

**Summary Notes from Anxiety and Depression Network Patient Forum
12th October 2016
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), MR (Bucks Healthy Minds), Tara Butcher (PPIEE Lead Oxon Talking Space), GP (Bucks Healthy Minds), Michelle Lee (Reading University Researcher and project support officer for the Network), Jessica McKell (Bucks Healthy Minds PPIEE lead), Tanieque Noel-George (Berkshire PPIEE Lead)

Apologies and Introductions: TS (Oxon Talking Space), AH (Patient Representative on A&D Network Steering Group), AG (Oxon), DF (Bucks Healthy Minds), Jan Wright (Bedfordshire Wellbeing Service PPIEE Lead), MH (Luton), MT (Talking Space Oxon), SR (Berkshire Talking Therapies),

Ineke informed the group that S had contacted her to say that she had now started her Masters Degree and was too busy to attend for the time being. The group expressed their thanks to Sara for her input over the past year and wished her well with her studies.

Jess was welcomed to the group as the Bucks Healthy Minds PPIEE lead.

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. Mo had hoped to attend this meeting but the M4 was closed and this meant that he was not able to make it in time (it also affected other members).

New Action: Ineke to post signed off July meeting notes on webpage.

Web-based Patient Forum interactive discussion forum

Michelle had started a **YAHOO group** but, on reflection, the group wondered if a Yammer account might be preferable. She will further explore this and report back at the next meeting.

ACTION: Michelle to open a Yammer account

Updates on all projects

Ineke shared the good news that all Thames Valley services had been awarded funding from the national team at NHS England to become 'Early Implementer Sites' and set up new, co-located services to provide more opportunities for people suffering with Long Term Conditions and anxiety/depression to receive treatment. Other projects were on track in terms of increasing number of patients who 'achieve recovery' at the end of treatment and the Children and Young people work continues to focus on helping staff working with CYP to use Routine Measures

Outcomes so that we can evaluate what works well and what doesn't . We know from our talking therapies treatments in adult services (where 96% of patients have outcomes recorded) that being able to demonstrate effectiveness is important so that patients get the best treatment whilst it also supports any bids for additional funding of services.

Durability and Employment Project

Michelle reported back and let the group know that the questionnaire had now been signed off by Prof David Clark. Ineke and Michelle also shared the learning to date as part of this project which aims to follow-up patients over a longer period of time to evaluate if the benefits from therapy lasted. All patients discharged from the IAPT/ Talking Therapies services during the month of June in Berks, Bucks, Oxon, Beds, Luton and Milton Keynes had been contacted and asked if they would consent to participate in this. Disappointingly, only 10% have returned consent forms/ given consent on the phone when contacted so the patient sample is only some 200 people.

A useful discussion followed and patient members wondered if 10% was such a low number considering the fact that the calls took place in August and that they imagined many people, although favourably disposed to the Talking Therapies service, may not have responded because of a sense of relief at discharge and a reluctance to commit to re-engaging.

On-line Mindfulness courses

G reported back on trying out the 'Be Mindful' course by the Wellmind Media and Mental Health Foundation whose focus is on running effective, evidence-based, reputable and popular online training programmes for managing pain, stress, anxiety and depression, and achieve outstanding performance and participant outcome results. The programmes are served from their platform which enables the effective reporting and delivery of online training to participants, as well as ongoing technical advances to keep the courses current and running smoothly. They're also active in research trials with academic partners to help expand knowledge in the field of mental health training.

Wellmind Media Ltd was established in 2002 in Brighton, UK. They are a team of researchers, writers, producers and programmers. Directors of the company are Richard Latham and Willem Mulder.

This course did have a fee attached to it (£60) but this did give a 'connection' with the providers in terms of reminders etc. It is 4 weeks long with short, modular sessions (about 10 minutes) which suited Gary and included things like How to introduce mindfulness into daily activities and Bodyscanning and other techniques were covered through video and audio material. Feedback from Gary:

- Realistic approach was helpful (e.g. acknowledging that someone might feel silly doing certain things)
- G felt it had left him with useful techniques afterwards to integrate into daily life going forward
- He acknowledged that it was a bit like going to the gym: easy to put off! You needed to be motivated and the group wondered if paying for it helped?

- Overall G felt this was a 'pretty cool' course with personal emails back when encountering technical problems etc.

The group talked about the difference between someone who is open to mindfulness ideas (like G) and someone who might take a more defensive position on outcomes/ usefulness. M considers herself less open to these ideas and has offered to also try this course! Both G and M have offered to share their thoughts at the Extended Network Conference on 15th November.

Action: Ineke to send links to various on-line mindfulness options to all PF members

Link between physical health and mental health

Michelle reported back on this and shared that she found some 20,000 articles on this topic when she started looking! So she chose a couple of articles which had summarised the research available and which demonstrated clearly that there are strong links both ways. She talked about the fact that if you suffer with a long term condition you are twice as likely to also develop depression/anxiety (coping with the impact) and if you suffer from mental health disorders you are more likely to develop physical problems (as you may not feel well enough to engage in 'healthy lifestyle' activities such as balanced, fresh diet or taking exercise). The group discussed this for a while, drawing on real life examples they recognised in the literature.

M highlighted the 'ten minute workout' session that can be found on-line and which she found a fun way to do some exercise.

ACTION: Michelle to distribute a couple of summary papers

Recruitment

Ineke has now updated all Patient forum materials that can be used for recruitment. The following are available to be used at the local service's discretion:

- Application Form for Patient Forum
- Person Specification for Patient forum Members
- Role description for PF member role
- Terms of Reference for Patient Forum
- Full PPIEE plan

Berks, Bucks and Oxon PPIEE leads were present and it was decided that they would start the recruitment process as soon as possible, contacting patients from their People Banks.

It was agreed that the initial e-mail would be very short (Dear..., Our records show that you might be interested in becoming involved with our service (add your local name) and I am contacting you to ask if you would be interested in joining our Patient Forum to review talking therapies (add your own name). We meet every 3 months for 3 hours in High Wycombe over a working supper and travel expenses will be paid. Etc etc.... ***This should be going out in the next 2 weeks.***

It was agreed that you could attach the person spec to the initial e-mail but no more

When someone expresses an interest send through an application form and start the personal relationship, maybe following up with them if you haven't heard. **Give people 3 weeks** to respond, ensure you let them have the date of the next meeting: **18th January 4-6.30 in High Wycombe**. It would be good to have all new members start together in January so we can ensure a general introduction to the patient Forum and its objectives.

We thought we would get responses in by end of November/ beginning of December and should send people more information e.g. Terms of Reference only after they had sent through the application form and had been accepted as this could be overwhelming otherwise.

We have agreed to hold a **teleconf on 14th December at 4 o'clock for PPIEE leads, Michelle and Ineke** to catch up on number of responses. **If we get lots of responses** we need to talk through a process for appointment, please keep Ineke informed over the next few weeks. Increased numbers of PF members would be welcomed, we also need a new strategic lead as Ailsa has now moved away.

Importantly, 2 members from Berks have already expressed an interest and need following up.

ACTION: Tanique to contact them and talk about joining the Patient forum

ACTION: Ineke to send through details for teleconf and all documentation

No AOB

Date of next meeting **18th January 4-6.30 in High Wycombe**