UK PIN Steering Group Meeting
Held in the CUHK Meeting Room
at the Royal Society of Medicine
on Thursday 31 March 2011

Present:	Phil Wood (Chair) Fran Ashworth (Secretary) Lucia Russell (Secretary) Chris Hughan (PiA) David Edgar Terry Flood Rashmi Jain Sarita Workman Aarn Huissoon Scott Hackett Claire Bethune Matthew Buckland
Apologies:	Carrock Sewell
Partial presence by telephone conference:	D Kumararatne (Treasurer) Joe Unsworth Berne Ferry Paul Williams

Phil Wood welcomed Claire Bethune, Berne Ferry and Matthew Buckland as new members to the UK PIN Steering Group

1.	**Apologies**	
	Apologies were made for Carrock Sewell	
2.	**Minutes of the Previous Meeting**	**Action**
	The minutes of the previous meeting held on 14 October 2010 were accepted as a true and accurate record.	
3.	**Matters Arising**	**Action**
	Management Document The management document is now complete and is now with Oyster in readiness for the May parliamentary reception. After launch the document will be made available as a pdf on the website to enable centres to use it at a local level.	P Wood

4.	**Finance Update**	**Action**
	Because of generous donations there is a healthy balance of £54,000 at the end of March. It is unclear at this moment whether the funding from Baxter's for the web base registration is included in this figure. Kumar to confirm. Companies have also kindly agreed to give separate funding for the UK PIN Forum for this year, despite their previous funding to UK PIN core activities.	Kumar
5.	**UK PIN Membership Update**	**Action**
	At this present time there are 229 UK PIN members registered. Aarn Huissoon asked Olga Bryce to devise a database dividing UK PIN members into lists of consultants, SpRs, nurses etc.	O Bryce
6.	**UK PIN Website Update**	**Action**
	Joe Unsworth and Phil Wood have been working with a company called UBS who have carried out work funded by Baxter to develop the web based registration site. There will be a log-in on the website, behind which people are going to be able to either register or re-register every 2 years. The system uses drop down menus which will be a lot quicker to complete than the current paper-based system. The final issue is to clarify if whether it is possible to populate the data that is currently held off-line onto it, which will be a preferred option so as to save registered centres having to register again. This still requires verification. There will also be statistics placed on site showing average numbers of consultants, nurses etc overall at Centres. Individual centre data will not be available to other centres. At this stage the site will be on a membership log-in basis only and is expected to go live in the next month or so. The data will be the same as is currently on the paper based registration documents previously completed and will be behind an individual Centre's log-in. Once all data is collected and correct and the website is live and updated for easy accessibility, the site will then go public. It was agreed that there shouldn't be open access to everyone's data, but that the Accreditation Committee will be able to have full access.	J Unsworth/ O Bryce

7.	UK PID Registry Committee Report	Action
	In terms of membership of the Registry Committee, Craig Simon from Liverpool has joined as replacement for Janet Burton. There has been good progress with both numbers of Centres involved and also with the operation to UK server. There are approximately 1400 patients registered on the UK Registry at the moment and the committee are putting together a report of the progress on the registry to date, which will also include some data on quality of life issues etc. Hopefully, this will be finalised by the middle of May. David Edgar confirmed that the UK Registry runs through the UK PIN website. Ongoing discussions are being held with David Guzman regarding potential options on redesign of the website. In terms of funding in the long term, there have been discussions about going for NIHR fund, which has not developed. Bodo Grimbacher and others have put together a separate application to the NIHR, looking at a personalised version of the Registry. The committee are also looking in Northern Ireland at some European funding and to try and get funding to do something similar.	
	Vivienne Knerr, the Registry Co-ordinator is in the process of leaving to work in Switzerland. One option to replace Vivienne is, because of funding, to employ someone for a lesser amount of time and Cathy Bangs, Manchester Royal Infirmary, who is working on the prion project, is already visiting centres and is quite experienced in the registry. She is already putting on data in Manchester and would be willing to replace Vivienne on a one day a week basis.	
	Phil Wood has had some correspondence with Cathy regarding breakdown of costs, which would have to be funded out of core UK PIN funds. Cathy estimated salary costs would be around £7,500 and travel costs could be around £1,500 per year for travel, which Phil thought was reasonable and that her services to Centres to help with completing the registration documentation and would be a great incentive to incite Centres to register. This was supported by Steering Group. Phil Wood to take forward.	P Wood
	It was agreed that MREC qualification is required to allow the personalised version to have MREC approval.	
	Marie Kirwan the CT nurse is due to leave the committee, but David Edgar is hoping to persuade her Trust to let her stay.	

