

UK PIN STEERING GROUP MEETING
Held on Friday 15 March 2013
In the Marcus Beck Library
The Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE

Participants: David Edgar – Chairman
 Lucia Russell (Secretary)
 Fran Ashworth (Secretary)
 Richard Herriot
 Sara Marshall
 Paul Williams
 Claire Bethune
 Sary Workman
 Scott Hackett
 Terry Flood
 Aarn Huissoon
 Matthew Buckland
 Olga Bryce

1.	Apologies	
	Gavin Spickett, Emily Carne, Berne Ferry, Helen Baxendale, D Kumararatne	
2.	Minutes of the Previous Meeting	
	The minutes of the previous meeting held on 14 December 2012 were accepted as a true and accurate record.	
3.	Matters Arising	
	It was agreed to continue with the existing travel expenses policy.	
4.	UK PIN Membership	
	<p><i>a. Update on review of membership contact details</i></p> <p>An email was sent out to all UKPIN members asking them to check and update their location and contact details.</p> <p><i>b. Need for annual update</i></p> <p>This proved to be successful and will be carried out on an annual basis.</p>	
5.	Patient Advocacy Groups Update	
	The PID UK was discussed and its existence was confirmed. A medical advisory panel has been established, but no	

	further details could be given.	
6.	Accounts	
	<p>a. Statement</p> <p>The finance situation has been reviewed and the situation is stronger than last year with a balance of £217,000, which is a combination of sponsorship we hadn't received, also continued sponsorship and the funding from the annual meetings.</p> <p>b. Current and anticipated expenditure</p> <p>The finances are now held by the BSI with all funding kept in a single account. The current annual total expenditure is around £63,000 per year with more than sufficient income received.</p> <p>c. Expense reimbursement forms</p> <p>Expense forms and receipts will continue to be sent to Olga, who will send them to Kumar for approval before going to the BSI for payment.</p> <p>d. Additional expenditure proposal</p> <p><i>i. Best Guideline/SOP annual award</i></p> <p>As the financial situation is good, UKPIN are potentially considering expenditure proposals. Kumar suggested an annual prize for the best Guideline and the offer of £500 for the best Guideline to be presented at the annual dinner. It was agreed that a second and third place prize could be awarded if submitted guidelines were of sufficient merit and funding permitted.</p> <p><i>ii. Junior Clinical secondment award</i></p> <p>Another recommendation was the establishment of a junior clinician secondment award, which could be for trainees or nurses to spend time in another department. An award of up to £2,000 per person as refund for expenses was suggested. Kumar suggested a maximum of 5 awards per year on the assumption that there would not be many applicants. This would also be put forward to the nurses group. This could also include foreign travel. Sara Marshall will devise criteria this award which will be publicised on the website.</p> <p><i>ii. UKPID Registry proposal</i></p> <p>There is further funding from HQIP to support Cathy Bangs' post, but there is a need for further data entry capacity. It</p>	

	<p>was proposed to look for a part-time person, possibly a band 5, not necessarily a nurse, for possibly 3 days a week. Including travel costs it is anticipated this will cost £36,000/annum, which would increase total annual expenditure to about £98,000 per year. Cathy Bangs will make enquiries to try to identify someone who may be suitable and interested.</p> <p><i>iii. Website</i></p> <p>Further investment for the website will be discussed at item 15 of the meeting.</p>	S Marshall
7.	Proposal for Closer Relations with BSI	
	<p>David Edgar updated on the proposed closer links with the BSI. Discussions initially took place with Judith Willis and Bill Egner last June. The ACP was suggested as a possible host, but the ACP did not respond, when they eventually replied they agreed it was a good idea, but by then it had already been decided to go with the BSI. The BSI then came back with a different proposal, which included an aspiration to establish an 'Immunology Clinical Trials Network'. Initial suggestions from BSI suggested this would closely involve UKPIN. There were also issues in relation to financial governance, representation on the UKPIN board and ring fencing of UKPIN funding. Having discussed the proposals face to face with Bill Egner in February, yet having subsequently received significantly different proposals by email, David requested the views of steering group on the proposals to date. These were discussed in detail and a range of concerns were raised by members. It was agreed that David & Richard Herriot should have a face to face meeting with BSI to clarify a number of issues prior to proceeding any further.</p>	
8.	Proposed Revision of Constitution	
	<p>The proposed draft amendment of the constitution, (which assumed closer links with the BSI) was discussed. Paul Williams thought the document was good and also made some valid comments. He proposed that the UKPIN Steering Group should have a face to face meeting at least once a year. The committee felt the AGM should be annually with the BSI or on a standalone meeting basis.</p> <p>Claire Bethune pointed out that now that the Accreditation Committee no longer exists, this should be taken out of the Constitution and Claire Bethune will email her views to David Edgar. The demit dates for members of the UKPIN Steering Group was verified, most of which is 2014. There would be a need to phase demitting of office to ensure continuity. The vacant trainee representative position was discussed and agreed to advertise the position through the trainee group.</p>	C Bethune

