

**MINUTES OF THE UKPIN STEERING GROUP MEETING**  
**Held on 29 January 2009**  
**at the Royal Society of Medicine, London**

**Present**

Fran Ashworth, David Edgar, Matthew Helbert, Chris Hughan (PiA), Aarn Huissoon, DS Kumararatne (Treasurer), Cathy Cale, Bodo Grimbacher, Carrock Sewell (Sec), Joe Unsworth, Phil Wood (Chairman).

<b>1.</b>	<b>Apologies</b>	<b>Action</b>
	Olga Bryce, Terry Flood, Lucia Russell, Carl Wheeler	
<b>2.</b>	<b>Minutes of the Previous Meeting</b>	
	The minutes of the previous meeting held on 15 September 2008 were accepted as a true and accurate record.	
<b>3.</b>	<b>Matters arising</b>	
<b>3a.</b>	<p><b>Administrative Assistant/Secretary</b></p> <p>Olga Bryce is currently off work due to illness; the Steering Group wishes her a speedy recovery and will make enquiries regarding her return to work plans. The Steering Group noted that in Olga's absence, there is no access to the UKPIN email account and this has disrupted UKPIN activity, including administrative access to the website. In future, backup plans for access to this account need to be made. The SG agreed that if Olga is unable to return to work, UKPIN would seek to retain the post at Newcastle as the administrative infrastructure is in place there.</p> <p>The Job Description for the Administrative Assistant/Secretary was accepted subject to the following amendments: (1) change the name of the post from Secretary (which is a Steering Group officer post) to Administrative Assistant, (2) note the Agenda for Change Band 4 payscale, (3) remove the location of the Steering Group Chair, (4) add the role of supporting the Guideline Writing Group (Now called the Standards of Care Commissioning Group).</p>	P Wood
<b>3b.</b>	<p><b>Consensus Document for Managers</b></p> <p>Publication of this document by the PiA has been delayed until Financial year 2009 because of the reduction in income from the <i>Jeans for Jeans</i> campaign. Chris Hughan confirmed that the PiA has a firm commitment to publish this document in 2009. This delay will permit the addition of material regarding PbR and HRG as well as managed networks. Matthew Helbert will provide this material within a week, and it is hoped to publish the final document in late March.</p>	M Helbert
<b>3c</b>	<b>Pandemic Influenza Guidelines</b>	

	<p>The draft document has not yet been received from the Royal Colleges; the Chair will chase this up with the Chair of the Immunology SAC of the RCPATH.</p>	P Wood
<b>4.</b>	<b>UKPIN PID Registry</b>	
	<p>The Registry Steering Group met in November 2008 and are working closely with the Accreditation Committee. Amendments will be made to the MREC application in two stages: (1) a description of the transfer of the database from Freiburg to the UK, and (2) adding the option of upgrading the system from being an anonymised database, to one capable of storing personalised information. Completion of this process is anticipated by late March.</p> <p>The National Institute of Health Research will be approached regarding possible funding of the Registry. The proposal to form subregistries was accepted. It was noted that the Registry would become part of the Royal Free Hospital's Clinical Governance structure. The Registry Committee will now formulate advice for each local centre as to how to enter their patients. It was thought unlikely that centres currently holding MREC approval would require additional approval procedures for the UKPIN PID Registry.</p>	
<b>5.</b>	<b>Finance</b>	
	<p>The current balance is £18,950.18.</p> <p>It was noted that CSL Behring sponsorship is due to continue to 2010. Given the current financial downturn, future funding options were discussed, as outlined in Appendix 5. Option No. 2 was accepted following discussion, leading to the following agreements: (1) in the future, other companies (including immunoglobulin manufacturers, laboratory equipment suppliers, and other pharmaceutical companies) would be asked to sponsor UKPIN jointly, rather than have a single sponsor as in the current arrangements. (2) Sponsors would be awarded differing levels of recognition, eg bronze (£2500), silver (£5000), gold (£10000) and platinum (£20000). P Wood will collect suggestions of companies to approach from all members of the Steering Group, and will draft a letter requesting sponsorship.</p> <p>The option of charging a membership fee was discussed, including the risks of poor uptake versus the advantage of inclusivity; no firm decision was agreed. Kumar will discuss the possible mechanisms for this with the Finance Department administering the accounts, in order to form future discussion. P Wood and C Sewell will arrange an on-line survey of the membership regarding their views about charging a membership fee. This issue will also be raised at <i>Immunology Forum</i>.</p> <p>It was agreed that funding for the <i>Immunology Forum</i> biennial</p>	<p>All Steering Group</p> <p>P Wood</p> <p>Kumar</p> <p>P Wood C Sewell</p>

