

National Metabolic Biochemistry Network

Minutes of Stakeholder meeting held on 11th November 2003 at Birmingham Dental Hospital

Present:	Mike Badminton (MB)	Jean Kirk (JK)
	Guy Besley (GB)	Helen Losty (HL)
	Jim Bonham (JB)	Mary Anne Preece (MAP)
	Jacqui Calvin (JC)	Geraldine Roberts (GR)
	Fiona Carragher (FC)	David Stansbie (DS)
	Ying Foo (YF)	Janet Stone (JS)
	Peter Galloway (PG)	Elizabeth Trimble (ET)
	Anne Green (AG)	Valerie Walker (VW)
	Mike Henderson (MH)	By invitation:
	David Isherwood (DI)	Kim Bartlett (KB)
	Helena Kemp (HK)	Neil Hamilton (NH)

ACTION

1. Apologies:

Hiliary Wastell, Mike Addison, Lesley Tetlow, Liz Trimble, Maureen Boxer (GTN)

2. Minutes of the Meeting Held on 10th February 2003

These had been previously circulated. There were no comments.

3. Matters Arising

There were no matters arising which were not on the agenda.

4. Progress Reports – National Issues

4.1 Genetics White Paper

AG updated the meeting on progress with the Genetics White Paper. The main initiatives currently under way are the bids for upgrading laboratory facilities and the education and training centre. Several laboratories present had submitted bids. AG requested that she be kept updated on outcome from these bids.

ALL

The areas where metabolic biochemistry might benefit also include:-

Clinical Scientist Training (see item 5.2)

IT for the Genetic Testing Network

Pilot sites for familial hypercholesterolaemia – sites to be agreed by April 2004.

ACTION

Members were urged to keep themselves informed of the developments by accessing the DOH Genetics web site.

4.2 Joint Committee on Medical Genetics (JCMG)

There have been two meetings, 1st May 2003 and 21st October 2003. The main topics relevant to our Network discussed were:-

Clinical Scientist Training (see 5.2)

The Clinical IMD service

There is now considerable concern about the need for a national strategy for clinical IMD, particularly relating to the pressures for provision of adult services. AG has been in contact with Graham Shortland as Chairman of the BIMDG and it is hoped that the next JMGC will include a presentation about these issues.

Copying of Laboratory Reports

There is considerable concern from within the Genetic Laboratories that some genetic reports are not being appropriately communicated back to the requesting clinician, i.e. some laboratories are not copying all the information. This matter has been referred to the Royal College of Pathologists as it is an issue wider than genetics.

Consent and Confidentiality Document

AG reported that the JMGC has produced a comprehensive document which will shortly be available for consultation.

4.3 Genetic Testing Network

In the absence of Maureen Boxer, the Chairman updated members with progress on the Genetic Testing Network. The molecular tests relevant to clinical IMD have been submitted to the GTN and it is hoped that most of these will be included in the directory which is shortly to be published on the DOH web site. A summary document of the molecular tests for IMD which has been produced by the Network has already been circulated – members should contact AG if copies of this are still required. The main issues which will require addressing are the need to consider tests currently being undertaken in non-GTN laboratories, e.g. porphyrias, oxalurias. This is an important issue and will need discussion within the GTN early in 2004.

ACTION

The other issue relates to molecular test requesting in the context of the speciality and other diagnostic tests. **It was agreed** that this is very important and molecular tests cannot be prioritised outwith the clinical context.

The GTN Test Directory would comprise several lists. List 1A, which will be all tests available in GTN laboratories in the UK which the Commissioners have agreed should 'be funded'.

List 2A are new tests with a workload of over 100 per year for which new funding is to be negotiated. These tests will be listed individually.

List 2B are new tests less than 100 per year. These will be considered as a 'bundle' of low-volume tests with a sum of money to be negotiated per year.

List 3 are the rarer tests, e.g. 1 or 2 per year.

List 4 are the rare diseases which are provided outside the UK and in UK specialist laboratories for which new money is required.

