

Minutes of the UK PIN Steering Group Meeting

Held on Tuesday 28 September 2004

Novartis Foundation, 41 Portland Place, London W1B 1BN

Present: Richard Herriot - Chairman
Carrock Sewell - Secretary
Dinakantha Kumararatne - Treasurer elect
Fran Ashworth
Andrew Cant
Graham Davies
Teresa Green
Matthew Helbert
Alison Jones
Lucia Russell
Joe Unsworth
Phil Wood
Olga Bryce

Apologies: Tim Wallington
Cilla Freud
David Webster

Richard Herriot welcomed Cilla Freud (nurse representative), Kumar (Treasurer-elect) and Joe Unsworth (chairman of the Accreditation Committee)

Agenda Item 2. Matters Arising from Previous Meeting	Action
<p><i>vCJD Update</i></p> <p>The recent incident involving possible contamination of Vigam with vCJD was discussed. Matthew Helbert was thanked by the Steering Group for his hard work in coordinating the immunology aspects of the patient notification exercise. He noted that there had been operational difficulties with the exercise (particularly in respect of transferred and remotely managed patients), that the DoH had moved the deadline for this three times over the summer and that four centres had failed to receive the email notices sent out to immunologists. Kumar suggested that future information and notices may more effectively be sent out by the UK PIN office. The PIA had only received 5 calls from patients. Matthew is now auditing the notification process and an audit document will be globally e-mailed around the UK PIN membership in the near future. Kumar noted that the patient notification deadline was impractical and could have resulted in mistakes. Alison Jones asked what happened to non-immunology prescribed</p>	<p>Olga Bryce</p>

<p>immunoglobulin - this should have been accounted for by Pharmacy and Medical Director notices, although it was appreciated many hospitals had no batch tracking procedures. Several members felt that the patient information letter was too long and over-complicated, so had abbreviated their centre's letters or added covering letters. Joe Unsworth was concerned that the exercise may have alarmed more patients than it helped; it was pointed out that an individual risk assessment approach was designed to alleviate this (ct. haemophilia patients, where an umbrella approach was used as more patients affected). Matthew Helbert informed the committee that he has obtained a grant for prion surveillance in PID patients and that an MREC application was being put together. Several Steering Group members were concerned that some of the approaches suggested (eg ante-mortem consent for autopsies and retention of brains) may be very difficult to put across to patients without undue alarm, and it was agreed that this area was very sensitive and would need careful patient selection. The PiA is being consulted at all stages about this proposal. Carrock Sewell mentioned that a similar study had been successfully undertaken for motor neurone disease, and that a meeting to discuss prions and IVIg was to be held at the Royal Society of Medicine on 8 November (see www.rsm.ac.uk for details). The Steering Group concluded that this was a difficult area for research but that Matthew should proceed to put together an MREC proposal for further discussion.</p>	<p>Matthew Helbert</p>
<p><i>Epinephrine for Home Therapy</i></p> <p>Following the recent Clin. Exp. Immunol. paper on the incidence of adverse IVIg infusion-related reactions during home therapy, the Steering Group agreed the UK PIN stance that epinephrine was not required for all home therapy patients, but that individual centres could make decisions on this for individual patients. Richard will write a UK PIN position statement on this for posting on the News section of the website.</p>	<p>Richard Herriot Mike Laycock</p>
<p><i>Potential Viral Transmission</i></p> <p>Fran and Theresa were thanked for their work on this patient information leaflet. This will be offered on the UK PIN website for centres to use during the consenting process when immunoglobulin therapy is prescribed for new patients. Olga will pass the formatted document to the web master for posting.</p>	<p>Olga Bryce Mike Laycock</p>
<p><i>Consultant & Nurse Exchange Programme</i></p> <p>No update on this item at the meeting. Tim Wallington will be</p>	<p>Tim Wallington</p>

