

**Summary Notes from Anxiety and Depression Network Patient Forum
21st September 2017
4-6.30, High Wycombe Holiday Inn**

Present: Ineke Wolsey (Network Manager), G P (Bucks Healthy Minds), Michelle Lee (Reading University Researcher and project support officer for the Network), D B (Berks Talking Therapies), Ruth Tipping (PPIEE Lead for Milton Keynes Talk For Change), D A (Bucks Healthy Minds)

Apologies: MT (Talking Space PLUS Oxon), Tanieque Noel-George (Berkshire PPIEE Lead), KP (Berks Talking Therapies), M R (Bucks Healthy Minds), Jessica McKell (Bucks Healthy Minds PPIEE lead) Raj Kumar (PPIEE Lead for Oxon Talking Space PLUS)

Notes from last meeting

Outstanding action: Michelle to send Ruth Durability of clinical gains questionnaire

No inaccuracies noted, it was agreed that anonymised notes would be posted on the website.

Deferred agenda items remain:

*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

Michelle gave an update on **preliminary findings from the two follow-ups as part of the Durability of Clinical Gains study.**

Out of 3027 discharges during the month of June 2016 only 323 people gave consent to be contacted for the follow-up study, and in total (though not all participated in both follow-ups), we received **106 responses** for the 2 follow-up dates (December 2016 and June 2017).

Of interest was the fact that **over 80% of patients** who were 'recovered' or 'reliable improved' at discharge had maintained their improvement at 6 months

Over 80% of those who had maintained their recovery or reliable improvement at 6 months continued to be well at 12 months.

This seems to indicate that, if you stay well for 6 months you have a **very good chance of staying well** for a longer period.

Some **40%** of people reported seeking support after discharge from CMHTs, private therapists or their GP. No further detail is available on this but the Maintaining Therapeutic Gains questionnaire should offer more detailed information

Additional feedback from PF was;

- Lack of flexibility within IAPT on adapting to patient's needs, especially step2
- A smoother transition is needed between step 2 and 3
- There is a greater need for relapse prevention work

As Audit Committee still had not given the green light and PF could therefore not progress the 'Maintaining Therapeutic Gains' project it was agreed that the group would mainly work on the **Durability of Clinical Gains App** which is to be developed as the next phase of the project and which needs a high level of PF input.

ACTION: Ineke to set up teleconference mid-October with all PPIEE leads to update on Maintaining Therapeutic Gains project

Michelle showed the group a first 'mock-up' of the App and a detailed discussion developed about which features would be of value and should be offered. Issues discussed included:

- The need to ensure patient confidentiality
- The need to ensure returned assessment questionnaires are monitored and, if need be, services are alerted if there was any concern about any of the participants (which is a problem to solve as researchers at the AHSN are only allowed anonymised data so will have to find a way of being able to flag up concerns about a patient with one of the services without having a patient name, and for the service to be able to link an anonymous patient identifier to a patient name/ identity.
- The group approved the first draft categories for content and there was a discussion about the usefulness of being sent local 'what's on to stay well' information.

ACTION: Ineke and Michelle to explore how much the App can be localised by geography

- There was also a discussion about how 'personalised/ bespoke' the App could be e.g. to offer support on a low/ medium/ advanced level.
- The group agreed that prompts are needed regularly for it to be used by people including prompts for the monthly upload of assessments **Action: Ineke and Michelle** to explore other Apps including Headspace.

Next meeting: Wednesday 1st November 4-6.30, Holiday Inn, High Wycombe