

**Summary Notes from Anxiety and Depression Network Patient Forum
24th May 2017
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), MR (Bucks Healthy Minds), 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), TS (Oxon Talking Space), DB (Berks Talking Therapies), DA (Bucks Healthy Minds), KP (Berks Talking Therapies).

Apologies: Raj Kumar (PPIEE Lead Oxon Talking Space PLUS), MT (Talking Space PLUS Oxon)

Notes from last meeting

No inaccuracies noted and all actions closed except for:

1. **Get in touch with Raj from Oxon and ask him to invite Mo along to our next meeting**

Deferred agenda items as follows:

*The group discussed various issues and has asked that the following items are included on the **agenda for a future meeting** (agenda got hijacked by Post discharge staying well: maintaining therapeutic gains' project planning)*

1) On-line therapy

- How to motivate yourself/ get the support you need to start/ continue/complete
- Would a 'buddy system' be helpful where patients can support each other?
- Do people apply themselves properly?

- 2) **Roadmap** for patients would be really helpful to give them more information up front about what will happen

Update on budget and work programme for the Anxiety and Depression Network to April 2018

The network's clinical lead Professor David Clark and the network manager Ineke Wolsey have managed to find funding to secure the network manager's position (Ineke Wolsey) as well as the project support role (Michelle Lee) and to keep *some* of the work programme going through 17/18 as planned. Ineke outlined the following;

CYP: Very sadly no funding has been secured for the Children and Young People work which the network was engaged in and the work with the Children and Adolescents MH services (CAMHs) on increasing the use of Routine Outcome Measures to ascertain if treatment has been effective has now ceased. We are still trying to place this project with other organisations within the NHS.

Continuously improving patient outcomes/ enhancing recovery rates: we have funding to continue with our core work on continuously improving patient outcomes and recovery rates. This consists of monthly collation of anonymised data from all our talking therapies services across Thames Valley and Milton Keynes and looking for variables in performance and development needs for the services. Themes have included the importance of recording of a good assessment interview and ‘problem descriptor’ so that patients will get the correct evidence based treatment (e.g. the treatment approach for anxiety disorders is very different and needs to be CBT based from the approach in the case of depression when different approaches can be used according to the evidence base). This work has led to the Thames Valley talking therapies services (IAPT) being amongst the best in the country. We will continue to meet with Prof Clark (who is also the national advisor to the IAPT programme) and all service and data leads quarterly for half a day to explore the data and agree on service developments and action plans to continuously improve patient outcomes. We have committed to increasing the number of people able to access talking therapies as well as increasing number of patients successfully treated.

Durability of clinical gains project (are we staying well post therapy?): we have funding to finalise the pilot for this project where all patients who were discharged in June 2016 are invited to participate in a follow-up study 6 months and 12 months after finishing therapy. Within the current financial restraints we aren’t able to start phase 2 (due to start June 2017) but will finish a paper on Findings as well as a paper outlining ‘Lessons learned’ as, more than anything else, this pilot has taught us much about how not to try and conduct a follow-up study. These deliverables are due November 2017.

Integrated treatment for patients suffering with Long term Conditions such as diabetes, COPD or cardiac disease and depression/anxiety: Thames Valley talking therapies services are setting up additional services for patients who fall in the above categories offering therapy which combines physical and mental health. We will continue to work with our services and support them implementing this as well as lead on the health care utilisation evaluation (do patients need to make use of health care services less after treatment?). A clinical evaluation is also part of this project (do patients feel better able to manage their long term conditions after treatment? Are they feeling better in themselves?).

Implications for Patient Forum: In terms of budget for Patient Forum activity Ineke let the group know that there is enough funding for the May meeting and two more (July and September?) and possibly beyond that. There is also about £1,000 available for the Post Discharge Support project if Patient Forum decides to go ahead with this. If the latter budget isn’t used up for the Post Discharge project, Patient Forum could decide to use it instead on more Patient Forum meetings as well as on paid, strategic Patient Representative activity for the network.

