

UK PIN STEERING GROUP MEETING
Held in the CUHK Room, Royal Society of Medicine
1 Wimpole Street, London W1G 0AE
Thursday 29 September 2011

Attending: Phil Wood (Chair)
D Kumararatne (Treasurer)
Fran Ashworth (Secretary)
Lucia Russell (Secretary)
David Edgar
Terry Flood
Aarn Huissoon
Rashmi Jain
Claire Bethune
Matthew Buckland
Carrock Sewell
Olga Bryce

Apologies: Joe Unsworth
Berne Ferry
Paul Williams
Scott Hackett
Chris Hughan

Partial presence by telephone conference: Scott Hackett
Paul Williams

1.	Apologies	
	Apologies were made for Joe Unsworth, Berne Ferry, Paul Williams and Scott Hackett	
2.	Minutes of the Previous Meeting	
	The minutes of the previous meeting held on 31 March 2011 were accepted as a true and accurate record.	
3.	Matters arising	
	The Management Document and Clinical Guidelines on Immunoglobulin Use are now ready to be placed on the website.	
4.	Finance – update	
	The current status is that £18,000 towards the website has been received during the last year. To date £44,000 has been spent, most of it on the website at £36,500 and meeting costs excluding travelling is £995, salary £4,600 and travel is £1,800. The current balance is now a healthy £36,944. We are now into the second year of funding of the 2 year agreement negotiated. Over the next 6 months the process will have to be repeated. There has been no	

	<p>negative feedback from the companies who have sponsored UK PIN so far, but because of the current climate, may not want to contribute as much next time. £20,000 was given for the website, in addition to the original sponsorship money. In terms of alterations in costs, the main issue is that at the last meeting it was agreed that UK PIN would fund Cathy Bangs to do her one day a week. David Edgar agreed at the last meeting to submit an application for registry to HQIP, who have agreed to give funding.</p>	
5.	UK PIN Membership Update	
	<p>At this present time there are 230 members of UK PIN. Phil Wood will demit office at the UK PIN Forum in December and David Edgar has been nominated and agreed to take over as Chairman of UK PIN.</p>	
6.	Website	Action
	<p>There has been a slight glitch with the website situation, which is separate to the registration system. Negotiations are ongoing with Mike Laycock to renew his contract with UK PIN, who has more or less agreed to continue. Phil Wood will contact him and formally reach an agreement regarding rates, software and training and also appoint someone to act as a back up when Mike is not available.</p> <p>There is now a tab on the UK PIN website which takes you straight on to the new online registration system. A letter will be sent out to explain that it is now up and running and that UK PIN would request that every centre now register on line, rather than on the old paper base system. There were some teething problems, but it is user friendly using drop down tabs. The registrations should be carried out before the UK PIN Forum in December 2011. There is a deadline, which is 25 November 2011, so that they can be analysed before the UK PIN Forum. Registering to be biennially after that.</p>	Phil Wood
7.	UK PID Registry Committee Report	
	<p>There have been a number of changes over the last 2-3 months, Viviane Knerr has left to start a new job and Cathy Bangs has taken over. Viviane was part time supported by the PiA, but they are not in a position to continue the support any longer, because of a change in their financial position. UK PIN will support Cathy, who is doing a very good job, for one day per week. Cathy is very experienced in Research.</p> <p>Bodo Grimbacher is moving back to Freiberg and is on a part-time basis at the moment doing 3 days a week at the Royal Free and 2 days in Freiberg and then from January</p>	

	<p>he will reduce his days. David Guzman will be staying as IT support. David Edgar will have a meeting with Hans Strauss and Bodo Grimbacher during the next couple of months to discuss keeping David Guzman, or may be have a junior person who he could supervise. It is likely his work will increase and the reason is UK PIN are now in a position where have 80% of UK centres signed up with either final approval or near final approval. There is only data on the Registry from 14 centres, so need to move on to more data entry. Or it may simply be to ask centres to enter their own data, where most centres don't really have the resources to do that. Otherwise, find a way to secure more data entry, which will mean more IT requirements, because centres may want to run queries etc. The feedback from Specialist Nurses, is that that once Cathy has explained what is required in completing the registration forms, they have found it fairly straightforward to complete. The difficulty will be the detail collection, because that is what takes the time. Once everyone has become familiar with what is required, it was felt that it will be much less of a hurdle. Once the core data is complete it will be easy to complete the annual updates. Patients could fill in a sheet stating how many days they have been absent from work etc while sitting in the waiting room.</p> <p>It was agreed that data entry was very important and to use £10,000 from core funds for the next 2 years plus the £20,000 from HQUIP to enable Cathy to work another day per week over the next 2 years</p> <p>It was suggested that a person be appointed to do a presentation on the registry and the personalised version of how it works in clinic, at the nurses meeting scheduled for May 2012. Or perhaps an open session which hopefully Cathy would be prepared to do ie. a stand with a big screen.</p> <p>7a. Request from SWIAG to survey assessment of antibody deficiency (circulated)</p> <p>It was agreed that there will be no duplication in collection of data.</p>	David Edgar
8.	Accreditation Committee Report – Change of Chair	
	<p>The registration process is the main issue, which is now up and running, encouraging everyone over the next 6-7 weeks to use the on-line system to enter their data on-line. It is the same data as the previous paper version, which most centres have already completed, so therefore, it is a case of transferring details onto the on-line system. For those who are not in possession of their original registration, can contact Olga Bryce who will email a copy out to them.</p>	

