

Thames Valley Patient Experience Operational Group
Monday, 22nd May 2017, 11:00 – 13:00
Meeting Rooms 2-3, AHSN offices, Oxford Science Park, OX4 4GA

Action Notes

Raj Arora (RA)	Acting Co-chair
Sian Rees (SR)	Co-chair Oxford AHSN
Mildred Foster (MF)	Oxford AHSN
Daisy Camiwet	NHS England South
Polly Kerr (PK)	NIHR Oxford Biomedical Research Centre
Sandra Regan (SaR)	NIHR Oxford Biomedical Research Centre
Lynne Maddocks (LM)	Department of Primary Care Health Sciences Oxford University and CLAHRC
Paul Hewitson	NIHR R&D Service
Apologies:	
Douglas Findlay	Oxford AHSN lay partner
Rebecca Day	Oxford AHSN lay partner

Item No.	Item	Action
1.	Welcome and Apologies	
	Paul Hewitson was welcomed to the group	
2.	Introduction	
	All participants introduced themselves to the new members of the group.	
3.	Minutes from Mar meeting – outstanding actions and approval	
	Meeting notes were approved	
4.	Strategy away day	SR
	The meeting planned for July was cancelled. SR will re-organise in the Autumn.	
5.	Leading Together Programme Update	SR
	<ul style="list-style-type: none"> Funding has been secured for LTP for learning disabilities. Programme will be designed in collaboration with My Life My Choice an advocating charity for learning disabilities based in Oxford. The first programme planning meeting with members of the advisory group will take place in July. 	
6.	Level 2 Training Programme update	
	<ul style="list-style-type: none"> New workshop will take place 30 May at AHSN. Topic: “Working Together: approaches and techniques” 	
7.	Strategy Development	
	<ul style="list-style-type: none"> All organisations to find synergies in preparation to Strategy review SaR will organise programmes themes mapping document with information sent by all group members. <p>Action: everybody to send information to SaR</p>	all
8.	Brief Updates from:	
	Clinical Senate	
	The Senate Council has not met during this period but work has continued to develop the project briefs for the priority work areas for 2017/18. A key piece of work is the clinical review of the 2nd phase of the Oxfordshire Transformation. Detailed plans are not yet available but the Senate has had	

the opportunity to comment on the proposed process and it has given feedback that the plans for patient involvement need to show how patients will be involved in the design of new pathways. Contact details to link with the Patient Leaders, via Mildred, has been shared to facilitate this. Work has been commenced to explore the feasibility of introducing thrombectomy within the Thames Valley and we are currently scoping a role for patient input to the pathway re-design. The Cancer Alliance, which replaces the Cancer SCN, has held three group meetings in the last 6 weeks: Children's; Brain & CNS; and Head & Neck. Both the Children and the Head & Neck Group have at least 2 patient representatives. The Brain & CNS group had recently held its first meeting following a change in the group lead and is currently addressing the loss of patient representatives which it had previously. Patient representatives on these groups are all required to have lived experience. There is also a Head & Neck Project, in partnership with Macmillan Cancer Support, which is focussing on repatriation of ongoing care post-surgery at the OUH to the patient's home area. The first phase will be for patients from Swindon. The project has been driven by patients and although no meetings were held in this period, the patient rep is working with the Allied Health Professionals and the Clinical Nurse Specialists to source patient stories to support the case for change. The Children and Maternity SCN is planning 4 Perinatal mental health training days for all stakeholders and each day will commence by hearing the experience of a service user who has experienced perinatal mental health issues. Development of the Local Maternity System is well underway and each of the Chairs of the local user groups have been invited to join. The Local Maternity System is aligned to the STP and has been tasked with delivery of the STP aims for maternity services. In addition, the patient participation lead from Buckinghamshire Healthcare Foundation Trust has joined the Thames Valley Children and Young Peoples Mental Health Strategic Group. This is already paying dividends as he links into many children's and young people's groups and can contribute from a wider perspective.

NHS England – Patient Experience Group

NHSE is changing some of its geographies. Thames Valley will no longer be linked with the Wiltshire and Gloucester patch which will now come under a South West region and Thames Valley will be linking with Wessex under a South East region.

South West: Mark Cooke will work with Devon; Cornwall; Somerset and Dorset, and Rachel Pearce will work with Bristol, North Somerset and South Gloucestershire (BNSSG); Bath, Swindon and Wiltshire (BSW) and Gloucestershire.

South East: Felicity Cox will continue to work with Surrey Heartlands, East Surrey and Sussex and Kent and Medway, and Dominic Hardy will work with Berkshire West, Oxfordshire and Buckinghamshire (BOB); Hampshire & Isle of Wight and Frimley Health and Care. At the moment, we don't know who will be leading for us on PPI.

Clinical Research Networks (CRN)

CLAHRC Oxford

Involvement: working with patients, carers and the public to improve care delivery, training, education, research and innovation for the whole

population.

- Theme 3 which is our Patient Reported Outcomes Theme led by Professor Ray Fitzpatrick is from now on going to form our PPI steering group. A new PPI Strategy is in development with this group
- PPI Contributor training – BRC, CRN, AHSN, CLAHRC, OUH and OxINMAHR. Pilot held and reviewed today

Engagement: working with patients and their families to improve their own care

- Oxford Health led a Leading Together event for dementia which was chaired and had speakers with dementia

Experience: listening to and acting on what patients, carers and the public say - collecting, understanding and using patients' and the public's feelings about their involvement and engagement in care, research and innovation.

