

LIKEMIND

A mental health companion
for young people



MYTH-BUSTING INFORMATION

Social Groups



Contents

| | |
|---|----|
| What is the Early Youth Engagement (EYE-2) project? | 1 |
| Firstly, what is a Social Group? | 3 |
| How do the EYE-2 groups run? | 5 |
| How often and what is the duration of the group? | 6 |
| What do you do at a Social Group session? | 7 |
| Are there any ground rules for these groups? | 8 |
| Social Group risk plans | 9 |
| Using lived experience in Social Group facilitation | 10 |
| The successes of EYE-2 Social Groups | 11 |
| The challenges of EYE-2 Social Groups | 12 |
| EYE-2 online Social Groups | 15 |
| Successes of EYE-2 online Social Groups | 17 |
| Challenges of EYE-2 online Social Groups | 18 |
| Summary | 20 |

What is the Early Youth Engagement (EYE-2) project?

This Early Youth Engagement (EYE-2) project is about improving services for people who have a first episode of psychosis so more people stay with the service and benefit from its support. The project builds on the work of the first Early Youth Engagement project in the Sussex Partnership Foundation Trust, and in Kent and Surrey, which developed a new approach with young people, their parents and Early Intervention in Psychosis (EIP) staff.

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, working with the whole social network to help young people achieve their goals.

The project ran across five site locations; London, Manchester, Hampshire, Thames Valley, and Cambridge-Norfolk. A key part of the programme has been the development of social groups for people in the EYE-2 programme led by someone with lived experience.

When we use the term 'lived experience' we mean the lived experience of a mental health issue.

This booklet was co-produced by the EYE-2 Patient and Public Involvement (PPI) team who facilitated the groups. It explores how the social groups were run as well as the successes and challenges of both face to face and online formats.

If you want to see more materials from the first Early Youth Engagement project, visit our website likemind.nhs.uk



Firstly, what is a Social Group?

A Social Group is two or more people interacting with each other, sharing similar characteristics and collectively having a sense of unity.

These groups aim to give the members the opportunity to meet each other as part of their recovery from first time psychosis. The groups promote opportunities for improved physical and mental well-being; at the same time emphasising the need to introduce people to each other and provide peer support as a group, whilst exploring socially inclusive opportunities, in a safe and supportive environment.

The objective of these groups is to develop motivation by engagement in a regular and meaningful activity, whilst increasing the members' independence, confidence and self-esteem. In addition, the groups aim to decrease social anxieties, help develop effective communication by interaction with other attendees and encourage social interaction.

The groups also aim to increase the members' confidence in accessing community resources (such as cafés, museums, arts events and other social activities) outside of the group; and encourage fun and relaxation.



How do the EYE-2 groups run?

Vital to the success of the EYE-2 groups was the fact that the PPI leads had lived experience and could create the 'WE' feeling within that group.

They were able to relate, were empathic and had a genuine understanding of the experiences of group members.

Before the first Social Group took place, it was good for the facilitator to familiarise themselves with each possible attendee. A simple phone call of introduction, having a chat about what the group would entail and sharing a little information about each other set the foundations for a respectful, successful and safe group environment.

Once the group was established and there were regular attendees, it was good for the facilitator to take a back seat and hand control over to the members. The attendees decided what the next meeting would entail. This gave them the control and some responsibility for the running of the group – Reinforcing the fact that it was their group. They chose what they wanted to do, where and when and, as long as the facilitator could accommodate this, it could happen.



How often and what is the duration of the group?

The groups usually met on a weekly basis, for around 1–2 hours.

Consistency was vital, where possible. We tried to meet at a similar time and place each week. When deciding on a meeting place, we chose somewhere familiar to everyone attending, e.g. the town hall clock, or the local bus station. Attendees were reluctant to show up if they had to follow directions and were not sure where they were going.



What do you do at a Social Group session?

These groups were designed to give members a chance to socialise and interact with others on a regular basis.

It was important that they could identify with each other and have a feeling of belonging, whilst sharing their experiences of psychosis.

What kind of activities did we do?

- Walking groups to various places in the local area such as gardens, parks and arboretums
- Trips to museums and art galleries
- Trips to local theatre to see matinees

- An art course in local community centre
- Pool, badminton, table tennis, bowling and basketball
- Visits to the cinema
- Music sessions with facilitator
- Backstage tours
- Café/restaurant visits



Are there any ground rules for these groups?

