

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

Present: Ailsa Harrison (Patient Representative on A&D Network Steering Group), Ineke Wolsey (Network Manager), MR (Bucks Healthy Minds), ML (Oxon Talking Space), MT (Oxon Talking Space), TS (Oxon Talking Space), GP (Bucks Healthy Minds), DF (Bucks Healthy Minds), Dawne West (PPIEE Lead Berkshire Talking Therapies), Faz Parkar(PPIEE Lead Luton Wellbeing Service).

Apologies: Laura Bethel (Oxon Talking Space PPIEE Lead), Hayley Scanlon (Milton Keynes IAPT Service PPIEE Lead), Catherine McWhirter (Bucks Healthy Minds PPIEE Lead).

The meeting started with introductions to each other, the Oxford Academic Health Science Network and the aims of the Anxiety and Depression Network (<http://www.oxfordahsn.org/our-work/clinical-networks/depression-anxiety/>). The three Anxiety and Depression projects were described to those present and opportunities to get involved were outlined by Ailsa.

Information folders were handed out which included the Anxiety and Depression Network 'Patient and Public Involvement, Experience and Engagement' (PPIEE) plan which describes the activities planned to meaningfully involve patients and the public in improving talking therapy services (IAPT services). The plan also summarises both the Oxford Academic Health Science Network (OAHSN) aims and objectives as well as the Anxiety and Depression Network's aims and projects.

The draft Terms of Reference were signed off by the group (see Appendix 1) and a discussion followed which focused on the kinds of issues which patients face when attempting to access psychological therapy. This feedback is very important to the Network, will be shared at the A&D Network Steering group by Ailsa and Ineke and will be used to inform future project work undertaken.

The themes were:

1. The need for support after therapy finishes: buddy system, online forum, group events. Maybe the Network could map current support available and commit to sharing best practice/ introducing additional activity?
2. Clarity for patients on the potential journey ahead, to reduce uncertainty - a 'roadmap'. Maybe the Network could explore in more detail what explanation/ preparation patients who have been accepted for therapy are offered to help them understand the journey ahead?

3. GP awareness of services available. Maybe the Network could explore what else could be done to increase GP awareness of availability of Talking Therapies?
4. Waiting time for therapy vs outcome. Maybe the Network could explore this?
5. Reducing stigma. Can the Network do anything to reduce stigma with regards to MH problems?
6. Courses for parents whose children are receiving treatment. Can this be explored as part of the CYP work?
7. Reaching other communities (e.g. Asian). This was raised as an important issue and TS has offered to support any work the Network may want to undertake to improve referral rates from ethnic minority groups.
8. Increasing self-awareness. This was seen as important for people to self-refer as soon as possible. Is there any way the Network can support this?
9. Mental health in the workplace was also raised as an important issue. Maybe the Network could explore supporting this?
10. Older adults and low rate of referral/ low self-referral rate for talking therapies was discussed and MR has offered to work with the Network and Age Concern to raise awareness of the availability of talking therapy to older adults who suffer with anxiety and/or depression.

Next the group was asked to give feedback on a questionnaire/ survey the A&D network is planning on patient choice of therapy for patients suffering with depression. Ailsa took detailed notes which she will share with Prof David Clark, the A&D Network's Clinical Lead.

The meeting ended with a discussion on next steps and it was decided that:

- The next meeting should take place at the same time and venue end of September
- Ineke will ensure all attendees will be paid travel expenses ASAP
- Ineke will write to all attendees to explore next day/time for meeting and send summary notes
- The service PPIEE Leads (Laura, Catherine, Dawne) to contact their patient representatives to discuss future involvement (Patient Forum attendance every 4 months as a minimum and any additional participation in one of the 3 projects and/or special projects such as the Extended Network Conference on 21st October) and any support that may be needed.

It was felt that discussions had been rich and informative and with next steps agreed the meeting was closed at 6.30.

Oxford Academic Health Science Network (AHSN) Anxiety and Depression Network

Patient and Public Forum

TERMS OF REFERENCE

Introduction

About the Oxford Academic Health Science Network

The Oxford Academic Health Science Network (Oxford AHSN) brings together the NHS, universities, business, patients and the public to promote best health for our population and prosperity for our region.

Its aim is to break down traditional organisational boundaries and build stronger relationships between industry, scientific and academic communities – coupled with better knowledge exchange – which will bring lasting benefits as best practice is spread quickly and widely across the NHS.

The region we cover includes Berkshire, Buckinghamshire, Bedfordshire, Milton Keynes and Oxfordshire.

We will:

- Focus on the needs of patients and local populations
- Speed up adoption of innovation into practice
- Build a culture of partnership and collaboration
- Promote prosperity in the Oxford AHN region

About the Anxiety and Depression Network

The Oxford Anxiety & Depression Network will build on the already successful local IAPT (Improving Access to Psychological Therapies) network previously run through South Central Strategic Health Authority incorporating providers, commissioners and university based researchers who are at the cutting edge of psychological treatment research. The Clinical Network will extend its focus to medically unexplained symptoms (MUS) and to patients with chronic health problems whose management is complicated by the presence of anxiety and/or depression as well as to working with Children and Young People (CYP) IAPT.

