be continuing. There was a lot of discussion about the future of the MLC and what role it would play in after the proposed merger. These questions were answered by the session on the joint day dedicated to the proposed merger. It has been proposed that the MLC will cease to be and will be replaced by a communications committee. Roderick Murray from Edinburgh won the DAB radio and has received his prize. The winner was contacted by email and was announced to the membership using the ACC Discussion board. Overall feedback regarding the MLC, based on discussions at the MLC trade stand, was positive.

9 Genetic Technologists

Report compiled by AR and presented by RA. Feedback from 23/05/2011. AGTC had meeting via email.

- (i) New guidance notes that include career framework information have been produced and will be up loaded to website.
- (ii) Jake Miller collated ideas and suggestion to take forward Higher Specialist Training development, this was presented to GETB.
- (iii) It is becoming clear that the possibility of taking forward the voluntary register with HPC is currently unlikely, Michelle Felon in her capacity of VRC Chair, is trying to arrange a meeting with the Council for Healthcare Regulatory Excellence (CHRE) and will invite all PB chairs attend.
- (iv) Call for nominations sent out to replace AGTC members that have recently left. Currently waiting for responses.
- (v) The possibility of re-registration becoming bi-annual to mirror the HPC to address the problem of those on maternity leave having to defer a CPD audit twice and keeping the payment annual but made by direct debit was discussed and agreed at the VRC meeting. Problem with the direct debit at the bank as they will not accept the risk of a direct debit for such a low value. Michelle Fenlon is looking into this matter
- (vi) Voluntary registration of PTPs – This had been discussed by the VRC and there were no objections to forming a new group/modality with a new title. The VRC would request the usual new group fee.

It was generally felt that MSC had let this group down by not having a plan for registration. We discussed the possibility of registering this group along with the NTP trained GT's and it was generally felt that their entry route was so very different that it may cause problems in the future if a time came where we could register with HPC that they would not accept different entry routes. The possibility of finding a compromise was discussed, it was felt that there might be the possibility of mapping over the PTP competencies onto the NTP and that a period of consolidation of a year maybe acceptable compromise.

(vii) GT survey – the AGTC would like to thank the CMGS for their help with setting up the Survey Monkey Survey. The results are in and there were over 200 responses.

We had 197 responses for the registration questions that a 143 (72%) were eligible for registration

- 87 (56%) are registered.
- 68 (44%) are not registered

We had 212 responses for the professional body registration questions.

- 39 (18.4%) were ACC members
- 50 (23.5%) were CMGS members
- 6 (2.8%) were members of both
- 117 (55.2%) were not members of a professional body
- Overall 44.8% are members of a professional body and 55.2% are not members.

This survey has shown us that we are making headway in registration and professional body membership, although it is only a snap shot (of those GT's who answered the survey). It seems that although numbers are rising for both registration and professional body membership, there is still some work left to do to encourage registration and professional body membership.

Current numbers registered with the VRC are:

- Total = 232
- Cyto GT = 82
- Mol GT = 72

Action: AGTC to contact GTs to make them aware of position regarding registration

10

Scientific and Governance items

1. ACC/CMGS Bioinformatics Group

Report compiled by DM and circulated.

Input into MSC bioinformatics curriculum development with NGRL, NOWGEN and University of Manchester. CNV workshop still planned for later in 2011 after ACC Best Practice guidelines release. DM and Eddy Maher to lead on this but will seek input from wider community including DDD project.

2. NQAAP

Presented by TP and KS.

Mike Griffiths new Chair of NQAAP. Feedback and performance data were presented at meeting. There was some discussion on poor performances in constitutional and acquired schemes. Three poor performances results in a persistent poor performance. It was agreed to separate constitutional and acquired schemes so that labs will need 3 poor performances in either constitutional or acquired schemes to become a persistent poor performer. Fiona Coyne has taken over from Michelle Fenlon as secretary. TP finishes in Autumn, will need a new ACC nomination.

Action: AD to email HoDs to seek nominations

3. Cytogenetics currency system.

Report compiled by Katie Waters and circulated.