	<p>Joe Unsworth now wishes to stand down from chairing the committee at the end of this year and Claire Bethune has volunteered the take over as chair person.</p> <p>To date there have been 5 accreditation visits outside of the pilot phase.</p>	
9.	Standards – Patient Involvement	
	<p>Phil Wood explained that he was keen to legitimise the Standards with external bodies, which will give them more weight with things like the Chief Executives etc and clearly the Care Policy Commission is a body that UK PIN could engage discussions with. The PiA was asked to send out a questionnaire on the Standards, which didn't happen, but there now has been a Patient Questionnaire sent out by Phil Wood and a total of 70 replies from 6 Centres have been received. It was surprising that a number of responses, primarily from specialist nurses, said that they had decided that the questions were too hard for their patients to answer, so they weren't going to distribute the questionnaire.</p> <p>The question now is whether or not to have another go at trying to get more patient data and was it felt this was the first thing to try. Carrock Sewell felt that 70 replies was a good number to go on and asked if there were any surprising answers, which Phil explained that there was not. It was agreed that if a few more Centres would send in their patient questionnaires would be appreciated.</p>	ALL
10.	DoH Guidelines and Demand Management Plan	
	<p>It was agreed that these Guidelines were valid for a few more years.</p>	
11.	Writing Group Report	
	<p>Scott Hackett has had some Guidelines sent to him and he has actually got 259 documents to collate and put together and plans to hold a meeting of the Writing Group within the next 6 months.</p> <p>A very comprehensive document has been sent out by Phil Wood on 22q11 deletion syndrome for comments. He replied on behalf of UK PIN with some comments back to Richard Herriot, who was chairing that group. The main comments, whilst it was very extensive, was that it was slightly unclear on who should have all the tests done and how long should they be followed up and would they all want to have all the tests done in Immunology. There was no positive answer to any of those things. Phil Wood explained that the final version of document has not yet</p>	

	<p>been completed.</p> <p>Phil Wood wrote to Hilary Longhurst formally, to say that UK PIN would support an update of the 2004/05 Guidelines and made it clear that it shouldn't be a document that contained data that had been commercially sponsored directly. He hasn't heard anything further.</p> <p>Phil Wood also wrote to John White, who is the chair of the Standard of Care Committee for the British Thoracic Society, about management of lung disease and primary immunodeficiency and he was happy to consider the proposal and they wanted a scope and methodology document. Kumar said he would finalise the document and send it to them.</p>	Kumar
12.	Forum 2011 – Update	
	<p>It was agreed that Peter Arkwright has done a very good job with the Forum and that everything is running smoothly in terms of registration etc. The programme is finalised and looks good, but there is a shortage of abstracts and so the deadline has been extended because of this. The Forum starts on the Friday morning through to Saturday lunch time as previously and 'piggy backs' on the end of Travellers and ESR.</p>	
13.	BSI-CIAS Update	
	<p>Bill Egner has now taken over as chair of this committee. There is a telephone conference next week. Bill Egner is very happy with the current arrangement of the relationship as far as UK PIN is concerned.</p>	
14.	PiA – Update and Issues for UK PIN	
	<p>Aarn Huissoon was at the PiA annual general meeting and spoke to Chris Hughan, who is leaving the PiA at the end of October and the PiA as an organisation may cease to exist at the end of the year, because they have a funding gap between the start of 2012 until about June/July and funding will not make them sustainable again and will, therefore, have to dissolve. As a charity they cannot carry on during that time.</p> <p>Carrock Sewell suggested UK PIN could offer support to the PiA on this change, by offering to host a page on the UK PIN website and transfer the PiA domain name for a minimum amount of money. Therefore, typing in the PiA address would go to a holding page on the UK PIN website, which will explain what has happened to the PiA and that UK PIN are looking after things for now. Aarn Huissoon will speak to Chris Hughan to find out who owns the domain and ask to see if this is feasible. It was also</p>	

	agreed that PiA leaflets are invaluable.	
15.	AOCB	
	<p>Phil Wood congratulated Rashmi Jain on obtaining her post as Immunology Consultant at the John Radcliffe Hospital in Oxford.</p> <p>Carrock Sewell informed the Committee that the journal Immunotherapeutics Quarterly has ceased after 10 years. Oyster Health Care has promised to sell the legal rights to the title, which Carrock could keep going provided there was a sustainable model for doing so. If there is interest in making it the UK PIN Journal or something similar. It was agreed that it is good place to put things that wouldn't get published and so would be worthwhile considering.</p>	
16.	Date of Next Meeting	
	The next UK PIN Steering Group meeting will be held at 5.30 pm on Friday 9 December 2011 at the UK PIN Forum in Liverpool.	