

**Summary Notes from Anxiety and Depression Network Patient Forum  
9<sup>th</sup> March 2016  
4-6.30, High Wycombe Holiday Inn**

**Present:** Ineke Wolsey (Network Manager), MR (Bucks Healthy Minds), TS (Oxon Talking Space), CM (Bucks Healthy Minds PPIEE Lead), TB (PPIEE Lead Oxon Talking Space), MH (Luton Wellbeing Service), RT (Milton Keynes Talk for Change), MT (Oxon Talking Space), HS (PPIEE Lead Milton Keynes).

**Apologies:**

AH (Patient Representative on A&D Network Steering Group), TN-G (Berkshire PPIEE Lead), GP (Bucks Healthy Minds), SR (Berkshire Talking Therapies), D F (Bucks Healthy Minds), A.G. (Oxon Talking Space).

**Notes from last meeting**

No inaccuracies noted and all actions closed and Appendix 1 (summary of on-going themes) updated. Summary notes from November meeting to be posted on web site.

**Action:** As the Berkshire ethnic minority project has not started yet **TS and TB** will explore the possibility of working with a contact of T's in Cowley, Oxford. To report back next meeting.

**Summary of all projects**

Ineke distributed a 4 page hand-out describing what the 3 current Anxiety and Depression Network projects consist of and what has been achieved to date.

**Employment Project**

It was thought that questions about Durability of clinical gains (how long have you stayed well after treatment) and employment could be included in the same questionnaire but that people would not have tolerance for more than between 5 and 7 questions in total. The questionnaires should be sent out 6 to 12 months after treatment. The group also thought that in terms of the process to be used, a (hard copy) letter inviting people to take part followed by an e-mail with the link to the 'survey monkey' type questionnaire would work although people should also be given a choice on whether or not they want to fill in the questionnaire electronically or hard copy. The letter should offer an introduction stating a clear rationale for the research and making it attractive (and real) to participate.

Some specific questions/ issues to consider were suggested that could be added to the Q (as well as the questions already recorded in Nov PF meeting summary notes) which included:

- Did you change direction/ look for a different job following treatment? If so, why? Has this been a good move?
- Add voluntary work as a category and a tick box with job roles e.g 'teacher' as might be interesting to see if some professions are more represented than others
- Allow for non-English speaking people and those who might be dyslexic

### **Post discharge support project**

The group discussed how best to get to the desired outcomes for this project (following the mapping exercise of current activity which Ineke will undertake) and it was felt that this project should be owned by the Patient Forum and that the methodology should include focus groups facilitated by a PF member and the PPIEE Lead for the area. It was thought that the right time would be 3 months after discharge and that we should also do a literature search on efficacy of support mechanisms. The focus of this project should be on 'how to maintain well-being'. It was agreed that this work should fit in with current processes i.e. routine follow-up calls from the services. Some potential questions that could be asked (in addition to the ones already recorded in summary notes from Nov Meeting) include:

- Are you still using the techniques that you learned in therapy?
- Would something have helped you stay well in the past few months and if yes, what?
- What post-discharge support were you offered and what, if anything, was helpful?
- Do you need more treatment?
- Short-term needs vs long-term needs to be explored

We will take this forward during the next 6 months and must also discuss with PF members who were not able to join the meeting today. **Ineke** to bring back to May PF meeting.

### **Website**

Most members of the group had taken a look at the website and offered positive feedback on the PPIEE material available. We discussed the issue of having a more interactive forum that would be internet based and Ineke reported back that, following discussions with her communications manager and other network managers, it was thought that the best way forward would be a closed Facebook page for sharing thoughts, materials and anything else we might want to address in between Patient Forums. The group thought this could work but we have to:

- Check with other PF members that this is ok- **Ineke** to bring back to next PF in May
- Find out if trusts block Facebook? **Ineke** to find out
- **H** has offered to set this up if we want to go this way (Ineke offered the Maternity Network Facebook page as an example)