Each group developed their own ground rules or 'norms' that suited the members.

However, across all group there were two key similarities:

- **Confidentiality:** Personal information that attendees disclosed was not to be revealed outside of the group session. Members were informed that confidentiality may be broken if anything was said during a group meeting which the facilitator thought put someone at risk of harm
- **Respect:** Group members were required to respect other people's differences, and to not say or do anything prejudicial or discriminatory towards others. The groups operated on a belief that all input was valuable and deserved to be heard



Social Group risk plans

All social groups developed a site-specific risk plan reflecting local NHS Trust policies. These were adjusted when groups moved to the online format during the Covid-19 pandemic.

Core aspects of these risk plans included being aware of who to contact if an issue arose, how to manage emotional distress in the community and all group leads having a co-facilitator to help in case of an emergency.

Tips for making people feel included/keep attending:

- Having a facilitator with lived experience helps people feel understood and safe in the group
- Be welcoming and inclusive – try and include everyone in conversations and check in with how they are doing
- Offer to meet someone one on one or with one other group member first – this helps people feel more welcome in the larger group
- Have access to members contact details – this is easier and more efficient than having to communicate via the Care team
- Try to make contact with people before the group via email, text or telephone call. This helps to remind people of the activities and location as well as making them feel included
- Meet at the same place every week, before heading to an activity together. This can help ease anxieties about travelling to the group sessions
- Allow the group to choose activities and take leadership – this helps build a sense of ownership and control in the group
- Recognise individuals' strengths and work with them to improve confidence and self-esteem
- Try and initiate conversation about the members' interests – this helps them feel seen and heard within the group

Using lived experience in Social Group facilitation

Lived experience give experiential expertise that can enrich mental health services and research.

In the EYE-2 programme all PPI leads who ran the social group had their own lived experiences which they drew on in their role.

In EYE-2 relationships were built upon a sense of reciprocity, each giving and receiving support and building up a shared understanding that benefited both parties. Social connections were fostered through a “we” feeling – a sense of belonging and equality within the groups only possible where all members, including the facilitator, had experienced mental ill health.

Lived experience allowed the PPI leads to better relate, and offer more authentic empathy and validation. There was a understanding of what group members may be experiencing and the PPI leads were able to consider and adjust for things that someone without lived experience may not recognise, for example how

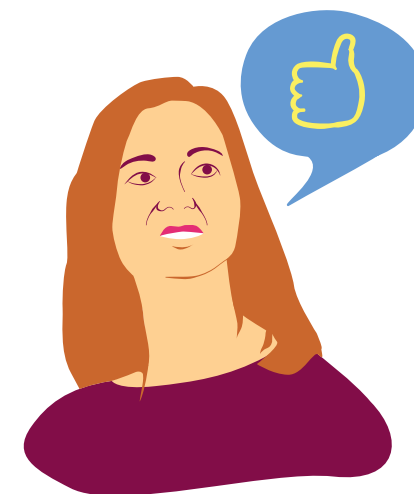
significant catching public transport might be or how to set up activities to allow participation from people with social anxiety.

The PPI leads were also able to use their own experience of overcoming mental health issues and share their story where it was appropriate, and when they felt comfortable. This helped build a sense of optimism, shared identity and respect within groups.

Having a lived experience facilitator has enabled the modeling and mentoring around interpersonal skills, problem solving skills, and building social relationships whilst allowing members to interact and learn at their own pace, in a safe and supportive environment. As a group who share a common bond, there is no anxiety about conversations that draw on or explore mental health experiences because there is a feeling of ease and an understanding of each other. The atmosphere of non-judgement helps the group to open up and laugh together.