KW presented cytogenetic workload units at meeting of laboratory membership and audit working group on 10th May 2011 in advance of UKGTN meeting. Labs are currently piloting the cytogenetic system and KW will collect data in July from participating labs. There was a strong desire to merge cytogenetic and molecular systems but this will be done after the pilot.

11

Reports back from external meetings

1. BSHG

Report compiled by DM and circulated.

(i) Financial and organisational report

Current account balance £187000 but owe £35000 in cheques leaving £150000. IT update for BSHG offices was delivered within the £1700 budget but there are still some networking and direct debit problems. The constituent society Spring Conference support document will be reviewed.

(ii) BHGC conference 2011

Helen Stewart is the new conference organiser. Due to financial constraints speakers will be from UK/Europe.

Jon Strefford reported to DM and Jonathan Waters (not BSHG Council) that abstract contributions from cytogenetic labs were down slightly. Submitted abstracts under review for 10/06/2011 by Jon Strefford, DM, Jonathan Waters and Maj Hulten.

Due to budget constraints on departments, cheaper options for the conference dinner are being discussed.

Several major companies not sponsoring BHGC eg Affymetrix and OGT might possibly be due to lack of satisfaction with venue.

Prices at Warwick are going up. This will impact on future of conference at Warwick.

(iii) European Human Genetics Conference in UK

ESHG has requested BSHG help in organising EHGC in the UK in 2015. The main issue is the timing of the constituent society conferences. Dina to contact each group for their thoughts.

(iv) JCMG

Trevor Cole to step down at end of 2011. Agreed that a strong clinician or scientist replacement was needed.

(v) Genethics club

At present neither the BSHG or the constituent societies have a formal group or mechanism for dealing with or responding to ethical and legal issues in medical genetics. The Genethics club serves a useful purpose for discussion of difficult cases but there is no remit beyond this.

Proposal:

1. The professionals involved in delivery of medical genetic services should have their own more formal group.
2. This group would be the reference body tasked with identifying individuals to contribute to working groups or special reports when needed.
3. They would help to maintain a healthy level of debate and awareness of ethical and legal issues within the medical genetics community.
4. The group would be the natural place to foster new interest in these issues among the junior ranks

of membership thus helping to nurture and identify our key spokes persons for the future.
5. BSHG should lead in this initiative because it should be representative of its constituent bodies. There was agreement with the points above but concern as to who would steer this and the time needed. Suggested ACC/CMGS members should be encouraged to engage more in Genethics club as we will be faced with more ethical issues related to findings from higher resolution technologies. Suggested Genethics club dates should be advertised on new/existing websites. Spring meeting organising committee in Birmingham to look into a session relating to this issue.

2. RCPATH SAC on Genetics and Clinical Embryology

Reports from JCMG 11th May 2011 and RCPATH SAC on Genetics and Clinical Embryology 12th May 2011 presented by JW.

(i) JCMG (Joint Committee on Medical Genetics)

a) The revision and update of 'Consent and confidentiality in genetic practice: guidance on genetic testing and sharing of genetic information' which covers general aspects of consent and confidentiality as applied to genetics; the sharing of information with other family members and between professionals; genetic investigations on stored material, the Human Tissue Act; consent and DNA analysis; the Data Protection Act and the processing of genetic information was due to be completed soon and published.

b) A joint ACC / CMGS report on Genetic Laboratory Workforce Report giving information on the proposed merger of the two organisations into a single professional body (report tabled). The respective Training Advisory Groups (ACC and CMGS) have already merged into a single Genetic Education & Training Board (GETB). The SAC Chair and the Chair of the Panel of Examiners (Genetics) are invited to attend the meetings of this Board to provide input on Higher Specialist Training and Examinations. The report also highlighted the continuing uncertainty around the regulation of Genetic Technologists and HealthCare Scientists – clarity may be forthcoming with the advent of the new Academy of Healthcare Scientists.

