

Minutes of a meeting of the UKPIN Steering Group

Held at UKPIN Biennial Conference - 9/12/11

Liverpool

In attendance

Fran Ashworth (FA)

Lucia Russell (LR)

Claire Bethune (CB)

D S Kumararatane (DSK)

Terry Flood (TF)

Matthew Buckland (MB)

Carrock Sewell (CS)

Berne Ferry (BF)

Scott Hackett (SH)

David Webster (on behalf of PIA CEO) (DW)

David Edgar (DE)

Apologies

Phil Wood (PW)

Joe Unsworth (JU)

Paul Williams (PW)

Aarn Huisson (AH)

Chris Hughan (CH)

The meeting was held after the AGM of UKPIN. No formal agenda had been prepared, rather the steering group worked from issues that had arisen at the AGM and the minutes of the September meeting.

The steering group were sorry to hear that PW was unwell and wished him a speedy recovery. It was disappointing that Phil was unable to attend this Forum meeting, his last as Chair. The steering committee were very grateful to Phil for all his hard work for UKPIN as chair over the last 4 years and had purchased a small gift as a token of our appreciation.

Minutes of 29th September meeting were accepted as a true and accurate record.

Matters arising

No significant issues arose

Finance

The treasurer had presented his report at the AGM.

- I. The issue of redesign of the website and associated costs were discussed. It was made clear that the generous funding to support this development had come from a specific company who had stipulated the provider. Steering group therefore had no influence on cost/selection of provider in this case.
- II. The HQIP funding was discussed. There had been some difficulty in accepting the funding due to uncertainty about the appropriateness of this being paid into a charitable fund rather than to a "legal entity". DSK had however resolved the matter successfully and the first payment had been received.

UKPIN Membership

The membership figure was 232 at December 2011. The question of membership fees was briefly discussed but it was not felt necessary at this time. The process for applications to become a member is that all of these requests are reviewed by the Chairman.

Website

CS confirmed that the arrangement with Mike Laycock was informal and ad hoc. An hourly rate of payment had been agreed but there was no commitment on either side in relation to duration or extent of commitment.

The online registration functionality has gone live. There were a number of teething problems but these appear to becoming less problematic.

UKPID Registry report

The report provided to the AGM was very encouraging. 35/37 centres are engaged with the process and > 1500 UK patients are registered. HQIP have provided £20k over two years but DE indicated that we need to seek additional resources to aim for completion of data entry over the next 2 year period.

MB has kindly agreed to chair the UKPID Registry and based on the recent survey monkey questionnaire, will undertake a modelling exercise with Cathy Bangs to establish what resource we anticipate requiring to complete this work, prior to negotiating upcoming funding from Pharma companies.

Accreditation committee & Centre Registration

CB has taken over the chair of the Accreditation committee from JU. There have been no new applications for accreditation, but it is hoped that will develop over 2012 once centres have registered. The linked process of centre registration is near completion with the roll out of the online registration system. Joe will continue to oversee the centre registration process with support from Olga

Standards of Care/ patient involvement

DE commented that PW has sought CQC endorsement for the standards. (CB has a contact at CQC)

Subsequent to the meeting CB advised DE that CQC were no longer interested in endorsing accreditation standards. It is possible that we could consider approaching UKAS to seek their endorsement however it is likely that their expectations in terms of international standardisation of standard setting and compliance requirements would be excessively demanding for our purpose. This issue will not be pursued further at this stage

Writing group

SH provided a brief update. He has been collating lists of available documentation and plans to contact members of the writing group in the near future to organise a telephone conference.

UKPIN Forum report

The forum was regarded as a great success both in terms of content, venue, social interaction, attendance and financial management. The Steering group congratulates the organising committee under the chairmanship of Peter Arkwright.

Meeting with Kenes

DE sought views of steering group on the effectiveness of Kenes in support of the meeting. There was a generally positive response, those on the organising committee felt that Kenes had been effective, there had been some glitches with organisation of the dinner on Thursday evening, and some difficulties with communications however attendance, representation of different interest groups and nationalities and sponsorship had all increased substantially. It seems likely that UKOPIN will have made a profit c £40k from the meeting.

Michael Foreman (Kenes MD) had held discussions and met with DE at the meeting. They are keen to explore how Kenes might become more involved with us.

They were interested in UKPIN holding a satellite meeting at ECI Glasgow in Sept 2012. The steering group felt this was unlikely to be well attended due to conflicts with ESID and including constraints on leave and funding.

Kenes also have experience in establishment of charitable / plc status, which may be of interest to us. (NOTE: Chris Hughan had previously indicated to us a firm of solicitors with similar expertise who assisted PIA with this and may be able to assist UKPIN if required.)

They have a strong international network with London based office hosting 16 staff. Their expertise includes, management of meetings, website development, organisational support, educational

programmes etc. They would be keen to host a small focussed meeting with 4-5 individuals from UKPIN to discuss this further. The initial suggestion from Kenes was that they would charge a fee of £2500 for this. Steering group agreed that we should explore this further, however DE would approach this as an opportunity for Kenes to market to us and we would not expect to pay a fee.

PiA update

DW attended on behalf of PIA and confirmed that the charity would close by end of December. The steering group reflected the mood of the AGM in seeing this as a very unwelcome and disappointing development. PIA having been a crucial advocate for patients since it's foundation and central to the development of UKPIN.

DE suggested that we needed to consider the potential role for UKPIN in carrying forward patient advocacy and there was discussion about migrating some patient support information from the PIA website to a dedicated patients area of the UKPIN website. DW advised that he has had discussions with some fellow trustees about the possibility of establishing a new patient support group and welcomed the offer of support from UKPIN. There had been some discussion of utilising office space at BSACI offices.

DW and DE to consider further and circulate the group

Future meetings

It was agreed that our next meeting would be by telephone conference, probably in February 2012, with possibly two face to face meetings later in the year.

AOB

CS indicated that he was scheduled to demit office in 2012, but that this would be his last meeting due to other commitments. DE thanked him for his contribution.