writing to the PiA to indicate how the supplied funding has been utilised to date.	
<p><i>Specialised Commissioning</i></p> <p>Julie Dent has not responded to the Chairman's letter expressing concern over the failure to fully progress PID specialised commissioning in London. Alison Jones pointed out that although formal specialised commissioning was unlikely to take place, the London Immunology centres had agreed an approved formulary which was likely to be implemented soon.</p>	
<p><i>Home Therapy Guidelines</i></p> <p>Congratulations were offered to Fran, Teresa and Lucia for their work on this matter. Update of the document will be complete and ready for distribution to the Steering Group for discussion by mid-October.</p>	<p>Fran Ashworth Lucia Russell Teresa Green Olga Bryce</p>
<p><i>Patient Questionnaire</i></p> <p>Thanks were given for work on this project. It was agreed that this questionnaire will be branded 'UK PIN' and Olga will complete the typing of the final version in the near future, then for distribution to all Steering Group members for comment. It was also made clear that patient responses will be sent to Olga at the UK PIN office, <i>not</i> to the PiA.</p>	<p>Sheila Cochrane Teresa Green Fran Ashworth Lucia Russell Olga Bryce</p>
<p>Agenda Item 3. Accreditations</p>	<p>Action</p>
<p><i>Accreditation Committee</i></p> <p>Joe Unsworth has accepted the nomination to chair the Accreditation Committee with other members being Mike Duddridge (for adult immunology), Lucia (for paediatric nursing), Fran or Sheila (shared duties for adult nursing). Cathy Cale to be asked by Richard Herriot if she would represent paediatric immunology. The duties of this committee were outlined and agreed.</p>	<p>Richard Herriot</p>
<p><i>Accreditation Documents</i></p> <p>Richard Herriot expressed concern over the variety of versions of accreditation documents which are kept by the UK PIN office under current arrangements, with the inherent risk of confusion. He will reassess and update the application form, explanatory guidance, inspection protocol and standards documents in draft and will forward these to the Accreditation</p>	<p>Richard Herriot</p>

<p>Committee for comment and for the subsequent approval of the Steering Group. The Accreditation Committee will develop a template for written assessment visit reports (once update of the above documents is complete).</p>	<p>Joe Unsworth</p>
<p>Standards</p> <p>The current accreditation standards F4, F5 and F6 were agreed to be problematic for many centres and in need of reconsideration in view of the experience of the pilot assessments carried out to date. Richard Herriot agreed to review these as part of the general document review and send them to the Accreditation Committee for approval.</p>	<p>Richard Herriot</p>
<p>Centres Undergoing Accreditation</p> <p>Plymouth has just been assessed and the assessment team (led by Tim Wallington) will forward its report to Joe Unsworth in the near future. It was unclear whether the Centre was asked to complete the self-assessment document prior to inspection. It was agreed that the Steering Group and Accreditation Committee chairmen would examine the final report carefully and discuss this with Tim Wallington, before reporting back to Dr Kaminski in the first instance (prior to any report being released, for example, to the Trust's CEO).</p> <p>Joe Unsworth raised the concept of provisional accreditation for centres which have had on-site visits by UK PIN but which have not managed to comply fully with all of the assessment standards. The Accreditation Committee can consider this potential development once the update of current standards and documentation is complete and take a proposal for adopting a system of provisional accreditation to the Steering Group if it is felt to be appropriate. The proposal has a number of benefits but there are concerns about the increased administrative burden that may fall on the Accreditation Committee and the UK PIN office. Phil Wood noted that UK PIN should support smaller centres as well as larger centres. Richard Herriot pointed out that the Plymouth assessment was still a pilot assessment and not a full and formal accreditation inspection.</p> <p>Leeds, Path Links, Hull, Leicester and Nottingham all have applications underway.</p> <p>Cambridge, Bristol are not ready yet</p> <p>Papworth, St Helier are unknown. Olga to contact.</p> <p>Oxford to be reassessed next year. It was agreed that they may utilise the existing application form as update of current</p>	<p>Tim Wallington</p> <p>Joe Unsworth Richard Herriot Tim Wallington</p> <p>Joe Unsworth</p> <p>Olga Bryce</p>

documentation remains work in progress. Tim Wallington is devising a letter to encourage those centres who have previously expressed an interest but have not yet applied for inspection. Olga will contact Tim.	Olga Bryce
<i>UKAS accreditation</i> There was no useful progress with this item despite further discussion with UKAS. Richard Herriot noted that UK PIN document control is not yet good enough for UKAS approval so directed Olga to look into the costs of obtaining the Q-Pulse software and necessary training.	Olga Bryce
Agenda Item 4. Research Collaboration	Action
Richard Herriot has written to Bobby Gaspar to invite him to form a group to progress the strategy of a UK PIN Research Committee and to report back on suggestions for who should sit on this body. It was agreed that the Research Committee should be multi-disciplinary and would ideally include representatives from a number of institutions involved in Primary Immunodeficiency, including smaller hospitals. It was felt that the Committee would ideally encourage development of collaborative research initiatives involving PID centres of all sizes across the UK.	Bobby Gaspar
Agenda Item 5. CPD Bulletin/Newsletter and Immunotherapeutics Quarterly	Action
Gavin Spickett has kindly agreed to continue to edit the UK PIN Newsletter. Olga will continue to circulate the Steering Group minutes to Gavin so that he is aware of the issues under discussion. Carrock reported that Ed Kaminski has offered to take over as Editor of the CPD Bulletin in Immunology & Allergy when David Webster steps down. He also noted that Immunotherapeutics Quarterly, although it covers immunodeficiency issues, is not solely confined to immunodeficiency, and the publishers are not keen that IQ is restricted to those areas which primarily interest and involve UK PIN.	Olga Bryce
Agenda Item 6. Consensus Document	Action
<i>PID for Managers</i> Matthew Helbert was congratulated on producing an excellent draft. Further information is being accessed, or is awaited, from	Matthew Helbert