Our understanding is that metabolic tests not in list 1A will be considered within 2B and 3.

Commissioners have agreed to new monies to fund the tests in the directory, although exactly how this will be forthcoming remains to be

seen. There has been considerable tension between the professionals within the genetic molecular laboratories and the Network Management. The tension is particularly around the commissioning process and exactly how this will work in practice.

The availability of the rare disease testing service was highlighted. To date no one has any experience of submitting a request; members were urged to contact one of the two reference laboratories should they require this service.

It was agreed that it would be useful to invite Rob Ellis from the National Reference Laboratory in Manchester to our next Network meeting, specifically to discuss the services for rare testing. **It was also agreed** that we should re-invite Maureen Boxer to have a discussion about the GTN.

AG

AG

ACTION

4.4 GENCAG

JB updated members on progress within GENCAG. There has been a suggestion from Allison Streetly that there should be better links between screening developments and genetics. This was supported by the Network membership.

4.5 Pathology Modernisation

There is no further information, although we are led to believe a document is currently under final discussion and should be available before the end of this calendar year.

4.6 Professional Bodies

Royal College of Pathologists

MH updated members on his discussions with Trevor Gray as Chief Examiner for Clinical Biochemistry. Considerable progress has been made with inclusion of additional questions on paediatric biochemistry in the MRCPPath examination.

Members were urged to provide questions and **it was agreed** that these should go via MH as the focus for the Network with the RCPPath. MH would circulate the whole group specifically requesting this, and ideas for questions.

MH

Association of Clinical Biochemists

AG updated members on very recent news that the sub modality of paediatric metabolic biochemistry had been accepted by the Association of Clinical Biochemists with immediate effect. There will shortly be some details about this on the ACB web site. Any clinical scientists who wish to make applications are now able to do so. Members were urged to keep the Chairman informed of any proposals for registration so that the Network could keep an overview on the numbers of individuals applying via this route.

5. Network Initiatives

5.1 Web Site

Report from Kim Bartlett/Neil Hamilton

NH reported on the developments to date. The web site is now fully

functional and is now being updated on a regular basis. Members were urged to use the web site and contact Neil with any problems.

ACTION

Next Stages would also include putting guidelines on the web site (see 5.4). The issue of ownership of guidelines and copyright was discussed. **It was agreed** that NH and AG should consult the DOH advice on web sites, as to whether these are DOH owned or individually owned?

NH/AG

The 'assay finder' has been developed and tested and is ready to go. JS has agreed to be the Network Co-ordinator and link with NH for this initiative. The list of tests has been provided as part of the service questionnaire, and once we have the returns it will be possible to finalise the list for putting on the web site. JS will put on the information which is received back from the survey questionnaire. It will then be up to individual laboratories to keep this up-to-date. **This is most important, otherwise the value of the web site will be seriously diminished.**

JS

It was suggested that once the assay finder is up and running, we should notify the ACB and ask them that the metabolic biochemistry web site be featured in the News Sheet as a 'web site of the month'.

AG

It was agreed that, in the short term, any comments about the web site should be directed via the Network infrastructure, i.e. either via AG or Mary Dowling for onward transmission to Neil. Eventually it would be useful and important to have another individual involved as this could become a substantial activity. The Chairman thanked Neil and Kim for their work in setting up the web site which has gone very well and a significant step forward. Once again, everyone was encouraged of the importance of using the web site.

The Chairman reported that, in response to a plea for some suggestions for the renaming of the assay finder, 22 suggestions had been forthcoming. This was extremely encouraging! After discussion, it was agreed that we should rename the assay finder 'metabolic assay directory'. A prize for the name was awarded to David Isherwood, with other prizes to Kim Bartlett, Helen Losty and David Stansbie.

ACTION

5.2 Training and Education

The problem of training for clinical scientists was outlined by MH and the proposal to establish three clusters to co-ordinate training. This has been summarised as a strategy document (September 4th 2003) which has been submitted to the Department of Health for consideration for Genetic White Paper monies. Members supported this proposal and endorsed that the strategy be taken forward as part of the wider genetics discussions nationally.

