

**Thames Valley Patient Experience Operational Group**

**Monday, 24th July 2017, 11:00 – 13:00**

Meeting Rooms 2-3, AHSN offices, Oxford Science Park, OX4 4GA

**Action Notes**

Douglas Findlay (DF)	Co-chair
Sian Rees (SR)	Co-chair Oxford AHSN
Mildred Foster (MF)	Oxford AHSN
Polly Kerr (PK)	NIHR Oxford Biomedical Research Centre
Oliver Evans (OE)	NIHR CRN
Lynne Maddocks (LM)	Oxford University Primary Care Health Sciences and NIHR CLAHRC
Paul Hewitson	NIHR R&D Service
<b>Apologies:</b>	
Sandra Regan (SaR)	Oxford Health NHS Foundation Trust
Di Hilson (DH)	Oxford AHSC

Item No.	Item	Action
1.	<b>Welcome and Introductions</b>  Apologies: Sandra Regan, Di Hilson and Daisy Camiwet who informed the group she is leaving NHS England South end of July.	
2.	<b>Minutes from May meeting</b>  Minutes were approved	
3.	<b>Training and development</b> <ul style="list-style-type: none"> <li><b>Level 1 training</b> – there was a second lunch time seminar hosted by Oxford Group. This training is aimed at lay partners with little experience of participation. Some professionals attended the seminar and found the training very useful. In future participation from professionals will be accepted but clarifying the training is aimed to lay partners new to PPI.</li> <li><b>Level 2 training</b> – This workshops are aimed at lay contributors and professionals who are more actively involved in co-production. The learning is designed to help applying their knowledge and experience in practical ways to improve their participation. We are planning to repeat the same workshops to invite new participants. Proposed dates: Oct, Dec and Feb. Dates to be confirmed.</li> <li><b>Level 3 training</b> – Leading Together Programme The PPIEE team at the AHSN has received funding from Health Education England for the development of a Leading Together Programme for Learning Disabilities. An advisory group is in place with members from Oxford AHSN, TPC Health, NHS England Learning Disabilities directorate, Oxford Health NHS FT, My Life My Choice - a self-advocating charity for people with Learning Disabilities based in Oxford, Oxfordshire Family Support Network and lay partners. The advisory board had a successful first meeting in July. There had a productive conversation on co-design and co-production of the Leading Together Programme for Learning Disabilities and priorities for all stakeholders. The first cohort will be a pilot and will be completed by December 2017.</li> </ul>	
4.	<b>Strategy Development</b>	<b>MF</b>

	An initial theme mapping document was produced by SaR with information provided by some group members. The document was circulated to the group. Development of this map will be discussed further once SaR is back.	
5.	<p><b>Network Development</b></p> <ul style="list-style-type: none"> <li>Peer support network – the questionnaire developed by AHSN lay partners regarding frequency and format of lay partners meetings will be sent as a survey. All members of this group will forward link to survey to their appointed lay partners.</li> <li>Leading Together Graduates network – Leading Together Graduates are sent a quarterly newsletter. The first Leading Together Graduates Annual Event will take place on 23 November 14:00 – 16:30 at Newbury Racecourse</li> </ul>	MF
6.	<p><b>Communications</b></p> <p><b>Points of Communication</b> is a database by OE (CRN). It contains a very comprehensive list of outlets (newsletters, e-letters, websites, etc) in the Thames Valley and South Midlands areas which can be used to distribute information. The database is organised by name, medium, locality, district, contact name, position, contact email, contact phone, Twitter Facebook, Frequency / publication day, deadline and specialities.</p> <p>If you want to add new information to the database please contact OE and he will be able to update the database.</p> <p><b>Action - OE will send the link to Points of Communication.</b></p> <ul style="list-style-type: none"> <li>The NIHR CRN Thames Valley and South Midlands launched a new website to provide resources for healthcare professionals to engage and involve the public, professionals and industry in research.</li> </ul>	OE
7.	<p><b>Shared Database</b></p> <p>SR asked for comments to document circulated. All members should make sure their organisation position is accurate in every section of the document. The database will be developed once funding from Department of Health is available.</p> <p>Action – all to check organisational position is accurate in document</p>	SR
8.	<p><b>Recording and Impact Tool</b></p> <p>It is important to record the impact of our PPI work. The available tools (GRIPP and PIAF) are not fit for purpose. This tool is being developed for staff but in time the same tool could be developed for lay contributors.</p> <p><b>Actions- all to send comments to SR before next meeting</b></p>	SR & all
9.	<p><b>PPI network development</b></p> <p>A questionnaire developed by Raj Arora and Rebecca Day and will be made into a survey. Lay partners will be asked if they want to be part of a peer support group and which format they want the group to have.</p> <p>All members of this group will be asked to send the survey to their appointed lay partners.</p>	MF & Raj Arora
10.	<b>Brief updates from:</b>	

