UK PIN Steering Group Meeting
Held in the Cavendish Boardroom
at the Royal Society of Medicine
on Thursday 14 October 2010

Present:
Phil Wood (Chair)
Fran Ashworth (Secretary)
Chris Hughan (PiA)
David Edgar
Terry Flood
Carrock Sewell
D Kumararatne

Apologies:
Rashmi Jain
Paul Williams
Aarn Huissoon
Sarita Workman
Joe Unsworth
Matthew Helbert
Lucia Russell
Bodo Grimbacher
Scott Hackett

1.	**Apologies**	
	Apologies were made for Rashmi Jain, Paul Williams, Aarn Huissoon, Sarita Workman, Joe Unsworth, Matthew Helbert, Lucia Russell, Bodo Grimbacher, Scott Hackett	
2.	**Minutes of the Previous Meeting**	**Action**
	The minutes of the previous meeting held on 11 March 2010 were accepted as a true and accurate record.	
3.	**Matters Arising**	**Action**
	Management Document This was still not published. There was a discussion on the requirements to update this. Phil Wood explained that the draft of the Health Management Document has been changed only very slightly over the last few years. Chris Hughan suggested re-circulating the document again, asking for opinions of whether or not there should be some things that should be added or removed from the document at this stage. Phil explained that when it was reviewed last time it was decided that it was generic enough to actually apply to whoever was commissioning the service, rather than being specific for a group. In Phil Wood's opinion the NHS commissioning board may well devolve all of this back down to GP commissioning, so it should still be adequate although further updates	Phil Wood/Chris Hughan

	may be required when new commissioning systems become clearer. All were agreed that publication was vital given the upcoming changes in commissioning proposed in the White Paper.	
4.	**Finance Update**	**Action**
	There is a balance of £46,000.00, which will be available each year from the sponsors, which is a considerable improvement on previous years. There was £8,000.00 carried over from the previous year and so far £8,000 has been spent on salaries, £2,000 for supporting meetings and travel, and £600 for the website. There has been a substantial saving on the cost of meetings. Phil Wood explained that the funding was procured very much on the idea that we would have national data, national accreditation or at least registration etc., therefore we need to endeavour to deliver in these areas. We have signed agreements with each of the companies, which are a generic agreement, which do have a clause, which states they are entitled to reimbursement if it is not used for these purposes, so a conscientious effort will be made to comply with this. Chris Hughan suggested contacting the Binding site for sponsorship, but Phil Wood explained that the Binding site funds the dignitary that comes from somewhere else to give to comply with this. Chris Hughan will send names and details of others who may wish to sponsor UK PIN. Chris Hughan also suggested that UK PIN could register as a charity, but Phil Wood explained that after careful consideration a previous decision was against it and all agreed it was not a top priority, although remained an option for the future.	C Hughan
5.	**UK PIN Membership Update**	**Action**
	At the present there are 227 members registered. ***5a. Steering Group Membership*** An email will be circulated to say that as per the Constitution and list, there are 3 members whose service as members of the Steering Group is coming to an end. They are Terry Flood, Matthew Helbert and Bodo Grimbacher. It was agreed that a member could express their wish to stay on with the group, which would be permitted. Terry Flood expressed an interest in continuing as a representative for Paediatrics. Phil Wood would email the membership asking for expressions of interest and dependent on the response a	Phil Wood

	ballot of members may be required. As this would potentially be the last meeting for Bodo Grimbacher, Matthew Helbert and Terry Flood, Phil as chair expressed his thanks on behalf of UK PIN for their contributions to UK PIN activities.	
6.	**UK PIN Website Update**	**Action**
	6a. Update of progress on Registration and Funding for Modernisation of Website Baxter have given a one off funding grant, initially with a purpose of trying to drive the registration process to completion. Having discussed this internally, it was decided that it would not necessarily be the best use of the money and they came back with the suggestion that they could try to develop a web based data entry system, with tools to then analyse and potentially have that on line. The proposal is that a secure part of the website, behind a log-in, would provide a platform for data entry. In addition, some kind of comparative data for each centre would be available for each centre, on an anonymised basis, comparable to the Keele benchmarking process. It was agreed that each centre could compare itself to the ‘average’ number of consultants, nurses or patients etc. Due to the fact that some centres were still not registered (30 out of 36 registered), a decision on who should be allowed access will have to be decided and a decision made as to whether it should be within the public domain or not. David Edgar suggested that some data could have public access, but Kumar thought that this could be complicated. Carrock Sewell felt that it should have public access. Once the web tool is devised this facility should allow UK PIN effectively to collect information and export to an excel spreadsheet that can be analysed. A whole set of regional maps, which show the number of consultants, nurses etc and number of cases can be developed from the data. Once this is complete, a further discussion on who should have access will be discussed. Phil Wood had a conversation with UBS who have carried out the work on this project so far and Mike Laycock, who is at the moment responsible for the website and who will only be able to do so until the end of the year. Both Mike and UBS advised that the website should be redeveloped in a more modern format, which will allow it to be manipulated more easily. A decision will be required on whether to approach a professional company to update and maintain the website with the appropriate software and link it to the	

