METABOLIC BIOCHEMISTRY (BIOCHEMICAL GENETICS NETWORK)

Meeting held on 7th May, 2002
Birmingham Children's Hospital Pathology Seminar Room

Attendees

Mike Badminton, Cardiff
Guy Besley, Manchester
Sue Bird, Guys, London (for Professor Swaminathan)
Jim Bonham, Sheffield (JB)
Jacqui Calvin, Cambridge
Neil Dalton, Guys, London
Monica Goldfinch, Newcastle (for Hilary Wastell)
Anne Green, Birmingham (AG)
Mike Henderson, Leeds
Helena Kemp, Bristol
Diane Kerr, Liverpool (for David Isherwood)
Margaret Rae, Glasgow
Tony Reynolds, GOS, London

Please note attached to the minutes are copies of the presentations

	ACTION
1. Apologies Jean Kirk, Rob Ellis, Mike Addison	
2. Feedback from GENCAG on the proposals for a UK Network	
JB summarised the original bid which had been sent to GENCAG as a request for funding for a UK Network (see presentation for details). The full bid was not funded; funding offered is £50,000 for each of two years, plus an additional £5,000 start up costs. Diane Kennard had confirmed with JB that the arrangements for the spend could be undertaken by way of exchange of letter rather than a formal contract, and that it was envisaged that there was one lead host centre which would administer the funding. The proposals for years 1 and 2 were presented. It was noted that other functions of the Network would be to be a platform for audit and research. The issue as to whether metabolic biochemistry should be in the genetics or the specialist pathology commissioning arena was discussed. There seems to be no reason why this could not be a flexible arrangement depending on the local commissioning arrangements.	
3. Stakeholder Group	
A proposed stakeholder group was discussed and it was agreed that we should seek clarification on the position for Scotland, Wales, Northern Ireland and Ireland. The group felt that all parts of the United Kingdom and Ireland should be included, but it may be necessary in the future to seek some additional funding for specific aspects of the work to be undertaken.	
It was agreed that everyone send email address details to JB.	ALL
It was agreed that we should have an official list of deputies and that members should notify these to JB	ALL

	ACTION
It was proposed that Bristol also be represented by the Bristol Royal	JB

Infirmary and that David Stansbie be approached.

4. Objectives

The following were discussed:-

Documentation of service provision
Training needs and manpower planning
Quality and accreditation
Links with the genetics reference laboratories

The aims of this session were to agree some objectives and priorities and discuss how we might achieve these, e.g. questionnaire, email, small working groups, etc.

Documentation of service provision
These should include:-

i. *List of laboratories, to include Wales, Scotland and Ireland*

   The issue of the role of stakeholder laboratories was discussed, i.e. was this to be representative, e.g. who would collect data for Nottingham and Leicester? This needs to be clarified in the 'job description' for stakeholder membership.

ii. *What test to include, i.e. ? repertoire*
   This should be inclusive of metabolites and enzyme assay and to identify molecular testing where this complemented biochemical testing for particular metabolic disorders.

   It was noted that biochemical laboratories are increasingly undertaking common mutation testing, whereas sequencing and more sophisticated molecular analysis is being undertaken by the molecular laboratories.

   The need for links with screening was stressed, specifically to link with the UK Neonatal Screening Laboratory Network via David Isherwood.

   The test repertoire should include purines and pyrimidines, and we should consider other 'fringe' areas, e.g. porphyrias, bilirubin, pyruvate metabolism (Oxford), glycogen metabolism, neurotransmitters and mitochondrial disorders.

iii. *Workload*
   It was agreed that we should provide basic workload data on tests per annum and this should be split as to that provided in-house vs work purchased outside. It should also be split into work undertaken in and out-of-hours and should include some assessment of turnaround time and time for a fast track of an urgent request.

ACTION

iv. *Funding source*
   Clarification of routes of funding.

v. *The equity of access/availability of service*
   It was agreed that we should try to relate workload to a population

database. There was some discussion about the need to look at the availability of second-line tests, e.g. ammonia.

Risk assessment list to include equipment inventory, staffing needs and relationship of workload to staff establishment.

Rare test needs - need to collaborate with the molecular network and the genetic reference laboratories.