8.	Accreditation Committee Report	Action
	There was an accreditation visit to Oxford in December, there were 1 or 2 minor issues, but they will be reaccredited this year. It was mentioned that not many Centres have applied for accreditation visits. Those who have been accredited all agreed that it very useful and could stop small departments from being overlooked. It was agreed that people are starting to look for quality indicators for services and if accredited there will be documentation to show what led to that process. Some specialist service commissioners may want to develop quality indicators for specialist services and that the current UK PIN standards could serve this purpose and would be preferable to more generic CQC standards. It was suggested that a map showing which centres are accredited should be shown on the website.	
9.	**Standards and Patient Involvement**	**Action**
	It was agreed that UK PIN should have user involvement in the Standards for all of the services. The Care Quality Commission requires that users will have been involved in defining quality standards for a service. Phil Wood had received input from the Expert Patient programme and individuals who had been involved with the King's Fund on the current standards in the development of a version suitable for patient review. This had been sent to the PIA for comment and Chris Hughan reported that this had been disseminated to the members. At the Travellers' meeting it was suggested that, as some patients are not necessarily actively involved with the PiA, it would be helpful to send those documents directly to specialist nurses at individual Centres, so that patients could have an opportunity to comment on the standards. It was decided to ask patients to complete a survey giving their views on the current Standards by giving an 0-5 score. The survey could be carried out whilst the patients are having their infusions. The results of the surveys will be collated for each Centre. Phil Wood to send out.	P Wood
10.	**DoH Guidelines and Demand Management Plan**	**Action**
	There is now a third edition of the Guidelines, which is about to be released and Alison Jones, Phil Wood and Richard Herriot were involved from the Immunology side and have preserved immunology in a broadly similar state to previously. It was clear that the DoH want less use of Immunoglobulin. Overall PID is relatively safe and that all red uses have no requirement to produce	

	outcome data. Blue indications, which currently include specific antibody deficiency, are likely to need some outcome data. Kawasaki's disease has been moved out of the PID section into paediatrics. Phil Wood would update the steering group when the final version was available.	P Wood
	Phil Wood stated that Octapharma are still going through the process with regulatory authorities and there is a deadline for further submissions. They are attempting to be included in the new framework agreement.	
	Phil has had a request from Octapharma to ask what UK PIN can do to promote Octagam, and the committee agreed to say that as an organisation, UK PIN are fully supportive of the maximum choice for patients in terms of products.	
	Subcutaneous treatment was discussed in length. The VTE event profile with Vivaglobin, identified by the FDA, was noted. There has been a survey carried out on subcutaneous and intravenous in the south west of England, but there was very little response. Phil Wood agreed to send this out to UK PIN members again.	P Wood/ O Bryce
	Claire Bethune raised concerns that other products may also have similar adverse events but we were not aware of the data. Phil Wood agreed to write to MHRA to ask for an update on this issue.	Phil Wood
11.	**Writing Group Report**	**Action**
	a. HAE guideline issue	
	Scott Hackett now chairs the Writing Group, which everyone agreed is a real uphill task. It was originally agreed to remove all of the out of date Guidelines from the website but because most of them have not yet been updated, it was decided at the last meeting to un-archive the documents and put them back on to the website until they are replaced by updated guidelines - this has been carried out. The difference between Guidelines and Standards of Care was discussed.	
	Lucia Russell and Fran Ashworth agreed to update the Home Therapy Guidelines.	L Russell F Ashworth
	Sarita Workman will send out an email to the nurses for input for the Guidelines, Rashmi Jain also offered to act as contact.	S Workman R Jain
	The issue of C1inhibitor deficiency and its management was discussed at length. Belfast had produced a very good set of guidelines for emergency management of angioedema, particularly highlighting hereditary	

	angioedema and these had been placed on the website. However as these had not included Icatibant Shire had raised objections and currently the guidelines have been taken off the website pending review. Phil Wood explained that for the last couple of years Shire has been requesting an update to the Consensus document, to include newer therapies including icatibant and the feedback has consistently been that this is required but nobody feels that they are not quite experienced enough with icatibant. Shire have produced data on the management of HAE across the UK, presented at the BSI meeting last year and would like t UK PIN into at least endorsing the use of icatibant as indicated in more recent international guidelines. The steering group did not feel comfortable promoting a company's product, and Phil Wood stated that this is explicitly excluded by the UK PIN constitution. It was agreed that the best approach would be to produce an update to the existing guidelines. Phil Wood will have some correspondence with Hilary Longhurst explaining that UK PIN could endorse the production of an addendum/update to the existing guidelines.	P Wood
12.	**Forum 2011 – update**	**Action**
	The Forum will start on Friday 9 December 2011, which will follow on the from the clinical session of the BSI, which will be held on Thursday 8 December 2011, for which a draft programme has been circulated. Kenes UK, the organisers of the Forum are in the process of setting up a flier for the website, giving all relevant information of the Forum.	
13.	**BSI-CIAS update**	**Action**
	Bill Egner has now taken over as chair of the group. Their next meeting is on Friday 6th May 2011.The group were happy to continue with the current links between the two organisations	
14.	**PiA – update and issues for UK PIN**	**Action**
	The PiA have exited from Jeans for Genes. The CGD Trust have taken back the trademark and will be handling Jenes for Genes from this point on, on their own. The PiA annual meeting is on 10 September 2011 in Birmingham and Aarn Huissoon has agreed to co-host along with Scott Hackett and their teams.	

	There is also a Parliamentary reception on 11 May 2011 in the House of Commons when they will be trying to raise the profile of PID and the work of the PiA. They have asked Phil Wood to speak on behalf of UK PIN and they also have some patients attending. The document for managers will be formally launched at this event.	
15.	**AOCB**	**Action**
	At the last meeting Kumar presented a proposal around management of respiratory disease in Primary Antibody Deficiencies. Kumar updated the committee and Phil Wood suggested approaching the RCP Clinical Standards Unit to try to develop a Guideline that could go in the RCP Journal, which provide some support around literature, searches etc. UK PIN will write to the British Thoracic Society officially to ask for their involvement.	P Wood
16.	**Date of Next Meeting**	
	Friday 9 December 2011 at 5.30 pm at the UK PIN Forum, ECHO and Arena Conference Centre, Kings Dock, Liverpool Waterfront L3 4FP.	