

Thames Valley Patient Experience Operational Group

Monday, 18th Sep 2017, 11:00 – 13:00

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

Action Notes

Douglas Findlay	Co-chair
Mildred Foster (MF)	Oxford AHSN
Polly Kerr (PK)	NIHR Oxford Biomedical Research Centre
Oliver Evans	NIHR Clinical Research Network
Apologies:	
Lynne Maddocks (LM)	Department of Primary Care Health Sciences Oxford University & CLAHRC
Sian Rees (SR)	Co-chair Oxford AHSN
Rebecca Day	Oxford AHSN lay partner
Sandra Regan	Biomedical Research Centre, Mental Health
Di Hilson	Oxford Academic Health Science Centre (AHSC)
Paul Hewitson	NIHR R&D Service

Item No.	Item	Action
1.	Welcome and Apologies	DF
2.	Minutes from July meeting – outstanding actions & approval Meeting minutes were approved	DF
3.	Training and development <ul style="list-style-type: none"> • Level 1 training – last meeting was well attended and received positive feedback. Some researchers who attended found it useful. It was decided that future workshops would be opened to professional and lay participants. Next meeting will be held at Oxford Brookes. Jo Brett will provide new date. • Level 2 training – Three workshops have been planned. PPI: Approaches and Techniques in Oct and March and Outcomes that matter the patients and the public in Dec. All workshops will be repetitions of previous events in an attempt to involve new participants. Venues outside Oxford will be explored. • Level 3 training – Leading Together Programme for Learning Disabilities 	MF
4.	Operational Group stakeholder gathering We will try to find a date for half day meeting in Oct-Nov	SR
5.	Network Development Peer support network – link to a survey developed by Raj Arora and Rebecca Day was sent to all members of the operational group to forward to their strategic lay partners. Action: MF to re-send link to survey for further distribution	MF
6.	Shared database – bring forward to next meeting	SR
7.	Recording Impact Tool – bring forward to next meeting	SR
8.	Brief Updates from:	
	AHSN <ul style="list-style-type: none"> • Leading Together- Leading Together for Learning Disabilities advisory group meeting took place 18th July. The group discussed how LTP could be adapted to the Learning Disabilities community and how the Programme could be 	

	<p>used to address, priorities like health inequalities or improvement of a particular health service for the LD community.</p> <ul style="list-style-type: none"> • The themes emerging from discussions will be the starting point for co-production of LTP-LD course content. • Initial meeting of My Life My Choice, TPC Health and a carer representing people with profound disabilities to discuss size of the group, location and recruitment process. The Pilot Programme will early 2018. <ul style="list-style-type: none"> • Leading Together Graduates Annual Event – 23 Nov 13:30:00 – 16:30 @ Newbury Racecourse. The purpose is for all participants to reconnect and reflect on their development, their partnerships and new opportunities for participation as a result of the Leading Together Network. If you are interested in attending please email leadingtogether@oxfordahsn.org • Living Well Oxford - There was an event at The Oxford Academy on 17th July to celebrate the success of the pop up shop event at the Templars Cowley Centre. The event was attended by researchers from OUH and Oxford Brookes, colleagues from Science Oxford, 6th form students, teachers from The Oxford Academy and members of the public who took part in the event. • We had performances from the Dementia Choir and poetry reading by 2 Dementia Patients and attendees were asked to give ideas on topics for Living Well Oxford future events. Public feedback was recorded in a poster by Creative Communications. • Certificates and awards were given to the Security team at Templars Cowley Shopping centre and Spec Savers team for sending the greatest numbers of staff to Dementia Awareness training. <p>Wellcome Trust reps attended the pop up shop at Templars Cowley shopping centre. They were positively impressed with the activities designed to increase interactions between researchers and the public raising awareness of opportunities available to be part of research projects in Oxford. Independent Evaluation of LWO pop-up shop was very positive.</p> <p>Clinical Senate Children & Maternity SCN - Children & Young People: Youth participation groups</p> <p>In east Berkshire, meetings have been held with youth participation leads from public health, Buckinghamshire Healthcare Trust, youth services and Local authorities with the aim of getting young people’s views on commissioned services. A survey will be created and the participation leads will holding focus groups which will look at:</p> <ul style="list-style-type: none"> • where young people go if they are not feeling ok • what services they are aware of and what they would like <p>The outcome of the survey and the focus groups will be fed back into the local transformation groups and boards and will inform the refresh of the commissioning plans. In Oxfordshire, there will be similar activities with an organization commissioned to get the views of young people across a wide range of services. In West Berks, service leads will be reporting back on how they are getting young people’s views and using these in service development and the local transformation plans.</p> <p>In BHFT youth participation groups are established to get the views of those</p>	
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young people who have accessed specialist CAMHS services. They help feed into changes on environment, services, advice, and guidance for schools, etc Young people in these groups across Berkshire created a booklet for young people on mental health with some tips. This has been distributed to schools across Berkshire

