

Steering Group Meeting

UKPIN



Client Name:	UKPIN	Teleconference
Today's date	5 th May 2017	

Meeting Participants:	<p>UKPIN Tomaz Garcez (TG) Bill Egner (BE) Rashmi Jain Matthew Buckland (MB) Richard Herriott (RH) Claire Bethune (CB) Kimberly Gilmour (KG) Gavin Spickett (GS) Ravi Sargur (RS)</p> <p>MCI Karen Clarke (KC)</p>

	Responsibility	Action date
Apologies		
Stephen Jolles		
Introduction		
TG welcomed everyone to the meeting and thanked them for attending.		
Minutes of previous meeting & matters arising		
<u>Registry Lead</u> TG reminded the group that a volunteer was required to be Registry lead on the Steering Group and asked that all consider this before the next meeting. The minutes were approved.	SG	
Reports		
Treasurer's Report		
RJ presented the Treasurer's report. The main income for Q1 was from CSL Behring and Octopharma. UKPIN continue to pay UCL a monthly amount towards the outstanding invoices from previous years for David Guzman's salary.		

<p>TG reported that Shire have confirmed that they are unable to honour an outstanding invoice from 2015. UKPIN increased the requested amount of support for coming years to cover this invoice so TG has increased the requested amount by £12k per annum. Requests over £15k must be approved by Shire Europe, who have rejected this as it is linked to the registry and what they consider, a research project. This must then be discussed with their medical division, TG will take this forward and report back to the group.</p> <p>KG confirmed that this should not have an impact on sponsorship for the 2017 meeting as both Shire and Baxalta have confirmed they will have separate packages.</p> <p>RJ confirmed that she will meet with a representative from Profile Productions, who have taken over the management of the 2017 meeting. KG asked how the finances of the meeting should be managed. MB confirmed that, from experience of the previous meeting, it is preferable for the conference organiser to hold a separate, ring fenced meeting bank account. All agreed.</p>	TG	June 2017
Registry Report		
<p>MB presented the registry report. He noted that a decision needs to be made on the staffing of the registry as Cathy Bangs will retire in November 2017 and David Guzman has now left his post and is employed as a casual worker for UKPIN by UCL. The SG are asked to consider if Cathy Bangs should be replaced as like-for-like or by two part-time staff in geographically distinct parts of the UK. The SG are also asked to consider if this position should be replaced at all. All agreed that it was necessary to maintain the staffing of the registry.</p> <p>MB expressed a preference to replace Cathy with 2 lower banded part-time staff members in different areas, to lower travel costs. All agreed that this is a preferred way forward and MB agreed to put together a proposal paper based on this, with costings from the Trust and University.</p>	MB	June 2017
Accreditation		
<p>CB presented the accreditation report. The process is going well with over 30 centres registered. All centres will receive information on the census during week commencing 8th May and already accredited centres will be asked to complete their annual return. CB asked for help from the SG in chasing those who have not completed the census, in due course. All agreed to assist with those in their geographical area.</p>	SG	Ongoing
Website		
<p>The report was taken as read. TG asked if anyone had specific questions, to contact Peter Arkwright directly.</p>		

