

**UK PIN STEERING GROUP MEETING**  
**Held by telephone conference**  
**On Friday 14 December 2012**

**Participants:** David Edgar – Chairman  
Richard Herriot  
D Kumararatne  
Sara Marshall  
Emily Carne  
Paul Williams  
Claire Bethune  
Berne Ferry  
Sary Workman  
Scott Hackett  
Olga Bryce

**Query:** Helen Baxendale?  
Aarn Huissoon?

<b>1.</b>	<b>Apologies</b>	
	Terry Flood, Gavin Spickett, Fran Ashworth, Lucia Russell,	
<b>2.</b>	<b>Minutes of the Previous Meeting</b>	
	The minutes of the previous meeting held on 29 September 2012 were accepted as a true and accurate record.	
<b>3.</b>	<b>Matters Arising</b>	
	No matters to discuss.	
<b>4.</b>	<b>UK PIN Membership</b>	
	To date there are 227 members. It was suggested that an email, with a list of membership attached, should be sent out to all members, asking them to check their details and to also let us know if anyone on the list has moved on or left the department and to also encourage those who haven't already registered to register with UK PIN. It was agreed that anyone who had previously been a member of UK PIN could remain as an emeritus member, by informing Olga on retirement.	<b>D Edgar</b> <b>O Bryce</b>
<b>5.</b>	<b>Patient Advocacy Group: Update</b>	
	<b>a. UKPIPS</b>  UKPIPS formed earlier this year and they held a meeting on 26 November 2012. There were a few clinicians and nurses at the meeting, and there was a large representation from pharmaceutical companies, who were asked to attend as	

	<p>support. Sary Workman attended on behalf of the nurses group and reported that she was impressed with their aims and targets. They are working with HAE UK, Genetic Alliance UK, Rare Disease UK, Rare Disease Consultation, Disability Rights Association and Information Standards Capita. She felt they were ambitious in what they would like to achieve, and that they required financial help to carry this out. Sary will send out bullet pointed minutes to the committee. Sary also mentioned that they do have a medical panel which includes Hilary Longhurst, John Hurts and John Dempster.</p> <p><b>b. PID-UK and IPOPI</b></p> <p>PID-UK was launched in mid November, 2012. PID-UK and IPOPI are meeting next week to discuss how they will work together. Susan Walsh (PID-UK) and Liz Macartney (UKPIPS) have stated they wish to work together for the benefit of patients. The Steering Group welcomed the fact that there are active patient organisations.</p>	
<b>6.</b>	<b>Accounts</b>	<b>Action</b>
	<p><b>a. Report</b></p> <p>David Edgar will circulate the finance statement/current balance sheet from the BSI. After discussions between David Edgar and Kumar, it was agreed that responsibility for management of the funds for UK PIN would be managed by the BSI. The income accrued consists of sponsorship of £55,000 received in 2012/2013, which was transferred to the BSI and they also hold £45,000 accrued from the UK PIN Forum. There was also a balance of £23,800 transferred over. Funds available on 11 December 2012 were £184,360. The closing balance of £6,100 will be retained until any late bills are paid and then the account will be closed. The plan is to transfer the balance to the BSI account. The billing of staffing costs was also discussed.</p> <p><b>b. Expenses policy</b></p> <p>It was agreed that expense forms should continue to be sent to Olga and suggested that they are sent to Kumar by pdf to avoid delay of payment. This was considered as an option.</p>	O Bryce
<b>7.</b>	<b>Sponsorship</b>	<b>Action</b>
	<p><b>a. Feedback from sponsors</b></p> <p>The sponsors are happy to be billed for their annual sponsorship and have all maintained their sponsorship at the same level as previous years. There are some sponsors that may want to sponsor individual projects.</p>	

	<p><b><i>b. Proposed annual information meeting</i></b></p> <p>It has been agreed that there will be an annual meeting with sponsors, to update them on the progress of UK PIN, including registration and accreditation. The first meeting will be held on 15 March 2013 in London. The next UK PIN Steering Group meeting will also be held in London on the same day.</p>	
<b>8.</b>	<b>UK PIN Constitution</b>	<b>Action</b>
	<p><b><i>a. Feedback from ACP</i></b></p> <p>This was discussed earlier on in the year and considered the possible linkages with either BSI or ACP. Gavin Spickett was tasked to approach ACP to ask if they would like to offer to host UK PIN in any way, or in a manner analogous to the BSI offer. He has not received any response from the ACP, therefore, the BSI is our most likely future host. Current suggestions suggest that if we proceed, it is likely that the CIAS and UK PIN would alternate the clinical seat on the BSI board.</p> <p><b><i>b. Proposal for closer relations with UK PIN</i></b></p> <p>It was agreed that Judith Willett's briefing paper should be discussed further and then send out to membership. David Edgar will speak to both Judith and Bill and then come up with a proposal and sent to the Steering Group before sending circulating the paper to membership.</p> <p><b><i>c. Patient representation</i></b></p> <p>In the past when UKPIN was formed, part of the structure of UKPIN was that the PiA was the patient representative body. There are now multiple disease related charities related to PID. This needs to be addressed in a revision of the UKPIN constitution. In the event that we become more closely allied with BSI, there is a BSI patient public engagement (PPE) body, which meets twice a year. Therefore, this is a consultation structure within the BSI, which could potentially provide UKPIN with an effective patient consultation mechanism.</p>	<b>D Edgar</b>
<b>9.</b>	<b>Specialised Commissioning</b>	
	<p>Bill Egner, Phil Wood and David Edgar sent out an email regarding specialised commissioning, particularly relevant to England and Wales. The parallel process to that is payment by results (PBR) and for the last year Ronnie Chee and Phil Wood have been working together to try and develop a PBR</p>	

