

**Summary Notes from Anxiety and Depression Network Patient Forum
5th June 2019
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), Michelle Lee (Reading University Researcher and project support officer for the Network), Alisha Smith (Research Assistant with Professor Clark), Kiran Sharma (Oxon Talking Space Plus PPI lead), Ruth Tipping (PPIEE Lead for Milton Keynes Talk For Change), G P (Bucks Healthy Minds), Anisha Gangotra (Employment Advisor), Bucks Healthy Minds), H B (Berks Talking Therapies), D A (Bucks Healthy Minds), Christina Webb (Talking Space Plus Oxon)

Apologies: KP (Berks Talking Therapies), M R (Bucks Healthy Minds), D B (Berks Talking Therapies), Shannon Wilson (Berks Patient Engagement Lead), Fiona Giles (Bucks PPI Lead)

Introductions: The group welcomed D, a newly recruited PF member from Oxfordshire and Christina who will be the PPI Lead from Talking Space Plus, Oxfordshire when Kiran leaves. Ineke gave them a quick overview of the Anxiety and Depression Network's activity and purpose. The group also thanked Kiran for his contributions.

Notes from last meeting: notes signed off as accurate. No outstanding actions.

Developments since last meeting

Ineke and Michelle outlined the various developments since the last meeting. The Paddle website is now under construction, the instruction video has also been commissioned and the app itself is close to Beta piloting phase. The new, step 2 Staying Well protocol and materials booklet has also made very good progress with the training video commissioned and currently under development. The final graphics for the protocol and booklet have been finalised and a detailed project plan for the next 18 months had been pulled together for both the Paddle and the Staying Well testing, piloting and roll-out.

Evaluation: the 'preparedness' survey as part of the step 2 Staying Well new protocol evaluation

Michelle introduced this agenda item, asking for feedback on the nature of this piece of work. The proposed piece of work consisted of asking step 2 patients about their level of 'preparedness' just before discharge *before* introduction of the new Staying Well protocol and then with a group of patients *after* the introduction of the new protocol. A very useful discussion followed about the difficulty doing this as it would be important to distinguish between 'normal' apprehension at the thought of discharge and 'excessive anxiety/ insecurity' and that there is a difference between 'feeling prepared' and 'having the tools' to work at staying well. It was felt that there is a difference between a patient's feelings versus actual obstacles and, at the end of the discussion, it was agreed that a more meaningful and objective measure would be to check in with patients at the usual follow-up call and ask them then how they got on and that this should be measured *before* the new

protocol was in place and then again *after* the new protocol had been incorporated into the therapy. It was also agreed that quantitative as well as qualitative feedback was important and that it was important that there should be concrete, specific questions relating to the staying well materials booklet and tools. It was also thought that the survey might explore both the patient's expectations about how they would do after discharge as well as the reality of how things went. It was also pointed out that it will be important to ensure the group samples are not self-selecting but as diverse as possible. And, finally, it was agreed that the number of questions will need to be kept at a minimum. **ACTION Ineke and Michelle:** re-design this part of the evaluation plan.

The above discussion took up a lot of the meeting and a couple of agenda items were moved off-line:

User Experience Protocol: both Paddle and the step 2 Staying Well new protocol will need to be tested on 'user experience'. Michelle has pulled together a first draft of both of these and feedback was given during the meeting whilst it was agreed that the documents would be sent out to all for feedback by e-mail.

It was also agreed that PF needs a teleconference meeting in July before the next one in September to ensure all aspects of Paddle and Staying Well protocol have been approved by PF. **ACTION on Ineke:** set up teleconference call.

Finally, a discussion took place about uptake of follow-up appointments and variation between services and between type of IAPT treatment. The group is interested in looking at this in more detail and PPI leads have agreed to bring more detailed data on this to the next meeting (% of FU calls offered, % of FU calls attended and what type of treatment i.e. step 2 or 3 or IAPT-LTC). **Action on PPI leads:** bring some figures as outlined above to next meeting in September.

PPI leads have agreed to be involved in the Paddle and step 2 piloting activity.

No AOB

Dates for meetings for 2019:

- **18th September**
- **27th November**