

Present:

Kathy Bailey, George Eliot Hospital - Chair •
Clive Ryder, Birmingham Children's Hospital (Vice Chair)
Dr J Packham, University Hospital of North Staffordshire
Dr Karen Davies, New Cross Hospital
Janine Hackett - Birmingham Children's Hospital
Pam Whitworth, Birmingham Children's Hospital
Julia Greensall, Partners in Paediatrics

Apologies:

Ruth Upton, Parent Representative
Richard Brough, Shrewsbury Hospital
Annabel Copeman – New Cross

The meeting agreed to discuss item 3 on the Agenda first.

• **Meeting with Mick O'Donnell**

Kathy gave a summary of the issues discussed with Mick O'Donnell. Mick is the Associate Director for Specialised Commissioning Services.

Mick had explained that Rheumatology was not commissioned as a specialised service, and there is no intention for this to change in the next 1 -2 years. Mick had acknowledged that in some respects it was a service that would fit into the definition of a 'specialised service' ie - small numbers of patients, often requiring complex / expensive drugs.

Mick explained there are now 5 Local Collaborative Commissioning Boards (LCCBs) in the Midlands.

It was recognised there is an opportunity to progress the development of a business case as Stuart Poyner is Chair of the LCCB and of PiP now.

Aspects of the service that could be separately identified for regional provision were discussed. The safe provision of methotrexate, for which there is a regional disparity, was a clear example. No structure for commissioning across PCT/LCCBs makes this difficult, but may be easier than considering the whole service.

Important areas for LCCBs and commissioners are where there is NICE guidance or issues relating to drugs and equity of provision. Infliximab was highlighted as such an area that would warrant guidance from the network, working with public health, for its appropriate use. Inequity across the partnership areas was again highlighted.

Action: Clive to speak to Penny Davies at BCH, who is taking a lead for sorting out patients requiring infliximab, and Julia to speak to Jonathan Howell.

The importance of having nationally agreed standards of care, ratified by BSPAR, that encompasses the national drivers such as NSF, Every Child Matters, and Adolescent documents. It was suggested to produce a document for commissioners that incorporates

- Rheumatology is a hidden but important specialty
- The change in complexity and treatment used by the service (modernisation and change to the service is required to meet the needs of patients)

- Succession planning/CPD/governance
- Impact of delay in diagnosis and use of expensive drugs
- Inefficient practice – cost vs savings

It was suggested that in addition to working for service development the network should be responsible for offering guidance on service provision, which is put into a national context

Agreed: Important to push this issue through BSPAR in the future, but also need to address things at a local level too.

Action: Clive Ryder to attend the PIP Steering Group meeting - scheduled for Wednesday, 24th October to discuss the work of the Network Group and to try and get direction on what information needs to be collected for the development of the Business Case.

2 Matters Arising

- **Corporate presentation**

- The issue of how much the Consultants are teaching specialist registrars was discussed.

Agreed: It is important to continue to reach those doctors working in orthopaedics and A & E departments. Paed rheum is now standard item on regional teaching for paed, orthopedics, A&E, rheumatology

Actions: Clive to e-mail his 'corporate' presentation to all.

The organisation 'NHS Networks' was addressed. This to be looked at and see if the organisation can help with the commissioning side of things. The Rheumatology network to be put on.

- **Website**

The PiP website is being updated.

Action: The Rheumatology section will be updated in due course.

- **Questionnaire**

The Questionnaire is finalised and ready to be sent out, with supporting letter.

Agreed: Janine will look at results once finalised. We will then be able to show where there are deficiencies in service provision.

Action: This to be sent (both e-mailed and hard copies sent) to the Head of Therapy Services - at both the Acute & Community Trusts.

The Standard Assessment tool for physios /OTs & AHPs was discussed.

- **Audit**

Need to demonstrate deficiencies/inequalities across network with audit. Consider network audit of:

- o Methotrexate – against RCN guidance
- o Etanercept – NICE guidance
- o Standards of care, BSPAR if available or ARMA in interim

Agreed: Important to have Frameworks for audit - these to be agreed at the Medical Sub-group meeting to be held the following week.

- **Regional supply & distribution of Methotrexate & links with Pharmacy Consortium**

Clive had met with his Business Manager; he is supportive and agreed to talk to Pharmacy at BCH. The overall aim is to discuss and agree with the Pharmacy Consortium a mechanism for the central provision and administration of a home delivery service for Methotrexate (MTX), which ideally would be consistent for all patients across the region. Clive is keen to link with the interface technicians who deal directly with the PCTs over getting agreement for patients to receive MTX. All the required drugs are supplied on a 'named patient' basis.

It was noted that if drugs are delivered to the patients' home, it takes the VAT off the cost so it is cheaper for PCTs.

There are still different practices across the region. UHNS has a 'pan-agreement' across Shropshire & Staffordshire. There are problems at George Eliot with those patients from Warwickshire.

It was noted that some nurses are now coming to BCH, from local DGHs, to do training.

Action: Karen to speak to the Pharmacist, Saeeda Ahktar, at New Cross.
Clive to speak with Pharmacy at BCH, with a view to going to the Pharmacy Consortium to agree a consistent approach (in line with what the network agrees).

3. Second parent's day – 10th November 07 - New Cross Hospital, Wolverhampton.

There was considerable discussion about this second parents' day.

Agreed: Invitations will be sent to new patients and to those who attended the first day in January. Also, young people over the age of 11 (ie from Year 7 onwards) will be invited.

A separate letter will be sent to those who had previously expressed an interest in helping with the web-site and development of a newsletter.

The Flyer from the last event to be adapted and circulated.

Programme: For the AM - similar programme to that used in January.

Presenters:

Kathy - overview.

Pam or Nicky (to be agreed) - Drugs

Janine - Therapy issues (new diagnoses / patient assessment)

Then Break out groups for sharing experiences - to be facilitated.

For the PM –

Split group for adults and young people.

Adult Group:

Advances in Treatment - update on what's new - Clive (or Tauny)

Update on the network

Discussion with parents about issues teenagers may have - Janet?

Parents and young people's perspective - Ruth and ? young person?

Young People's group:

looking at the support for adolescents / coping strategies- Janine to lead.

break out groups - involve young people.

Parents will not be asked to make a financial contribution to the November event, but a question about contributions (about £5) for subsequent events will be included on the evaluation form.

Actions:

Janine to do a separate flyer for the young people and talk to Irene Bannister, 'Kids Like Us' about supporting the event. Also liaise with Bernie about attending.

Kathy to draft the letter to be sent out to those who attended in January.

Kathy to contact Caroline at CCAA, 'Contact a Family' and Ruth Upton about supporting the event.

Karen to talk to Wyeth about supporting the event.

Clive to talk to Tauny Southwood, Janet McDonagh and Penny Davies about the event.

5 East and West Midlands CPD meeting.

Agreed: The next meeting will be held in Nuneaton - for the West Midlands only. (Proposed date, 5th December). It is hoped that the date of the next joint meeting can be set for January 2008.

Action: Karen to speak to Helen Venning about this.

7 AOB

The next PiP Steering Group meeting is on Wednesday, 24th October. Clive attending.

The 'Kids Like Us' Ball is on 14th October at the Eaton Hotel - Hagley Road (£30 per head).

Peer Review / Audit - subject to be included on the Agenda at next meeting.

8 Date and Time of Next Meeting: Friday, 18th January 2008

10 am – 12.30 pm

Venue: Room 3, Stafford PGMC.