

**Minutes of the UK PIN Steering Group Meeting  
Held on Monday 1 June 2009  
in the Cavendish Room at the Royal Society of Medicine  
1 Wimpole Street, London, W1G 0A**

**Present:** Phil Wood (Chair)  
Lucia Russell (Secretary)  
Fran Ashworth (Secretary)  
Aarn Huissoon  
Sarita Workman  
Cathy Cale  
David Edgar  
Terry Flood  
Joe Unsworth  
Olga Bryce  
Carl Wheeler (CSL Behring)

<b>1.</b>	<b>Apologies</b>	<b>Action</b>
	Carrock Sewell, Matthew Helbert, D Kumararatne, Bodo Grimbacher	
<b>2.</b>	<b>Minutes of the Previous Meeting</b>	<b>Action</b>
	The minutes of the previous meeting held on 29 January 2009 were accepted as a true and accurate record. Noted that Mark Gompels is not a member of the steering group but could be asked to attend meetings	O Bryce
<b>3.</b>	<b>Matters Arising</b>	<b>Action</b>
3a.	Phil Wood welcomed Sarita Workman to the Steering Group and welcomed Olga Bryce back from her recent illness.	
3b.	<p><b>Cover arrangements for Administration Assistant</b></p> <p>Phil Wood's secretary is now in possession of all UK PIN members' email addresses.</p> <p>Lucia Russell will be obtaining access to all UK PIN files and emails via the Newcastle Trust's IT department.</p> <p>The purchase of a conference digital voice recorder has been agreed for use at all UK PIN Steering Group meetings.</p>	<p>L Russell</p> <p>O Bryce</p>
3c.	<p><b>Consensus document for managers</b></p> <p>The PIA is publishing the document, but have been held up because of recent changes in funding arrangements.</p>	P Wood

	Phill Wood will speak to Matthew Helbert & Chris Hughan and this will be discussed at the next meeting	
3d	<p><b>Influenza pandemic guidance</b></p> <p>The UK PIN 2008 document, which cross-references to the RCP guidance, is now on the website.</p> <p>Under current guidance, in the event of a PID patients being in contact, they must be treated with Prophylaxis for 5 days, which will be prescribed by their GP under the HPA guidelines. This is likely to change if the pandemic status changes.</p> <p>Aarn Huissoon has devised a paper on questions and answers, which is now on the website. Aarn thanked the Steering Group for their contribution to the paper.</p>	
<b>4.</b>	<b>UK PID Registry Committee Report</b>	<b>Action</b>
	The UK PIN Registry Committee met on 21 May 2009. MREC and governance approval was secured in March 2009. Information regarding UK PIN Registry will be set up on the website. This will be emailed to the Steering Group within the next week for approval/comments. Hopefully this will go live on 1 August 2009. It is hoped that some interest will be shown by Centres by September 2009.	
<b>5.</b>	<b>Finance – update</b>	<b>Action</b>
	<p>The current balance is £14,847.23</p> <p>There are multiple sponsorship arrangements ongoing at the moment and will hopefully be settled by the next UK PIN Steering Group meeting</p>	
<b>6.</b>	<b>UK PIN Membership Update</b>	<b>Action</b>
	UK PIN membership stands at 218.	
<b>7.</b>	<b>UK PIN Website Update</b>	<b>Action</b>
	Carrock Sewell will simplify a revised UK PIN Registration Form, which will be placed on the website. Phil Wood to discuss with Carrock Sewell	C Sewell P Wood
<b>8.</b>	<b>Accreditation Committee Report</b>	<b>Action</b>
8a.	There are 3 fully accredited centres to date: Derriford Hospital, Plymouth, Sheffield Teaching Hospital and St James Hospital, Leeds. Salford Royal Hospital are in the process of debating issues.	