Manpower
The current position regarding the assessment of training needs was outlined by AG. A document has been finalised outlining the need for supernumerary trainee posts, and also 'trainer' establishments and was circulated at the meeting (further copies are available by email – contact AG). This has got full support from the professional bodies, ACB, RCPath, BIMDG, and has been sent to the Department of Health Manpower Work Planning. In addition, under the umbrella of the Joint Genetics Committee, a working group has been set up together with the Department of Health under the Chairmanship of Steve Abbs. AG confirmed that she had been invited to sit on this committee to represent the needs for paediatric/metabolic biochemistry. The date of the first meeting is awaited.

The difficulties of recruitment and training for metabolic biochemistry were discussed. Ideas such as fast-tracking, linking posts to vacancies as proleptic appointments were discussed. All these ideas need consideration in subsequent discussions.

Education/training programme
It was agreed that we should try to establish a programme for existing staff, but to co-ordinate with plans by the BIMDG. Perhaps a 2-day training course for Grade B clinical scientists and MLSOs was suggested.

Provision of teaching and education for other health professionals was supported, to include paediatricians, DGH consultants, SpRs in other disciplines, etc.

The need to 'sell' metabolic biochemistry as an exciting specialty with good career opportunities was emphasised. ? perhaps to include something at one of the trainee meetings, e.g. Focus, etc.

Quality and accreditation - requirements for accreditation
The need for a specification of the service was agreed and that this could perhaps be undertaken by a small sub-working group. This should include standards of turnaround times, guidelines, etc.

The special needs for metabolic biochemistry need to be emphasised.

ACTION

Audit of methodology, test effectiveness and production of protocols for symptom-based presentations could all be part of the network. Again, the need to link with BIMDG was emphasised.

5. Links with Genetic Reference Laboratories

It was unfortunate that Rob Ellis was unable to be with us. The UK

Metabolic Biochemistry needs to link with the Genetic Reference Laboratories and the other genetic networks. The importance of communication and liaison, and a key function is to determine the need for the rare biochemical tests.

The priorities which the group felt were most important were:-

i. To undertake a survey of existing services
ii. To pursue the training and manpower needs and to try to address the need for additional trainers
iii. To identify the risk and possible backup arrangements for the service

6. External Quality Assessment

EQA providers
Current EQA providers include NEQAS and ERNDIM, but could include others, e.g. WEQAS.

It was proposed that the BIMDG Quality Group be dispersed and the network take on the functioning of the quality role in monitoring and stimulating the development of new schemes and promotion of EQA for this specialist area.

It was agreed that JB should take this forward. — JB

The commissioning arrangement survey
It is clear that currently there are various different arrangements for funding and that it would be useful to clarify this. Commissioning via GENCAG for specialist pathology needs to be clarified. The role of NSCAG also needs to be understood.

7. Logistics and organisation lead co-ordinator
JB presented a possible way the money could be spent by employment of a lead co-ordinator with administrative support. This would also leave some money for educational meetings and other small, specific projects. There was general support for this proposal.

It was agreed that JB should seek views from those not able to be present regarding the nomination for lead co-ordinator. AG expressed her interest in taking this role on, although exact details need to be fully worked through. The role could not be taken on before July or August 2002 at the earliest. There was unanimous support for this by the members present at the meeting. — JB

ACTION

Subject to confirmation from JB's 'ringing round' AG would take forward discussions with Birmingham Children's Hospital Trust to explore the possibilities for her taking on this role later in 2002. — AG

It was agreed that a 'job description' for the lead co-ordinator and stakeholders needs to be drawn up and agreed. JB agreed to take this forward. — JB

It was thought that most work could be done by email and by small group meetings and that the full stakeholder group should perhaps meet again in about 6 months time.

It was agreed that part of the service review should try to ascertain the need for our-of-hours activity, i.e. both analytical and advisory.

The stakeholders will need to undertake a significant amount of work to provide data for the survey and the importance of their support was stressed.

It was suggested that web site for the network be established. This was thought to be a good idea but perhaps not a high priority. We should perhaps ensure and understand exactly how the web site would be used before spending resource on this.

AG
May 2002