		D Edgar
9.	PID Registry and Registration	
	<p>a. Update on patient numbers and centre involvement</p> <p>The email sent out by the person handling the registration site, confirming a biannual registration, has been rectified, as it is in fact to be updated bi-annually during the autumn. Additional tools have been requested to make it easier to extract and maintain data. There are now 28 active documented centres and 2 centres who are not actively documenting and the latest number of patients is 2490.</p> <p>b. HQIP update</p> <p>HQIP are aware of the need for additional funding for the increase in activity and have offered a further £20,000 for this year, which will help support both Cathy Bangs and David Guzman's salary. HQIP are unable to commit themselves with regards to subsequent funding, but as long as they continue to exist, they would like to support UKPIN.</p> <p>c. Data entry strategies</p> <p>It was agreed another person is required to assist Cathy Bangs preferably a grade 5, because of the volume of work.</p> <p>d. ESID Registry redesign</p> <p>There are changes to the ESID registry, which will make data entry easier with improved quality.</p> <p>e. Revisions to Clin Exp Imm submission</p> <p>The proposal submitted to the CEI and access for entering data was discussed. This will be revised and circulated for comments by Matthew Buckland, with a deadline of 6 weeks.</p>	M Buckland

10.	Centre Accreditation	
	<p>a. Proposal and SOP for accreditations</p> <p>There have been 4 accredited centres since 2007 and there are 4 accreditation visits organised for this year, with 4 Centres interested for next year. It has been decided that to keep it up to date, there should 4-6 new inspections each year. Claire Bethune also recommended updating the Standards, she will read through them and then make suggestions and felt they should be updated every 2 years, but to first of all, make some minor changes and let them run for a while and then take on board comments from centres. As there is no charge for accreditation, this will also need to be removed from the Standards.</p> <p>b.. Training and re-training of inspectors</p> <p>As there is a need for further inspectors, Claire suggested that consultants and nurses from accredited centres could act as observers and then eventually inspectors. Training and retraining of inspectors has been agreed. A room will be organised by Sara Marshall to accommodate the inspectors for an informal get together at the annual conference.</p>	<p>S Marshall</p> <p>C Bethune</p>
11.	Writing Group	
	<p>Scott Hackett talked about the number of Guidelines and Protocols and stated he has reduced them from 450 down to 350, but that there could still be some duplication and hopefully will be reduced further to around 130. There are 2 or 3 nursing groups, but understandably people are extremely busy, so not able to get back to Scott. Fran Ashworth sent Scott a very comprehensive document. The idea of the document is to get everything into one document for ease of reference. Matthew Helbert sent out an email to trainees around one month ago and Scott has had one person respond, who has picked a fairly simple guideline, which Scott is happy with. He also felt that it is good time to let trainees know about the prize, which would also be supportive for their appraisals and portfolios and that the trainees would be given support and guidance. He also suggested that they could do one guideline per year each. He will ask Matthew Helbert to send out another email giving further information.</p>	<p>S Hackett</p>
12.	UKPIN Forum Meeting	
	<p>There has been a draft programme submitted. David Edgar will suggest that it should show more of the business of UKPIN eg. accreditation, registry and practicalities. The next</p>	<p>D Edgar</p>

	meeting will be held on Tuesday 19 March 2013, which has been scheduled to discuss the whole programme, when these suggestions will be made.	
13.	Meeting with Sponsors	
	The purpose of the meeting to be held this afternoon with sponsors, is to discuss public relations with sponsors. David Edgar will update them on what has been achieved over the past year and what the proposals are for the future. They will be invited to offer advice in areas not already considered and have a general open discussion.	
14.	Website Update	
	<p>a. Review of website</p> <p>It was agreed that the website is very good, but is due for a redesign. Sara mentioned the BSI website, which is very impressive and suggested that it would be a good idea to have input from the BSI. David Edgar felt that there was a need for a group of people to sit down and review it to decide what is required.</p> <p>b. Proposal for website redesign</p> <p>The website will be reviewed and then a decision will be made on redesign.</p>	
15.	Membership Consultation	
	<p>a. Proposed changes in structure/constitution</p> <p>Joining the BSI and provisions for the constitution was discussed.</p> <p>b. Awareness of and desire to be involved in UKPIN activities</p> <p>For any centres contemplating accreditation should be aware that requests will now have to be made for 2014 on a first come first served basis. With regards to accreditation guidelines, registry and registration, David Edgar asked for the Steering Group to forward to him any details they felt relevant for a membership survey.</p> <p>c. Specifically request interest in web redesign subgroup</p> <p>David Edgar will send out an email to enquire if there are any members interested in participating in the redesign of the website.</p>	<p>Steering Group</p> <p>D Edgar</p>

16.	Any Other Business	
	There was no other business to discuss.	
17.	Date of next meeting	
	To be arranged.	