# Minutes

| Meeting | Date |
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| **UKPIN Steering Group** | Friday 4 April 2014 |

| Place | Time |
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| Royal Society of Medicine, London | 10.30am |
| 1 Wimpole Street | |
| Marcus Beck Library | |

**Attending**
Dr David Edgar (DE)
Dr D Kumararatne (DK)
Dr Matthew Buckland (MB)
Berne Ferry (BF)
Professor Sara Marshall (SM)
Dr Paul Williams (via phone) (PW)
Dr Richard Herriot (via phone) (RH)
Dr Scott Hackett (via phone) (SH)
Rachel Frankel, Contendam  (RF)

Apologies
Fran Ashworth
Dr Claire Bethune
Dr Helen Baxendale
Terry Flood,
Sarita Workman
Aarn Huissoon
Emily Carne
Gavin Spickett
Suzy Elcombe

| Item | Responsible | |
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| **Standards and guidelines – Scott Hackett report (SH)**<br>SH gave a full update on standards and guidelines:<br><br>*Three new guidelines* were put forward by prize winners at the 2013 annual conference. The three guidelines relate to<br>• CVID<br>• CGD<br>• IVIG administration<br><br>It was suggested that these guidelines should be circulated for one week to the Steering Group and if no one comments, then these three guidelines would be formally added to the existing guidelines.  It was agreed that this may be preferable to sending round to the entire membership.<br><br>SM suggested that the review of the guidelines (1) should be someone's responsibility and that (2) there needs to be 'executive control.'<br><br>DK suggested that the review should be evidence-based and cross referenced.<br><br>SM suggested that one of the newly-elected Steering Group members should be co-opted to review these guidelines. | | |

SH suggested that following this process of review by the Steering Group, the new guidelines might be circulated to the membership for final tweaks. PW suggested that the guidelines should be circulated for comment only (BSI takes this approach.)

It was agreed to take the approval and circulation process forward following the publication of the final results of the elections of the new members to the Steering Group.

*9 new guidelines* have also been proposed

The review is in process and each guideline has been assigned for review. The issue is chasing for results.

SH suggested two deadlines for review and comments from the current reviewers, then re-assignment if results are not forthcoming.

DK suggested suggests evidence-based review as the BSI does.

It was agreed to speak to someone at the BSI: It was also mentioned that Fiona Rayner (BSACI) can help with consulting on this. SH agreed to take forward and he will make contact.

**SH**

**UK PIN 2013 conference – Sara Marshall report (SM)**

Sara has already circulated slides to the Steering Group.

Overall there has been excellent feedback.  A very positive overview emphasised the fact that the Great Debate was a success as were the symposia, dinner, social – all worked well.

The strong thematic idea for the first day, the introduction of podcasts, and the inclusion of patient groups were all seen as positives and worked well.

In 2013, there were fewer discussions of short cases. Question: Can these be re-introduced in 2015?

Suggestions and comments for 2015
- Need more time for networking. Overall, networking was perceived as a good thing and comments indicated that participants want more of it.
- Nurses: How to be more inclusive?

Financial summary
- The conference earned £34K in profit; the profit budgeted was £20K.
- UKPIN made less of a profit this time, spent more, and got less sponsorship
- There were increased costs to deliver the event in 2013 as compared to 2012
- There was also increased investment in activities/products/services

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| such as podcasts etc. all of which received very positive feedback | |
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SM summarised suggestions for 2015 / future meetings: These include

- A Thursday-Friday conference, instead of one overlapping into the weekend
- 2 full days of meetings
- A need to engage/attract more young people and satellite sessions
- More/better use of posters
- A main theme worked well and should be retained
- There is a need to ensure a solid handover to next conference teams

SH asked: Should nursing content be the focus of one standalone day? There was a feeling that this might make nurses feel that 'the rest of the meeting is not for them.' It was suggested that
- a nursing-friendly session may be proposed for day 2,
- the important thing is for the nurses to come to the dinner,
- But can the nurses receive 2 days of study leave?

It was agreed that representative from key areas (areas that are now under-represented or not represented on the conference committee) should be drawn from the following groups
- Nurses
- Paediatrics
- Trainees

**2015 meeting**

Note: In 2015: MB is the Chair.

