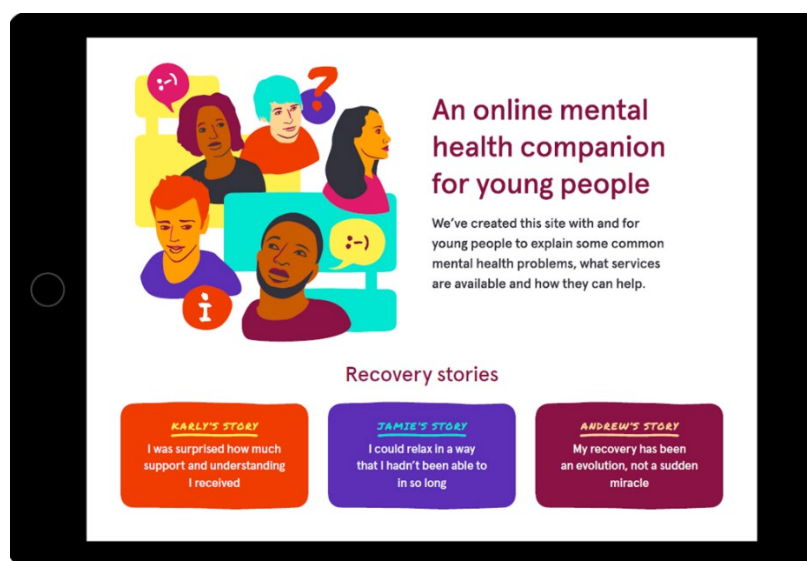


# The EYE-2 Consultation and Training Manual



By

**Professor Kathryn Greenwood**

**Stacey O'Donnell**

**Dr Rebecca Webb**

**Dr Stuart Clark**

**And the EYE-2 EIP teams**

## **The Authors**

Kathryn Greenwood is a Professor of Clinical Psychology. She has worked clinically for over 15 years in EIP, community, specialist and inpatient services for psychosis. She wrote, developed and led the original EYE-1 and the current EYE-2 project.

Stacey O'Donnell is trained as a nurse and is the current Sussex EIP Service Manager. She has experience of leadership in both inpatient and community mental health setting. She is a co-applicant on the current EYE-2 project and has an MSc in Healthcare Management.

Rebecca Webb is the post-doctoral research fellow on the EYE-2 study. She has a PhD in Health Psychology.

Stuart Clark is a clinical psychologist and the Sussex EIP service Clinical Lead. He was involved in the original EYE-1 project and is a co-applicant on the current project. He has over 10 years dedicated EIP experience, including the initial set up of the EIP service in West Sussex, and was previously the South East Clinical Lead for the South Regional EIP programme.

The final version of this manual is developed in conjunction with all the EIP teams involved in delivering the EYE-2 intervention. The names of all those who wish to be named are included below.

The EYE-2 EIP teams:

## **Acknowledgements**

With thanks to the **Sussex Service User Research Forum**. A group of fantastic EIP service users whose input shaped the entire project and all the booklets and resources.

Thanks also to Emmeline Hamm (EIP care co-ordinator and team leader) who provide comments on an early draft.

This manual is dedicated to **Ruth Chandler**, Service user and carer involvement lead, who worked tirelessly on this project until her untimely death in December 2017. Your legacy lives on.

## **Copyright © 2019 Sussex Partnership NHS Foundation Trust.**

This manual is part of independent research commissioned by the National Institute for Health Research (NIHR) under its Health Services and Delivery Research Scheme reference (16/31/87). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

## Contents

### How to use this manual

What you need to know about the Early Youth Engagement Project (EYE-2) in First Episode Psychosis....	5
What did service users and their families say about EYE-1? .....	8
What did clinicians say about EYE-1?.....	8
Why are care co-ordinator, lead practitioner and support worker roles are so important? .....	8
The EYE Intervention.....	10
Communication, Goals and Social involvement' in EYE-2.....	10
Open, Honest, Transparent Communication.....	11
How to make sure we've identified service users' own needs and goals .....	11
The face of the service - Collaboration and Choice in the context of risk .....	17
<sup>5</sup> Steinberg, L. (2007). Risk Taking in Adolescence: New Perspectives From Brain and Behavioral Science. Current Directions in Psychological Science, 16(2), 55–59.....	21
Knowledgeable care-coordinators and clinicians .....	22
Knowledge about ethnic and other minorities and cultures .....	23
The social network in Open Dialogue and EYE-2 .....	27
Personal Barriers.....	36
The EYE-2 Website - How and when to use it.....	43
Facilitators to implementing the EYE-2 Approach.....	45
Benefits of the EYE-2 Approach .....	46
Barriers and Solutions to implementing the EYE-2 Approach .....	48
Resources.....	51

## How to use this manual

This manual provides a guide, checklist and introduction to EYE-2 resources and papers, aimed at supporting engagement of service users with EIP services.

It is designed to be:

- An aid to engagement approaches in EIP services
- A collaborative manual. It will be finalised with input from you, and all the EIP teams involved in the EYE-2 research project.
- A flexible application of the EYE-2 approach, that fits with your team and service context.
- A core set of approaches, with optional methods for utilising these.