	meeting should be kept separately from the UKPIN accounts, and that whatever option is chosen, access to the website would remain freely available to all.	
<b>6.</b>	<b>Membership</b>	
	No data was available regarding the current number of members	
<b>7.</b>	<b>Website</b>	
	The website is being updated, but the process was stalled by loss of access due to a password change during the administrative assistant's period of sickness absence. Access has now been achieved and updating is proceeding including adding a map of the Registered Centres. Consideration will be given in the future to a Press & Media page.	
<b>8.</b>	<b>Accreditation Committee</b>	
	<p>There are currently three fully accredited centres: Plymouth (2004-2009), Leeds (2005-2010) and Sheffield (2005-2010). No accreditation visits are planned for 2009 while a push is made to get as many centres registered as possible. There are now 27 registered centres, with several centres remaining unregistered. Reasons for this were debated at the Travellers Club, and may be due to a misunderstanding about the purpose and method of becoming a Registered Centre. It was agreed that circulation of the revised Standards should help reassure centres that have previously declined to be registered. The new Standards have now been finalised by the Accreditation Committee – and will be circulated amongst the Steering Group for final approval (along with the Assessors 'Crib Sheet').</p> <p>UKPIN has been asked about the possibility of sponsoring assistance with the process of data collection for Registration and patient entry into the Registry, by using Covance for administrative support. The Steering Group had concerns that simply funding general administrative support would lead to poor quality data, but the special skills of a dedicated clinical trial support company may obviate this problem. P Wood will explore the type of services that Covance can offer.</p> <p>It was noted that the Accreditation process may facilitate funding of clinical services through the various NHS quality assurance systems being developed, and that the Academy of Medical Royal Colleges has informed Royal Colleges that the Department of Health is looking for Colleges to support specialist Accreditation programmes. P Wood will raise this at the Immunology SAC.</p>	<p>J Unsworth</p> <p>P Wood</p> <p>P Wood</p>
<b>9.</b>	<b>Immunoglobulin Demand Management Plan</b>	
	The National Immunoglobulin Database continues to be developed in England, although not all centres have registered patients yet. This may relate to poor server speeds hindering the	

	data entry process.	
<b>10.</b>	<b>Steering Group Membership</b>	
	Jackie Moor has resigned from the Steering Group. It was agreed that the current Chair of the RCN Clinical Immunology & Allergy Group should be an <i>ex officio</i> member of the Steering Group (currently Sarita Workman). Carrock Sewell demits office as UKPIN Secretary and was thanked by the Steering Group for his work; he will remain on the Steering Group as Informatics Lead. Lucia Russell and Fran Ashworth replace Carrock as Secretary.	
<b>11.</b>	<b>Guideline Writing Group/Standards of Care Commissioning Group</b>	
	<p>The purpose of the Guideline Writing Group was discussed, and it was agreed that the group would be renamed the Standards of Care Commissioning Group, as Standards of Care (SOC) replace UKPIN Guidelines. All UKPIN Guidelines (draft and substantive) will now be withdrawn and archived. SOC will be drafted by an interested UKPIN member, discussed at the Commissioning Group, and emailed to the entire membership for comments. The Commissioning group will incorporate those suggestions and amendments that it sees fit, and the final version will be placed on the website; this process does not involve the UKPIN Steering Group which has delegated this responsibility to the Commissioning Group.</p> <p>Two SOC are now ready for publication: CVID and SCID. C Cale will send these final versions to C Sewell for putting on the website.</p> <p>Draft SOC are ready for circulation to the membership on: IVIG and SPAD. The email to members will include information about the process, and will ask for further suggestions of SOC and contributors.</p> <p>It was agreed that SOC will be reviewed every two years (unless there is a major unforeseen development requiring revision sooner). It was agreed that the current iterations of SOC will not have to state levels of evidence, but inclusion may be considered for subsequent revisions.</p>	<p>C Sewell M Laycock</p> <p>C Cale C Sewell</p> <p>C Cale O Bryce</p>
<b>12.</b>	<b>Specialised Services National Definition Set</b>	
	These were discussed with the following recommendations: (1) the frequency of primary:secondary immunodeficiencies should be quoted as 1:10 "but will vary according to local referral practices". (2) the title should be changed to "Primary Immunodeficiency Services (all ages)"	P Wood
<b>13.</b>	<b>Immunology Forum</b>	

	<p>The dates of the next <i>Immunology Forum</i> will be 27/28 November at the Assembly Rooms in Bath. The BSI will assist with administration. Accommodation will be arranged by delegates, not as part of the meeting registration fee, and the Steering Group were informed that Bath has adequate capacity for anticipated numbers of delegates. Information about the meeting is needed as soon as possible for the UKPIN website.</p>	M Gompels
<b>14.</b>	<b>BSI-CIAS</b>	
	<p>It was confirmed that UKPIN and BSI-CIAS will remain as separate organisations, that will work closely on related issues.</p>	
<b>15.</b>	<b>Any other business</b>	
	<p><b>JACI Letter</b> an article in <i>Journal of Allergy &amp; Clinical Immunology</i> has strongly recommended that IVIG infusions should not be delayed if the patient has an active infection, although no evidence was presented to support this statement. The Steering Group agreed that this is against UKPIN recommended practice and will draft a Letter to the Editor.</p> <p><b>CGD Consensus Document</b> Dr Chee has asked if UKPIN intends to produce a consensus document for CGD. P Wood will contact Dr Chee to clarify whether he means an SOC document or a substantive article in the style of the HAE Consensus Document; this may be something the CGD Research Trust would like to undertake.</p> <p><b>Proposal for pre-consented autopsies of CVID patients</b> Dr Longhurst has asked if UKPIN would consider setting up a tissue bank for CVID and look at the possibility of pre-mortem consent for autopsies. The Steering Group had concerns that this was a major project, lacked testable hypotheses for research, and that uptake would be likely to be low, as well as being a difficult issue to discuss with patients. P Wood will reply to Dr Longhurst asking for further information, but suggesting that discussion with the PiA may be more appropriate.</p> <p><b>PiA Steering Group for HAE</b> C Hughan asked the Steering Group for suggestions regarding medical advisors for the PiA; it was felt that UKPIN does not intend to have disease-specific subsections, but interested members should approach the PiA, who should also contact the BSI-CIAS for suggestions.</p>	<p>P Wood F Ashworth</p> <p>P Wood</p> <p>P Wood</p> <p>C Hughan</p>
<b>16.</b>	<b>Date and time of next meeting</b>	
	<p>Dates to be circulated.</p>	