

UK PIN STEERING GROUP MEETING TELEPHONE CONFERENCE
Held at 02.00 pm on Monday 10 September 2012

Attending: David Edgar
 Berne Ferry
 Claire Bethune
 Sary Workman
 Matthew Buckland
 Scott Hackett
 Aarn Huissoon
 Richard Herriot
 Emily Carne

1.	Apologies	Action
	Kumar, Sara Marshall, Paul Williams Terry Flood, Gavin Spickett, Lucia Russell, Olga Bryce	
2.	Minutes of the last meeting	Action
	The minutes of the previous meeting held on 21 May 2012 were accepted as a true and accurate record.	
3.	Matters Arising	Action
	There were no matters arising to be discussed.	
4.	UKPIN Membership	Action
	To date there are 225 members.	
5.	Patient Advocacy Group: Update	Action
a.	<p><i>Update from group chaired by Caroline Harding</i></p> <p>There was a meeting held on 24 March 2012 sponsored by UKPIN and the BSI. A working group was established to try and create an umbrella organisation. This seems to have stalled a little bit, probably because of some procedural reasons and some misunderstandings. Caroline Harding and David Watters are working together to create a group and they hope to have something launched by the Autumn, which should be a positive development. It was unclear at present whether UKPIPS were actively involved with this project or whether we would end up with more than one PID charity. We would just have to wait and see what comes out of ongoing discussions. It was felt that the involvement of IPOPI in discussions with GDUK would be of reassurance that this is a useful and constructive organisation. The UKPIN Constitution will need to be revised in relation to patient representation, but it was agreed there was no urgency at the moment.</p>	

<p>b.</p>	<p><i>Proposal for strategic review meeting</i></p> <p>UKPIPS are very keen to meet with pharmaceutical companies involving UKPIN and the BSI but the purpose of this meeting was not presently clear and, therefore, it was probably not felt to be appropriate at this stage. It was agreed that when whatever patients' group emerge, UKPIN will need to work with them, but at the moment the position is rather uncertain.</p> <p>The costs of the patient support group facilitatory meeting held jointly with BSI in March were minimal to UKPIN.</p>	
<p>6.</p>	<p>Accounts</p>	<p>Action</p>
<p>a.</p>	<p><i>Initial budget build (2012-013)</i></p> <p>As shown in the minutes, the previous account showed a balance of £34,000 in May 2012. Kumar was concerned about the financial position, so David Edgar drafted costings for 2012/13 with input from Kumar, to try and establish prospective financial needs. This was previously circulated to the Steering Group. Essentially it appeared that an annual requirement of approximately £70,000 was needed, but looking back over the funding of sponsorship agreements, this was broadly in line with sponsorship raised over the previous years.</p> <p>In fact the funding situation was not as bleak as first thought. It was identified that some funding had not been received, that there was a second account held in BSI with a balance of £55,000. A further £68,000 is now held in the Cambridge account and there may be a small amount of funding in a third account that may be held in Newcastle. Invoices are also to be raised for a further £55,000 for funding not yet received.</p> <p>This means that UKPIN is in a very healthy financial position. How to manage future funds and the business side of UKPIN and moving all of the funding into one place was discussed and David Edgar felt that it should be placed in the BSI account and asked for views on this. There was general agreement that funding should be in a single account and David Edgar agreed to discuss the possible arrangements for this with the finance officers of BSI.</p>	
<p>b.</p>	<p><i>Review of previous sponsorship</i></p> <p>David Edgar had met with all current sponsors individually over the summer months. They were all very Keen to carry on supporting UKPIN. Even though a couple of the companies support has run out, they have</p>	

	<p>agreed to give support for this financial year.</p> <p>It was also agreed that the current level of sponsorship would be maintained, which should allow support for all necessary activity.</p> <p>c. Meetings with sponsors</p> <p>It was suggested that there will be a more business like approach with them in the future i.e. providing an annual report of activities and meet with them on an annual basis. Project specific sponsorship and global sponsorship ie. Baxter's sponsoring the central registration page was debated.</p> <p>d. Annual meeting funding (BSI)</p> <p>David Edgar is meeting with Peter Enyon and will discuss how the BSI would handle UKPIN funding, what support would be given and the costing if it was agreed to have them handling it in one individual place.</p> <p>e. Current financial position</p> <p>To date the financial position is very healthy</p> <p>f. Future requirements/proposals</p> <p>It was agreed that maintaining the current level of sponsorship will support all necessary activity.</p>	
7.	Review of Business Plan and Agreement on Strategic Priorities	Action
	<p>There was a review of the Business Plan and it was agreed on strategic priorities ie. UKPIN registration and centre registration and also raising the profile and function of the network.</p>	
8.	Meeting with BSI: Proposal for Closer Relations with UKPIN	Action
	<p>During June, David Edgar had a meeting with Bill Egnor and Judith Willetts when they discussed UKPIN having a closer relationship with the BSI and subsequent to the meeting Judith Willetts has produced a one page document suggesting how this would work.</p> <p>David Edgar has also drafted a SWOT analysis, which has been circulated, on BSI versus ACP as a potential home for UKPIN. David Edgar has asked for comments on both papers from the group before circulating to UKPIN members to give their point of view. It was agreed that apart from the BSI's paper from Judith</p>	Steering Group