All clinical staff who are involved, are welcomed and encouraged to contribute ideas, examples and quotes, to be used in the manual. We will include all staff and teams who would like to be named, as contributors to the final manual.

The manual assumes a certain level of basic clinical and therapeutic knowledge and skills. There is particularly, an expectation that everyone already has a basic understanding of motivational interviewing. If you are unfamiliar or unconfident with MI approaches you might find it helpful to read one or more of the MI manuals below and/or to undertake some basic MI training alongside the EYE-2 training.

## MI manuals

Miller WR and Rollnick S. Motivational interviewing: preparing people to change addictive behavior. The Guilford Press, New York, USA (2013).

Miller WR and Rollnick S. Motivational interviewing: Helping people change (3<sup>rd</sup> ed.) Guilford Press, New York, USA (2012).

Rollnick S, Mason P, Butler C. Health behaviour change: a guide for practitioners. Churchill Livingstone, Edinburgh, UK (1999).

Rollnick S, Miller, WR, Butler CC. Motivational Interviewing in health care: Helping patients change behavior. Guilford Press, New York, USA (2008).

## MI website

[www.motivationalinterview.org](http://www.motivationalinterview.org) – this has lots of useful information and advice

## What you need to know about the Early Youth Engagement Project (EYE-2) in First Episode Psychosis

The EYE-2 Project is based on work we have been doing since 2010. All of this work has been supported by funding from the Department of Health, and all of the work has been developed together with service users, and clinical staff.

Approximately 25-30% of service users disengage from EIP services in the first 12-18 months<sup>1</sup>. This figure is consistent both nationally and internationally, including in flag ship EIP services in the UK and Australia. There is a risk that poor engagement and disengagement lead to poorer mental health outcomes in the longer term, as young people don't get all the support that they need at the time that they need it. There are lots of factors that affect disengagement. Substance use, younger age, less family involvement, and ethnic minority status all appear to contribute to disengagement. However, few studies have asked young people and their families, about their views on disengagement. The EYE-2 project aimed to address the issue of disengagement or drop out of young people from EIP services, by listening to, and addressing service user's needs.

In EYE-1, we wanted to know from young people themselves, why they don't engage, or they drop out of mental health and Early Intervention in Psychosis (EIP) services. We started by talking to over 60 EIP service users and families, and young people in

homeless hostels, schools and colleges who were not using services. We covered 3 counties and learnt a lot about young people's views about services.

**One of the most important parts of the EYE project is that we have worked *really closely with EIP service users, their families and clinicians*, in all aspects of developing the intervention and the resources. Service users have guided the approach and co-written and endorsed all of the materials. They think it is really important that we try to reach out to those who might disengage.**

Next, we took what we had learnt back to EIP clinicians from all disciplines, including nurses, psychiatrists, pharmacists, social workers, support workers, vocational workers, psychologists, team leaders, lead practitioners or care co-ordinators and National EIP leads. We showed them what young people had said and asked them what we should do to improve our services. They developed a set of recommendations and chose the ones that could be achieved and that were the most important.

Finally, we turned these recommendations into the EYE intervention. We supported the intervention with a website, a series of

**The aim of the EYE Intervention is to provide EIP teams with tools and guidance to support even better engagement and mental health outcomes for their service users.**

booklets and a training package – and then we tested the intervention in 2 counties.

We compared a group of service users before we started the EYE project with a group who received the intervention. We found that the EYE intervention reduced disengagement by 10%. If we used the EYE approach and booklets with 11 people, we would stop one of them from dropping out of services in the next year!

**The EYE intervention improves engagement ... and service users, families and EIP staff really like it too.**

Service users and their families said that communication was better. They said they were more involved in treatment and decisions, and that they had choices. They said that there was more focus on working with their needs, and goals that mattered to them. They felt more supported socially and felt that staff were more hopeful for them. Service users and their families felt less isolated and stigmatised. Service users felt more trusting of the service. Families felt more reassured because they knew what to do and how to help. Staff felt more pride and professionalism in their service.

1. Doyle R, Turner N, Fanning F et al. (2014) First episode psychosis and disengagement from treatment: A systematic review. *Psychiatric services*. 65:5. 603-611.

## **Engagement is everyone's business**

We are ALL involved in engaging service users and their families, regardless of discipline, role or background. The EYE approach is relevant to everyone, from administrators, who are often the first point of telephone contact, to lead practitioners/care co-ordinators who are often the main point of contact, to all other disciplines which each have their unique role.