Post Discharge support project: the group discussed continuing this project and the decision to proceed was supported by all. The project was originally scoped as follows:

The Post Discharge Support project was then scoped by Patient Forum as follows:

- Design questionnaire questions by July 2016 (all patients discharged in June 2016 were to be followed up)- **Completed**
- Map current activity in the different services by October 2016- **completed**
- Examine similarities and differences between the services by December 2016- **completed**

- Plan a series of focus groups with ex-patients run by a Patient Forum member and the PPIEE lead for the service to explore what patients found most helpful/ what was not helpful and what they think would be helpful post discharge by February 2017
- Run focus groups by June 2017
- Collate all feedback from focus groups and follow-up questionnaires and compare to what is available by October 2017
- Write up guidelines and support implementation of best practice post discharge support mechanisms by December 2017

The first 3 steps in the process have been completed, the next steps in the project now need to be decided on by PF members. Below headlines of discussion:

The project is to be called 'How to support patients to maintain therapeutic gains post treatment'

The output will be best practice guidelines for services by end of March 2018

There was a very productive discussion on whether to, and if so, how to use focus groups. It was felt that focus groups might not be a realistic prospect within the reduced timescales for the purpose of exploring answers to questions but that, instead, they would be very useful for testing out the questions themselves which, when finalised, would then be sent out by Survey monkey to those patients who consented to being contacted by the services after treatment finished.

One of Berkshire's existing focus groups is running in the next few weeks and it was agreed that the PF would use this opportunity to test the questions which would form the basis for the survey monkey looking at post discharge support and maintaining therapeutic gains.

Timeline agreed is as follows:

- Ineke and Michelle to create a strawman questionnaire based on questions generated by PF on the 24th May- **by 5th June**
- To be distributed to all PF members- **by 9th June**
- To be discussed at teleconference **21st June @4.30**- Ineke to book and send through dial-in details
- Ineke and Michelle to incorporate feedback into second iteration and distribute to all PF members **by 27th June**
- Tanique and Dave to take second iteration to Berkshire Patient **Forum 29th June** for additional feedback/ road testing and get this to Ineke/Michelle
- Ineke and Michelle to incorporate this second round of feedback into 3rd iteration for final discussion and sign-off during next PF face to face meeting **on 5th July.**
- Decide on next steps for finalising questionnaire, sending it out and collating responses on **5th July.**

Questions generated during the meeting to be included in questionnaire:

- Need to ask *if* people feel they benefitted from the treatment and what, if any gains, they feel they got from treatment
- Need to ask what they had treatment for i.e. depression/ anxiety disorder etc

- How long ago were you discharged?
- Were you given signposting information on discharge offering possibilities for continued support? If so, was this helpful?
- Can you remember what method of therapy you received i.e. phone, on-line, face-to-face? Did you develop a discharge/ relapse prevention plan? If so, do you continue to implement this? If so, how?
- Do you know what your triggers are for potential relapse?
- What, if anything, worked to help you stay well?
- What else do you think might have worked?
- Do you have continuing access to helpful materials/tools?
- Have you found other ways of maintaining gains?
- How would you feel about regular reminders as texts on how to stay well?
- What would be your preferred method of contact (phone, text, e-mail)
- If you started out ensuring you looked for 'refreshers' after therapy stopped, did you stop doing that? If so, how long afterwards?
- Do you find yourself 'slipping back' and drawing once more on your 'therapy tool box'?
- Have you found other ways of maintaining the therapeutic gains and learning from the therapy? If so, what are they?
- Have you experienced specific obstacles in your attempts to stay well following therapy? If so, what are they?

There were also very useful suggestions about using technology more to support people to stay well including through receiving texts with links to very short 'refresher modules', reminding people of their triggers etc. it would be good to test this idea out with people i.e. would they be interested in this kind of support? It could be linked into the idea of moving towards positive self-image, banishing negative self-talk and developing resilience

Oxford Collaboration of Leadership for Applied Health Research and Care (**Oxford CLAHRC**) Proposal: Ineke shared the fact that the CLAHRC had awarded the network 15k to develop a research proposal. Steering group proposes we continue work on our Durability of Clinical Gains and apply for a grant to start phase 2. Patient Forum thought this to be an important project and supported this choice.

AOB: T reported back from her work at the college that the issue of lack of support 'post-discharge/post end of well-being course' was widely reported across the board by people and not only a reported issue within talking therapies treatments.

Dates of next meetings:

Teleconference Wednesday 21st June 4-5: Ineke will send through details on how to dial in nearer the time

Next face to face Patient Forum meeting at **Holiday Inn High Wycombe Wednesday 5th July 4-6.30**

Health and Wellbeing

Tanveer shared details of a national project which is currently running called 'Learning for wellbeing'. She is involved with this through Abingdon and Witney College but there are 58 providers across the country. Many different courses are run including stress reduction and assertiveness (depends on provider) and the purpose of the research (funded by the Department of Education) is to investigate the effect of adult learning on personal well-being. More details can be found on the website: www.mhfe.org.uk

Patient Forum members are asked to raise awareness of this project if there is activity locally (there is in Bracknell and Milton Keynes). Contact person for Oxfordshire is Julie Bennett, Adult Education mental health research project manager 07771946132.

No AOB

If we find funding the next meeting date is **24th May 4-6.30 in High Wycombe**