	data entry anticipated.	
	It was agreed that centres should be able to register their entries via the website. Phil Wood advised that the central aim is to make the website a dynamic resource for the organisation, which also has a public face which people will look at and it may have an interactive base with government/GP consortium/whoever, who will be using it as an information base.	C Sewell
	Phil Wood suggested asking Mike Laycock to provide a technical spec of what we have now. Carrock Sewell will ask Mike to put together a holding spec for keeping it just as it is and being able to turn the website on or off remotely for the time being. There is access to UK PIN membership via email to allow continued communication in the event of suspension of the website.	P Wood
	Phil Wood will send Carrock a copy of the specification of the data entry site agreed with UCB.	C Hughan
	Chris Hughan will send Phil Wood the name of the company responsible for the PiA's website. Carrock Sewell will seek advice from a professional, who will check out the website to give a ball park figure of cost, then advise whether or not to put it out to tender.	
7.	**UK PID Registry Committee Report**	**Action**
	David Edgar felt that the Registry meeting held prior to the Steering Group meeting was a very useful meeting. The main points were that they have lost Janet Burton as a member, but Fran Ashworth is going to put out an invitation to the nursing group. A name suggested during the meeting was Sari Workman.	F Ashworth
	The committee are trying to link with Teresa Cole, an SpR in Newcastle, who is currently redoing some CTD data. Linkage to the CTD Trust and the Aspergillus website was recommended. David Edgar will email Olga Bryce with instructions.	D Edgar
	The Centre status was discussed and there are 13 centres already approved centres and 13 in the process of approval, which gives a total of 26 out of the 36, which is good progress. There are a couple of others who have expressed interest.	
	The main concern was funding. Tony Williams and Chris Hughan have agreed to work in the next few weeks to putting towards a draft NIHR submission so that an application can be submitted, hopefully before the end of November and seek funding for additional data entry.	
	David Edgar was disappointed that none of the UK data	

	was yet on the UK-based servers, but there has been an issue with transferring data from Freiberg. After a meeting with Hans Kindl and Benjamin Gautchmann, operators in Freiberg last week, he thinks there is now an agreement that the data will be entered to allow a flow of information within the next month. There are some technical issues to resolve. David Edgar spoke to Ulrich Baumann, a Paediatric Immunologist from Hanover, about standardisation and follow up. He will send a power point presentation to David, who will circulate it to the Steering Group, which he feels is something UK PIN would want to support. David Edgar felt that there should be a link between the Registry and UK PIN website for access, which was discussed in length and it was decided that this should be accessed via the UK PIN website with a link to the Registry.	D Edgar
8.	**Accreditation Committee Report**	**Action**
	(Written information from Joe Unsworth who had sent apologies). Oxford is due a reassessment visit on 18 November 2010. There are 4 centres who say that they are entirely compliant with all standards, so they are going to be invited to apply for accreditation. A list of the minimum set of documents each centre would need was listed, which was well received, in that there were far fewer documents than was anticipated, and has begun to overcome the perception that there is a huge amount of work involved. Sharing information between Centres who have already been through the accreditation process and those Centres who wish to be accredited was suggested. Patient input for the Standards was discussed. Phil Wood wrote to a long list of patient organisations, asking them if they would provide UK PIN with any input into our Standards by virtue of pointing their membership to the Standards themselves - the only response received was from the PiA, with no acknowledgement from the others. The Steering Group and Chris Hughan had a full discussion about the PiA's views about the Standards and a questionnaire for the patients. A draft questionnaire will be devised by a joint effort between the PiA, the Steering Group and points of view from the nursing side. Fran Ashworth will send the nurses' views on to Chris Hughan. Fran Ashworth will make enquiries about Leicester's registration. An information leaflet on the definition on IgA deficiency was also discussed.	F Ashworth C Hughan
9.	**DoH Guidelines and Demand Management Plan**	**Action**