## Box 1 – The EYE Intervention

### What is the EYE Intervention?

- Motivation and Family oriented – it draws upon motivational interviewing & emphasises the importance of open social communication (aspects of open dialogue).
- Delivered by the whole EIP team, but especially by care co-ordinators/lead practitioners
- Built on the core principles of the EIP approach
- Gives information about *how to engage people, in real world clinical settings*
- Gives detail about how to be hopeful, motivational, open and honest in challenging situations – where there are significant variations in defining problems, severe and distressing symptoms, risk concerns, service targets and too much to do.
- Supported by training and a manual for clinicians
- Provides and promotes access to a website and series of 5 booklets for service users
- All developed by and for EIP service users, their families and clinicians

### What is the main focus of the intervention?

- ***Improving Communication:*** *transparent, open & honest communication*
- ***Increasing Social Involvement:*** *support across the whole social network, friends, family & peers*
- ***Developing a collaborative service approach:*** *Collaboration & choice regarding difficult treatment issues*
- ***Supporting a consistent staff approach:*** *Hopeful support for meaningful goals & needs*
- ***Overcoming Personal Barriers:*** *Identifying and addressing personal barriers to engagement*

### What are the EYE tools and resources?

- **The manual**
- **The social groups**
- **The supporting resources for staff**
  - The EYE engagement checklist
  - The EYE letter templates for (i) first meeting (photograph), (ii) family and (iii) friends.
  - The EYE business card template
- **The website**
  - The EYE forum and stories
  - The EYE social group calendar
  - The EYE self-help resources
  - The EYE video
  - The EYE non-English language resources
- **The booklets**
  - Mental health and help-seeking,
  - The Early Intervention in Psychosis Service
  - For friends and family
  - Treatment choices
  - Getting the most out of hospital

## What did service users and their families say about EYE-1?

Well...I mean...there was times when, I got worse and I needed information to kind of, help me, to feel like yeah I wasn't alone. So, from here [booklet], I went on the internet.

And then, I read a few stories or something...it stopped me feeling like I was.... alone.

I've gotta admit I think if I, hadn't have been so stubborn, and used some of these. Sort of like websites where you can, like a forum and all that sort of, I think I probably could've got over...it quicker but...I just, ate Ben and Jerry's and watched Netflix.

"The good thing I like about that [treatment choice] booklet, it's not all about medication. There's only a bit at the back and I'm like ooh, that looks interesting."

If I had this booklet or found information like this when I was (first in) early intervention it would have probably helped me, it would have probably stopped me going to the hospital, cause I would have known what to do much better and id be like okay, okay I'm really ill. I should allow them to treat me rather than being forced treatment

## What did clinicians say about EYE-1?

...The EYE project is a perfect fit for our style of working, our ethos, our approach, our values... the goals are the same. You know, remove barriers to engagement, encourage more positive meaningful engagement, encourage collaboration, bust stigma and myths around...mental health problems

My initial contacts with clients are now much different since the introduction of the EYE materials. They very much form the basis of initial discussions with clients and their friends and carers and relatives. So in that regard I guess it is quite a positive development in terms of that initial engagement with clients.

For me it was just another tool to use in my job and it was a really good thing, yeah that enhanced how I work.

## Why are care co-ordinator, lead practitioner and support worker roles are so important?

Young people have told us that they are more likely to stay engaged with EIP if they have one key person who is knowledgeable, consistent, open, honest and trustworthy.

**Some young people, and especially those who find it hard to trust others, find it hard to get on easily with everyone. This doesn't mean it's our fault if someone doesn't get on with us, but if we can be extra flexible, then young people who find engagement difficult, can find the right person for them.**

Our research has shown that EIP care coordinators' knowledge and attitudes are critical to their service users social and work outcomes.

**The more hopeful EIP care coordinators are for their service users, the more hopeful and socially included young people feel, and the more likely they are to be in work or education 6 months later<sup>2</sup>**

Everyone doesn't simply prefer someone their own age, gender, ethnicity or spiritual background, and most young people are flexible and can get on reasonably well with anyone. However, some young people have also said that they get on better with some people than others.



2. Berry C., Greenwood K. (2015). Hope-inspiring therapeutic relationships, professional expectations and social inclusion for young people with psychosis. *Schizophrenia Research* 168: 153–160.

## The EYE Intervention

The intervention *is based on what service users, families and clinicians said in the first EYE project, that we need to focus on **even more**, in EIP services.* It includes (i) a style of working that is open, honest, motivational, inclusive, needs and goal focussed and that offers choices; (ii) a set of resources to be used in the treatment of EIP service users

**The EYE-2 intervention doesn't involve doing anything enormously different or extra to what most EIP teams already do. It just involves taking slightly different approaches and holding different goals and aims in mind in meetings we already have with service users and families**

### Communication, Goals and Social involvement' in EYE-2

Some clinicians have argued that a strong relationship or connection between us and our service users is the most important part of EIP<sup>3</sup>. This relationship is critical to enable us to offer treatments or provide advice or support.

#### The way we communicate influences engagement

In the first EYE project, service users said that they are more likely to stay engaged if we are honest, open and transparent in our communications with them. They understood that we conduct 'assessments' of them, and their mental health but they wanted to know the outcomes - What do

we think, why? And what next? They are suspicious when we have meetings and write notes about them but don't tell them what we've discussed and what we've written. Sometimes they feel patronised, ignored or controlled. This can lead to disengagement and dropping out from services. Service users are more likely to trust and engage, if they feel trusted and that their views are respected.

