

National Metabolic Biochemistry Network

Minutes of Stakeholder meeting held on 25th February 2004 at Birmingham Children's Hospital

Present:	Guy Besley (GB)	Jean Kirk (JK)
	Jim Bonham (JB)	Steve Krywavych (SK)
	Don Bradley (DB)	Philip Mayne (PM)
	Andy Brown (AB)	Mori Pourfavzam (MP)
	Jacqui Calvin (JC)	Mary Anne Preece (MAP)
	Fiona Carragher (FC)	Geraldine Roberts (GR)
	John Fyffe (JF)	David Stansbie (DS)
	Anne Green (AG)	Valerie Walker (VW)
	Mick Henderson (MH)	By invitation:
	David Isherwood (DI)	Maureen Boxer (MB)

ACTION

1. Apologies

Mike Badminton, Ying Foo, Peter Galloway, Helena Kemp, Liz Trimble, Hilary Wastell

2. Minutes of meeting held on 11.11.03

These had been previously circulated. There were no comments.

3. Matters arising

Genetic White Paper bids for laboratories

Jim Bonham confirmed that Sheffield are taking forward their bid to the second stage.

Guidelines on the web site

The first guideline, on the Investigation of Hydrops, is now on the web site. Plans for the following further guidelines are well advanced:-

Hyperammonaemia, Hypoglycaemia, Seizures, Rhabdomyolysis

Electronic Learning

MH and JB confirmed that they were planning to meet with Kim Bartlett in the near future to discuss the way forward. It was felt that we should chose something 'do-able' and link these with other initiatives, i.e. The Association of Clinical Biochemists and the Genetics Knowledge Parks/Manchester Reference Laboratory.

MH/JB

ACTION

Accreditation

CPA has confirmed that they are happy to have a list of QA schemes which are available for specialist metabolic biochemistry assays (JB has already sent this to CPA).

After discussion, it was decided not to take forward any ideas about specific standards with CPA at this stage until it was clear about how the new CPA process was operating. At the moment, only three members of the Stakeholder

Group are inspectors.

Workshops

Successful workshops have been held on very long chain fatty acids (November 2003) and lysosomal enzymes (February 2004). GB plans to organise a follow up workshop on lysosomal enzymes in about one year.

Future workshops to be organised:-

Organic acids	Jim Bonham	
Acyl carnitines	Neil Dalton (FC will clarify whether he is still planning to organise this)	JB FC
Carbohydrate Disorders	Jacqui Calvin (excluding Galactosaemia as this is the subject of a BIMDG Workshop later in 2004)	JC
Non- Lysosomal Enzymes	It was agreed that AG ask George Gray to organise this.	AG
Mitochondrial Disorders	Jim Bonham	JB

Patient Links

AG confirmed that both CLIMB and GIG had welcomed the formal association with the Network. This would take the form of written and electronic communication and the potential to be invited to specific meetings/initiatives if the need arose.

Department of Health/Future of the Network

Ag confirmed that Dianne Kennard had confirmed that the Network would be funded for a further two year period, i.e. April 2004 – April 2006. Birmingham Children's Hospital would continue to host and AG would continue to provide the lead scientist role.

ACTION

4. Genetic Testing Network

The Network welcomed Maureen Boxer as Lead Scientist of the Genetic Testing Network. Maureen presented an overview of the Genetic Testing Network outlining the setting up of the test directory and the next stage of the application process for membership of the Network.

It was agreed that we should establish a molecular group to provide advice for inherited metabolic disorders testing, which would input into the Genetic Testing Network. Guys Besley agreed to take a lead on this initiative.

GB

5. Training Strategy and Plans

AG outlined the progress which had been made with the DOH Genetics branch with the Network training strategy. The following had been agreed:-

To appoint the equivalent of three trainer posts for England - funding was available for three years. Appoint up to eight HST posts across England – funding available for three years.

Initially it had been agreed that the first stage would be the appointment of two or three HST posts.

The job description for the lead trainer post had been agreed with the DOH. It would be a full time or a part time post (minimum of four sessions).

It had been agreed that Birmingham Children's Hospital would act the host Trust with an SLA, with the appropriate Trust where the lead trainer was employed.

It was agreed that the trainer post should be advertised in the ACB News Sheet with expressions of interest to the lead scientist. The appointment process to include an ACB assessor and members of the Stakeholder Group appointed by the lead scientist.