### **Raising awareness**

The group explored a little how awareness might be increased of the existence of Talking Therapies and the potential for self-referral. We discussed the fact that if you googled 'depression' for each of the different counties the local IAPT (Talking therapies) service would appear at the top. However, as

members of the group pointed out, there will be many people with lots of symptoms who may not recognise it as depression or anxiety and so wouldn't use this for their search term. Instead it was suggested that services use questions that describe symptoms like 'Do you find it more and more difficult to enjoy life? Do you find yourself feeling very uptight very often? Are you bursting into tears a lot?' **Ineke** to feedback these suggestions to the service leads

#### **AOB**

Ineke raised an e-mail she had received from Sian Rees, Director Oxford Health Experiences and PPIEE lead for the Oxford AHSN, to explore if any of our Patient Forum members might be interested in planning an event which would '**showcase local research and service development involving patient representatives**' linking together various research organisations. MH and TS expressed an interest in participating. **Action: Ineke** to liaise with Sian and forward details on.

**Next meeting to be held Wednesday 25<sup>th</sup> May 4-6.30 Holiday Inn, High Wycombe**

**Appendix 1: Summary of themes from previous Patient Forum meetings and current status**  
**9<sup>th</sup> March 2016**

- 1 GP awareness of services available. Maybe the Network could explore what else could be done to increase GP awareness of availability of Talking Therapies? *The group spent some time brainstorming ideas for raising awareness amongst GPs. **NEXT STEPS:** The highlighted ideas will be fed back for discussion to steering group as this would need national support. All the other ideas can be taken by PPIEE leads to share with their colleagues and adopt locally if appropriate.*
- 2 Clarity for patients on the potential journey ahead, to reduce uncertainty - a 'roadmap'. Maybe the Network could explore in more detail what explanation/ preparation patients who have been accepted for therapy are offered to help them understand the journey ahead? **NEXT STEPS:** *This will remain on our wish list for now*
- 3 Waiting time for therapy vs outcome. Maybe the Network could explore this? **NEXT STEPS:** *This will remain on our wish list for now. UPDATE 9<sup>th</sup> March: national data analysis taken from 3<sup>rd</sup> Annual IAPT Report suggests a link between (long) waiting times and recovery rates.*
- 4 Reducing stigma. Can the Network do anything to reduce stigma with regards to MH problems? **NEXT STEPS:** *Already a national campaign underway, no further steps at this moment in time proposed*
- 5 Courses for parents whose children are receiving treatment. Can this be explored as part of the CYP work? **NEXT STEPS:** *this will be discussed with CAMHs as and when possible(Children and Adolescents MH services); parents can make use of MindEd <https://www.minded.org.uk/>*
- 6 Reaching other communities (e.g. Asian). This was raised as an important issue and TS has offered to support any work the Network may want to undertake to improve referral rates from ethnic minority groups. **NEXT STEPS:** *Ineke reported that she has had a meeting with the East Berkshire MH Commissioner who is interested in working on this for Slough locality. Ineke has contacted the Berks service lead to explore interest in this as a project but not heard back yet. Will chase and report back at next meeting. TS, AG and SR are interested in being involved with this project. 25/11: still no MH Commissioner appointed in East Berks which means we can't take this forward. UPDATE 9<sup>th</sup> March: can't take this forward until new commissioner for children's services has been appointed*
- 7 Increasing awareness. This was seen as important for people to self-refer as soon as possible. Is there any way the Network can support this? **NEXT STEPS:** *Brainstorming ideas for this will be on the agenda for the next Patient Forum in March: see notes*
- 8 Mental health in the workplace was also raised as an important issue. Maybe the Network could explore supporting this? **NEXT STEPS:** *this was raised again and we explored some of the things services are doing in the workplace (e.g. Luton).*
- 9 Older adults and low rate of referral/ low self-referral rate for talking therapies was discussed and MR has offered to work with the Network and Age Concern to raise awareness of the availability of talking therapy to older adults who suffer with anxiety and/or depression. **NEXT STEPS:** *Ineke reported that the network is proposing to work on ensuring that older adults are offered talking therapies when needed if funding is awarded for 2016-18. 25/11: We have already started talking with an old age psychiatrist about this and hope to take it further. MR has offered to be on the project group if possible from a logistics point of view.*