Mick emphasised the training needs were not just for higher specialist trainees, but also core training for Grade A scientists, biomedical scientists, metabolic medicine specialist registrars and genetic specialist registrars. All these activities are placing increased demands upon the same few people, and we are really struggling to meet current training requirements/demands.

There was some discussion about how much time Grade A trainee should ideally spend in a specialist laboratory. This appears to range widely from as little as a few weeks to six months. **It was agreed** that it would be important to undertake a mapping exercise as to exacting what is happening across the UK and to try and come up with an agreement about the 'ideal' for the future. This could be one of the first activities if we can get some training infrastructure established.

There was also interest as to what was happening regarding higher specialist trainees post, and again a mapping exercise would be useful.

Jacqui Calvin reported that she has put in a proposal to her WDC for an HST post. Birmingham has got an HST post (although ongoing funding is not confirmed). Other centres have submitted bids. AG urged people to keep this high on the agenda and make requests, and even if posts are only part funded, there could perhaps be a sharing of funds to create cross-centre posts. In principle there was support to go forward with the proposals as the Network strategy. It was noted that Scotland, Northern Ireland and Wales were outwith this proposal as the White Paper monies only applied to England. However, an initiative in Wales has already been commenced to have a similar arrangement for the one proposed for England. It would be hoped that a training structure could eventually link across the whole of the UK as an overall strategy.

ACTION

Strategy and Proposals

i) **Electronic learning, Kim Bartlett**

The background to this item was an initiative by the National Reference Laboratory, Manchester, which took the form of a meeting on 26th September, 2003 which AG had attended (minutes circulated at the meeting).

There are monies available, both at the National Genetics Laboratories and the Genetics Knowledge Parks, to initiative e-learning for genetics. We have been invited to submit ideas as a pilot e-learning project. Kim presented proposals for the web delivery of an interactive curriculum. Members are very supportive of a pilot initiative, but feel that it is important to 'keep it simple'.

There was insufficient time to discuss in detail, and a small group was asked to take this forward, Mick Henderson, Kim Bartlett, Helen Losty and Guy Besley (Mick to lead).

MH

It was important that we develop a do-able focused project that we could submit for funding.

5.3 Quality

JB reported on the highly successful workshop which had taken place on 22nd October. A written report will be available.

JB

An action from the workshop had been to look at amino acid references ranges, and Maggie Hancock had agreed to take this forward. JB agreed to follow this up.

JB

The next annual workshop, October 2004, will take place at Great Ormond Street; YF has kindly agreed to organise.

YF

Accreditation

AG updated everyone about CPA. Paediatric metabolic biochemistry is now recognised as a sub-specialty by CPA, and members completing the CPA application will have to declare this. There was discussion about what this meant in practice, and how we should move forward. It was felt useful to provide CPA with a list of EQA schemes which laboratories should belong to if they are providing specific specialist tests. Jim Bonham agreed to provide this to forward to the Chair.

JB

The issue of whether we should be producing standards specified to metabolic biochemistry was debated. It was felt that the next useful stage might be to produce a short document about what is considered to be appropriate staffing. MH agreed to produce a first draft for circulation.

ACTION

MH

5.4 Specific Projects Workshop Update

The first workshop on very long chain fatty acids will take place on December 11th at Great Ormond Street (Ying Foo and Tony Reynolds). We are awaiting dates for lysosomal enzymes, urine organic acids, acyl carnitines.

GB
JB and ND

Best Practice Guidelines Update

It was noted that one guideline has been sent for peer review (hyperammonaemia) and four others are in first draft format. It was hoped that the first guidelines would soon be on the web site.

5.5 Survey of Service Provision

The questionnaire has already been circulated to all members with a closing date of 1st December. Members were urged to be honest and open in their responses. **It was agreed** that we needed a meeting in February 2004 where the majority of the time was to be devoted to discussion of the data from the survey questionnaire.