Actions and next steps include:
- Setting up of the 2015 local committee
  - The Steering Group was informed that suggestions for people to be 2015 LOC members have been received
- Confirming venue and destination
  - Belfast has expressed interest and will offer subvention income into the conference
  - The LOC will need to consider this among other options
- Confirming dates of conference
- Handover: SM will be handing over: Arrange time and place for handover to local committee (LOC)
- Determine and agree theme – MB asked for suggestions

**Steering Group**

**Accreditation – Claire Bethune report (CB)**

6 inspections are planned for this year; 2 have been completed.

4 sites were inspected last year, 2 centres have been accredited, 3 are working on accreditation.

Review of standards completed in December. The committee has approved these and they will go on website 1 May.

Notes on potential accrediting bodies / partners:
- **UKAS**: 'Badge of accreditation'
  UKAS are enthusiastic in terms of having a clinical scheme in their portfolio. They will look at our current standards vis a vis international standards. The Steering Group is waiting to hear.
- **CQC:** CB has met with the College of Physicians and the **Care Quality Commission** (already approving) are also interested in linking to accreditation schemes and have produced a set of standards which must be fulfilled.
- **RCP:** Very interested in running a portfolio accreditation scheme. Encouraged by the fact the immunologists have been running the scheme for 10 years.
  There was a meeting earlier this week. The Chair was interested in running the UKPIN scheme under the RCP umbrella. Their staff will look at UKPIN standards and do a gap analysis which will examine both UKPIN and CQC standards.
  Question: Will one of their team will join the next UKPIN inspection to better understand the system?

Background and notes on advantages to outsourcing the management of the accreditation scheme:
- The increase in activity has time and resources issues for UKPIN.
- Working through an accrediting partner would help to ensure impartiality.
- In terms of governance, it may be prudent to have some distance between UKPIN and schemes
- DE and DK noted:  accreditation will be paid for by the Trusts.  The advantage is that costs to develop the scheme are high. If costs are shared, benefits are shared by all parties.

PW commented: There are lessons to be learnt from allergy and from the practices of BSI and BSACI.  There is a feeling that the process will benefit from being a bit more simplified in order not to deter participation. Thoroughness, frequency, cost and detail need to be agreed and balanced against practicality.

DE commented: We will need a very well defined accreditation committee in view of this.

SM congratulated and complimented Claire and David for their hard work and success thus far.

SH and DE agreed that paediatrics must remain fully integrated in the scheme.

PW commented that not just the RCP but all Colleges should endorse. Might there be a parallel scheme through the Royal College of Paediatricians?

Timing: DE asked: Can this be finalised before the end of the year?

It was also noted that now, reaccreditation is every 5 years. Under the new system this is likely to be moved to annual inspections, which would place stress on the resources of UKPIN if managed in-house.

**Registry and registration – Matthew Buckland report  (MB)**

*Registration* is now heavily dependent on website. Needs to be overhauled as part of the new support service. Needs to be incorporated within accreditation.

*Registry:* staffing: Numbers have increased noticeably.
  • 2011 – 16 centres, 1300 patients
  • 2014 – 33 centres, 3027 patients

Staff update:
  • The new member of staff, Stephanie, is now on a month's trial .
  • Cathy: renewal of contract, can we increase her status to reflect .6 personnel  - up from .4 - overall.

New emphasis needs to be on data verification and quality.

New format and database being adopted in Germany and will roll over to the UK. The change is that there is a verification of field on verification of diagnosis.

Need to produce an annual report. DK asked if these can go on the website.

New projects and potential partnerships:
  • Projects between Royal Free and Peter Arkwright – this is the kind of project we want to do more of
  • Bronchiectasis network.  They are keen to include immunodeficient patients. Trials before the end of next year

**Constitution**
Has been adopted

**Membership of Steering Group – David Edgar report (DE)**

It was noted that 7 people self-nominated, 120 people voted.

In the recent nomination process there were no specifications for professions to be represented by members of the Steering Group.  In future such specification could include representatives from given disciplines such as nursing or the number of people from a given centre, etc.