**This may seem a bit obvious!**

**We are after all, trying to be engaging and collaborative! But this can be a challenge** when

service users have unusual views and perspectives, or when they don't agree with the treatments offered...



#### The way we involve someone's social network influences engagement

Service users in the original EYE project said that sometimes their family are better able to speak for them than they are themselves. They said that we should engage their families even more, and families generally wanted this too. Although we do need to carefully consider how we engage families if a service user is not keen, and adapt our approach accordingly.

Service users also tell us that sometimes they miss sessions because they would rather meet friends than their EIP worker.

This is very understandable. Maintaining and developing one's social life is certainly important in most people's recovery from psychosis. They also tell us that friends are important, because they remind them



what is important in life, and what their goals were before the psychosis started.

**But there are concerns** about confidentiality when we involve family and friends. Friends and families have another set of views and that complicates things. Sometimes it's easier and quicker for busy staff to just meet the service user on their own...

**Service users told us we can still do more to work with their own goals and what is important to them**

Service users told us that they are more likely to stay engaged if we are doing even more that is important and a priority for them, from their perspective, and we work with more of their goals.

**But sometimes service users** don't have goals, or the goals they want to work on are unwise ones, risky ones, or not the most critical ones for their immediate mental health...



**This section describes how to work in an even more open, honest, transparent, hopeful, and goal-focussed way in the REAL world – in the context of risk and safety issues, competing demands, targets and not enough time.**

**Open, Honest, Transparent Communication**

The EYE approach combines elements of two existing therapeutic approaches: Motivational Interviewing (MI) and Open Dialogue (OD).

There are several ways in which a motivational focus is relevant for the EYE approach. First, it is specifically

- **client centred** – so it gives guidance for focussing on our service user's own perspective at all times. It is a way to steer service users through their own difficulties and decisions towards their own goals. Second, it gives tips for an
- **open and honest** way of listening and communicating with our service users that takes their perspective seriously. Third, it is always
- **collaborative**. We move together with the service user towards a new goal or a new way of doing things. But, it is importantly also
- **directional**, the aim is to move our service users towards changes for the better in terms of their mental health and wellbeing.

**In the EYE-2 intervention, the active ingredient for change is in part through the therapeutic relationship with the care co-ordinator. The style of communicating aims to support the service user in considering their options, making choices and reaching their goals.**

**How to make sure we've identified service users' own needs and goals**

A first step is to ensure we identify the needs and goals of our service users. This is straightforward for some, whereas others might struggle to identify goals, or just seemingly 'go

along with' our own suggested goals, but make no progress. Some service users need help and time to find the goals that are important to them.

### Identifying goals in discussion with our service users

Useful topics for discussion to identify goals might include

- What is important to our service user?
- What are their values?
- What is an average day like, and how would they like this to be different?
- What would they change in their life?

### Using the QPR and DIALOG outcome questionnaires to identify needs and goals

It might help to identify areas of life that our service users are dissatisfied, or unhappy with as this indicates that a change is needed.

In this respect, we can actually use the DIALOG and the QPR with service users to identify areas of life where they are dissatisfied or unhappy. We can then discuss which area/s they would like to change, the types of change they would like to make, whether they would like additional help and the types of support that might be helpful to them.

The DIALOG can help to identify broad areas of dissatisfaction and need such as mental health, physical health, job, leisure activities, accommodation, friends, family, treatments, relationships with mental health services and other practical help.

The QPR on the other hand, can identify beliefs about life, self, isolation, social skills, personal control, direction, motivation, understanding, outlook, mood, abilities and time, which may contribute to dissatisfaction and to an inability to make positive changes.

We can use these two measures together to help us and our service users to reach agreement regarding areas where they would like to make changes, and would like some support, and where personal barriers might be preventing them from moving forward. Clinicians have said that we could use these questionnaires when someone first comes into the service, and at regular care plan reviews.

See the EYE-2 manual on “Improving the Collection of Routine Outcome Data in Early Intervention in Psychosis” for more information on using the QPR and DIALOG to identify service user needs and goals.

### Using friends and family to identify goals

Service users have said that friends might be helpful in reminding them what their goals used to be, what's important in their life and what they might like to get back to. Siblings and family may also be helpful in this respect.

**BUT, beware, it is important that the goals we agree on are those that our service users want to work on, and not ones that only matter to us, other clinicians, the team, friends or family. Service users**



are more likely to stay engaged if we are supporting them with what matters most to them.

**How to tell if we've got the right goals and needs – the ones that matter to our service users?**

Again, this is where motivational interviewing approaches can come in handy. Critically, motivational skills don't involve telling someone what is best for them, even if we already believe we know this.

**In fact, it can be helpful for us to understand more about our own values, culture and what matters to us. It will then be easier to understand our service users own distinct views.**

#### Activity 1- Values and Culture

In pairs or groups of 3, discuss

- What are your values in life? What is important?
- What is your culture and where does it come from?
- How does this affect your own approach to health and mental health?