Parents

In East Berkshire parent forums have been developed to help feed into the local plans. Many have children who are on autism, ADHD, and other mental health pathways and this work will link to the work the child centre for disability is doing on SEN/D parent participation.

Cardiovascular Disease

Although there is no longer a network for this disease area, the team continues to maintain relationships with the patient members who supported the work. The members are still involved in local groups and continue to promote the needs of cardiac patients.

Cancer Alliance

Michael Mawhinney is new in post with the Cancer Alliance as a Quality Improvement Lead for Patient Engagement. He will be working to improve to patient engagement across the Thames Valley and to assist providers in improving patient experience of cancer services.

In late September he will be putting out a call for further patient representatives to sit on several Alliance Tumour groups which assist with the planning and delivery of cancer services across primary and secondary care. Assistance with advertising this call would be greatly appreciated. Written information and an advertisement will soon be available.

Michael will also be hosting a series of engagement events across the Thames Valley in November and December in response to the recently published national cancer patient experience survey. The purpose is to present summaries of the results of the survey to people who have received cancer care and using a workshop style, discuss potential approaches to improving patient experience.

Head and Neck Cancer

The work to transform post-surgical services for head and neck cancer patients from the Swindon area has made real strides. We have been lucky to have the full involvement of a patient representative who has been instrumental in development of the patient section of the business case and he also joined us to put the patient view when we presented the case to the Swindon contract board.

Clinical Senate

Lay/patient members continue to provide a strong patient voice at the Council meetings and it is good to see that they are very comfortable with some quite challenging topics. The Senate is preparing for a further clinical review which will be undertaken in October/November. The topic is sensitive and there is a strong local feedback. Patient involvement in the panel will be particularly important to provide an independent patient perspective on the case and we will need to link with colleagues in other areas to identify appropriate patient members.