ACTION

HST Posts

The following centres are able to host HST posts, and have confirmed (* Bristol to confirm) that they will be able to provide the two-year pick-up funding for years four and five.

Birmingham
Bristol
Cambridge
Liverpool
London
Manchester
Sheffield

It was agreed that the way forward would be a joint advert option for all these centres. AG to discuss with the DOH the possibility of appointing more than two or three posts in this first round.

AG

It was suggested that we have an article in the ACB News Sheet about these HST posts in the same edition as the advert.

AG

It was suggested that this information is provided to the next ACB Training Course at Guildford in April. Contacts to be made with the organisers.

AG

Workforce Numbers Advisory Board (WNAB)

Lesley Tetlow debriefed on a meeting which had been held (see appendix)

Lesley agreed to continue with this initiative and take the lead for the Network. The following members were also suggested to form a small working group:-

Ying Foo
Jacqui Calvin

There was a need to link with the IBMS and a suitable senior BMS is required. This would need to be somebody senior, grade 3 or 4, working in the paediatric metabolic arena. Any suggestions to AG.

Further information for the WNAB is required for 6th May.

All

On a related subject, AG had been approached by Graham Beastall to

ACTION

provide numbers for a mini-workshop to take forward the national occupational standards (NOS) data sets. A workshop is planned for March 12th. It was agreed that JC, YF and Lesley Tetlow would represent the Stakeholders.

6. Metabolic Assay Directory

As part of the questionnaire, several members had suggested missing tests. These will be included in the repertoire.

AG/Janet Stone

Data via the questionnaire had been received from eleven laboratories ready for input into the directory. Missing data was required from Liverpool, Belfast, London (GOS), Newcastle, Manchester (Chemical Pathology). It appeared that several labs had sent this data but it had not been received in Birmingham.

DI/GR/YFH W/MA

It is noted that the plan for the future is to have an interactive directory whereby the test list is linked to a disease list. This is a future development.

It is also noted that the plan is to link with the Genetic Testing Network directory for molecular tests, i.e. the Metabolic Biochemistry Network will not include molecular tests.

AG/Janet Stone

It was agreed that the assay directory should have a disclaimer to the effect that the directory provides guidance on where to find tests, and users should refer to QA schemes and accreditation status before choosing. To check with ERNDIM disclaimer.

AG

It was agreed that mandatory fields should be included for accreditation status and EQA participation. The EQA participation to be a standard list format with a tick box style. JB's list of QA schemes could be used for this.

It was agreed that the remainder of the information, e.g. clinical interface etc., would be in free text format. To be communicated to Kim/Neil.

AG/Janet Stone

7. Service Questionnaire

This discussion was prefaced by thanks to all Stakeholder Members for returning the questionnaire which had been **100%**. It was a major achievement.

Preliminary data was presented (see attached file).

ACTION

Redundant Tests

It was agreed that oligosaccharides were of limited value. Use was clarified in the context of investigations for neurominidase deficiency, sialic aciduria and as part of a glycogen storage disease algorithm.

It was agreed that galactose-1-phosphate appeared to be of limited use and that this should be debated by the BIMDG Workshop with some clear recommendations forthcoming.

Thiosulphate was not clear cut, although it was accepted that the methodology was poor.

Cystine uptake continued to be needed.

Tests not easily available/required

A whole battery of molecular tests clearly need to be considered and made available. These should be taken forward by a sub-group (see item 4).

It was agreed that other specialist areas, e.g. specialist enzymes, need further discussion with individuals concerned. AG to consider setting up individual sub-groups.

AG

It was agreed that we needed further information about specific tests, i.e. how often had it been a problem obtaining the service? were labs in the UK planning to set specific assays up and when? AG to circulate a further mini-questionnaire.

AG

8. Staffing

The lack of a more formal out-of-hours analytical service was felt to be not sustainable for the future. There were accommodation issues for several laboratories for the future.

It was agreed that a small working group should take forward some of these ideas to prepare some proposals for discussion at the next full Stakeholder meeting. AG to establish a small working group to work on this. This will need to link to the Workforce Numbers Advisory Board agenda.

AG

ACTION

In summary, the preliminary questionnaire data analysis is as follows:-

Core Tests

The workload relates to population. There is a deficiency in acyl carnitine services in some laboratories.

Turnaround Times

Routine core tests – 30% were compromised by lack of clinical scientists time.

Accommodation for the next 5 years

50% of labs have inadequate lab accommodation.

