

**Summary Notes from Anxiety and Depression Network Patient Forum
20th July 2016
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), AH(Patient Representative on A&D Network Steering Group), MR (Bucks Healthy Minds), TV (Oxon Talking Space), Tara Butcher (PPIEE Lead Oxon Talking Space), GP (Bucks Healthy Minds), Michelle Lee (Reading University Researcher and project support officer for the Network), Dawne West (Berkshire Talking Therapies project lead).

Apologies: Catherine McWhirter (Bucks Healthy Minds PPIEE Lead), AG (Oxon), D F (Bucks Healthy Minds), Jan Wright (Bedfordshire Wellbeing Service PPIEE Lead), MH (Luton), MT (Talking Space Oxon), Tanieque Noel-George (Berkshire PPIEE Lead), SR (Berkshire Talking Therapies), Jessica McKell (Bucks Healthy Minds PPIEE lead).

Ineke informed the group that Catherine McWhirter is moving into a different post outside of Healthy Minds and that she therefore will not be attending the PF meetings anymore. The group expressed their thanks to Catherine for her many valuable contributions over the past year. Catherine's replacement is Jessica McKell who wasn't able to make this July meeting but can hopefully join us for the next meeting in October.

Notes from last meeting

No inaccuracies noted and all actions closed except for:

New Action: Tara to invite Mo to the next Patient Forum meeting 20th July- Mo couldn't make this so Tara will invite him to the October meeting.

New Action: Ineke to arrange for summary notes from May meeting to be posted on web site.

Web-based Patient Forum interactive discussion forum

A discussion took place about the pros and cons of a closed Facebook page and, on balance, people felt that this was not the most desirable option. Instead, it was agreed that we should try and set up a Yahoo group for sharing ideas and information.

Michelle has now started a **YAHOO group** and we will further explore this over the next couple of months after people are back from annual leave

ACTION: Ineke and Michelle to work with SR and update group in October

Durability and Employment Project

A great deal of work has been done on producing a first version of the questionnaire for the follow-up study incorporating all Patient forum feedback and suggestions.

Michelle presented the first draft and the group spent quite a long time making further decisions on the content/ phrasing of the questionnaire. All this feedback will be incorporated into vs 2 of the questionnaire.

ACTION: Michelle to incorporate this round of feedback and produce vs 2 of the questionnaire by mid-August and for sign-off by Prof David Clark by 20th September

Long Term Conditions and depression/ anxiety

Ineke presented a short summary of the LTC work undertaken by the IAPT services in Thames Valley over the past few years. She described the Diabetes, Persistent Physical Symptoms, COPD and Heart2Heart projects and commented on their successful clinical outcomes.

The group engaged in a discussion about the high prevalence of anxiety and/or depression in people suffering with LTCs and MR shared her difficult and frustrating journey trying to get help and support for a less well known LTC, Sjogren's Syndrome. There was some discussion about the patchy awareness in the NHS of the need to support those patients living with LTCs and possible anxiety/ depression and it was recognised that patients are not always signposted for psychological help when they should be. MR has been in touch with the Oxon Sjogren's association and wasn't clear if they are aware of the existence of Talking Space PLUS as a source for potential psychological support if needed.

ACTION: Ineke to produce short summary about Talking Space PLUS for MR to present to the Sjogren's Association

There was also a discussion about the link between physical and mental ill-health and whether there is any evidence for identified triggers in certain disorders.

ACTION: Michelle to undertake a search for any evidence on the above for presentation and discussion at next meeting

Expanding Talking therapies (IAPT) services for people suffering with Long Term Conditions

Ineke shared with the group the fact that Bucks, Oxon and parts of Berkshire are submitting proposals and applying for funding to become 'Early Implementer sites' for a national programme which aims to increase the number of people suffering with LTCs and anxiety/depression receiving integrated treatment i.e. physical health and psychological health professionals co-located and working very closely together. To be updated in October.

ACTION: Ineke to give update in October

On-line mindfulness courses

The group had previously discussed the great benefit people felt they got from learning Mindfulness techniques following therapy to help them stay well. As part of Talking Therapies services patients

may be offered Mindfulness therapy following 2 episodes of depression and whilst they are in recovery (as Mindfulness based therapy can be harmful for people with severe depression). Patient Forum members expressed an interest in the possibility of accessing good internet based Mindfulness programmes (acknowledging the above criteria) and Ineke shared that she had explored a number of different credible on-line courses. GP has volunteered to compare and contrast a few and give feedback at next Patient Forum.

ACTION: Ineke to write to Gary with 3 links to courses and reimburse Gary for joining fee for one of them (£60).

New membership of Patient Forum

The group discussed the fact that numbers of patient reps had fallen for a variety of reasons (starting course of study, moving away, increased work commitments etc) and a discussion took place about the possibility of widening membership and including people who had not received therapy. The group decided that the fact that all members had shared the experience of receiving talking therapies was invaluable and allowed them to do the detailed work the Patient forum had become involved with and so the decision was taken to stick to the current criteria for membership: 'members should have received a course of treatment but not be currently in therapy'.

It was decided that the best way of recruiting new PF members would be to repeat the recruitment process which was undertaken last year and which resulted in the current membership. It was also thought that we should ensure we target newly discharged patients as these may have a fresh/ more recent take on the quality of the service they received.

ACTION: Ineke to update all patient member documentation and initiate a recruitment cycle in September

AOB: no AOB

Next meeting to be held Wednesday 12th October Holiday Inn, High Wycombe