<p>a number of sources within the Immunology community to complete areas of missing detail in the draft. Matthew is also sending the document to Susan Schonfield for comment from a public health/commissioning perspective. It was agreed that the document did not require specific sections, or significant additional detail, in order to be relevant to healthcare systems in Scotland and Wales. A simple generic statement about mechanistic differences in these devolved systems, within a broadly similar arrangement as outlined for England in the document, would suffice. This was also agreed after the meeting in respect of Northern Ireland (telephone discussion between the Chairman and Dr. Edgar).</p>	
<p><i>Consensus Document on the Diagnosis and Management of Primary Antibody Deficiencies</i></p> <p>Phil Wood has made significant progress with the draft update of this document aimed at professionals rather than Health Service managers as above. Further information and some detail is, again, needed, including data from Gavin Spickett's UK antibody deficiency audit. Richard Herriot reported that the Royal College of Physicians was keen to support and lead development of this document through its Concise Guidelines to Good Practice format. This route has a number of real and potential advantages but there was some concern from Steering Group members that the quality of evidence available may mean that it is ineligible for consideration as a formal Concise Guideline by the RCP. Further discussion with the RCP Clinical Evidence and Evaluation Unit may be needed. Feedback is also awaited from Helen Chapel concerning the practicality of the Concise Guidelines route. Richard Herriot will, again, informally discuss with the RCPPath whether it would feel the lead College role is appropriate for it. The RCPCH has not yet commented on its desire for formal involvement in the development of the document. Richard Herriot wrote to Linda Haines at the College. The paediatric representatives on the Steering Group suggested direct contact with the College Registrar, Sheila Shribman.</p>	<p>Phil Wood</p> <p>Richard Herriot</p> <p>Richard Herriot</p>
<p>Agenda Item 7. Appointment of New Officers</p>	
<p>Kumar will take over as Treasurer next year, but is currently shadowing Tim Wallington. Carrock assumed the role of Secretary as of 9/6/04.</p>	
<p>Agenda Item 8. Business Case</p>	<p>Action</p>
<p>One further year of funding for UK PIN is available from BPL (£20k) under current arrangements. It was noted that UK PIN is still a long way from being able to be self-funding by means of</p>	

<p>either charging for accreditation and/or charging membership fees. Carrock Sewell suggested that membership fees may be acceptable to the Immunology community on the basis of robust voting rights in respect of the Steering Group and its Officers. Inherent subscription to e.g. CPD BULLETIN or reduced bi-annual meeting fees may be other possible visible benefits of paid membership. There was a feeling that, despite these perceived benefits membership fees may not be an attractive prospect. This would be particularly relevant if such fees, even if in place, failed to substantially cover the operating expenses of the Network. It was noted that UK PIN could apply to become a charity. As an initial interim step for the next few years Richard Herriot will sound out potential sponsors.</p>	<p>Richard Herriot</p>
<p>Agenda Item 9. UK PIN Membership</p>	<p>Action</p>
<p>The website is now set up to accept membership applications. Richard Herriot will email all existing members (from the current database) inviting them to formally join using the website mechanism. Applications will be emailed to Olga who will enter them into the database and forward this on a weekly basis to Richard (or in his absence, Carrock) for formal approval. He will return the spreadsheet to Olga who will inform applicants of their success (or lack of) in becoming a member using a standardised email. Membership criteria are laid out the UK PIN constitution.</p>	<p>Richard Herriot (Mike Laycock reminder)</p>
<p>Agenda Item 10. Databases and Registries</p>	<p>Action</p>
<p>The ESID general registry is now active and a paper was circulated summarising the purpose and operation of that database. Oxford have kindly agreed to pilot the practicality of the ESID system for UK centres and report back to the Steering Group. Steering Group members raised issues around the utility of such a database and await feedback from Oxford with interest. Graham Davies presented the Access database used at Newcastle and GOS. Although strongly orientated around bone marrow transplantation this system should integrate with the ESID database in the future. Graham kindly offered blank copies of the databases to other centres if they are interested. The hard work of Kieran the GOS database manager was acknowledged. Funding maintenance for the GOS-based database is a major issue. It is hoped that a Newsletter article about the database will be forthcoming.</p> <p>The UK PIN standard D5 pertaining to databases was viewed by the Steering Group as problematic in view of the current position of the UK and ESID databases. Richard Herriot will draft an amendment to this standard for approval by the Accreditation Committee and, subsequently, Steering Group.</p>	<p>Graham Davies Graham Davies Gavin Spickett (for information) Richard Herriot</p>