<p>Clinical Research Networks (CRN)</p> <p>Inclusive opportunities</p> <ul style="list-style-type: none"> • Patient Research Experience Survey sent to study teams to be returned by December, survey of patients' experiences of taking part in research • PPI training for staff / public to take place in October • Induction day for Patient Research Ambassadors planned for January. Steps being taken to help them keep in touch – WhatsApp group, message board. <p>Working Together</p> <ul style="list-style-type: none"> • Interviews taken place for new patient representative. Decision taken not to appoint but to discuss way forward with Patient Research Ambassadors. <p>Supporting public involvement</p> <ul style="list-style-type: none"> • Booklet being produced aimed at industry and another aimed at research professionals, to increase engagement with LCRN. • Website launched with PPIE materials e.g. posters, leaflets, for researchers to use to support engagement. See https://sites.google.com/nih.ac.uk/tvsmcrnresources/home • Poster on “5 good reasons to take part in NHS research” being produced and will soon be available to all, to include a TV screen sized version. • Publicity around 26/9 staff awards planned to promote research. <p>Communications</p> <ul style="list-style-type: none"> • Industry symposium to be held with CLAHRC in Maths Institute 6/12/17, invite sent out to invitees from industry and PIs. • Public drop-in event held in Reading 12/9, there were 11 attendances. LCRN now re-thinking strategy around events to focus on attending existing events e.g. health fairs and stands in public places e.g. shopping centres. • Attending Oxford Older People's Day 2/10 and Bucks New University Fresher's Fair 21/9 <p>CLAHRC Oxford</p> <p>Inclusive Opportunities:</p> <ul style="list-style-type: none"> • Involvement Matters ebulletin continues to increase readership and feedback received that people are recruiting through it, including to national positions. <p>Open Doors event nationwide – took advantage of chance to show public round our new building to recruit PPI Contributors and got 4 signed up.</p> <p>Proactive recruitment drives including attending the city's PPG forum.</p> <p>PPI Pulse newsletter for our volunteers now sent using software where we can track opens and clicks. Slightly surreally have readers in Korea!</p> <p>Working Together</p> <p>CLAHRC has PPI embedded within each of its projects. An example of impact of this:</p> <p>Project - Optimising Treatment for Mild Systolic hypertension in the Elderly James went to his gran's day care with specific questions that he wanted answers to but found that the older people wanted to talk about other things! This proved very fruitful because they raised the transport problems for older people in attending their GP practice and as a result James changed the study so that taxi fares are now offered to participants.</p> <p>James also wanted to get approval for his Patient Information Sheet but found</p>	
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that the older people were not interested in even reading it! As a result he developed a short animation video to explain the project which can be used with participants. <https://www.youtube.com/watch?v=bIIU-Ko9I7A>

Supporting Public Involvement: Running a series of training options:

- For PPI Contributors only – 6 through the Autumn term on 1) What is being involved? What is the impact of PPI? 2) Research terminology and the research cycle 3) Ethics – the process within the application and PPI role within it 4) Management of trials (including multi-site, phases and styles of research) 5) Medical Statistics 6) Evidence Based Methodology and PPI role within it
- For researchers only – a seminar billed as an open opportunity to hear about case studies of PPI activity by colleagues and to talk about PPI and the real issues that people encounter. 2nd Nov.
- For researchers only – monthly [Q & A sessions](#) done jointly with RDS and BRC
- For PPI Contributors (and staff together?) – joint with AHSN, BRC, CRN, OxINMAHR and local Hospital Trust – quarterly. Topics to date have been ‘Increase your impact in public involvement’ and ‘Introduction to Patient and Public Involvement’. OxINMAHR leading next one and waiting on Jo Brett for a date.
- For PPI Contributors and staff together – joint with the AHSN and CRN shared ½ day workshops on two themes repeated throughout the year; Oct Approaches and techniques in PPI Dec Outcomes that matter to patients and the public Mar 2018 Approaches and techniques in PPI

Governance: Two PPI Contributors are on the [Management Board](#). All of the Themes that have steering groups also have PPI Contributors on those groups.

Communications: Raising awareness, collaborations and events:

Comms Officer produces monthly internal [ebulletin](#).

Comms Officer continuing a programme of [website](#) improvements including infographics, new BITES, videos and impact case studies.

Other: Peer support network meeting for PPI staff in the Thames Valley. – next meeting on Tue 26th Sept

BRC3

Working Together - Patients Active in Research (PAIR) group met to discuss identity and direction for the future – keen for more hands-on opportunities to help with PPI and for a more joined up approach to PPI across the local area. Meeting again in October.

Supporting public involvement - Running six training sessions with Lynne Maddocks (Oxford CLARHC) during September to December – these are for PPI contributors to increase their confidence in taking part in involvement opportunities.

Three drop-in Q&A sessions for researchers to come and bring their PPI queries will run over the autumn.

Meeting with Sandra Regan and Di Hilson to try to draw up a ‘map’ of organisations and their PPI outputs across the region.

Communications - Hosted a shared learning event on 6 Sept for BRC PPI leads focusing on strategy development and impact of PPI.

	Impact - Researchers within the Partnerships theme of the BRC are comparing numerous tools and frameworks designed to assess PPI impact with a view to establishing what will be the best method for the BRC to do this.	
9.	AOB	