	<p>Willett, the ACP should be given the opportunity to produce a paper on how they would host UKPIN. It was agreed that Gavin Spickett would be asked to speak to Mike Galloway, Chairman of ACP about producing a one page document on how they would host UKPIN if they are interested.</p>	G Spickett
9.	Meeting with Kenes (June 2012)	
a.	<p><i>UKPIN biennial conference 2013</i></p> <p>David Edgar had a meeting in June with Michael Forman at Kenes who are very keen to get the ball rolling for the 2013 conference. Sara Marshall has agreed to take this forward, who will keep everyone posted as to progress.</p> <p>There is a view at looking towards an annual conference as opposed to a biennial conference. Both because sponsorship are keen to support this and because there is a big gap between conferences. This will be up to the Conference Planning Group. With the development of the Clinical Trials Network they expressed an interest in combining their meeting with the conference. Combining the nurses meeting with the conference was also discussed. Emily Carne pointed out that this had been discussed with the nurse group board who had some concerns about merging the meetings. Discussions are still ongoing and Sarita Workman and Emily Carne were asked to keep Sarah Marshall and the committee updated on their final decision.</p>	
b.	<p><i>Proposal for strategic review meeting</i></p> <p>Kenes are keen to have a Strategic Review meeting with UKPIN regarding assisting with the website, communication, meeting schedules etc. It was decided to put this meeting on hold until a decision has been agreed with BSI.</p>	
10.	Specialised Commissioning	
	<p>Bill Egner has undertaken an extensive amount of work on specialised commissioning and defining the needs of an immunodeficiency specialised service. The model proposed is that Centres should organise locally into a minimum of 3-4 linked centres, which would become one specialist centre to meet Department of Health expectations. Paediatrics and adults and sections 2.2 on accreditation and section 4 on outcomes were discussed and further suggestions made. David Edgar will contact Bill Egner with relevant amendments/additions.</p>	David Edgar

11.	PID Registry and Registration	Action
	<p data-bbox="280 264 1098 297">a. <i>Update on patient numbers and centre involvement</i></p> <p data-bbox="373 331 1121 432">Matthew Buckland gave an update on the registry. There are 27 centres who have submitted data. He would like to send out a regular update on the registry.</p> <p data-bbox="280 465 751 499">b. <i>Mechanisms for data entry</i></p> <p data-bbox="373 533 1121 936">At present Cathy Bangs travels around the country entering data for centres. To make better use of Cathy's time, she will train Olga to enter some of the data, leaving Cathy time to train staff locally, where possible, to enter their own data, carry out governance and data audit work and quality control, which are clearly important. Olga Bryce will receive completed fax forms from centres for data entry. A few more centres should be coming on line. There are still some centres having problems with adoption locally and Matthew Buckland has been in touch with HQIP and they are interested in helping to facilitate this.</p> <p data-bbox="280 969 587 1003">c. <i>Quality control</i></p> <p data-bbox="373 1037 1121 1339">It was agreed that any kind of patient registration requires quality control ensuring that all necessary research governance is followed and that Cathy Bangs has demonstrated good strength and a huge amount of expertise with this and that her time should be used to this advantage. It was suggested that either Cathy Bangs or someone equally experienced to visit centres periodically to check everything has been entered correctly.</p> <p data-bbox="373 1373 1121 1507">Matthew Buckland will circulate the relevant forms, which will be completed by the patients to the steering group. It was unanimous that it is too much for Cathy to do it all.</p> <p data-bbox="373 1541 1121 1709">David Edgar pointed out that Belfast are entering their own data. He also stated that David Guzman has been asked to report any queries he has had already. The German registry is keen to have the reports completed at the same time, so that they be published together.</p>	
12.	Centre Accreditation	Action
	<p data-bbox="373 1814 1121 1881"><i>Proposal and SOP for accreditations and the possibility of interim/online accreditation status</i></p> <p data-bbox="373 1915 1121 2004">There are no accreditation visits organised. Claire Bethune contacted the Royal College of Physicians and the college feel they are not in a position to take on pre-</p>	

	<p>existing accreditation, but did express an interest in possibly becoming involved at some level i.e. accrediting the accreditors. There were concerns about the practicality of full accreditation. Self accreditation was discussed and deemed a possibility with a peer review at some stage. Accredited membership was also a possible idea.</p> <p>It was suggested carrying out 1-2 inspections and then to review the process</p> <p>The nomination of inspectors was discussed. It was suggested that 2 centres who have agreed to be inspected should be inspected within the next 4 months with 1 trained inspector and one another, over a one day period instead of over 2 days and then review the process.</p>	
13.	Writing Group	Action
	<p>There are 2-3 nurses who have volunteered to review guidelines at the moment, but there have been no volunteers from any medics. There are 400-500 various guidelines and protocols to send out to the group. Reviewing the documents as opposed to rewriting them was agreed. Asking juniors who have past their Part 2 to review 1 document per year, liaising through the Writing Group, as part of their portfolio was suggested and agreed to be a really good opportunity for them. Scott Hackett will circulate a spreadsheet of what he has got and on structure and progress.</p>	
14.	Website Update	
	<p>There are now live figures for the registry on the website updated manually by Mike Laycock who is now working actively on the website liaising with David Edgar and Olga Bryce.</p>	
15.	Any other Business	
	<p>Travel Expenses Policy has been reviewed and following the policy of the College of Pathologists was suggested by Kumar which was circulated to the Committee and agreed.</p>	
16.	Date of Next Meeting	
	<p>Telephone Conference to be arranged November/ December 2012.</p>	Olga Bryce