Agenda Item 11. UK PIN Pulmonary Interest Group	Action
<p>Kumar presented a paper about considering the formation of a UK PIN interest group to develop research proposals relevant to, and cross-sectional surveys of pulmonary disease in PID patients. It was decided that Kumar and Richard will discuss this concept with interested chest physicians to consider appropriate research questions which may be addressed, usefully in concert with the Research Committee.</p>	<p>Kumar Richard Herriot</p>
Agenda Item 12. PiA Training Days for Medical Students	Action
<p>The PiA have expressed a desire to 'hand over' organisation and running of the medical student days to UK PIN. Phil Wood suggested the possibility of UK PIN sponsoring places for students at the Immunology Forum. There was discussion around whether medical students were the optimal target for such events designed to encourage entry to the specialty, with events for junior doctors perhaps being a more efficient outlet for any efforts. Carrock drew parallels with the AAAAI who encourage both medical students and SHOs to take an interest in Immunology. Richard Herriot and Andrew Cant can discuss this further at the PiA MAP meeting in December. The Steering Group was keen that the PiA should still maintain some involvement, perhaps to help with a venue for such meetings.</p>	<p>Andrew Cant Richard Herriot</p>
Agenda Item 13. Any Other Business	Action
<p><i>Jeffery Modell Foundation</i></p> <p>An immunodeficiency meeting will be held in Cambridge next year, sponsored by the JMF, who aim to promote better recognition and understanding of PID in both the public and physicians. It was agreed that Kumar would investigate the possibility of UK PIN having a stall at this meeting. Kumar and Richard Herriot will also initiate discussion with the JMF over ways of developing/improving education around, and understanding of PID disorders in health professionals and the public across the UK with the aim of improving rates of diagnosis and reducing diagnostic delay. This will be done in concert with the PiA.</p>	<p>Kumar, Richard Herriot</p>
<p><i>Immunology Forum</i></p> <p>Alison Jones reported that a Steering Committee has been established for Immunology Forum 2005, the meeting will be held on 18-19 November in York.</p>	

<p><i>Max Appeal</i></p> <p>Kumar drew the Steering Group's attention to the excellent website of the Max Appeal, which is concerned with patients with chromosome 22 deletion syndromes (http://www.maxappeal.org.uk/)</p>	
<p><i>Additional Steering Group Members</i></p> <p>Claire Bethune has expressed an interest in joining the Steering Group; Olga will remind the Steering Group when an existing member demits office.</p>	Olga Bryce
<p><i>CDROM of UK PIN Guidelines</i></p> <p>Carrock reported that Oyster Healthcare Communications have expressed an interest in producing a CD-ROM of UK PIN Guidelines. The Group felt that this medium was no longer appropriate and raised important issues of document control. The Guideline Writing Group will, however, discuss this further.</p>	Matthew Helbert
<p><i>NeLH Guidelines</i></p> <p>Matthew Helbert noted that the National Electronic Library for Health are interested in listing speciality guidelines. The Steering Group felt that future iterations of our existing guidelines might be better suited for this than the current 'first editions' of the UK PIN Guidelines.</p>	
<p><i>Refresher Training for UK PIN Assessors</i></p> <p>Refresher training for UK PIN assessors was requested by Fran Ashworth. A new-assessor/refresher-update training day should be organised before this duty can be formally handed over from Tim Wallington to the Accreditation Committee.</p>	Tim Wallington Joe Unsworth
<p><i>Professor John Soothill</i></p> <p>Graham Davies informed the Steering Group of the recent sad death of Professor Soothill, one of the 'founding fathers' of immunodeficiency in the UK. The Steering Group expressed its sadness at this loss to Immunology.</p>	
<p>Date and Time of Next Meeting</p>	
<p>Olga Bryce will contact Steering Group members with the date and time of the next meeting, expected to be in late January 2005.</p>	Olga Bryce