The successes of EYE-2 Social Groups

- Some sites achieved a group of regular members over of an extended period of time, who built well established social relationships
- Members enjoyed the social aspect and the sense of belonging
- Activities allowed people to interact in an informal way with minimal pressure
- Members became more aware of social opportunities and activities and they developed the confidence to take them up
- Members noticed that physical and leisure activities reduced stress, improved sleep patterns, increased energy levels and they gained skills in maintaining a balanced lifestyle
- Members supported each other and became friends outside of the group
- Members were very enthusiastic about doing different activities
- Members improved their interpersonal and communication skills within the group



The challenges of EYE-2 Social Groups

- Difficulties associated with travel including cost, time and access as well as anxieties associated with public transport
- Finding suitable venues for activities that had no, or minimal cost
- Finding enough variety of engaging but low-cost activities
- Engaging new service users was difficult as building new social connections may not be a priority when people first begin at the service
- Some Care Coordinators were not highly engaged in referring service users to social groups
- A core aim of the Social Groups was to have service users facilitate the groups. However this was not possible for the majority of sites. The primary challenge to this was sporadic group attendance and the changes to group format associated with the Covid-19 pandemic



EYE-2 online Social Groups

The purpose of online EYE-2 social activities was to replace face to face gatherings during the Covid-19 pandemic.

The online groups aimed to continue providing a safe and supportive space for young people experiencing their first episode of psychosis. As with the face-to-face groups, online groups were about staying connected to others with similar lived experience, making friends, normalising mental health issues, feeling empowered and being included. As with face-to-face meetings the members discussed what activities they might like to try virtually, supported by the facilitator.

The success of online groups was mixed, in some instances people joined who may not have done so face to face, and there were opportunities for new activities.

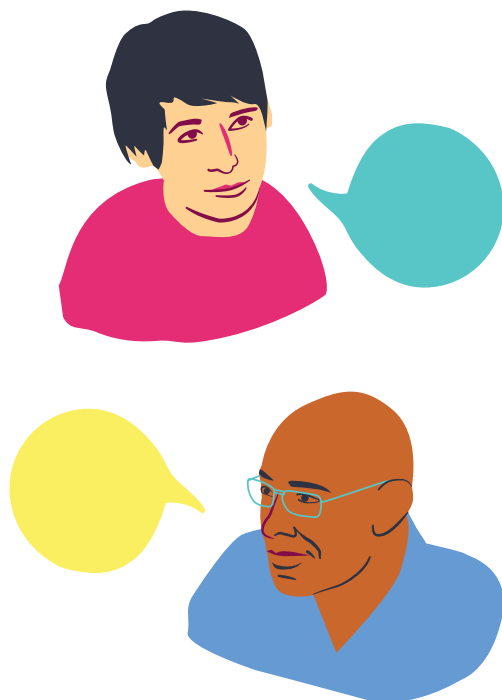
However, the main feedback has been that most people would prefer a face-to-face format. There was a notable decline in attendance numbers when the groups moved to an online format, and the PPI leads found it difficult to engage new service users to join.

However, the team did find that discussing ideas for activities with other PPI leads was extremely helpful. Learning from colleagues about what works and what doesn't and being there to offer each other moral support when things don't go according to plan was also very reassuring.



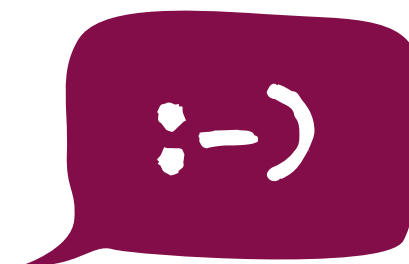
What kind of activities did we do in online social groups?

- Watched and discussed TED talks
- Watched and reviewed plays, movies and documentaries
- Watched online museum and art tours then discussed these as a group
- Online quizzes and treasure hunts
- Virtual art groups
- Guest speakers (for example the local Recovery College, a local therapeutic garden, the local Mind, an organisation which organises local volunteering and Peer Support Workers)
- Social chats, including sharing experiences of, and strategies for wellness, during Covid-19 lockdowns