<p><b>AHSN</b></p> <ul style="list-style-type: none"> <li>• <b>Living Well Oxford (LWO)</b> On 17<sup>th</sup> July at The Oxford Academy (OA) we celebrated the success of the pop up shop week at the Templars Cowley Centre. The event was attended by researchers from OUH and Oxford Brookes, colleagues from Science Oxford, 6<sup>th</sup> form students and teachers from OA and members of the public.</li> <li>• We had performances from the Dementia Choir and poetry reading by 2 Dementia Patients.</li> <li>• Participants at the event were asked to give ideas on topics for Living Well Oxford future events.</li> <li>• Wellcome Trust representatives visited the pop-up shop at Templars Cowley and were positively impressed with the activities and interaction between researchers and the public</li> <li>• The independent evaluation of LWO pop-up shop week at the shopping centre was very positive.</li> </ul> <p><b>CRN</b></p> <ul style="list-style-type: none"> <li>• Public information drop-in event, Reading, 12 September. Another planned for High Wycombe in November.</li> <li>• Public information drop-in event held in Oxford in June.</li> <li>• Public engagement at Oxfordshire Science Festival in June. Further opportunities at similar, existing events being sought.</li> <li>• Press releases being prepared for publication of NIHR league tables on August 3.</li> <li>• Further stories planned around vaccine for RSV and flu.</li> <li>• Event for industry planned in Oxford on December 6 at the Mathematical Institute.</li> <li>• Website launched to provide PPIE resources for researchers.</li> <li>• Monthly newsletters continue to be distributed for patients / staff.</li> <li>• Two-minute films to be produced about the CRN for public / partners.</li> <li>• Induction event for Patient Research Ambassadors (PRAs) held in June. Online forum to be set up for PRAs</li> <li>• Survey to be provided to study teams to record patient experiences.</li> <li>• Facebook page up and running.</li> <li>• Patient Representative to be appointed to provide PPIE input into CRN.</li> </ul> <p><b>CLAHRC Oxford</b></p> <p><b>Report on Involvement Matters</b></p> <p>Period 1/1/17 – 31/6/17 (first 6 months of publication)</p> <p><b>The statistics</b></p> <ul style="list-style-type: none"> <li>• Copies sent during this period = 1,726 reaching 99% which is very good</li> <li>• 867 recipients opened it = 50% 15 – 20% is typical</li> <li>• 6 bounced</li> <li>• 328 clicked to open items 38% of opened and 19% of delivered</li> <li>• Had no spam complaints</li> <li>• Nobody has shared the bulletin 5 people have unsubscribed = 0.6% 5% is typical</li> </ul> <p><b>The new people signing up to receive it</b></p> <ul style="list-style-type: none"> <li>• 241 recipients in January</li> <li>• 325 recipients in June</li> </ul>	
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- Increase of 84 which is 25%

**Some of the new sign ups have been from:**

- Carers Oxfordshire
- Oxfordshire County Council
- Vale of White Horse District Council
- Healthwatch Reading
- OUH staff
- Researchers in other Medical Science departments
- Bucks County Council
- Bucks Healthcare
- VCS groups incl; Stroke Association, Restore, Breathe Easy, Archway
- Oxfordshire CCG
- A few people from outside the Thames Valley

**The narrative**

- It tends to get a peak of opens in the first 3 days and then a second smaller peak after a week.

Most popular items that have been clicked on were:

- × BMJ Freelance Patient Editor post
- × Pets and healthcare blog × Fun Kids Live × AHSN partner documents
- × USPEX booklet (resource for front line medical ward staff)
- × Health Education PPI roles × NIHR PPI roles
- × Patient Leadership Summit
- × Berkshire PPGs

**Some members of the Patient Experience Operational Group have never opened it!**

During the first 6 months the editor has to source over 95% of the content. In July the editor did make contact with some of the groups whose work had been in the e-bulletin, to point out that in future they should send it direct. More content from the Patient Experience Operational Group would be appreciated.

**BRG**

- The strategy and work plan for year one (up to 31 March 2018) for the Partnerships theme of the BRG (within which PPI sits) have now been approved by the Advisory Group. Main streams of work are measuring PPI and benchmarking its impact; training; methods of setting priorities for research and service design/delivery; updating website; establishing how we work better with PAIR group.
- Hosting another PPI Q&A drop-in session with CLAHRC and RDS – will then discuss if worth continuing with these and if so, in what format.
- National Standards for PPI are still open for consultation – encourage PPI groups to comment.
- Meeting with Lynne to take next steps towards organising joint training for PPI contributors around research process and language.
- PSPs are continuing, heart failure one has now been started.
- Meeting with PAIR group – first time they had got together since start of BRG-3. Lots came out, much of which is relevant to PEOG as well including request for clarity over different local research organisations and how they fit together, and thus where PPI contributors can get involved.