

National Metabolic Biochemistry Network

Minutes of Stakeholder meeting held on 10th February in the Seminar Room, Department of Clinical Chemistry, Birmingham Children's Hospital

Attendees:	Mike Badminton	(MB)	Mary Anne Preece	(MAP)
	Jim Bonham	(JB)	Tony Reynolds	(TR)
	Jacqui Calvin	(JC)	Geraldine Roberts	(GR)
	Fiona Carragher	(FC)	Lesley Tetlow	(LT)
	Neil Dalton	(ND)	Elizabeth Trimble	(ET)
	Peter Gallagher	(PG)	Valerie Walker	(VW)
	Anne Green	(AG)	Hilary Wastell	(HW)
	Mike Henderson	(MH)		
	David Isherwood	(DI)	By invitation:	
	Helena Kemp	(HK)	Kim Bartlett	(KB)
	Jean Kirk	(JK)	Neil Hamilton	(NH)
	Helen Losty	(HL)		

ACTION

1. Apologies:

Philip Mayne, Guy Besley, Mike Addison.

AG welcomed everyone to the meeting; it was particularly gratifying to have such wide support from across the UK.

2. Matters arising from the minutes of the inaugural stakeholder meeting, 7th May 2002.

2.1 Stakeholder list

A full list of stakeholders with deputies has been circulated, together with associated laboratories. JB confirmed that he had discussed representation with David Stansbie and that Helena Kemp would liaise with the BRI.

The lead scientist job description had been finalised and circulated.

2.2 Network Infrastructure

The network officially commenced 1st October 2002 for a two year period. Birmingham Children's Hospital is hosting the network for this two year period. AG confirmed that links with the newly formed Genetic Testing Network (GTN) have been formed with a 'seat' as observer status on the GTN.

2.3 Links with Genetic Commissioning Advisory Group (GenCAG)

JB is our ongoing link with GenCAG.

ACTION

2.4 EQA

JB confirmed that the EQA role via BIMDG had been transferred to the network. This will require further discussion by the stakeholders.

AG

3. Progress Report - National Issues

3.1 Joint Committee on Medical Genetics (JCMG)

AG outlined the functioning of this committee. Meetings had taken place in June, October 2002, and January 2003. The main items affecting metabolic biochemistry were:-

i. Training of clinical scientists

A working party under the chairmanship of Steve Abbs had taken place and a national strategy document, which would include metabolic biochemistry, was being finalised for discussions with the chief scientist and the WDCs.

AG

The JCMG were aware of the particular difficulties with regard to training and recruitment for clinical scientists in metabolic biochemistry, and correspondence from the Chairman has gone to the ACB and the RCPATH.

ii. Consent consultation

There has been a huge amount of discussion and consultation on the issue of consent. This is ongoing.

iii. Education, Commissioners and Health Professionals

AG confirmed that there was a teaching and education initiative which will be undertaken by the Public Health Genetics Unit at Cambridge. The aim was to develop a genetics education programme, building on GenCAG's guidance to PCTs. Members were encouraged to contact their respective local commissioners to find out how this education initiative was going to be delivered in their respective area. AG to contact the Genetic Testing Network for further information.

AG

ACTION

National Strategy got Inherited Metabolic Disorders

The JCMG had raised concerns about the clinical services for inherited metabolic disorders, particularly those for adolescents and adults.

A workshop organised by the BIMDG had taken place on October 30th 2002 to discuss the national strategy for IMD, organised by Graham Shortland. It is important that a report from the meeting is fed back to the RCPATH and the Joint Committee on Medical Genetics.

3.2 Genetic Testing Network

AG outlined the organisation and terms of reference of the GTN. GTN is a sub-group of GenCAG (Specialist services definition set number 20), operates UK-wide and complements the metabolic biochemistry and haemophilia networks.

Meetings had taken place in September and November 2002, and in January 2003. The infrastructure comprised a full time lead scientist and two administrators.

Terms of reference and membership of the group to be circulated.

AG

AG, as lead scientist for the metabolic biochemistry network, has observer status membership of GTN.

Major items under discussion are:-

i. Laboratory designation for molecular tests

The steering group is finalising an invitation for laboratories to apply for membership of the GTN. A first wave of invitations will be to laboratories which are regional genetic services. A second wave will take place to cover the rest.

ii. Commissioning

A commissioning mapping exercise is to take place. There is considerable frustration and tension from within the genetic services about the need to resolve an efficient commissioning process.

iii. **Evaluation of a molecular test**

An exercise to assess clinical utility by way of a gene dossier is being established for use to evaluate requests for new molecular tests.

iv. **Website/database**

The GTN is to establish its own website and database and plans to include the ability in due course to use for specimen tracking.

v. **Workload Units**

The work already taking place in molecular genetics to measure workload as contract currencies will be taken forward.

3.3 Specialised Pathology

There is no information as to where this particular initiative was going. Some of the molecular biochemistry tests are included within specialised pathology but it is unclear as to whether this was going to be progressed in any way.

3.4 Pathology Modernisation

A network response as part of the consultation had been sent by AG and previously circulated to members. A response to the consultation process has now been published - see DOH web site www.doh.gov.uk/pathologymodernisation. It appears that the impetus for this initiative is receding.

