

## **Academic Health Science Network Case Study**

Patient and Public Involvement, Engagement and Experience (PPIEE)

### **The Anxiety and Depression Network Patient Forum: alive and kicking!**

The Anxiety and Depression Network (all Improving Access to Psychological Therapies/Talking Therapies provider services) wanted meaningful engagement with patients and started preparing for this as part of its' launch event in December 2014. Following the appointment of a patient representative onto the A&D Network steering group and a PPIEE Lead staff member from each of our IAPT/Talking Therapies services, a Patient and Public Involvement, Engagement and Experience (PPIEE) Strategy was signed off by the steering group and the process of recruiting patient members for our Patient Forum was started in June 2015. Now, nine months later, our Patient Forum is alive and kicking!

*'Over the moon with the service that has been given, starting to feel that I am getting my life back. Something that I never thought was possible has been made possible and I just thank you all so much'.*

*'Any way that I can be used for the good of others I would be most definitely interested to assist'*

### **Key points at a glance**

- The A&D Network covers a large and diverse area and includes Oxfordshire, Berkshire, Buckinghamshire, Milton Keynes, Luton and Bedfordshire
- Our Patient Forum meets every 2 months for consultation, feedback and active involvement in project work
- It is attended by both the PPIEE Lead staff member from each service as well as at least one patient representative from each service. The network manager and steering group patient representative co-facilitate the meeting
- The A&D Network PPIEE strategy, role descriptions and recruitment processes can all be found on our website as can the minutes from Patient Forum meetings
- Meetings cover consultation and feedback on project work, problem solving real issues that come up and moving forward new projects.

### **Background Summary**

The A&D Network wished to find a way of engaging as many patient representatives as possible, representing all services, to actively participate in the network's activities. The focus was on finding a way of building long-term relationships with patient members and, together, embark on a highly participative journey which would result in real and lasting contributions and impact by our patient members on the work the A&D Network undertakes.

The A&D Network also wanted to find ways of ensuring there would be clear rules of engagement in place, both for the network and the Patient Forum members. Time was taken to discuss and agree on eligibility criteria e.g. only patients not currently in treatment, time commitment, any expenses payments, agenda items, expectations and responsibilities.

## **Challenges identified and actions taken**

- Following on from appointing a steering group patient representative, the network started building its PPIEE communication and implementation structure with the appointment of PPIEE Lead staff members for each of the services.
- The network then poached, created and adopted various Patient Forum recruitment tools such as role descriptions, person specifications and a framework for payment of expenses and the PPIEE Leads each recruited Patient Forum members from their own services.
- Local recruitment of Patient Forum members is crucial as this means that patient representatives have a local contact and relationship, someone to turn to if they feel in need of support and someone who can quickly mobilise any support that may be needed.
- A central meeting point was chosen to hold 2 monthly Patient Forum meetings which run from 4-6.30, include a working supper and follow an agreed agenda structure which was worked up over the first few months
- With the Patient Forum established and supported by PPIEE Leads and with the network manager and steering group patient representative having access to steering group and, with that, all service leads the feedback loop is closed. The A&D network now have a clear line of communication and feedback from 'grassroots' up to decision makers and budget holders and vice versa.
- Patient representatives also contribute to specific projects as members of project teams

## **Outcomes**

- The A&D Network now has real and meaningful patient representative input into many of their projects e.g. questionnaire design for their recovery rates work
- This has already resulted in projects being shaped differently e.g. including more qualitative questions to better understand the patient's perspective. Rather than only asking questions aimed at academic research and clinical outcome measures, we will also include questions on what patients felt had supported them back into work, if they had changed direction in terms of career/ job role following therapy and, if so, why.
- The patient Forum was consulted carefully about prioritising projects put forward for funding for 2016-18 and 2 of the (sub) projects accepted for funding were highly influenced by Patient Forum opinions

## **Plans for the future**

We are only just getting going! The Patient Forum has decided that it wants to undertake the 'post discharge support' project itself which seeks to establish best practice in supporting patients immediately after discharge to keep themselves well.

The work will involve mapping what services are currently doing, using focus groups to explore what patients found most helpful and collating all this into a report which will then be used to agree on best practice and disseminating this across the A&D Network.

## **Tips for adoption**

- Clarity of purpose, roles and responsibilities
- Processes and lines of accountability which ensure issues get followed up and addressed
- Co-production of the how and what
- Large measures of fun

- Always some 'real work' every meeting i.e. something that needs problem solving or guidance for one of the projects or maybe something that has come up in general feedback and discussion (e.g. 'How to engage patients in our research?' or 'How to increase awareness of availability of talking therapies?')

**Contact for further information**

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