	<p>template for PID. The funding of the activities was discussed. It was agreed that using April as the finalisation date was a bit ambitious. Paul Fenlon who is leading the DoH national commissioning group spoke to David Edgar and explained that they are keen that UKPIN are seen as leading some of the processes initially, mainly because of the central patient registry centre registration and accreditation schemes.</p> <p>Phil Wood is concerned that developing payment by results, was not necessarily appropriate for the Royal College of Pathologists, so he was suggesting that Ronnie Chee and himself should be doing that under the auspices of UKPIN.</p>	
<b>10.</b>	<b>PID Registry and Registration</b>	
	<p><b><i>a. Update on patient numbers and centre involvement</i></b></p> <p>There are now 2,334 patients registered on the website, so it is going very well in terms of recruitment.</p> <p><b><i>b. Submission of paper to CEI</i></b></p> <p>A paper was submitted to the CEI on the first four years of the UK registry, based on figures in October 2012, but 100 more patients have registered since then and continuing at a very good rate across all centres. A poster was submitted at ESID.</p> <p><b><i>c. Data transfer with ESID</i></b></p> <p>Matthew Buckland commented on some transfer issues and once this is downloaded from ESID, the figures are expected to rise. The route now, is to go through the servers at the Royal Free and then onto ESID. A paediatric update is expected next week, so the figures are expected to be higher.</p> <p><b><i>d. Mechanisms for data entry</i></b></p> <p>There has been some frustration about IT support, so an agreement has been made at the Royal Free that David Guzman will work one day a week on the UKPIN registry, which will be of a great benefit to those entering data onto the registry. The cost including overheads was agreed to be a reasonable amount.</p> <p><b><i>e. Quality control</i></b></p> <p>Cathy Bangs and Olga are to have further discussions on entering details onto the database.</p> <p><b><i>f. ESID registry modernisation project</i></b></p> <p>The ESID database is undergoing review, so the structure of this is likely to change towards the end of 2013. If so, UKPIN</p>	

	<p>will probably do the same thing. The idea is to try and improve the quality of data going in and data being analysed. There will be a more limited level 1 data set that everyone has to complete. UKPIN have received £28,000 from HQUIP in May 2011, which helps support Cathy Bangs' post and Matthew Buckland presented the progress to them. They were very pleased with the progress and very apologetic that they had only given limited funding and they have proposed that further funding will be forthcoming. Scott Hackett will speak to David Guzman and Cathy Bangs regarding the systematic way of entering data.</p> <p>Matthew Buckland's registration report was discussed. The registration is bi-annual, which means that re-registry is at the end of 2013. Matthew is meeting with David Guzman on a monthly basis to discuss any issues arising.</p>	<b>S Hackett</b>
<b>11.</b>	<b>Centre Accreditation</b>	
	<p>So far there are 2 centres arranged to be accredited in March and May this year. The system on the website for application for accreditation is dysfunctional, so all applications should be sent to Olga at the UKPIN office, until it has been sorted.</p>	
<b>12.</b>	<b>Writing Group</b>	
	<p>Scott Hackett explained that, so that he can work out what things are missing, he has put all the documentation he holds onto an excel spreadsheet and sent it around to the Steering Group. There are 3 groups working on Home Therapy, Immunoglobulin, Scig and ivig. Scott suggested that if all the documents were put into one Standard of Care format would be beneficial and that there was a need to simplify documents. It was also agreed that there were too many versions of each document and the need to bring everything together, making it very simple and basic and putting it back onto the UKPIN website, stating that this is the most up to date information. It would also make it much easier for accreditation purposes.</p> <p>Trainee registrars taking on one of the documents each was discussed and agreed that it would be advantageous to their portfolio. It was suggested initially, that Scott liaise with Matthew Helbert to take the lead in terms of delivering this.</p>	<b>S Hackett</b>
<b>13.</b>	<b>Website update</b>	
	<p>There is now a monthly update of patients on the Registry and also an acknowledgement on the Registration on the website. Mike Laycock maintains the website and the Steering Group are happy to continue with this arrangement.</p>	

<b>14.</b>	<b>Any other Business</b>	
	<p>The UKPIN biannual conference was discussed and the fact that the conference will be held at the same time as the IPOPI Organisation Conference organised in Portugal was also mentioned. The Steering Group felt that whether or not changing the date of the UKPIN conference should be considered.</p> <p>David Edgar will establish the names of members who are on the Conference committee, alongside Efrim Eren and inform the Steering Group</p>	<b>D Edgar</b>
<b>15.</b>	<b>Date of Next Meeting</b>	
	The next UK PIN Steering Group meeting will be held in London on 15 March 2013. Venue to be arranged.	