75% have inadequate office accommodation.

Equipment

There was urgent replacement needs for 30% of the amino acid analysers. Three year replacement was required for 50% of the amino acid analysers and GCMS equipment.

Training

There was inadequate training capacity – trainer time a limiting factor.

Staffing

There were major issues for clinical scientists posts.

Future Work

There was support to work on producing workload units and the disorder register. However, both these items were felt not to be the highest priority at the moment. CE marking may drive the agenda for a Network approach to methodology.

A summary report of the questionnaire will be produced for the Department of Health. However, **it was agreed** that we would need some solutions and proposals for the way forward for some of these major issues before presenting this. This will be the subject of the next meeting.

9. Any Other Business

The RCPATH and the ACB have agreed to more formal links with the Network. The ACB link will be via the Education Committee and the RCPATH link will be via Paediatric Clinical Chemistry – Lesley Tetlow is on the SAC.

AG is exploring the possibility of links to the RCPATH SAC in Genetics via John Crolla.

10. Date of Next Meeting

It was agreed that we should try to meet in late June – dates to be circulated.

ACTION

AG

MD

APPENDIX

WRT REVIEW OF WORKFORCE NUMBERS IN HEALTHCARE SCIENCE IN CLINICAL BIOCHEMISTRY, TOXICOLOGY, PAEDIATRIC METABOLIC BIOCHEMISTRY

4 February 2004

Other Attendees

Howard Worth

Alan Wainwright (Exec Director of Education, IBMS)

Virginia Murray (Clinical Toxicologist, Guys and St Thomas)

Graham Groom

John Kane (Chair Elect, WAC)

Robert Simpson (Head BMS, St Thomas)

Brief Summary and Action Points

- Debbie Hilder was grateful for your efforts in part completing the proforma at such short notice. Deadline for full completion early May. She is happy for us to omit anything we feel is inappropriate or irrelevant and to add information that we feel is needed.
- Is a WRT website – if you e-mail Debbie (Debbie.hilder@hants-wdc.co.uk) she will provide password access to the website.
- Problems exist with completing the proforma for biomedical scientists since IBMS does not represent the whole workforce. We need to obtain the figures and info regarding biomedical scientists in paediatric metabolic biochemistry. Robert Simpson was happy to assist with this exercise but asked if we could find a BMS through the network who could work with him. We need also to give some consideration to MTOs.
- There was long discussion about appropriateness of collecting information on the workforce groups as they currently exist when career pathways are about to be redefined by the National Occupational Standards Group. Howard was adamant that the key was to identify numbers of staff required for particular roles with defined competencies. These can then be slotted in as appropriate to the new career pathway.
- In assessing workforce numbers for paediatric metabolic biochemistry we must include:
 - staff required for expansion of newborn screening.
 - Staff required for training (both within the laboratory and the community i.e. midwives, health visitors etc). We need to describe how we intend to deliver training UK –wide and any additional resources that we will require to do that.
- We need to look at such things as NSF for Children's services, NICE guidelines, MDA reports, National Recommendations for Screening etc etc to see if any of their recommendations have implications for the delivery and manpower requirements of our service.
- What are the implications of "importing" experts (e.g. from outside the NHS)? What resources might be needed to support their training requirements? Training of this group of staff to registration should be supported by the WDC.
- For medical trainees funding up to Consultant level is through the WDC. As a group we should consider whether the same should apply to Healthcare Scientists.
- AHP often given an increment above basic salary in recognition of training role.
- We need to consider the implication of out-of-hours/EWTD for our workforce. There are two aspects of this:
 - where the metabolic/paediatric service includes staff who participate in the overall departmental CPP/shift system.
 - Resources required to deliver a 24/7 service (or whatever we feel is necessary) specifically for paediatric/metabolic biochemistry UK-wide.
- Timescales: WONAB meet 7th/8th June. Papers need to be ready 2 weeks before. Debbie needs our contribution 4 weeks before. Aim is to target funding for 05/06. Is a further meeting of WONAB in Oct/Nov.

The date of the next meeting of the whole group is set for 5th May. This will really just be to tidy up the individual documents. It was thought it might be useful for us to have a separate meeting soon with Howard and Debbie. Robert Simpson and whoever we identify to work with him on BMS requirements for metabolic/paediatric biochemistry would also attend.

I am happy to continue to be involved if you think it would be useful. Graham Groome has booked me a room for 4th May (and paid for it) but it can be cancelled if need be.

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