

# Early Youth Engagement in First Episode Psychosis (EYE-2) Study

Gill Macafee worked as the PPI Lead on the EYE2 study for 2 years looking at whether Social Groups would keep young people with experience of 1<sup>st</sup> time psychosis engaged in Early Intervention Services.

Many young people drop out of services within the first 12 months but engaging appeared to help them and running Social Groups was thought to be a way to keep them engaged and help them on their recovery journey.

The study finished in July 2021 and Gill was asked to write a blog about her experience of running these groups.

<https://mcpin.org/4-things-i-learnt-running-a-social-group-for-people-with-psychosis/>

Gill thoroughly enjoyed the role as PPI Lead and thought the Social groups were a success. Gill hopes the group members got as much out of them as she did.

“I think similar groups within the community would be very beneficial to Mental Health Service Users.”



## What is the project about?

This study is about improving services for people who have a first episode of psychosis so that more people want to stay with the service and benefit from its support.

The first Early Youth Engagement (EYE) project at the University of Sussex developed a new approach with young people, their parents and Early Intervention in Psychosis (EIP) staff. The EYE approach addresses the issues that can put people off services, like the way staff talk with them, how much family & friends are included, and how much it helps with their goals, treatment choices and preferences.

The EYE approach includes a website, booklet series and other resources to support young people and families, and a training programme for staff in how to work flexibly, honestly and openly using key, well established “motivational” techniques to help young people achieve their goals.

The EYE-2 project looks to refine this toolkit, resources and training and evaluate its effectiveness, implementation, and cost-effectiveness with participating research sites and EIP teams before disseminating it more widely.

## Why is this research important?

Around 7,500 young people in England develop psychosis every year. It is a severe mental health problem that generally starts in people aged 14-35 years and has long-term effects on the individual and society.

Early intervention in the first 3 years of psychosis can improve long-term outcomes. However, at least a quarter of all young people drop out of Early Intervention in Psychosis (EIP) services in the first 12 months, leading to greater risk of poor outcomes.

Ensuring that young people receive a service quickly is a current NHS priority, but there are no interventions to improve engagement with services.

## How are McPin and people with lived experience involved in this research?

The trial benefits from advice and support from people with lived experience in different ways.

The Service User Research Forums (SURF) were consulted over several meetings to develop the research question and design for the first EYE project.

People with lived experience collaborated to develop the EYE intervention, training, materials, analysis and dissemination strategy, and continue to support the study. e.g. recently organised Lived Experience Advisory Panels (LEAPs) provided advice on the design of questionnaires used in the trial.

In addition, a Patient and Public Involvement (PPI) Lead works closely with each participating research site, supported by Tanya Mackay at McPin. PPI Leads are involved in providing part of the trial intervention by organising social groups and events with service users. They also provide additional training to support new research staff joining the study sites.

## What's the current status of the project?

Several work packages of the study are now complete. The implementation material, training and process evaluation tools have been developed. The intervention resources (booklets, website, training packs) have been updated to be more accessible and reflect the diverse background of service users of the different study sites.

The identification of over 1000 eligible participants for the randomised clinical trial has now been completed, with follow-up data collection on engagement and other outcome measures ongoing until Spring/Summer 2021.

**There are also two poems written by Gill Macafee based on her experiences facilitating the groups. The 1<sup>st</sup> one was written at the beginning of the study and the 2<sup>nd</sup> one was written at the end:**

### **EYE2 Social Group poem**

The research group, Early Youth Engagement Project,  
Has set up social groups, of which the object,  
Is to meet other service users who,  
Have experienced 1<sup>st</sup> time psychosis and want to,  
Talk to peers with whom they connect,  
Maybe meet over coffee, have mutual respect,  
And understanding, and as a group will chat,  
Play pool, table tennis, bowling and things like that,  
There are classes too, like art and walking,  
And you're not just occupied, you are also talking,  
Everyone is friendly and has lived experience,  
So if you are new to the group do not feel tense,  
Come join us, relax, you soon will be,  
A part of your wonderful group and you'll see,  
That the Early Intervention Team is so good,  
And successful in helping service users who could,  
Have relapsed if not part of this team,  
So if you think that this group may seem,  
A good idea for you, come along,  
We have so much fun and we all belong,  
Together, helping each other to cope,  
With situations where we didn't hold much hope,  
But now we see that the sun does shine,  
On us as a group and we laugh more than cry,  
Honestly, and you'll make friends too,  
Come along, join us, I'm sure they're for you.

## **A poem about Social Groups**

When I first started one of the Social groups,  
There was the marvelous one, who was soon to become two,  
Then along came another, who was indeed,  
A man with whom to take heed,  
As he came along, leg in plaster,  
But that didn't stop this determined master,  
Then joining the group was a man who,  
Was to become a valued member too,  
So instead of three it was the four musketeers,  
Who overcame many things during the next two years,  
We watched one grow, another return to the gym,  
One always showed up, despite the voices within,  
And let's not forget the incredible peer mentors who,  
Were to become known as the dynamic two,  
Plus the STR worker, where do we start,  
A dedicated member with a very big heart,  
In the last few months the group grew,  
Four young ladies joined the crew,  
Each bringing their own individual thing,  
To us all, now it's time to sing,  
A song to rejoice in the glory of "Us",  
An amazing group who, with very little fuss,  
Grew and furthered their individual recovery,  
On this journey of life, each making many discoveries,  
About themselves, their capabilities and such,  
We have all grown so very much,  
And together we have done this,  
At the same time creating a situation of bliss,  
At least on a Thursday afternoon when we could,  
Relax, chat, laugh, opening up like a bud,  
I will miss you, but hope that you can all,  
Continue the group, and climb any wall,  
That's needed to help keep everyone in touch,  
Because we created a bond that was such,  
A powerful, lovely, friendly thing to be part of,  
Goodbye, Good luck, I'll sign off with love,  
But first, I want to remind all of you,  
To be proud of yourselves in all that you do,  
You are amazing and have come so far,  
Aim for the skies, be the brightest star.