Steering Group Meeting
UKPIN

Client Name:	UKPIN	Teleconference
Today's date	15th February 2017	

Meeting Participants:	**UKPIN** Tomaz Garcez (TG) Bill Egner (BE) Rashmi Jain Matthew Buckland (MB) Richard Herriott (RH) Sara Marshall (SM) Claire Bethune (CB) Kimberly Gilmour (KG) Suzanne Elcombe (SE) Stephen Jolles **MCI** Karen Clarke (KC)

	Responsibility	Action date
Apologies		
Gavin Spickett Peter Arkwright (PA)		
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. The main income for Q1 was from CSL Behring and Octopharma. The main expenditure related to the meetings in London, MCI and staff salaries. UKPIN continue to pay UCL a monthly amount towards the outstanding invoices from previous years for David Guzman's salary.		

TG reported that Shire have confirmed that they are unable to honour an outstanding invoice from 2015, therefore TG has revised the requested amount for the next 2 years, to reflect this.		
Registry Report		
MB presented the Registry report. Patient entry is doing well with over 4000 patients recorded. There will be changes to the staffing of the Registry as Cathy Bangs will retire in November 2017 and David Guzman is being made redundant from UCL. MB recommended replacing the technical role with a data scientist with up to two members of staff to do the data input and consider where they should be based to reduced travel expenses. A discussion took place on possible options and associated costs. It was noted that the costs of maintaining the Registry need to be circulated to the group in order to make a fully informed decision. It was agreed that a more developed financial model should be brought to the next meeting of Steering Group in May. It was also agreed that the IT support role should be covered in the interim once David leaves his post. MB to check if UCL can provide this on a consultancy basis. TG asked the group to consider who could lead on Registry from 2018 as MB's term comes to an end. CB suggested a member of the Registry sub committee.	**TG/MB/RJ** **MB** **All**	**10th March**
Accreditation		
CB presented the Accreditation report. There are currently 29 registered centres, 10 of which were previously accredited with UKPIN. CB asked that all present visit the QPIDS website and check that they and their colleagues are listed. The first assessment visit will take place in May.		
Website		
In the absence of PA, TG reported on his behalf. There are no issues to report.		
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KG reported that a Memorandum of Understanding with BSI has been signed.		
Guidelines		
CB confirmed that this project will be split 50/50 with UKPIN and BSI, developed through National Guidelines Centre. A plan will be produced in March 2017 and a meeting will take place in London of the Guideline Committee. It is expected that the first guideline will be written up as an article and published at the end of 2017.		
Membership Fees		
KC updated the group on the progress on the introduction of membership fees. An application has been made to a merchant account provider and it is expected that the approval of this will follow shortly. Once a merchant account has been opened, testing and integration will begin to ensure that the website is compliant and secure for taking payments.		

Patient Groups as members		
TG explained that this was brought up at the Stakeholder meeting in London. A discussion took place on if patient groups should be members of UKPIN. It was unclear as to why a patient group would want to be a member. The group discussed the possibility of an affiliate membership. It was noted that the UKPIN constitution does not allow for patient members. TG to respond to all patient groups.	**TG**	**Completed**
Newsletter Process		
TG explained that it is proposed that, going forward, each newsletter will have a specific theme and will be led by a different member of the Steering Group. The lead would be required to identify and send content for the newsletter to MCI and provide a short introduction and picture. It is believed that this will give the communications a more personal touch. A rota and deadlines document will be circulated.	**CB/MCI**	**3 March**
AOB		
TG reported that Ravi had sent a GMC statement for review. All agreed they were happy with this however it was suggested to remove the word 'recommended'. TG to report to Ravi.	**TG**	**3 March**
TG thanked all for attending and close the meeting.		