

**Summary Notes from Anxiety and Depression Network Patient Forum  
25<sup>th</sup> November 2015  
4-6.30, High Wycombe Holiday Inn**

**Present:** AH (Patient Representative on A&D Network Steering Group), Ineke Wolsey (Network Manager), MR (Bucks Healthy Minds), TS (Oxon Talking Space), GP ( Bucks Healthy Minds), Hayley Scanlon (Milton Keynes PPIEE Lead), Catherine McWhirter (Bucks Healthy Minds PPIEE Lead), MH (Luton Wellbeing Service), Tanieque Noel-George (Berkshire PPIEE Lead), AG (Oxon Talking Space), RT (Milton Keynes Talk for Change), SR (Berkshire Talking Therapies), Tara Butcher (Oxon Talking Space),

**Apologies:** Faz Parkar (PPIEE Lead Luton Wellbeing Service), DF (Bucks Healthy Minds), MT (Oxon Talking Space).

**Notes from last meeting**

No inaccuracies noted and all actions closed except for the GP Raising Awareness ideas which were brainstormed and recorded at the last PF. This is now on the agenda for the December Steering Group of the Anxiety and depression Network. There was disturbing feedback from members of the group who had tried to publicise their local talking therapy service by posting leaflets only to find that people were not willing to do so (a surgery) or that leaflets were removed swiftly (police station staff board, church notice board). It was agreed that the group will spend more time on this at the next PF meeting.

Going through the 'Themes from previous meetings, Courses for parents of children receiving treatment' Ineke highlighted MindEd (<https://www.minded.org.uk/>) which is a free educational resource on children and young people's mental health for all adults. This should support parents. **Action on Ineke:** put Gary in touch with Viv Pollard to support PPEPCare teaching sessions in Bucks: **DONE**

**Funding**

Ailsa and Ineke shared with the group the good news that the Anxiety and Depression Network had been awarded a further 2 years funding up to end of March 2018. Both the funding for projects suggested by the Patient Forum (post discharge support and promotion of mindfulness) as well as continued funding for quarterly Patient Forums and PPIEE involvement in project work had been accepted and funded.

**Feedback on October Extended Network Conference**

Ailsa, Tanveer and Ruth had been able to join the conference which was attended by some 70 people and included IAPT service leads and commissioners from London, Buckinghamshire,

Oxfordshire, Berkshire, Bedfordshire and Hampshire. It was agreed that it had been very informative, especially the sessions by Prof Clark (Clinical Lead and National IAPT Advisor ) on improving recovery rates, the session by Kevin Mullins (Head of Mental Health, NHS England) outlining the national MH strategy and the session by Jackie Prosser (Programme Lead, primary care MH, ill health prevention for Bucks CCGs) which was felt to be inspirational in terms of integrating physical and psychological care from the start of a patient's journey. The Children's session had also been an eye-opener in terms of the rising need for supporting children and young people with mental health problems (Prof Shirley Reynolds, Network Clinical lead CYP).

### **Leadership Programme** for Patient Leaders and Lay Partners

Ineke shared details of an exciting new Leadership Programme (**The Leading Together Programme, Developing Patient, Lay Partner and Professional Leadership**) with the group and urged people to apply. Ineke to send details through electronically.

### **Website**

Ineke shared with the group that the Anxiety and Depression Network website is currently being refreshed and that the network would like to ensure that the Patient Forum and its work is prominently displayed. It was agreed that all the PPIEE and Patient Forum materials should be posted (**Action on Ineke-DONE**) including **anonymised** minutes from Patient Forum meetings. The group was asked how else we could make the PPIEE/Patient Forum a more dynamic presence/opportunity for feedback and it was agreed that people would think about this and discuss it more at the next PF (**Action on Ineke/Ailsa to include this agenda item in the March meeting-DONE**).

### **Scoping projects for the next 2 years**

As Ineke has to submit a first detailed draft of the Project Initiation Documents for all projects that have received funding by the 1<sup>st</sup> December it was agreed that the rest of the meeting would be dedicated to supporting this scoping exercise and that other, non-urgent, agenda items would be deferred to the March meeting (Raising Awareness of talking therapy availability, Website ideas. **Action on Ailsa/Ineke-DONE**)

#### **1 Post Discharge support**

The group agreed that post discharge support had been very important to them and went round the table to explore what different options are available across the different counties. It was agreed that Ineke will be mapping exactly what support is offered by each of the services as part of the project next year to identify best practice but, from the discussion, a number of things were thought to be very important from the patient's point of view:

- Opportunities for face to face interactions with others (Bucks 6 weekly support groups) as well as on-line support (SHARON peer support system in Berkshire)
- For support to be on-going i.e. no 'cut off' point so that people will have continued access to 'a place of safety' and can 'stay toned' i.e. go for 'top ups' to keep their well-being on track
- That patients are routinely asked if they would like to join some sort of post discharge activity AND that more effort should be made to engage those patient who may be especially vulnerable to relapse (the group thought that social isolation whether age, culture

or geography was an important risk factor as well as thinking younger people may be more at risk)

- We should do some work on specific characteristics of those more likely to relapse and then ensure we find ways of reaching out at regular intervals post-discharge (call and letter?)
- Many members of the group shared how useful Mindfulness had been to them post discharge and requested the Network look at making this available to all patients post-discharge (explore an on-line version?)

It was also noted that in Oxon, MIND is exploring post-discharge support (**Action on Ineke to ensure this is part of the mapping exercise**).

## 2 Employment following treatment

To date this project has mainly been discussed in terms of assessing number of people who returned to employment following treatment but the group thought it should be broadened to also explore some other important questions:

- Have you been supported by your organisation to get back to work? If so, how?
- Have you changed jobs as a result of therapy? If so, please describe if this has been a positive or negative change and why?
- When asking people if they are employed we should include the option of 'full time carer' and 'employment without remuneration'
- Quality of work (presenteeism): If you were in employment at the time of treatment and have continued to be in employment, would you say the quality of your work has remained the same, improved or deteriorated? Please explain
- Would you have benefitted from (more) support following discharge? If so, how?

It was noted that the Richmond Fellowship continues to support Bucks (**action on Ineke to ensure they are consulted**).

### Next meeting

It was agreed that the next meeting will take place on **Wednesday 9<sup>th</sup> March 2016, 4-6.30** including working supper at the Holiday Inn, High Wycombe.

Agenda items to be included:

- Website (add 'Talk to us' or 'Feedback' buttons? Use social media?)
- Raising public awareness of talking therapies to increase self-referral
- Summary of all 3 projects (with summary document), **Action on Ineke- DONE**
- Decide on work programme for the 2 years
- Decide on standing items for the agenda

**Appendix 1: Summary of themes from previous Patient Forum meetings and current status  
25/11/2015**

- 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 list of ideas can be found in Appendix 1. 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*
- 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 Tanveer 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. Tanveer, Ali and Sara 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.*
- 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*
- 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 Margaret 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. Margaret has offered to be on the project group if possible from a logistics point of view.*