

**Summary Notes from Anxiety and Depression Network Patient Forum
23rd May, 2018
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), M R (Bucks Healthy Minds), Michelle Lee (Reading University Researcher and project support officer for the Network), D B (Berks Talking Therapies), Dawne West (Talking Therapies PPI Lead), Sabaa Mahmud (Healthy Minds PPI Lead), Emily Gray (Research Assistant with Professor Clark), G P (Bucks Healthy Minds), D A (Bucks Healthy Minds), Ruth Tipping (PPI Lead for Milton Keynes Talk For Change), Hannah Jones (Oxon PPI Lead).

Apologies: K P (Berks Talking Therapies), AG (Bucks Healthy Minds). Hannah was welcomed to the group.

Notes from last meeting: notes signed off as accurate and all actions closed. To be anonymised and posted on the Anxiety and Depression Network's web page. There was an important discussion on the last bullet point re: sustainability of the app and the group agreed that it is very important that a plan for sustainability/ maintenance of the app is in place ahead of Thames Valley roll-out so that patients who will start using it will know that it will remain available to them throughout and beyond their course of therapy. The possibility of a one year free use followed by an annual subscription was discussed and it was felt that charging a fee might result in some people not able to continue using it.

Maintaining Therapeutic Gains update: Michelle talked the group through her final draft of the paper reporting on this survey. There were 44 responses from across Thames Valley, the majority of respondents had received treatment for depression (60%) and around 50% had received treatment for anxiety including health anxiety, social phobia, OCD, panic disorder, simple phobia and PTSD.

Half of respondents had received step 3 treatment (8 or more sessions) face to face and the other half of respondents had received telephone treatment by a Psychological Wellbeing Practitioner, group work or online help via a computer treatment programme.

About a third of respondents had received further help for their difficulties post discharge, including GP, mindfulness, private therapy, additional group work, on line therapy, referral to a clinical psychologist and input from Mind.

The vast majority felt that treatment had benefitted them (connecting with others, understanding one's difficulties better, learning new skills to cope). The vast majority of respondents who were offered a follow-up appointment took up this offer and the vast majority of respondents felt that having a FU appointment booked in before finishing treatment was a very important 'life line' and support mechanism post-discharge.

The paper also lists a summary of FU resources which were popular (includes various peer support initiatives and books/ websites) as well as the specific tools/ skills learned in therapy which proved most useful post discharge (including worry time, mindfulness, behavioural activation, not avoiding things and keeping physically healthy).

Finally, it is worth noting that respondents who reported *not* being able to maintain their therapeutic gains expressed barriers such as 'not knowing *how* to play an active role in staying well' or 'not being sufficiently familiar / the difficulty of practicing techniques' which, once again, demonstrates the importance of engaging patients in their 'staying well' plans early on in therapy so that it becomes a well-rehearsed, daily occurrence after treatment finishes.

The paper lists many specific examples of what respondents felt was most helpful in staying well.

The full paper will be posted on the A&D Network website as soon as it has been signed off:

<http://www.oxfordahsn.org/our-work/clinical-networks/depression-anxiety/>

Feedback from first Relapse Prevention (now renamed 'Staying Well') working group: Ineke reported back on the first meeting of this working group which is looking at Staying Well activity for step 2 treatment (8 or less sessions, often over the phone, in groups or on line). This working group was set up following a survey of all Psychological Wellbeing Practitioners (PWP's) to find out the degree of Staying Well/ Relapse Prevention currently undertaken as part of treatment. This highlighted a need for further training and a number of service model improvements. The SW working group includes a number of experienced senior PWP's from across the Thames Valley who agreed to develop the following:

- New guidelines/ protocol indicating when SW work should start in treatment
- Materials to underpin this
- A training programme for PWP's to be piloted in the Thames Valley

At a follow-up teleconference call with this very competent and knowledgeable group it was reported that they had made good progress on completing the first task of pulling together the SW materials which will underpin the therapeutic journey. Next meeting 27th June.

The group discussed the need for patient representation on this group and D has offered to explore if she can change a current commitment to be able to attend.

Patient Forum members expressed the view that an early start with RP/SW work is indeed desirable but needs to be done with sensitivity to the patient and at a point when they can 'hear' and process this i.e. not in the middle of an acute crisis that may have brought them into therapy. Wording is also important.

Minutes from the App Expert Reference Group: Ineke took the group through the group's minutes and gave verbal feedback on the second ERG which was held just before Patient Forum. The final app development brief was shared and the update included the news that a formal invitation was issued to the preferred app developer Global Initiative who have awarded the project an additional £15,000 from their social fund which is very welcome as it had become clear that the original budget (£25,000) was very tight to achieve the desirable product.

AOB

Ineke let PF know that 2 issues would be taken to June steering group: work undertaken in services to reach out to **'poor outcome' groups** as we need to get feedback from this group (i.e. people who had not achieved recovery/ had dropped out/ had expressed negative experiences) as well as the issue of the need for every patient to be offered a **follow-up appointment** as this was a strong theme in all the feedback from patients.

A discussion took place about the benefits of 'support workers' as part of the IAPT services i.e. people who would support patients with practical issues and tasks including getting places, paperwork etc. Whereas the original model for IAPT services included support workers this was never really implemented and no Thames Valley currently employs them. The group expressed a desire to work on this as a future project and look at ways in which it might be possible for IAPT services to link with the voluntary sector maybe to provide more practical support for those who need this. **Action on Ineke:** put on agenda for next Patient Forum. **Action on Dawn:** explore what is offered in Slough (Friends in need).

Date of next meeting: 11th July 4-6.30 at Holiday Inn High Wycombe.