UKPIN Meeting 2017		
<p>KG confirmed that Profile Productions are the new PCO for UKPIN 2017. They will also meet with RJ and MCI. A meeting of the organising will take place on Friday 12th May to finalise the programme. Profile are keen to finalise sponsorship and exhibition packages and distribute as soon as possible.</p>		
Guidelines		
<p>CB confirmed that work on the first guideline is progressing well. The first meeting has taken place and the group have started to put statements together. It is hoped that by autumn, there will be a publication with a literature review and consensus which will be ready for submission to publish with BSI in CEI.</p>		
Association Management/Conference Management		
<p>TG reported that following a survey of UKPIN Steering Group members, the consensus was for UKPIN to explore options of partnering with another organisation. Discussions had taken place with BSACI and BSI. Informal discussions with BSACI were not progressing however BSI were largely positive. A teleconference took place between Jo Revill (CEO) and Sofia Grigoriadou (Clinical Secretary) for BSI and TG, RJ and CB for UKPIN, which was a positive initial meeting and demonstrated that both organisations are keen to work closer together. BSI will bring this matter for discussion at their Council meeting. TG explained that a decision needed to be made soon. He recommended that if discussions with BSI do not progress rapidly that UKPIN should consider engaging with an external consultancy to help with the transition to an alternative association management company, but should continue to engage with BSI for the medium and longer term. All agreed with this way forward, should BSI not be able to provide support in the near future.</p> <p>TG asked the committee to consider how a partnership with BSI might work e.g. no change but continue to engage jointly on projects, a Memorandum of Understanding where both organisations remain separate but with enhanced joint working including secretariat functions or a complete merger or the two organisations into a new organisation. It was agreed to start with a MoU and in time, the two organisations can work closer together if appropriate.</p>		
Membership Fees		
<p>KC reported that, since the member communication regarding fees was sent, a total of 17 had paid their membership dues. It was agreed that the new communications will be included in the next UKPIN 2017 mail out as members are offered discount on registration fees and so this should act as an incentive for people to pay.</p>		
Disclosure of Interest		
<p>KC reported that only 9 members of the Steering Group have returned the disclosure form that was recently circulated. KC reminded the</p>		

committee that those who have not returned this will be listed on the website as 'no declaration received.'		
Patient Groups Requests		
<p>TG reported that following the stakeholder meeting in November 2016, there had been some queries from patient groups which need to be discussed by this committee.</p> <ol style="list-style-type: none"> 1) Request from PID UK re endorsement of PILs BE stated that this would be a good way in order to help UKPIN become more widely known however it would be essential to have a mechanism to ensure that the documents are reviewed adequately. After some discussion, the group agreed that UKPIN does not currently have the resource to be able to review these documents. It was agreed that TG would respond to PID UK and explain the decision and recommend that this role should remain within the remit of the PID UK medical advisory panel. 2) Patient representative on the Steering Group TG confirmed that this is not included in the Constitution of UKPIN however, it is important to discuss as a group. All agreed that the annual stakeholder meeting is the best forum for feedback to the patient groups however, throughout the year they can contact UKPIN via the office email address and a member of the Steering Group will get back to them. TG to respond as above. 3) UKPIPS literature review After discussion, the group confirmed that TG should respond and advise that UKPIN are unable to undertake a review of literature for UKPIPS due to resource limitations. 4) Regular meeting between patient groups (UKPIPS) and UKPIN Chair The group discussed this matter and agreed that the best forum for this would be the annual stakeholder meeting, with communications via the UKPIN office. TG to respond. 	<p style="text-align: center;">TG</p> <p style="text-align: center;">TG</p> <p style="text-align: center;">TG</p> <p style="text-align: center;">TG</p>	<p style="text-align: center;">Complete</p> <p style="text-align: center;">Complete</p> <p style="text-align: center;">Complete</p> <p style="text-align: center;">Complete</p>
Bank Account		
<p>TG explained that there had been some difficulty in accessing the UKPIN bank account, due to password issues with the MCI administrator account. After the change in directors in 2015, the signatories of the account were also changed to the new director, however it has since come to light that this request was never completed by the bank. The bank is located in Northern Ireland and TG asked if UKPIN should consider changing banks so that the branches are more accessible or just to change the signatories on the existing account. All agreed to maintain the existing account and to change signatories. MCI to initiate this process.</p>	<p style="text-align: center;">MCI</p>	<p style="text-align: center;">June 2017</p>

AOB		
<p>TG explained that a request had been received from David Edgar regarding UKPIN supporting medical students through awards and bursaries. TG reminded the group that a decision had already been made by this committee not to offer awards and bursaries to medical students. All agreed to maintain this policy but TG to advise David Edgar that other organisations such as ACP and BSI offer medical student bursaries.</p>	TG	Complete
<p>TG thanked all for attending and close the meeting.</p>		