The Steering Group also felt it would be sensible to have only one nomination from each centre, to ensure diversity of representation.  It was agreed that in future more than one nomination from a single centre should not be permitted in an election.

SM commented: We would be well advised to seek representation from underrepresented groups which include nurses, paediatricians, and scientists. Should we co opt members? It was agreed that next year, this should be encouraged.

RH commented: geographical spread should be taken into account.

It was agreed that if a multi-professional line-up of people is presented, more diverse groups are likely to vote.

The 4 successful candidates were as follows
- Tomaz Garcez
- Rashmi Jain
- Stephen Jolles
- Ravishankar Sargur

The following colleagues who are standing down were thanked
- Helen Baxendale
- Aarn Huissoon
- Lucia Russell
- Paul Williams

DE commented that he will notify all candidates - winners and losers -  and then the membership can be informed and updated.

**Networks**

It was noted that centres have been asked to tell UKPIN what their network arrangements are. DE's table, illustrating networks, will be placed on the website. DE noted that there are gaps as well as some excellent responses.

SM commented: Scotland does not participate, however: can we actively note "no network"?

The Steering Group will email additions and comment on data that needs to be deleted.

**Links with other societies**

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| What formal links should be set up?<br>Activities and benefits to be shared include: discounts, sharing education etc<br>• FOCIS<br>• CIS (They are discussing the link internally and have placed link on their website.) They were very positive.<br>• ESID has been approached. DE will circulate what has happened thus far.<br>• African society for immune deficiency. RH reported:<br>Positive feeling towards British medicine. The society addresses standards of care, training etc. In the early stages of developing the society.<br>Podcasts may provide a way though: Can we discuss<br>    ○ a library for training?<br>    ○ Subsidised registration, particularly for those submitting and having accepted abstracts.  Coordinate with BSI and other organisations for joint grants to African interactions. Revive the joint travel awards.<br><br>SM suggested: A UKPIN ambassador to ASID?<br><br>Action: DE will send an email to the secretary of ASID and we see a number of ways in which we can help and support | **Steering Group**<br><br><br><br><br><br><br><br><br>DE |
| **Prescription charges coalition – does UKPIN want to support this|?**<br><br>= a pressure group with the aim of removing charges for people with long-term conditions. Not popular with Government – but the argument is that this ultimately lowers health costs.<br><br>MB has supported as part of PID UK.<br>College of Physicians already endorses.<br>It was agreed that UKPIN will support<br>Action: DE will write to them to confirm support | DE |
| **Medikidz: Children's book on immunodeficiency**, needs comments and possibly badging with UKPIN<br><br>SH has already reviewed – BPL may sponsor - possibly will be downloadable online.<br><br>Action: the Steering Group review and comment and feed back through SH. DE will indicate UKPINs support to the developers | DE |
| **Oyster communications**<br>Clinical communities: will UK PIN support? Steering Group agreed they are familiar with clinical communities but do not use them. The group scans and circulates articles.<br><br>SM commented that this group seems quite commercial. Action/ response: right now this is not something to take forward. The reasoning is that UKPIN | SH |

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| is now concentrating on other more pressing issues and its own growth and administration. | |
| **Travellers**<br>A group of recently appointed consultants had a telephone conference that UKPIN facilitated. Richard Herriot thanked the Steering Group. | |
| **Standards and evidence**<br>IQAS standards and gone to the wrong address. The Steering Group was asked for comments. To be fed back to DE | **DE to respond** |
| **Financial report : DK report**<br>**Annual expenditure 2012-13 financial year**<br>In the current financial year UKPIN achieved £165k income – spent £65K – DK will forward the spreadsheet to Contendam. About £100K is being transferred to the new bank account. | |
| Action: DK will send the final accounts, including what is in the bank. | **DE** |
| **AOB**<br>Sara: working party on molecular diagnostics– 9 people want to be part of it and she will report back | |
| Action: It was agreed that flowers will be sent to Helen Baxendale | **DK** |
| Next meeting: telecom end of May or June. To be set up. Contendam to arrange with the Steering Group | **DK** |
| | **SM** |
| | **DE** |
| | **RF/Contendam to circulate dates** |