Successes of EYE-2 online Social Groups

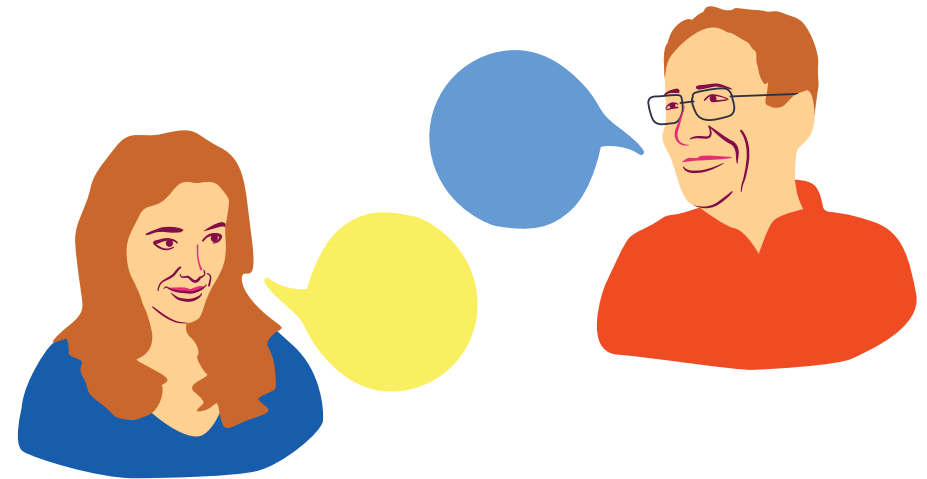
- Members felt the groups helped their confidence
- Members found it reassuring to know they are not alone
- Groups had fun trying new activities and overcoming the challenges of technology together
- Virtual meet ups are more convenient for some members. They do not need to leave the house if they are not feeling up to it, but can still be part of an activity
- Some members described the virtual meetings as 'life lines', particularly if they were isolated. Members who regularly attend the groups have reported them to be really valuable and have appreciated that they have continued during lockdown. It has allowed people to stay connected while social interaction has been difficult
- Online groups have been more accessible to people who may not have their own transport or live further away
- The online groups are cost effective as there is no expenditure on transport or refreshments



Challenges of EYE-2 online

Social Groups

- Managing large numbers of people and ensuring everyone gets involved and has their say is harder virtually
- Only one conversation at a time is possible. You are speaking to the whole group rather than having a conversation with one other person which may deter people from speaking up
- Some members do not like video interactions and some people don't want to see themselves on a screen and turn off their video, this can make it hard to gauge their reactions
- Not as organic and spontaneous as face-to-face meetings
- The facilitator has to more actively chair the activities and lead the conversations to keep the energy up. This feels less group led than face to face
- Coming up with different activities every week which can be done both virtually as a group is really difficult!
- Less flexibility to change or adjust activities at short notice
- People who do not have a computer or smart phone are unable to join in
- Technology doesn't always work
- It is hard to introduce new people to each other virtually
- Managing the sharing of confidential, sensitive or personal information. We ask that members do not record any part of the group and that they try to join without others in the room and use headphones where possible
- It is harder to read body language online, inevitably people can talk over each other and people may find it hard to assert their wish to contribute
- There is pressure to fill silence, which does not occur as much face to face
- People have other commitments in lockdown – some people are dealing with childcare and jobs and it was very hard for them to join in during lock-down
- Zoom fatigue, due to the pandemic many people were using online platforms for school, work and mental or physical health support. This resulted in less motivation to join for voluntary social groups



Summary

The social groups have provided an opportunity for people in the EYE-2 program to develop new social connections. The main type of groups we have run are either general knowledge and current affairs, sport and exercise, games, culture and the arts or have involved a guest speaker.

They have been built on confidentiality and respect and allowed people to meet, connect, build relationships and confidence, and develop a sense of safety and mutual belonging. By drawing on our own lived experience in facilitating we have been able to run the social groups with empathy, understanding and flexibility to member's needs.

We've learnt a lot along the way. We hope that you find this booklet inspiring and helpful in setting up and running your own service user led social groups.

In association with:

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



US
UNIVERSITY
OF SUSSEX

UEA
University of East Anglia

 **Queen Mary**
University of London



**INSTITUTE OF
PSYCHIATRY,
PSYCHOLOGY
& NEUROSCIENCE**

MCPin
Foundation

NHS
Pennine Care
NHS Foundation Trust

NHS
South London
and Maudsley
NHS Foundation Trust

NHS
Cambridgeshire and
Peterborough
NHS Foundation Trust

NHS
Greater Manchester
Mental Health
NHS Foundation Trust

NHS
Oxford Health
NHS Foundation Trust

NHS
Sussex Partnership
NHS Foundation Trust

NHS
Norfolk and Suffolk
NHS Foundation Trust

NHS
Southern Health
NHS Foundation Trust

NHS
Berkshire Healthcare
NHS Foundation Trust

NHS
Central and
North West London
NHS Foundation Trust