

Steering Group Meeting

UKPIN



Client Name:	UKPIN	UKPIN, BMA House London
Today's date	16 th November 2016	

Meeting Participants:	<p>UKPIN Tomaz Garcez (TG) David Edgar (DE) Peter Arkwright (PA) Bill Egner (BE) Rashmi Jain Matthew Buckland (MB) Richard Herriott (RH) Sara Marshall (SM) Claire Bethune (CB) Kimberly Gilmour (KG) Suzanne Elcombe (SE) Christine Symons (CS)</p> <p>MCI Karen Clarke (KACL) Georgie Leonard (GELE)</p>
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	Responsibility	Action date
Apologies		
Gavin Spickett Ravi Sargur		
Introduction		
TG welcomed everyone to the meeting and thanked them for attending.		
Minutes of previous meeting & matters arising		
There were no matters arising.		
Reports		
Treasurer's Report		
RJ presented the Treasurer's Report and gave an update on the income and expenditure of UKPIN for 2015/16.		

<p>She advised that the main areas of expenditure are the Registry staff costs and administration. The income received this year was from corporate sponsors and the 2015 conference.</p> <p>RJ explained that it is very important that UKPIN look to secure further funding to ensure that they can continue with their existing work and TG advised that UKPIN have approached sponsors and have asked them to consider an increased amount of support and for a commitment of three years. To date 3 companies have confirmed that they will be supporting UKPIN in 2017.</p> <p>SM asked if the membership fees are projected figures. TG advised that they are, assuming that all current members pay the membership fee there should be an additional £17k - £20k.</p>		
<p>Registry Report</p>		
<p>MB reported that there are now over 4000 patients in the Registry. The Registry development plan includes a new website, combined reporting with MDSAS and simplified registration with access to historical data. Reduced staffing means that centres are only being visited once per year. For the future, MB would like to consider long term funding options and increased staff</p> <p>A discussion was held around the future of funding as The Registry does not qualify for NIHR funding. It was suggested that a small focus group work on an NIHR study in order to get NIHR funding. It was decided a Registry sub group will be created in order to look at future studies and funding options.</p>	<p>MB / SM Focus Group</p>	
<p>Accreditation Report</p>		
<p>CB presented a report on the Accreditation process. She explained how the process worked and that there are now 25 immunology services registered. Once a year centres that are registered but not accredited will be prompted to report on their progress. This update will run at the same time as an annual census of immunology centres – numbers of patients with different PIDs and staffing numbers will be collected to form an annual report. The committee agreed that it would be appropriate for this take the place of the UKPIN bi-annual registration process. Linking the census to the accreditation scheme means that the webtool can be used which keeps costs down and will also mean that centres don't have to repeatedly enter the same data for different schemes. However only centres registered with QPIDS will be able to take part, so need to encourage unregistered centres to register. There will be costs involved in chasing up centres to enter data and in data analysis. UKPIN steering group members agreed that they could help chase up those who had not completed the process if the RCP were able to provide a list of those who needed reminding. Regarding funding for data analysis, BSI are interested in working alongside accreditation team. A discussion was held on whether to share data with BSI. There was no objection to UKPIN working with BSI. CB asked all present to encourage their centres to register for the scheme. The</p>		

committee agreed to review again once financial implications of data analysis available from QPIDS team.		
Website Report		
PA informed the meeting that the website has been live for one year. The statistics suggest that the website traffic could be improved but this requires engaging content. He noted that visits to the website increase following the UKPIN newsletter. It was agreed that up to date content is needed to engage users.		
UKPIN 2017 Report		
KG updated the meeting on the 2017 Conference planning and confirmed times and meeting spaces that will be shared with BSI. KG confirmed that non-members will pay more for Gala Dinner and Conference fees. The next steps include reviewing the budget and looking at how to reduce costs.		
MDSAS Collaboration		
DE updated the meeting on the proposed combined UKPIN & MDSAS Annual patient and IVIG data base report. The production of a joint report is well underway. The aim is to produce data that will be useful for centres to compare their practice with other comparable centres. He noted that it will be crucial to ensure that we are comparing like with like. The report will be launched on 9 th December.		
Guidelines Report		
CB explained that a single first guideline is planned. The cost for professional guideline writers is approximately £10k. BSI have expressed that they too would like to be involved in the writing of the guidelines and are willing to share the costs. There were no objections. The next step is to meet in December to have a kick off meeting. It was suggested that CB take the lead on this project. All agreed.		
UKPIN Network Standards		
It was agreed that the UKPIN and Network Standards are to be put in the newsletter and on the website.	BE confirm version PA upload CB / MCI newsletter	
Department of Health Tariffs		
TG outlined the Governments plans for changing the tax structure around Plasma Protein Therapies. TG explained that UKPIN responded to this stating that the new pricing structure could force some small companies out.		
Max Appeal query regarding holistic care for 22q11 patients		
A discussion was held on the needs of 22q11 patients in adulthood. Most are discharged from immunology service as children. It was agreed that TG would respond to Max Appeal, UKPIN would host the	TG respond PA / MCI upload document	

advice sheet on the UKPIN website and QPIDS would add the document to the Knowledge Management System	CB add document to QPIDS	
Sharing complex rare cases		
BE advised on the background of the subject and made suggestions on how to discuss patterns such as online forums. A discussion was held on how to proceed with sharing information and suggestions included sharing cases within UKPIN, this will be for members only. Other suggestions include email notifications when new cases are added to a forum. MCI to see if email alert and forum is possible on website.	MCI	
Jonathan Sherrard Award		
The award is to be administered the same way as the UKPIN visiting scholar award. This will be included in the next newsletter.		
AOB		
No further business. TG thanked all for attending.		