Aims

The focus of the Anxiety & Depression Clinical Network will be on reducing IAPT service variation in clinical outcomes, a region-wide improvement in recovery rates, rapid dissemination of latest advances in treatments, reduction in waiting times and improved user involvement. The network will focus on both the Adult and the Children and Young Persons IAPT services and Professor David Clark is the Clinical Lead for adults and Professor Shirley Reynolds is the Clinical Lead for children and young People (CYP).

We have already appointed a patient representative to the Network Steering Group, who will work closely with members of the Patient and Public Forum.

The role of the Oxford AHSN Anxiety and Depression Network Patient and Public Forum

- To ensure the Anxiety and Depression Network understands and responds to patients' and the public's interests, needs and concerns about services planning, provision, research, innovation and improvement.

Responsibilities

- Provide wider patient, carer and public opinion, advice and guidance for the Patient and Carer Representative on the Anxiety and Depression Network Steering Group
- To be actively involved in aspects of the PPIEE plan including design of detailed feedback materials
- To make recommendations about how services could be improved to deliver a better patient experience
- To receive reports on how this feedback has been used to improve services
- Act as a conduit for ideas and views to and from Local Patient Groups relevant to this network
- To advise on dissemination of the work of the Anxiety and Depression Network so that communications from the Network reach as wide a cross-section of service users and professionals as possible
- To share information about other relevant work in progress, or about policy and practice developments, which they know about, providing additional context and information
- To use their own networks, where appropriate, to publicise the work, advice and decisions of the Anxiety and Depression Network
- To help guide the development of recommendations for further work
- To support patient/carers/public representation on each of the project groups

Membership

The Forum will be supported by the Anxiety and Depression Network's Steering Group Patient Representative, Ailsa Harrison, and the network's manager, Ineke Wolsey.

The network welcomes applications from people of all backgrounds from across the whole region.

The application to join the forum will be circulated as widely as possible through patient involvement groups and the voluntary and community sector.

We are asking forum members to be able to express the needs of patients and public as a whole, whilst not excluding specific communities and groups.

Membership will include:

- Anxiety and Depression Network Steering Group Patient Representative Ailsa Harrison
- Anxiety and Depression Network Manager Ineke Wolsey
- Patients, carers and members of the public who have an interest in enhancing 'Improving Access to Psychological Therapies' (IAPT Talking Therapies) services across our region
- The PPIEE leads from all participating IAPT services
- The Chair will be Ailsa Harrison
- The Chair will be supported by the network manager Ineke Wolsey

In addition:

- Clinical Leads and/or Service Leads will attend from time to time to provide specialist advice and support to the Forum
- The Oxford AHSN PPIEE Lead may also attend from time to time
- Forum members will be appointed initially until the end of March 2016.
- Total number of forum members is not likely to exceed 20

Quorum

- The meeting will achieve quorum if the chair and/or the network manager and at least four other patient/public/carer members of the Forum are present.
- Decisions are to be by consensus, or in specific instances of absence of time allotted by the Chair, by majority; where any decision is split, the Chair will have the casting decision

Attendance

- Members would normally attend meetings, and it is expected that members will attend 2 out of the 3 scheduled meetings a year
- The Chair may invite members of the Network to attend for particular items

Ways of working

- The Group will meet face to face at least 3 times a year, for the financial year 15/16 this will be in July 2015, September 2015 and January 2016. Meetings will be held in the High Wycombe area, 4-6.30 with a sandwich supper included.
- Members of the Group will receive any papers one week before each meeting
- Action Notes / Minutes of the meeting will be kept by the network manager and agreed by all members of the Group who attended the meeting
- Members may be contacted between meetings for advice should the need arise
- From time to time sub-groups may be formed to work on specific issues as appropriate
- From time to time individuals may be co-opted to provide specific advice and expertise as required
- The Forum will conduct its business in accordance with any national guidance, and relevant codes of conduct/good governance practice as appropriate.

Reporting

- The Minutes/ Action Notes of the Anxiety and Depression Network Patient and Public Forum meetings will be shared with the Network Steering Group and made available on the Network's website.

Measuring impact

- The Anxiety and Depression Network Patient and Public Forum, supported by the network manager, will produce an annual report detailing its progress and contribution to the network, including assessment against agreed measures of success.
- Measures of success will be discussed and agreed with the Patient and Public Forum

Support and Out of Pockets Expenses

- Forum members will be offered dedicated support on all practical issues such as help with claiming expenses, access to meeting papers, support during meetings, answering queries and any additional advice as needed
- Reasonable adjustments such as providing support for care, payment for carer, an interpreter, wheelchair accessible taxi, can be made – please discuss with the main point of contact
- There will be opportunities to meet other patients, carers and members of the public in similar roles within the Oxford AHSN and our partner organisations
- You will be offered training and development opportunities
- These are unpaid positions. Forum members will be able to claim out of pocket expenses as per the Oxford AHSN Lay Partner Expenses & Involvement Payment policy. Receipts must be provided for expenses to be paid.

For any queries, contact Ineke Wolsey, Network Manager for Oxford AHSN Anxiety and Depression Network

Phone: 07802 352251 | Email: ineke.wolsey-anxietydepression-iapt@oxfordahsn.org

For further information about Oxford Academic Health Science Network PPIEE (*Patient and Public Involvement, Engagement and Experience*), please contact:

Dr Sian Rees

Patient and Public Involvement, Engagement & Experience (PPIEE) Lead

Oxford Academic Health Science Network

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For more about the Oxford AHSN: www.oxfordahsn.org/about-us