

**Summary Notes from Anxiety and Depression Network Patient Forum
25th May 2016
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), AH (Patient Representative on A&D Network Steering Group), MR (Bucks Healthy Minds), TS (Oxon Talking Space), CMcW (Bucks Healthy Minds PPIEE Lead), TB (PPIEE Lead Oxon Talking Space), GP (Bucks Healthy Minds), TNI-G (Berkshire PPIEE Lead), SR (Berkshire Talking Therapies), Michelle Lee (Reading University Researcher and project support officer for the Network)

Apologies: AG (Oxon), DF (Bucks Healthy Minds), JW (Bedfordshire Wellbeing Service PPIEE Lead), MH (Luton), MT (Talking Space Oxon)

Ineke informed the group that H (Milton Keynes PPIEE Lead) had left Patient Forum as she has started her High Intensity training and R (Milton Keynes patient rep) has also left as she has started her Psychological Wellbeing Practitioner training. The group thanked them for their valued contributions and wishes them all the best for their future.

Notes from last meeting

No inaccuracies noted and all actions closed except for:

Page 1: 'TB and TS to follow up on starting ethnic minority project'. Following further discussions about this it was decided that T's colleague Mo should be approached (he is employed by the Trust to promote diversity/ work with supporting ethnic minority groups) and for us to meet to explore if there might be alignment between his work and what we are trying to set up in Patient Forum (focus on reaching out to minority groups to increase awareness of psychological therapies and increase self-referral)

New Action: T to invite Mo to the next Patient Forum meeting 20th July

New Action: Ineke to arrange for summary notes from March meeting to be posted on web site.

Web-based Patient Forum interactive discussion forum

A discussion took place about the pros and cons of a closed Facebook page and, on balance, people felt that this was not the most desirable option. Instead, it was agreed that we should try and set up a Yahoo group for sharing ideas and information.

Action: Michelle, Ineke and SR to explore setting this up. Michelle to take the lead

Durability and Employment Project

It was thought that questions about Durability of clinical gains (how long have you stayed well after treatment) and employment (what happened to your job/ career/ professional life after treatment?) could be included in the same questionnaire but that people would not have tolerance for more than between 5 and 7 questions in total. The questionnaires should be sent out 6 and 12 months after treatment. The group also thought that in terms of the process to be used, a (hard copy) letter inviting people to take part followed by an e-mail with the link to the 'survey monkey' type questionnaire would work if at all possible from a practical/ resource perspective although people should also be given a choice on whether or not they want to fill in the questionnaire electronically or hard copy. The letter should offer an introduction stating a clear rationale for the research and making it attractive (and real) to participate: who is going to use it and what will be done/ achieved?

The group also thought it would make sense to text people for follow up.

It was agreed that multiple choice questions should be used where possible as easier to process.

It was thought that there should be a clause in the follow-up letter/email stating 'If your mood has deteriorated in the past few months and you feel you need help please contact your GP or ring'
At the end local services should add their contact details

Employment questions for questionnaire

More work was undertaken on fine-tuning questions that could be included in the questionnaire in an attempt to reduce the number of questions:

- 1) Has your job/ voluntary work/carer/ professional situation changed since finishing therapy?
YES/ NO

If yes, was this change

Positive/ Negative

Please describe:.....

- 2) If you were in employment/ a student/ a carer/ undertaking voluntary work at the time of starting therapy and remained in this situation after therapy finished, would you say the quality of your work/ occupation has Remained the same/ Improved/ Deteriorated

Please describe.....

Add voluntary work, 'full-time carer', 'employment without remuneration' as categories if possible to standard questionnaire (MDS)

Add tick box with job roles e.g. 'teacher' if possible as might be interesting to see if some professions are more represented than others

Post discharge support project

The group discussed how best to get to the desired outcomes for this project (following the mapping exercise of current activity which Ineke will undertake) and it was felt that this project should be owned by the Patient Forum and that the methodology should include focus groups facilitated by a

PF member and the PPIEE Lead for the area. It was thought that the right time would be 3 months or more after discharge and that we should also do a literature search on efficacy of support mechanisms. The focus of this project should be on 'how to maintain well-being'.

It was agreed that we will run focus groups of 45 minutes to explore these questions and that groups will be facilitated by the PPIEE Lead and the patient reps locally. We looked at how this might fit in best with local processes:

- Berkshire already run focus groups and this subject matter could be included in this
- Oxon will be setting up Patient Forums and the post-discharge support could be part of this. Another option is to send out invites from the People Bank
- Bucks runs a regular peer support group and, after a discussion about whether or not this would mean a biased view from ex-service users, it was agreed that we could use the first half of these meetings as it will give us interesting views from patients who have continued to use a peer support group following discharge from treatment.
- Luton, Beds and Milton Keynes: we have to check what is already available when reps attend next Patient Forum

Questions fine-tuned for the focus group:

- 1) Were you offered any support by your therapist/ service when you finished treatment? YES NO

If yes, what support were you offered and how useful was it to you?

- 2) Can you think of anything/ anything else that would have been helpful after discharge and would have helped you stay well? YES NO

If Yes, please describe

- 3) Has there been anything that has prevented you from using the techniques you were taught during therapy to help you stay well? YES NO

If yes, please describe

- 4) What has helped you stay well, if anything? Differentiate between short and long term

Integrated care for people suffering with Long term Conditions such as Diabetes or COPD and depression/ anxiety

Ineke shared with the group that the OxfordAHSN is hoping to be considered for national funding to increase the work services do with people suffering with long terms conditions and depression/anxiety and asked the group to give their views on what would be most important to them if they were diagnosed with a long term condition and found their mental state deteriorated. This feedback will be used when writing the proposals in the event of being invited to bid for these monies. Answers included:

- Help to really understand your physical illness and having any emotional needs taking into account from the beginning (i.e. following diagnosis)

- Would want to be able to talk with others in the same boat
- Would want to have access to someone who would listen
- Would be looking to work with someone who would empower me to take charge of my illness and moods
- Screen for depression/ anxiety even at diagnosis and offer GP leaflets to distribute offering contact detail of talking therapy services
- Work pro-actively with charities

Action: Ineke to produce short summary on work undertaken to date on integrated care

Next meeting to be held Wednesday 20th July 4-6.30 Holiday Inn, High Wycombe

DRAFT