Whichever approach we use to discuss needs and goals, the aim is to elicit our service user's own goals and perspectives. To do this we need to encourage our service users to do more of the talking. This is again where our own 'motivational skills' can come in.

**Top tips to encourage service users to express their views (OARS)-**

**Open questions, Affirmations, Reflections and Summarising**



**O**pen Questions – that help our service users to open up – we can start with words such as 'what', 'why' or 'how'. For example:

- 'What are your values?'
- 'In what way is your culture important to you?'
- 'What are the important things in life for you?'
- 'How do you feel about your mental health?'
- 'Why do you think your friendships are less good than they used to be?'
- 'What do you think might improve your physical health?'

These are different from closed questions that can be answered with yes or no answers.



These next three approaches are really important as they are ways of encouraging our service users to keep talking, without us having to keep asking questions. Service users have said that asking lots of questions sometimes seem like we're interrogating them.

**A**ffirmations – are positive comments and Praise. The aim is to praise our service users' thoughts and efforts to think about

and make plans and changes. They are critical as they encourage service users that they are saying or doing something important and to keep going... we just need to watch out that we are genuine in our praise and not too over the top and patronising! For example

- 'It sounds like you've been trying really hard to get on with your parents?'
- 'It sounds like you've been doing a lot of college work at home, and it's just really hard to get in to college when you feel so anxious?'

**R**eflections – these are simply repeating back what our service users have just said, or the underlying emotions, or their extreme views or fears. It's a way to show we are listening and valuing what they're saying and encourages them to keep talking. The aim here is to repeat the things that our service user says that are particularly important, so it involves some quick thinking and decision making about what is most important.

**S**ummarising – is about pulling together a number of key points that our service users have said. By summarising, we can help our service user to pull together their own thoughts or the pros and cons of a particular course of action. It also allows us to check out whether we've got the important things right. For example:

- 'So it sounds like you're really worried about the effects of medication on your weight, and you really want to lose weight. At the same time the medication does seem to help at least a bit with your stress, and the doctor seems keen

that you stay on it when you leave hospital. You also really want to get home.'

### Activity 2- Using OARS

In pairs, pick a dilemma (e.g. a decision you need to make about which you are uncertain, or a vice that you are comfortable to talk about. Take it in turns:

- One person share your dilemma/vice
- The other person practice using
  - only OARS to respond
  - avoid being directive
  - use more ARS than
- What do you notice? How does it feel in each role?



**Once we've got our service users talking, the next challenge is how to pick out their needs and goals**

Again, this is where motivational approaches can be helpful again. According to MI approaches in order to pick out and help a service user to move towards their goals, we need to listen out for 'change talk', which is anything they say that is about something that they want to be different. They may have some potential goals or hopes, but are 'uncertain', or

'ambivalent' about them. They may have mixed feelings or are concerned about their ability to achieve them. Our job is to listen out for, any expressions of:

### **Desire, Ability, Reason, Need and Commitment (DARN-C) to a positive goal.**

We can identify someone's goals through open and honest communication, and through listening out carefully for

**Desire** –the extent to which our service user really *wants* to achieve a particular goal,

**Ability** – the extent to which they are *optimistic and able* to achieve a goal. Real obstacles to achieving goals include cognitive problems and symptoms while imagined obstacles include low mood and negative beliefs about self and abilities. The QPR can identify some of these obstacles.

**Reason** – the reasons our service user gives for why they want to reach their goals.

**Need** – our service user might identify a *need* to address an issue or a problem, but this doesn't necessarily mean they *want to* address it or that it is a goal. The need might come from someone else. So, for example they might want to carry on smoking cannabis, but their parents, doctor and clinical team are telling them they need to stop for their mental health.

**Commitment** – is how much effort a service user really wants to put into reaching their goals. This can change through discussion.

### **Our service user's goals are likely to be linked to their values and what is important to them.**

It can be really worthwhile to invest time early on, and throughout EIP work, to understand our service users' values. Their true goals will almost certainly be in keeping with these values, and they are more likely to stay engaged if we are helping them with their own goals and not just the goals that others wish them to achieve. Taking this time will help to make our work with our service users much more straightforward.

**Not only that** – there is a specific *affirmation based therapy approach*. It works by identifying, listening to, praising and reinforcing a person's important life values. Research has shown that this approach alone, can lead people to function better in college or work and to be more likely to take up health interventions about which they may be ambivalent about. <sup>3-4</sup>

### **Supporting a service user with their goals.**

Once we've identified the goals that are important to a service user, there are lots of ways in which we can support them to achieve their goals. This could include practical advice and support if they face real obstacles. If these obstacles include negative beliefs and attitudes, we might try to build self-confidence, self-esteem and hope, focusing on service users' strengths,

values, successes and positive qualities. Our aim is to step back from providing the solutions and instead help our service users to identify these – for themselves. It is also important to be hopeful ourselves, and to value all steps forward, however small. This will help our service users to believe that they can reach their goals for themselves.



