

Summary Notes from Anxiety and Depression Network Patient Forum

3rd April 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), MR (Bucks Healthy Minds), 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), Shannon Wilson (Berks Patient Engagement Lead), H B (Berks Talking Therapies), Fiona Giles (Bucks PPI Lead),

Apologies: K P (Berks Talking Therapies), D B (Berks Talking Therapies), D A (Bucks Healthy Minds).

Introductions: The group welcomed Fiona, who is now the Healthy Minds PPI Lead, and H from Talking Therapies and Ineke gave them a quick overview of the Anxiety and Depression Network's activity and purpose.

Notes from last meeting: notes signed off as accurate. Outstanding actions:

- Ineke to have further discussions with service leads on employment advisors and Paddle
- February notes to be anonymised and posted on the Anxiety and Depression Network's web page.

Feedback from 14th February national Patient Forum workshop

The PF was invited to run a workshop on patient engagement at the national 'IAPT at 10' anniversary celebrations. The A&D network PF is recognised as an effective way of ensuring ex-service users contribute to the network's direction of travel and all its projects in a meaningful way. D, G. and Ineke co-facilitated the workshop which was very well received with a number of people getting in touch with Ineke afterwards asking for more detail. With thanks to G and D for participating. The group also talked a little about the great success of the national IAPT programme and how it is now known across the world with a number of other countries trying to implement a similar programme.

Action on Ineke to let everyone have the NY Times article written after a journalist spent time with our Thames Valley services.

Updates on projects

Ineke gave a quick overview of progress on current A&D Network projects.

- The step 2 therapy (Guided self-help, often by phone or in groups) improved '**Staying Well**' protocol and materials booklet: this has now been finalised and signed off by steering group. Service leads wish to introduce this as soon as possible. An instruction videos for therapists has been commissioned and the working group is currently writing the various bits of script

for this. Once the video has been produced and final versions for protocol and materials booklet has been received Ineke and Michelle will work with the working group and the service leads to appoint Paddle app and step 2 staying well champions. The champions will be trained up centrally and will then take responsibility for rolling it out across their own services (Bucks, Oxon, Berks and Milton Keynes). The evaluation process is underway and a final decision on evaluation activity will be taken by service leads/ steering group early next month.

- **The health economics evaluation** of the new, integrated treatment for people suffering with long term physical health conditions (including diabetes, COPD and heart disease) and co-morbid depression/ anxiety has been concluded for phase 1 and a paper is being prepared for publication.
- **The Increasing Access to psychological therapies for older adults** project has been initiated and a scoping paper should be finalised by end of April
- **Paddle app is an agenda item**

Patient Member recruitment

It's great to have Kiran and Fiona on board as we now have all services represented by a PPI (Patient and Public Involvement) Lead. We need to undertake a round of recruitment of ex-patient members to make sure all services are represented (although it is acknowledged that travel from Milton Keynes may be prohibitive). Kiran has already started his efforts to recruit someone from Oxon and so far 2 people have shown interest. Fiona has started work on the people bank in Bucks and hopes to recruit soon and Shannon introduced H to the group. **Action on Ineke:** send Ruth and Shannon PF paper work (application form, role description, person spec). These templates serve as a suggested format but services/ PPI Leads should feel free to adapt as desirable for their area. The group also talked about the importance of having a people bank which can be used to reach out to ex-service users and invite them to participate in service improvement initiatives. It is imperative to obtain patients' consent. **Action on Ruth:** send through the consent form she uses.

Paddle app

The group discussed a number of aspect of this project.

Website and ex-patient testimonials. After some discussion about what could work well and have impact it was agreed that the home page should have patient quotes (anonymised) with a photo illustrating the idea. An example would be D's illustration at the extended stakeholder group, showing a huge pile of papers representing all the work she did during therapy and how difficult it was to retrieve the information she needed to stay well at any one time (this could be a 'before' picture) as opposed to the 'after' picture showing Paddle with everything in one place. Other examples we could use are the quotes from our pilot studies with patients suggesting more support to stay well after discharge. **Action on Michelle:** dig out any quotes that may be useful/ we could use on the website to explain why/how Paddle came to be. Also include staff quotes as and when we get these.

Feedback/ actions from ERG and further discussion by PF

The various issues raised/ discussions had/ decisions made at Expert Reference Group were discussed (please see notes from ERG) and then the group focused on a number of outstanding questions which needed PF input.

Should we have a feedback button on the website? After a detailed discussion it was agreed that this would be too complicated at this point as it would require monitoring and this function would be subject to strict data collection compliance rules which would be difficult to adhere to.

The group also discussed what **analytics should be run**.

A number of analytics have been agreed by ERG:

Activity by service: Knowing how many patients were using Paddle by service could be useful and wouldn't be difficult to get.

Utilisation/ time spent on app

When patients log in

It may be useful to see when patients are using the app (i.e. just in the evening for example). It may also be useful to see if it is possible to date stamp entries to My Sessions, with date of therapy session to be added to ascertain whether adding information soon after a session is helpful/predictive of better usage. **Action on Ineke** to check with GI if this can be done.

What tabs are used?

It would be useful to see which sections were being used – general consensus was that we needed to have a way of seeing actual ‘activity’ rather than just the app being open (but dormant), and it wouldn't be useful to see how many documents etc were being uploaded, as this may not be a true reflection of usage. It would be good however, to see items uploaded to the Staying Well section prior to discharge.

Other possible analytics were discussed including utilisation during and after therapy (problems were identified and discussed such as how to mark discharge (subscription? Patients requested to enter their discharge date? The latter was thought to be counterproductive. Make it part of the discharge process so admin flag discharge on the app data base/ admin function? Part of discharge letter? Add into questionnaires?)**Action on Ineke:** discuss with service leads/ steering group

Should we have target metrics? It was thought that, in the absence of any baseline figures, it might be wise to pilot the app first and then set targets.

No AOB

Dates for meetings for 2019:

- **5th June**
- **18th September**
- **27th November**