- Working with OxINMAHR on a community needs project in OX4

Raising awareness, collaborations and events:

Share information on our work with patient and public groups and health and social care organisations;

Collect and act on views about our work from patient and public groups and health and social care organisations

- Seminar open to all planned for 4th May at 10.30 in St Lukes Chapel on Radcliffe Observatory Quarter – 'Have you been mis-sold PPI?'

- PPI Pulse, the newsletter for our volunteers previously written by the PPI Coordinator to be developed by the CLAHRC Communications Officer. Next edition going out this week.

- 3rd of the Q & A sessions being held next week – BRC, RDS and CLAHRC will then review – if you have any feedback from staff in your sphere to share let Sandra Regan or Lynne Maddocks know.

Other: Requests: Will you please send me items for Involvement Matters and encourage colleagues to do so too.

BRC3

- A report by members of the Health Experiences Research Group that pulls out key messages from the Healthtalk.org modules on PPI (interviews with both PPI contributors and researchers) is now available on the Oxford BRC website:

<https://oxfordbrc.nihr.ac.uk/wp-content/uploads/2017/03/A-Researchers-Guide-to-PPI.pdf>

You can listen to/watch the original interviews here:

<http://healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics>

<http://healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/topics>

- We are bringing together the 'Patients active in research' (PAIR) group for a meeting on 21 July to discuss how we can best use their experience and skills, and get their thoughts on the best direction for the group. This will involve discussing the future of the PAIR database and website which we are considering discontinuing – there is a lack of firm evidence about how

well used it is and how many people who register go on to be linked up with a researcher.

- I am going to a national NIHR workshop on 31 May that will bring together PPI leads from BRCs, Clinical Research Facilities and Patient Safety Translational Research Centres. The aims are around developing and delivering PPIE strategies and action plans, and shared learning and networking.
- We will be commenting on the draft National Standards for PPI in research which are being developed by a partnership that brings together representatives from NIHR and Health and Care Research Wales. Anyone can sign up to be part of the Standards Network and get involved with reviewing and commenting on these (online form here: <https://sites.google.com/nihr.ac.uk/pi-standards/standards-network>). They will be available for comment from mid-June to Mid-August.
- We are looking at alternative ways to the James Lind Alliance Priority Setting Partnerships to go about doing this for research. As previously explained, we will continue to support the existing ones until they are completed (expected to be about a year's work).

AHSN

Living Well is a collaborative public engagement project between the Oxford AHSN, Science Oxford and the Oxford Health Experiences Institute to support the exploration and understanding of health and healthcare.

This work has taken place initially in Oxford exploring the concept of 'living well', drawing on areas that have significant public health impact, public interest and local research expertise, such as weight, diet and health, and ageing and dementia. So far we have: worked with a number of partners to deliver:

- a debate about genome data privacy funded by the British Science Assoc.
- a stroke storytelling event at The Story Museum as part of Oxfordshire Science Festival
- a stroke-themed stall at a health day at Templars Square Shopping Centre
- a health-themed session at children's summer holiday clubs in East Oxford and Rose Hill
- A "pop-up shop" entitled "Ageing: From Birth and Beyond" was held in Templars Square Shopping Centre, 15-21 May 2017 to coincide with the Dementia Awareness week. The event was well received by the community. There will be an independent evaluation on the event.

AHSN Best Care Clinical Networks update

Five of the eight Oxford AHSN Best Care Clinical Networks have secured funding to continue many of their projects. It follows the announcement earlier this year that Oxford AHSN could not sustain funding of the clinical networks beyond June 2017. The refocused networks are:

Anxiety & Depression – leading national implementation of digital tools relating to Improving Access to Psychological Therapies (IAPT) and continuing local improvement workshops.

Early Intervention in Psychosis – improvement and innovation work continuing and integrating with regional quality work.

	<p>Dementia – priority work includes webinars, care home support, driving and cognitive impairment, and younger people with dementia.</p> <p>Imaging – developing image and data sharing, improving detection of lung nodules and more patient information videos.</p> <p>Maternity is to move into the Oxford AHSN Patient Safety Collaborative with its projects - shared learning, standardised guidelines, detection of small babies, data sharing - continuing in the new structure.</p>	
9.	PPI network development	
	<p>1. Peer support Rebecca Day and Raj Arora at the AHSN have agreed to organise an initial meeting with lay partners. They have prepared a questionnaire to find out if people are interested in becoming part of a network and the format it should have.</p> <p>Action: RD and RA will send questionnaire to all members of this group and they will send it to their lay partners asking them to get in touch with RD to express their interest.</p> <p>2. Leading Together Network Next newsletter will be circulated in July. A meeting similar to Celebrating Success is planned for 23 November 2017 at Newbury Racecourse. Put the date in your diaries.</p> <p>PPI e-newsletter – Involvement Matters: Action: All members of this group are urged to send LM content to be included in the newsletter. E.g. Events, Training, Activities, Consultations happening locally.</p>	<p>RD and all</p> <p>MF / SR</p>
10.	AOB	all