### Activity 3- Using motivational approaches

#### Knowledge Quiz

Test your knowledge of this section, by yourself or with a colleague if you prefer. If using this in group training, the winner gets an extra biscuit (if they wish!)

1. Tick all of the motivational techniques from the list below (one point for each right answer)
  - a. Listening to the service users desire ability reason and need for doing something
  - b. Telling the service user what is important for them to improve their mental health
  - c. Using open ended questions and reflecting back any goals that we hear
  - d. Using affirmations (positive statements about the person's values, abilities and their successes)
  - e. Emphasizing the problems with the person's current attitude or behaviour
  
2. List the main ways that we can use to try to identify a service user's goals (one point for each valid method)

Total 6+ points

A service user may be at any stage in thinking about their goals from precontemplation (not thinking about action or change), to contemplation (considering an action or change), preparation, action and maintenance. To encourage a service user to start working toward a goal, we can discuss together where they are now, where they are aiming for, and the path that they might take. Breaking down a goal into manageable steps and feeling confident in the ability to reach one's goal helps to promote hope. BUT avoid getting into arguments or disagreements. We should 'roll with resistance' and learn from it. The service user may be communicating to us that they are not ready to move into goal-oriented action. Low Self-esteem or other barriers may well be present and impacting on them. There is more about motivational interviewing approaches and the cycle of change in the reference books listed in the introduction on page 4.

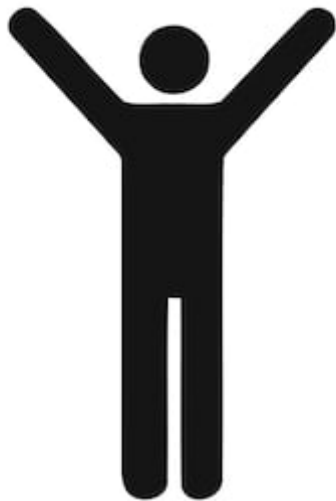
<sup>3</sup> – Epton, T., Harris, P. R., Kane, R., van Koningsbruggen, G. M., & Sheeran, P. (2015). The impact of self affirmation on health-behavior change: A meta-analysis. *Health Psychology, 34*, 187–196

<sup>4</sup> – Goyer et al. (2017). Self-affirmation facilitates minority middle schoolers' progress along college trajectories. *Proceedings of the National Academy of Sciences, 114*(29), 7594–7599.

## The face of the service - Collaboration and Choice in the context of risk

**Service users particularly emphasized the importance of collaboration and choice in the context of difficult treatment choices, relating to medication and hospitalization. This also applies to lifestyle choices. For young people in particular risk-taking can be normal and can be part of becoming independent. Depending on a service users lifestyle, we might consider discussing with them, the distinction between levels of risks, safer risks and harm minimisation<sup>5</sup>.**

Service users have said that they are more likely to stay engaged in the longer term if they feel that they have choices about treatments and hospital admissions. They want to feel supported by a clinician who works with them, in a non-judgmental way. They want to feel that they more than one option and that they aren't forced to accept something or to do something against their will.



**Autonomy and support** – Service users said that they want to be supported to make their own decisions, rightly or wrongly, and for clinicians to listen to and understand their perspective. As an EIP clinician our aim should be to support our service users to make decisions for themselves, that are weighted towards positive choices. By emphasizing service user's own abilities, skills and past successes, as well as their future hopes, we can support positive change without authority, judgement, or unsolicited education.

**But, there are lots of challenges to providing autonomy and choice,** for example when there are



- risk issues, such as risk of suicide or harm to others,
- when a service user is unable to take on board, remember and weigh up their options to make a decision,
- when we can see that a service user is making an unwise or risky decision
- when a service users' ability to make a choice is influenced negatively by current unusual beliefs or experiences
- when family members have conflicting views about treatment
- when there are real or perceived time constraints – these could be anything from a need to keep Duration of Untreated Psychosis short, limited availability of prescribing staff, or a desire to treat psychosis experiences quickly

**Activity 4**

**Group activity:** Take one of the case studies below.

Consider the challenges in providing autonomy and choice in this context

Next consider any options for collaboration, openness and honesty, and any ways in which you could offer autonomy and choice

Decide on the best course of action. If this does not offer collaboration and choice, consider how you could restore this as soon as possible.

**Case study 1-** John has been known to the service for some time and has had a previous hospital admission. He has become increasingly grandiose and thought disordered recently. He has been forgetting appointments and has struggled to concentrate and take in information. He is now very afraid that someone is trying to come into the house to kill him. He has barricaded himself in and it is thought that he has a weapon.

**Challenges**

-----  
-----  
-----  
-----  
-----  
-----

**Options for collaboration and choice**

-----  
-----

-----  
-----  
-----  
-----

**Best course of action/options to restore choice/collaboration**

-----  
-----  
-----  
-----  
-----

**Case study 2-** Ruby is fairly new to the service. She has been hearing voices and expressing suicidal thoughts for several days. Her family feel strongly that she should be in hospital but she feels strongly that she doesn't want to go and she is not keen on taking medication either. She is not yet receiving any treatment.