c) Report from the National Genetics Reference Laboratories (NGRLs) (Wessex and Manchester). The NGRLs had been granted another 12 months funding from the Department of Health, guaranteeing their future in their present form until April 2012. A subscription-based approach for the Manchester NGRLs Mutation database (MuDB) could be used to generate income.

d) a document entitled 'Developing a Themed e-Atlas for Diagnostics: Possible Content on Genetics', which is seeking input into a themed e-Atlas on diagnostics that was being developed as part of the 'Right Care' Programme, to ensure that it adequately addresses Genetics. The JCMG thought it was important to engage fully with this DH-sponsored process to ensure that variation in the provision of Genetics services is fully documented.

e) An update on the RAPID – Non-invasive prenatal diagnosis (NIPD) project was provided by Professor Lyn Chitty. A number of commercial companies were looking to provide non-invasive prenatal diagnosis and this could impact on or compete with the provision of a complete Patient Care Pathway (including laboratory testing) that was part of the ethos of the RAPID project.

f) Dr Hilary Burton for PHG (Public Health Genetics) Foundation reported that an invited meeting was being organised in June with the RCP on developing genetics in mainstream medicine. This follows on from the recent PHG Foundation report: 'Genetics in mainstream medicine' which was published in March 2011.

In addition the PHGF has launched to other key pieces of work:

1) A report on Whole Genome Sequencing and the impact of this technology on health
2) 'Born Healthy – tackling congenital disorders' – this is a web-based world-wide toolkit designed to provide information on congenital disorders to a world-wide audience including those in the third world.

g) Report from the RCP Medical Specialities Board (2nd February 2011). This meeting had reviewed progress with the Map of Medicine. The RCP continues to support the map.

h) RCPATH President's review of committee structures. Dr Trevor Cole, JCMG Chair had responded to the President. JCMG's response had submitted that the role of the JCMG and the Genetics and Clinical Embryology SAC were complimentary but distinct and had expressed support for the Genetics SAC continuing in its own right with a remit on examinations and training.

(ii) RCPATH SAC (Specialist Advisory Committee for Genetics and Clinical Embryology)

– see BSHG Newsletter (May/June)

- 1) Curriculum development
 - Background
 - HealthCare Science curriculum
 - Use of NGEDC website
- 2) Examinations/Examiners

- changes to existing examinations – SAC not pushing agenda for single examination
- new examiners

3) National Assessors lists (ex DH now RCpath curated)

4) Future of the SAC (Specialist Advisory Committee for Genetics and Clinical Embryology)

4. FASP

Presented by SM

- (i) Collecting 2010-2011 prenatal invasive procedures numbers for their annual report. Around 50% of labs have already responded.
- (ii) Paper ongoing with Pat Ward as discussed in previous council meeting re publishing data from previous years.
- (iii) National review group established to review policy for screening on trisomy 13 and 18 pregnancies. SM to represent ACC on working group. Travel expenses will be paid by the Programme Centre.
- (iv) T21 National Working Standards meeting - 15th July. SM to represent ACC.
- (v) FASP are working on a project with Medical Mosaics. Richard Jones and David Crook from Medical Mosaics are currently carrying out a scoping exercise to audit and monitor the quality of screening tests in terms of the reliability of a positive test to predict a positive outcome. They will need some input from the ACC.

12 Correspondence/Applications for Membership

There were 17 applications from membership, 5 scientist, 5 technologist, 1 PTP and 6 STP.

13 Any Other Business

- (i) AD invited to Technology strategy board (TSB) meeting on stratified medicine innovation platform – want to map out strategy to bring technology to the fore.

Action: AD will circulate final roadmap vision to Council

- (ii) Joint Spring Meeting will be at the International Convention Centre 30th April to 1st May 2012 with patient pathway based sessions.
- (iii) There was discussion over hosting another HoD meeting. It was decided to await the outcomes of HGSG reports before proceeding.

14 Date and venue for next meeting

Tuesday 1 November 2011.

Start time 11.15. Lunch will be provided.

Venue: British Society of Haematology, 100 White Lion Street, London N1 9PF

The meeting closed at 15.45.