3.5 Commissioning

A guide for PCTs has been prepared. This will be circulated to members.

AG

It was stressed that it would be important for individual members to find out who their lead commissioners are under the new organisation of PCTs and Strategic Health Authorities.

4. Network Web Site

AG welcomed Kim Bartlett and Neil Hamilton to the meeting. AG and KB had had initial discussions about the possibility of a web site for the network. KB outlined what could be provided. The importance of the role of the local laboratory, access levels, glossaries/terminology, were discussed. After discussion, **it was agreed** that we should proceed with a network web site. Further discussion to take place later on the agenda.

A summary of who the web site is for, what it is for and content, is included as part of the overheads from the meeting.

AG

5. Training and Recruitment

5.1 Clinical Scientists

Registration, MRCPATH and HST posts, were discussed. AG outlined the discussions that had taken place to date with the ACB and the RCPATH and tabled a short document which had been the basis of discussion with the RCPATH. After discussion, **it was agreed** to move forward on all three actions.

The need to link with Trevor Gray as chief examiner would be undertaken by MH as the link with the network.

MH

The work to prepare competencies for the sub-mortality of paediatric metabolic biochemistry would be prepared by AG in conjunction with Lesley Tetlow.

AG/LT

AG will pursue the HST post discussions via the ACB/RCPATH with the chief scientist, WDCs and Anthony Walsh DOH.

AG

5.2 Agenda for Change

Peter Galloway outlined his concerns about the need for input into this initiative. **It was agreed** that individuals should look at the documentation on the DOH web site, www.doh.gov.uk/agendaforchange and consider the model job descriptions in the context of metabolic biochemistry services. All comments should be returned to AG by the end of March so that an overview of issues for the network can be considered and taken forward.

ALL

Representatives from the Guy's pilot site were encouraged to find out what was going on in their Trust.

FC/ND

ACTION

5.3 MLSO Recruitment

JC outlined the local problems she was experiencing in Cambridge. It appears that no one else seemed to be having the same unreasonable restrictions placed on MLSO recruitment. **It was agreed** that if Jacqui required further support, it would be reasonable to request that the Trusts' management sought independent advice via the network.

The issue of MTOs was mentioned, and **it was agreed** that this should be put on the agenda for our next meeting

AG

6. Questionnaire on Service Provision

A major initiative is to undertake a questionnaire to define our current provision. After discussion, the outline of the questionnaire was agreed (see overheads). JK agreed to assist in the questionnaire production and piloting. It was noted that a questionnaire was currently being undertaken in Scotland.

AG/JK

7. Work Plan/Specific Projects

AG outlined the response to a previous questionnaire on what members felt were priorities for further work (see overheads)b.

7.1 'Best Practice' Guidelines

The following were agreed:-

1. The network should progress with production of 'best practice' guidelines. Individuals **agreed** to lead on the following initiatives:

MAP

HK

HL

PG

MH

DI

JB

Metabolic autopsy (SUDI - Mary Anne Preece)

IEM and hydrops (George Gray/Mary Anne Preece)

IEM and cardiomyopathy postmortem (Helena Kemp)

Hypoglycaemia (Helen Losty)

Hyperammonaemia (Helen Losty)

Developmental delay (Peter Galloway)

Fits and seizures (Mick Henderson)

Prolonged neonatal jaundice (David Isherwood)

Lactic acidosis (Jim Bonham)

Rhabdomyolysis (Jim Bonham/Simon Olpin)

Best practice guidelines initiatives would predominantly take place by email, but if individuals required to have small working groups, these would be funded by the network. Each topic lead to contact AG.

A full list of suggestion for best practice guidelines is included with the overheads.

7.2 Training for existing or new staff

JB

It was agreed that we should pursue a small number training sessions, ? one day, for existing/new staff for both clinical scientists and MLSOs.

The following were agreed:-

Organic acids (Jim Bonham)

Acyl carnitines (Neil Dalton)

Very long chain fatty acids (Tony Reynolds)

Lysosomal enzymes (Lesley Tetlow/Guy Besley)

Individuals would take the lead on each of the above and would request funding from the network via AG

8. Web Site

After further discussion, it was **agreed** that we should proceed to commission Kim Bartlett and Neil Hamilton to produce a web site. A specification would be prepared as a basis for commissioning. It was agreed that we needed a tightly managed time frame for this.

AG

AG

It was agreed that we needed a small group to work on this. Tony Reynolds and Mike Badminton 'volunteered' individuals from their departments, and would inform AG. AG would form a small group to take this forward.

TR/MB

AG

9. Any other business

Discussion on quality assurance and quality indicated for accreditation was deferred to the next meeting.

AG

It was agreed that we should plan a meeting for November 2003 and, in the interim, communicate predominantly by email.

A major item to include in the agenda for the next meeting is the impact of the 'agenda for change'.

AG thanked all members for contributing to the meeting and the meeting closed at 16.40 p.m.

Enclosures

Overheads from the meeting on 10th February, 2003

GTN - Terms of Reference

Genetics Services - A Guide for Primary Care Trusts

GTN - Genetic Testing Network Management Arrangements

Genetic Education and Training - Proposed Terms of Reference for the Management Group