

Steering Group Meeting

UKPIN



Client Name:	UKPIN	Regent Room, The Grand Brighton
Today's date	6 th December 2017	

Meeting Participants:	<p>UKPIN</p> <p>Tomaz Garcez (TG) Bill Egner (BE) Christine Symons (CS) Claire Bethune (CB) Kimberley Gilmour (KG) Matthew Buckland (MB) Peter Arkwright (PA) Rashmi Jain (RJ) Ravishankar Sargur (RS) Sara Marshall (SM) Suzy Elcombe (SE)</p> <p>BSI</p> <p>Liz Ambekar (LA) Jo Revill (JR) Angela Rausch (AR)</p>
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	Responsibility	Action date
Apologies		
Gavin Spickett (GS) Richard Herriot (RH) Stephen Jolles (SJ)		
Welcome		
TG welcomed all to the meeting.		
Minutes of previous meeting & matters arising		
The minutes were approved without amendment. All action points have been completed.		
Reports		
Treasurer's Report		
LA had circulated a draft profit & loss and balance sheet for 2016/17. The budget for 2017/2018 was noted. The main income was from membership fees, the annual meeting and sponsorship. TG stated there was no guarantee		

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<p>how much sponsorship would be received. The figures included in the budget were based on past figures. CB asked what would happen if no sponsorship was received. TG stated the registry would be stopped. SM stated the budget was very clear and easy to read. Sponsorship was discussed. MB felt this was an area UKPIN needed help with. PA asked how many people had paid membership and registration fees and how much money had been received. LA stated she currently did not have the financial figures. She had to chase outstanding membership fees and should have the figures early next year. JR stated that as BSI did not have a Congress every third year, they introduced three- and five-year membership to avoid a drop-off in membership numbers during non-Congress years. This seems to be popular with members. RJ asked whether payment by direct debit could be investigated. LA said she would look into the best options for UKPIN.</p> <p>It was queried whether Gift Aid could be claimed for membership fees. LA stated that in understanding as membership fees were not donations therefore Gift Aid could not be claimed. CB suggested to offer membership fees and conference registration as a bundle. Trusts would pay for the bundle. The issue of industry membership was raised and TG stated this would be discussed later in the meeting.</p>	LA	
Registry Report		
<p>MB had circulated the minutes of the last Registry Committee Meeting for information. Nearly 5,000 patients have been entered in the registry. The structure of the website has been changed and all patient data had to be re-evaluated. UKPIN entered data for most centres as centres did not have the capacity to do this themselves. Cathy Bangs has now retired and the recruitment process for a replacement is underway. David Guzman has a new full-time job but has agreed to continue on a casual basis until a replacement has been recruited.</p> <p>MB reported that NHS England was in the process of reviewing all national databases providing data on treatment and outcomes in specialist services. They currently funded some databases and could potentially provide funding for all such databases. UKPIN could consider stopping the UK platform and using the European platform. However, this would mean all patients would have to be re-consented and therefore this probably was not a sensible option.</p> <p>CRN has been considering exceptional adoption for nearly three months. CB asked whether there was anything UKPIN could do. MB suggested writing to them to inform them that Cathy Bangs had retired and UKPIN had no means of data entry. CB said she was happy to write to CRN.</p>	CB	

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<p>It was queried whether anyone had written to the MRC. MB has written to them but they replied they had no infrastructure for funding.</p> <p>JR asked whether industry requested access to data. MB said they did and they were charged based on the work required. TG suggested asking industry for a donation of at least £5,000 if they wanted access to data that did not involve significant work to extract.</p> <p>The Registry Committee has looked at MDSAS and UKPIN data with a view to publish data. The data sets are not an exact match as the data collection methods are different. CB asked whether UKPIN did not just duplicate the MDSAS work. MB stated MDSAS had no outcome figures. Data entry in the MDSAS database is compulsory and UKPIN have started a dialogue with them. MB feels publishing the data was important and the latest version has been written and is currently reviewed.</p>		
Accreditation		
<p>CB reported that currently 32/36 centres are registered with the QPIDS accreditation scheme. Nine centres were accredited under the UKPIN scheme and one centre was accredited under the new QPIDS scheme. Two centre visits are currently planned. A review of the existing QPIDS standards will take place over the next 12-18 months to bring them into line with CSAA standards. Changes will be phased in gradually and no changes will take effect in the next 12 months. Centres will be informed of all changes in advance.</p>		
Census		
<p>CB reported that the census will now be carried out annually and is open to non-members. The next census will be carried out in May 2018. The results will be published on the UKPIN website.</p>		
Website		
<p>TG had not asked for a report on the website as the site was going through some changes. PA thanked BSI for their help with moving the website. LA has sorted out all user accounts and the website is ready to be launched but some content was needed and decision made about the best way to launch. She will ask the Steering Group to do some testing and decide on a launch date.</p>		
UKPIN 2017		
<p>KG reported that the conference was on budget. There was a mixture of existing and new sponsors. The registration numbers were down from 2015. The Group discussed whether UKPIN should continue with biennial meetings and have more joint meetings. It was queried whether the meetings had to be held in December. TG stated this year's meeting was held in December as</p>		

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AGM		
TG asked Steering Group members to let him know if they wanted to make changes to the slides.		
New Trustees		
TG reported MB, RH, SJ and SM finished their term on the Steering Group at the end of the year. Five new Trustees have been elected: Austen Worth, Jill Edmonds, Lisa Devlin, Sarah Denman and Sinisa Savic.		
Sponsors might want individual time with SG to discuss joint working proposals		
<p>TG stated sponsors were keen to have individual time with Trustees and asked what process should be offered to them. After discussion, it was agreed to ask sponsors to contact UKPIN via the generic email address and requests would be reviewed on a case-to-case basis. If individual Steering Group members received requests from sponsors they should be forwarded to info@ukpin.org.uk.</p> <p>MB asked whether sponsors should be charged if they asked for advice. LA suggested that it may be worth writing a policy for accepting money. The policy did not have to be published. LA and JR will look into this and bring to the next meeting.</p>	LA/JR	
Vision		
TG stated the UKPIN vision was aligned with its charitable objectives, which are to advance care for PID, including to develop best practice approaches to diagnosis and management, guideline development, registry and education.		
Immunoglobulin Framework		
TG reported UKPIN had carried out a member survey and members had responded rapidly. UKPIN is not involved in the CMU process. They can offer assistance but it is not their role to insist on involvement, this was the role of NHS England. CB felt UKPIN should recommend that patients are involved in the process. TG said he could write to NHS England but the Group was unsure what would be achieved by more correspondence.		
AOB		
<p>MB expressed concern over the number of PID patients where a decision regarding transplants is made in childhood. Until 2015 the NHS position was to approve all transplantations but since 2015 adult transplantations are not considered. Some patients are well enough and have a donor but cannot be transplanted. The NHS England commissioning policy will be reviewed but this can take a long time. CB asked whether there was anything UKPIN could do. It was agreed that MB should write a UKPIN position statement and the Steering Group would then decide who to send it to.</p> <p>TG asked whether UKPIN should introduce industry membership. Industry membership was discussed. It was queried whether industry members would be allowed to sit on the Steering Group and vote at the AGM. There were some concerns regarding conflicts of interest and TG stated all Trustees had to complete conflict of interest forms which were published on the UKPIN website. SM felt there</p>	MB	

