

Thames Valley Patient Experience Operational Group
Monday 19th Mar 2017, 9:30 – 11:30
Meeting Rooms 2-3, AHSN offices, Oxford Science Park, OX4 4GA

Action Notes

Douglas Findlay	Co-chair
Mildred Foster (MF)	Oxford AHSN
Teresa Findlay	NIHR Oxford Biomedical Research Centre
Oliver Evans	NIHR Clinical Research Network
Lynne Maddocks (LM)	Department of Primary Care Health Sciences Oxford University & CLAHRC
Sian Rees (SR)	Co-chair Oxford AHSN
Alison Provins	Oxford AHSN lay partner
Claire Murray	Oxford Health Biomedical Research Centre
Paul Hewitson	NIHR R&D Service
tbc	Academic Health Science Centre
Apologies	
Wendy McClure	NHSE Clinical Senate

Item No.	Item	Action
1.	Welcome and Apologies	DF
2.	Minutes from March meeting	DF
3.	<p>Involvement Matters (IM) review – the e-bulletin has been in circulation one year and it was a good time to review its function. Lynne Maddocks-editor presented metrics to the group and asked for feedback. It was decided to:</p> <ul style="list-style-type: none"> Change header showing objective of the bulletin and organisations involved in the work behind it. Change email from ppi@phc.ox.ac.uk to involvementmatters@phc.oc.ac.uk – Action for Lynne Maddocks Operational Group members will add link to Involvement Matters on their institutional websites, contribute content and promote circulation. Action for all group members. Alison Provins will promote with Health Education England. Douglas Findlay will promote with Royal Berkshire Hospital and Berkshire Healthcare. To give visual identity and branding to the Joint Training and Development work by adopting unique logo. Sian will introduce Lynne Maddocks to Gayle Rossiter. Mildred will send Lynne list of contacts from Gayle Rossiter. 	LM and all
4.	<p>Training and Development</p> <ul style="list-style-type: none"> Joint Training future – promotional branding. The group identified the need for branding and visual identity for Joint Training and Development Programme. Action: M Foster will send proposed logos and collect votes. Introductory training – Oxford Health will join the participating group. Level 2 training – review workshops attendance, format, feedback and funding going forward. 	

<p>5.</p>	<p>Patient Experience Operational Group Review Results from the survey were discussed. Terms of reference will be updated to reflect changes in the group's function</p> <ul style="list-style-type: none"> Organise sharing PPI experience across Operational Group organisations possibly June at AHSN (half day event). Opportunity to review shared principles, strategies and experiences. Action Mildred will check room availability and will send a doodle poll with possible dates Organise a larger and broader event with organisations across Thames Valley sharing their experiences. Action – Sian and Mildred to explore event size, cost and venue. Operational Group would like to hear more about Oversight Group meeting work. Action: Mildred will add Oversight Group report as regular agenda item 	<p>SR / MF</p>
<p>6.</p>	<p>Network Development</p> <ul style="list-style-type: none"> Peer support group. Action: Douglas Findlay will organise first meeting with lay partners from AHSN, HEE and others that work closely with the Operational Group members 	<p>DF</p>
<p>7.</p>	<p>Brief Updates from:</p> <p>AHSN</p> <ul style="list-style-type: none"> Sian Rees visited Gary Hickey (INVOLVE) to discuss investment in the development of a PPI Shared Database in Thames Valley Oxford AHSN is working with the Oxford NHS Genomic Medicine Centre (GMC) to help patients and families with rare disease and cancer across the region join the NHS's 100,000 Genomes Project. The aim is to create a new genomic medicine service for the NHS and transform the way people are cared for. Sian Rees is the PPI lead for Oxford Genomic Medicine Centre. <p>Clinical Research Networks (CRN) Badges large and small with "Ask me about taking part in research" on them now available.</p> <ul style="list-style-type: none"> 18 banners ordered to promote research to public in healthcare settings, more to come. 'Thank-you' leaflet to give to patients taking part in research being developed. Patient Research Experience Survey to be run all year round. Film about patient / LCRN being produced. Photo exhibition about research being developed with NIHR in Oxford. LCRN supporting International Clinical Trials Day and July NHS 70th birthday. Patient Research Ambassador event to be held 18 April. Continued proactive media stories including meningitis vaccine in schools. <p>CLAHRC Oxford CLAHRC PPI Contributor list has hit 200! However, this is likely to go down again as I begin a process of complying with GDPR rules coming in on 25/5/18. Working Together: CLAHRC has PPI embedded in all its projects. Supporting public involvement: For researchers only – monthly Q & A sessions. Currently planning future dates, but next one is 29th March at 2 in the Common Room in Dept of Psychiatry at Warneford hospital site. Governance: One of the PPI Contributors on our Management Board resigned and we await instructions about finding their replacement.</p>	

<p>Communications: Involvement Matters ongoing PPI Pulse came out in February. CLAHRC website has had a major overhaul of its public involvement pages – would welcome any feedback</p> <p>BRC3 PPI Update PHWI Theme, BRC-3. BRC-3 Ops Meeting March 2018</p> <p>PPI Q and A sessions for researchers agreed for: (Date-Venue-Facilitators) 29th March - Warneford - Claire Murray & Paul Hewitson 2nd May JR (tbc) Ben Clyde & Paul Hewitson 7th June RPC - Lynne Maddocks & Paul Hewitson</p> <p>Framework development for PPI based on our Systematic Review of PPI frameworks continues. Met with patients and public reps at the end of February to try using laminated word cards extracted from reviewed frameworks. The aim was to see how everyone interpreted both the words and the activity of how to develop a framework in a group using them. This confirmed that the process of discussing what PPI means and entails is more important than the content. The next step is to source and use 3-D coloured foam shapes, which the (same) group will label and construct into a PPI framework.</p> <p>PAIR meeting in February to discuss and contribute to the draft PPI strategy for the NIHR. Very interesting meeting with firmly voiced and congruent opinions expressed by all.</p> <p>Draft PPI Strategy for NIHR completed and being handled by Nick Fahy in discussion with Lorna Henderson, Vasiliki Kiparoglou and Keith Channon.</p> <p>The Research Design Day for people with Diabetes being organised with OCDEM researchers had to be postponed due to the weather. We could not risk putting people's health at risk for a non-urgent event. It has been re-arranged for the end of April with minimal disruption to delegates, which is affirming of the difficult decision to postpone. This is a workshop to involve patients with Diabetes and clinical and research staff in co-designing an electronic patient portal.</p> <p>Ben Clyde is now working with us two days a week while Polly is on maternity leave. He contributes to administration and organisational support for the PHWI PPI work. This includes PPI Q&A days, the Research Design Day for people with Diabetes; advice for researchers on recruiting PPI participants, doing and finding PPI; comments on draft documents and reports. We are pleased to have met and established links with Claire Murray, the PPI Manager for Oxford Health BRC who is based at the Warneford.</p> <p>Oxford Health BRC</p> <ul style="list-style-type: none"> • Publishing our PPIE strategy before the end of the month. • Meeting arranged for our Patients and Research Group in April. • NIHR Oxford Health Biomedical Research Centre & cognitive health Clinical Research Facility Open Day organised for 22 May. More details to follow but all are welcome. 	
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