6. Network Infrastructure/Organisation

6.1 Membership Representation

The issue of Network membership and associate membership was discussed. **It was agreed** that laboratories providing specialist tests, but not necessarily providing the core tests, e.g. specialist neurotransmitter assays, should be invited to be associate members of the Network, and their tests should be listed in the metabolic assay directory. They should also be invited to provide data for the survey of service.

This would include the following laboratories:-

The Queen's Square Laboratory, London (neurochemistry)

University College Hospital, London (oxaluria)
Oxford (pyruvate metabolism/mitochondrial assays)

ACTION

It was agreed that other laboratories that do not provide specialist tests, but perhaps provide some of the core tests, should be encouraged to work with the other laboratories within their region/geographical area, i.e. as a 'cluster'. AG will contact those members who have expressed interest to put them in contact with the other laboratories within their area.

AG

BIMDG representation/links

AG reported that she had been circulating Graham Shortland, as Chairman of the BIMDG, with all Network correspondence. **It was agreed** that we should formalise this link by inviting the BIMDG to have an official representative to attend our Network meetings.

AG

Patient representation Links

It was agreed that we should formally write to the Genetic Interest Group and CLIMB to invite them to be formally linked with the Network, and to be involved, where appropriate, with specific initiatives.

AG

6.2 Network Action Plan

A revised action plan has been circulated to stakeholders electronically.

6.3 Financial

The financial position is healthy. Pay revenue is on target, and non-pay revenue at the moment is under spent for the financial year 2003/4. Members organising workshops or other initiatives were encouraged to expedite these within the current financial year.

6.4 Network Future

AG reported that a proposal to continue the Network infrastructure with some further developments had been submitted to the DOH in September. In the last two days, a response from the DOH has indicated that they would be prepared to continue funding for the infrastructure 'in principle' but that any additional funding, e.g. for trainer infrastructure, should be considered in the context of the Genetic White Paper bids. There was also concern that funding for some infrastructure to establish a disease data base gave concern as there was uncertainty about how this could be maintained. AG had been invited to re-cost the proposal, taking into account these comments. After

AG

ACTION

discussion, **it was agreed** that AG should re-submit the proposal to take account of these issues.

The on-going funding of the Network was discussed in brief, i.e. would it be eventually a subscription-based Network funded by commissioning. This requires further discussion and would be a topic for our next Stakeholder meeting.

The issue of who should undertake the role of Lead Scientist was discussed. AG indicated her willingness to continue, but equally well stressed the importance of making this opportunity available to others.

It was agreed that Jim Bonham would circulate the stakeholder membership requesting nominations for Lead Scientist so that we could have a clear way forward for our next meeting.

JB

7. Impact of the 'Agenda for Change'

Fiona Carragher presented some brief information about the Guy's pilot. There is concern about the impact of 'agenda for change'. There is very little information generally and members were urged to keep in contact with others.

8. Miscellaneous Items

A recent response from the MDRH to AG indicated that the matter was still under consideration and the issues raised have been referred to the legal department. Recent correspondence from Ian Young (Association of Clinical Biochemists) has shown a considerable adverse response to the interpretation of the regulations via the European route. We await the outcome of these further deliberations. Members felt that the 'do nothing' approach was the best action at this stage.

Jim Bonham outlined the EU bids which he is involved with. Bidders are invited to contact Jim for any further information.

9. Any other Business

AG reported that she has just had an invitation for the Network to attend a Health Care Scientists Event in London on December 9th and 10th. Nominations were suggested and Ying Foo, together with AG, agreed to attend the meeting to represent the Network.

The Chair thanked everyone for their continuing support and contributions.

There was no other item of business. The meeting closed at 4.35 p.m.

10. Date and Time of Next Meeting

It was agreed that we should meet in February 2004, and allow sufficient time to discuss the survey of service provision as a major item.

AG
December 2003

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