**Challenges**

-----  
-----  
-----  
-----  
-----

**Options for collaboration and choice**

-----  
-----  
-----

-----  
-----  
**Best course of action/options to restore choice/collaboration**  
-----  
-----  
-----  
-----  
-----  
-----

**Case study 3 – Troy has recently stopped taking medication. He has since become preoccupied and upset by beliefs that he has that people from work are trying to undermine him and make him look incompetent. In the past, he has been very paranoid that his work colleagues in a previous job were trying to get him sacked, and as a result it got so bad that he gave up his job. He has taken some time to find a new job and has only been there for a couple of months. It is a Friday, and you are worried that things may deteriorate considerably over the weekend.**

**Challenges**  
-----  
-----  
-----  
-----  
-----  
-----

**Options for collaboration and choice**  
-----

-----  
-----  
-----  
-----  
-----  
**Best course of action/options to restore choice/collaboration**  
-----  
-----  
-----  
-----  
-----  
-----

There are a few ways in which it might be possible to maintain elements of collaboration and choice, even in the context of significant risks, family or other pressures. A few options are to:

- offer psychoeducation and recommendations without pressure.
- Support your service user to make choices from a limited set of options you and the team provide e.g. hospital or medication
- make a decision in the service users best interest whilst they don't have capacity. Then discuss in detail the rationale for this and offer choice again as soon as possible.

In EIP, we have unique challenges to maintaining collaboration and choice. This is particularly the case when a service user has mental health related thoughts and behaviours which present significant risks. In such a situation, they may need a period of time in hospital but they may not agree with this decision. In this situation, we often have to make a decision to admit a service

user under section and against their will, under the mental health act. We may also need to defend this decision in a tribunal, which requires us to put very clearly, and in writing our views about a service user's mental health and their risks. Whilst this is arguably open and honest, this perceived lack of collaboration, has the potential to damage the therapeutic relationship. Where this does happen it can be tempting to change care co-ordinator.

However, changing care co-ordinator can reinforce the idea that the first care co-ordinator was 'bad' or 'wrong'. It can be worth trying to rebuild the relationship first, with even more honesty and openness, and an attempt to re-establish collaboration. Please read below the case study and the care-coordinator's response for an example of how to maintain the relationship after a hospital admission, then consider the questions listed in your group.

### **Activity 5 - A case study for discussion in groups**

Darren is a 26-year-old man with a 2-year history of psychosis. His parents are divorced, and he lives with his mother and sister. His mother holds strong spiritual and Christian beliefs. She attends church several times a week and holds spiritual gatherings at home. She believes that Jesus speaks through her.

Darren has had a recent hospital admission. There was a gradual deterioration in his mental state over a period of months. During this time, he increasingly heard voices coming from objects around the house. He stopped socialising and stopped speaking to his family. His team were very worried about his deteriorating mental state, personal hygiene, self-neglect and lack of communication. He had begun to barricade himself in his room.

The team tried to convince him to take medication, which he refused. His mother believed this was a spiritual crisis, and also strongly denied that he should take medication. The team, concerned about risk, requested a mental health act assessment.

During the assessment Darren expressed some unusual ideas but was not considered a risk to himself or others, and he agreed to keep engaging with the team. He was not admitted to hospital.

During the next few weeks he became more and more certain that he was Michael Jackson, and that his mother and sister were fakes who were conspiring against him.

Several weeks later, after several nights of not sleeping he barricaded himself into the kitchen of his mum's house, with a knife.

A new mental health act assessment was undertaken with support from the police, he was sectioned and spent several months in hospital. On discharge, he wanted to sue the hospital for wrongful detention. He was immensely angry about his admission. He was concerned that he could be picked up off the street at any moment and re-hospitalised.



## Knowledgeable care-coordinators and clinicians

Service users told us that they are more likely to engage with clinicians who are well-trained and knowledgeable. Whilst it is important to respect a service user's autonomy and choices. It is also important to be able to provide choices, and to be knowledgeable about the options available.

### Knowledge vs opinion?

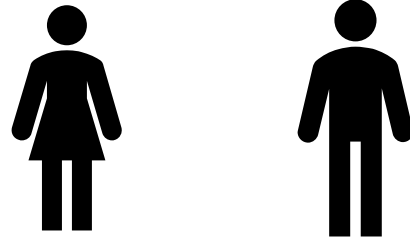
NHS services aim to provide up to date, evidence-based mental health care. Evidence based practice ensures that we provide the best, most effective and cost-effective support and interventions. This is especially the case in EIP, where access and waiting time standards have been explicit about which interventions have sufficient evidence to be offered. In considering, the interventions that we offer, we therefore need to draw on (i) recent research evidence (ii) clinical judgement and (iii) service user values and perspectives.

Most of our knowledge comes from our initial core professional training, with subsequent updates largely coming from our colleagues<sup>6</sup>, staff CPD training, or service users themselves. As most of our recent knowledge updates come informally this can sometimes lead to opinions as opposed to knowledge.

