

Thames Valley Patient Experience Operational Group
Wednesday 23 May 2018, 9:30 – 11:30
Meeting Rooms 2-3, AHSN offices, Oxford Science Park, OX4 4GA

Action Notes

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

Item No.	Item	Action
1.	Welcome and Apologies	DF
2.	Minutes from March meeting Minutes were approved	DF
3.	Training and Development Working Together - into the future LM will organise and facilitate a meeting to discuss joint training programme. Discussion will include challenges, achievements, current and future funding Meeting date 18 th June at the AHSN. Leading Together Programme - pilot for learning disabilities with Oxford Health in collaboration with My Life My Choice. Ten participants, five professionals and five people with LD. First work will be 5th June.	LM MF
4.	Patient Experience Operational Group <ul style="list-style-type: none"> • Updated ToR – SR gave a historic overview of the Operational group and the changes to date. ToR to be updated after Sharing Experience event • Sharing experience event – A half day meeting planned on 25th June at AHSN. SR will send programme for the day to all. 	SR
5.	Patient Experience Oversight Group update	SR

6.	<p>Network Development</p> <ul style="list-style-type: none"> Douglas Findlay organised first meeting at AHSN on 25th May. Meeting was attended by with 8 lay partners. A second meeting will be organised in autumn. <p>Action: MF to give DF the list of lay partners NHS England CCG assurances</p>	DF
7.	<p>Brief Updates from:</p> <p>AHSN</p> <ul style="list-style-type: none"> Sian Rees gave a presentation at the second meeting of the Oxford AHSN Patient Safety Collaborative regional emergency department collaborative. The focus of the event was caring for vulnerable patients in emergency departments. Sian Rees attended the “Undiagnosed Genetic Conditions” information event organised by SWAN UK (Syndromes Without A Name). Sian is the PPI lead for Oxford Genomic Medicine Centre. We have appointed three new lay partners. Alison Provins will join the Patient Experience Operational Group and the Patient Safety Collaborative Oversight Group. David Cooper and David Timberlake will join the Informatics Oversight Group. Adrian Barker and Larry Gardiner were appointed Lay Associates. They work with on AHSN specific projects when necessary. Regional sepsis meeting - ‘Sepsis – a patient-centred learning event’ organised by the Oxford Patient Safety Collaborative on 1 May brought together over 70 patients and relatives who have experienced sepsis and clinicians who manage patients with sepsis. The programme included patient stories, national and regional clinical updates and interactive workshops to improve sepsis care, information and support for people in the Oxford AHSN region. <p>BRC3</p> <p>CLAHRC</p> <ul style="list-style-type: none"> Work on GDPR has reduced list of PPI Contributors but happy that we now know those on the list are committed. CLAHRC has PPI embedded in all its projects. Lynne part of a national working group developing guidelines on public co-applicants. CLAHRC annual report showcases PPI element and will be publically available in due course. Q & A sessions. Now being booked for the rest of the year, venues TBC. Wed 11th July 11 am, Mon 17th Sept 2 pm, Tue 30th Oct 2 pm and Thur 29th Nov 11 am Working Together planning group going to meet to discuss L & D programme for 2019 Continue to do in-house training – research staff only on 6/9/18 and programme for our PPI Contributors being developed with two BRCs over the Autumn/Winter terms. Also speak to other groups – 21/3 spoke to research nurses at CRN. Inductions for new staff and volunteers are ongoing quarterly. Both of the lay members of the Board have now resigned and we are developing options around how we approach public involvement in our governance structures in the future, particularly as we prepare the third funding round bid. Lynne contributed to some Australian research about CLAHRC structures for PPI, as Monash university staff had funding to develop a similar model down under. <p>Involvement Matters and PPI Pulse ongoing.</p> <ul style="list-style-type: none"> Lynne doing outreach events to recruit PPI Contributors - Oxford city PPG locality forum on 15/5 and Banbury CRN planned. 	

- Theme 2 mySARAH pilot launched - Read more about the project [here](#).
- Theme 6 - Taxing sweet snacks may bring even greater health benefits than taxing sugar-sweetened drinks. Co-authored by our 'Behaviour Change: Diet and obesity' theme lead, Professor Susan Jebb: A 10% tax on sweet snacks could lead to a similar reduction in consumer demand as taxing sugar-sweetened drinks, with the potential effect expected to be greatest in low-income households. [Read more here](#).
- Theme 5 - Dr Kate Saunders, Director of Medical Studies at the Department of Psychiatry and Honorary Consultant Psychiatrist, who also works with Dr Mary-Jane Attenburrow on the CLAHRC's COMBO study spoke at the Women in Data Science conference hosted by the Alan Turing Institute. Research analyst and features editor for DataIQ, Toni Sekinah, wrote up this inspiring talk. [Read more here](#).

CRN

Oxford Health BRC

- We had a meeting of our Patients and Research Group in April to develop Terms of Reference and priorities for action
- We had an Open Day on 22 May attended by nearly 100 people, and a PPI session on the agenda with 2 presentations from PPI contributors, and 1 from a researcher about how PPI had benefited their research.
- We've developed a short animation to promote involvement in mental **health** research and our PPI strategy (I can share it with everyone when it's your tube later this week)
- We are working with CLAHRC and the **Oxford** BRC to put together a series of workshops for PPI contributors (similar to that which Lynne and Polly organised last autumn)