	<p>Derriford Hospital is now due for their 5 year revisit, but have asked for a delay until some time in early autumn. All Centres undergoing accreditation whilst still in the pilot process are not fully accredited.</p> <p>At present there are 25 Centres out of 40 now registered with UK PIN and some are now up for biannual registration.</p> <p>Carrock Sewell will be making changes to the data on the Registration form to make it easier to complete and it was agreed that bi-annual Registration forms already received, would be transferred onto the new version of the Registration form by Olga Bryce.</p> <p>Joe Unsworth has sent out a letter to all unregistered centres, but this has not generated the expected interest. It was agreed that a letter from Phil Wood should be sent to all head of services.</p> <p>Support for process Noted that Baxter has funded Covance to provide on-site support to the registration process.</p> <p>Joe Unsworth suggested a flagged map of all Centres registered should put on the website.</p>	<p>O Bryce</p> <p>P Wood</p>
<b>8b.</b>	<b>Feedback on standards</b>	
	<p>Comments from UK PIN members were discussed and appropriate changes have been made on the Standards, which are now complete and are now on the website. Joe Unsworth will reply individually to all members who have sent in comments.</p>	<p>Joe Unsworth</p>
<b>9.</b>	<b>DoH Guidelines and Demand Management Plan Update</b>	<b>Action</b>
	<p>Centres need to register all patients receiving immunoglobulin IV and subcutaneous as funding will not be provided unless patients are registered and approved by their Trust's committee.</p>	
<b>10.</b>	<b>Steering Group Membership – Trainee Representation Request</b>	<b>Action</b>
	<p>The steering group agreed in principle that this was desirable.</p> <p>Phil Wood to communicate with interested applicants to establish how nominations for the group would be organised, and how feedback to the trainees would be arranged.</p>	<p>P Wood</p>

<b>11.</b>	<b>Writing Group Reports</b>	<b>Action</b>
	<p>The first 2 standards are completed and have been emailed to UK PIN members. They should all be completed by 2010 for the use of all Centres.</p> <p>An email is to be sent out asking for a person willing to take over as Chairperson of the Writing Group in place of Cathy Cale who will remain on the Group.</p> <p>The Concise Guideline document is in process with the RCP – feedback at next meeting</p>	P Wood
<b>12.</b>	<b>SSNDS Update</b>	<b>Action</b>
	Documents have been endorsed and published by the DoH.	
<b>13.</b>	<b>Forum 2009 Update</b>	<b>Action</b>
	The current programme is now on the website. Sarita Workman to email the RCN nurse group regarding nursing break out sessions and possible nursing topics. The deadline for this will be 12 June. Hopefully there will also be parallel sessions arranged.	
<b>14.</b>	<b>BSI-CIAS Update</b>	<b>Action</b>
	There was nothing relevant to UK PIN at the last meeting. Phil Wood to contact Stephen Jolles for an update.	P Wood
<b>15.</b>	<b>Is it PID? Campaign Update</b>	<b>Action</b>
	Aarn Huissoon presented a patient survey which is still in discussion with other specialist groups (ie. ENT, others, as well as immunologists). Data will be put in clearer format before distribution.	
<b>16.</b>	<b>Relationship with PIA</b>	<b>Action</b>
	<p>It was agreed that Chris Hughan would attend the UK PIN Steering Group meetings once per year with a defined agenda and that a representative could attend if Chris is not available.</p> <p>UK PIN chair to meet with PIA in between steering group meetings. Phil Wood to discuss further with PIA</p>	<b>P Wood</b>
<b>17.</b>	<b>AOCB</b>	<b>Action</b>
	Carl Wheeler explained that the new PASA agreements for IVIg and subcutaneous commenced today 1 June 2009. Not all Centres have decided on volume required,	

	<p>but overall figures from Centres that have committed show there is a reduction in volume.</p> <p>SNBTS are retaining control of their own products and their new contract commenced 1 August 2009.</p>	
<b>18.</b>	<b>Date of Next Meeting</b>	<b>Action</b>
	<p>The next UK PIN Steering Group meeting will be held on Monday 7 September 2009 in The Cavendish Boardroom at the Royal Society of Medicine, London.</p>	<b>O Bryce</b>