	IgA deficient patients were discussed. The Transfusion Service have contacted Carrock Sewell because they issue a leaflet and card to IgA deficient patients, which basically reassures them, but have now realised that some people with IgA deficiency can have quite significant problems. Carrock Sewell is now upgrading their information, with the recommendation that if they are having problems, then an immunologist would be the appropriate person to contact. Once the information leaflet is completed Carrock Sewell will send it out to the Steering Group and the PiA. ***9a. Immunoglobulin supply*** The main issue was the withdrawal of Octagam 5% and 10%. Phil Wood will circulate an email he received on Octagam regarding causes of strokes and TIAs to the Steering Committee. Kumar expressed his disappointment in the lack of communication from the pharmaceutical company via their company representatives - he felt that there should have been some sort of management plan. He also expressed concern that once the Strategic Health Authority disappears and commissioning goes to GP consortia it would potentially be individual consortia that would have to be contacted regarding provision of immunoglobulin (and other) therapy. It was suggested that guidance on required medication should be produced. Phil Wood pointed out that the Strategic Health Authority only play a supervisory role in the process at the moment in the sense that PCTs and presumably the GP consortium once they have replaced them, are told that they must follow the guidelines around funding of immunoglobulin for PID patients.	Carrock Sewell Phil Wood
10.	**Writing Group Report**	**Action**
	Scott Hackett has taken over from Cathy Cale as chair of the Writing Group. There have been several attempts to rewrite all of the guidelines, but this is now considered unrealistic as it is a huge amount of work. Phil Wood will contact Scott Hackett regarding the core documents. A question was raised as to whether UK PIN should produce the guidelines, but it was pointed out that if not, other countries' versions would have to be followed and that this would not be practical. It was suggested that each Centre could produce a guideline each, but it was decided that this would not be feasible. A question to whether the original Guidelines should have been archived was discussed and to whether they should have had up to date changes made and used as skeleton guidelines only. It was agreed that the archived guidelines should be un-archived for review. A list of the	Phil Wood O Bryce

	archived documents to be sent by email to the Steering Group.	
11.	**Forum**	**Action**
	Forum 2011 will be held on 9/10th December 2011 in Liverpool following on from the BSI congress although separately badged. The BSI will provide the administrative support. Peter Arkwright will be chairing the forum and has made excellent progress with organisation so far. A review of the programme was positive although it was agreed that Peter Arkwright will be asked to provide a couple of hours on the 9th for the UK PIN business meeting as it was felt to be rather rushed last time. In addition there would be a UK PIN Steering Group meeting, for discussions on guidelines, constitution changes etc and for the handover from Phil Wood to the newly elected Chairperson of the UK PIN Steering Group.	P Wood
12.	**BSI-CIAS**	**Action**
	There has been some tension between BSI-CIAS and UK PIN over the last few months about involvement of the BSI-CIAS with PID issues, but it was agreed that it is important to keep identity with the BSI-CIAS.	
13.	**PIA – Update and Issues for UK PIN**	**Action**
	Chris Hughan reported that a new HAE patient organisation has been established in the UK, calling itself HAE UK. He said that it was being driven and supported by the US based HAEI organisation. At this stage all that exists is a domain name and some individuals who are named as principles. This new venture does not believe that HAE is a PID and therefore should not be handled by an umbrella PID patient organisation - a view not shared by the Immunology community in the UK or PiA. He pointed out that in many other countries HAE is handled by other specialists and therefore there may be a need for a separate HAE Association. However in the UK HAE is clearly classified as a PID and is treated as such by Immunology specialist teams. In this context Chris Hughan reported that HAE membership of PiA is growing steadily and is now around 300 patients and their families. He said that no members had resigned or defected to the new entity and it was his view that in the longer term HAE patients would probably belong to both organisations.	

14.	AOCB	Action
	Lung Disease A paper was circulated to the Steering Group on Lung Disease in PID with a proposal that UK PIN should develop some guidance in the area. It was agreed that lung disease is a major problem and should be addressed in this way. It was explained that if information from UK PIN on lung disease was to go into a relatively high impact medical journal, the group would have to be explicitly multi disciplinary and have appropriate expertise analysis beforehand. If it was primarily for the immunology community and interested physicians, then it could be done more as a systematic review or consensus set of guidelines, with engagement of the British Thoracic Society. Kumar suggested UK PIN compile an interested group of people to carry this out, including respiratory physicians through Kumar's and other's contacts. David Edgar was aware of potential interest and would make some enquiries.	D Kumararatne D Edgar
15.	**Date of Next Meeting**	**Action**
	To be arranged in March 2011.	