As a clinician working in EIP with psychosis, we need to be able to draw on a very broad set of knowledge. **This is a challenge as new knowledge is produced all the time,** and



every service user is different, with different backgrounds, requiring us to know or sometimes find out, unique knowledge all the time.



#### Activity 6: knowledge and opinion

**Group activity:** list all the areas in which as a clinician you may need knowledge. Think about:

- Where your knowledge comes from in these areas?
- In which of these areas are you 'up to date' and knowledgeable about the current information or evidence?
- Where are there gaps, and more reliance on opinion?
- How as a team could you keep as up-to-date as possible?

#### Areas where we need knowledge

-----  
-----  
-----  
-----  
-----  
-----

#### Where our knowledge comes from?

-----

-----  
 -----  
 -----  
 -----

**Knowledge gaps and how to address them?**

-----  
 -----  
 -----  
 -----  
 -----

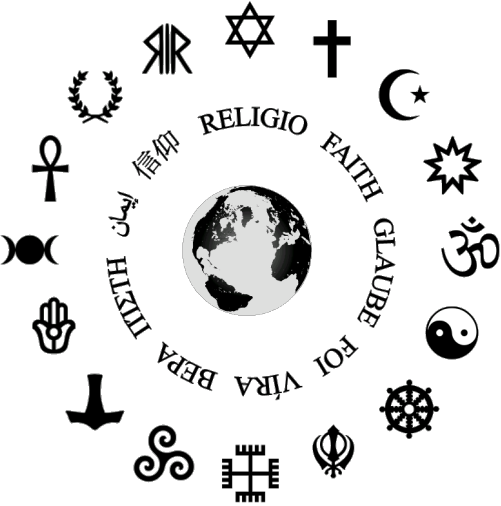
This is not an exhaustive list, but some of the areas in which we might need knowledge include:

- normal adolescent and young adult development,
- bio-psycho-social causes of psychosis,
- diagnostic criteria,
- medications,
- therapies and other treatments and the evidence base for their effects and side-effects,
- NICE guidelines,
- information about other mental health conditions,
- beliefs and practices in different cultures,
- spiritualities, religions and sexualities,
- risk and safeguarding practices,
- child protection issues and processes,
- the mental health act,
- housing and benefits,
- alcohol and substance use,
- personality influences.

We can address some of this through CPD, our own reading, local NHS trust and national training, discussions with spiritual leaders, books, websites and forums, and from sharing our new knowledge with each other.

We aim to include a resource library of links to key papers and books on the EYE-2 website. The treatment choices booklet contains up to date information about psychosis treatments. We can use the forum to ask colleagues for information too.

**Knowledge about ethnic and other minorities and cultures**



A particular focus of the new EYE-2 project has been to consider how we can be more knowledgeable about and inclusive of different ethnic minorities, religions, cultures, spiritualities and sexualities.

### **This is a challenge for a number of reasons**

First, because within the same culture or belief system there is enormous individual variation. If we make assumptions about a person on the basis of their culture, religious or spiritual background we risk 'stereotyping'.



Second, service users from ethnic and other minorities have said that representing them specifically in booklets and on the website risks them feeling targeted, or singled out.

Our experts in ethnic minorities and mental health have prepared some basic information about different cultures, ethnicities and religions. Please do add to and share this. However, everyone is different, so the best approach is to understand an individual culture by speaking to the service user and their social network of family, friends and spiritual leaders.

<sup>6</sup> Blanton, J. S. (2000). Why consultants don't apply psychological research. *Consulting Psychology Journal: Practice and Research*, 52(4), 235-247.

## Involving an individual's entire social network

Service users have told us that, in general, they are more likely to stay engaged with the service if we consider and involve their broad social network. Their social network also influences their treatment choices.

**Family, particularly parents,** know our service users well and can often speak for them when they are struggling to speak for themselves, enabling their concerns to be known.

**Friends and partners<sup>7</sup>** can provide important reminders about goals, future hopes, and desires.

**Siblings** can be the first person a service user speaks to about risk<sup>8</sup>. They often have privileged information that no-one else knows.

**Spiritual or religious leaders** are often the first person a service user speaks to regarding how to manage their experiences.

**Peers** can provide a normalizing network to enable the service user to reconnect and regain confidence socially, whilst also sharing experiences and suggestions for coping and support.



**The whole social network** has an enormous influence on a service user's perspective on engagement, mental health services and treatments. Each member in their own way, can support a service user's mental health but equally, they can divert a service user from engaging positively. If members of the social network don't understand or agree with the service and the treatments offered, they can also promote active disengagement.

Obviously, in Early Intervention we are used to working with families. The EYE-1 project research suggests that it is generally in the service user's interest to also involve the service user's broader social network in supporting their mental health.

## Open Dialogue - Involving the whole social network

In this aspect of the EYE-2 approach, there are overlaps with the open dialogue model.

Open Dialogue (OD) is a therapeutic approach that emphasizes mobilising support for a service user's mental health from within the service user's own family and community networks. It involves joint 'network' meetings with key members of the social network so that everyone is 'working together' to support the service user. These network meetings are central to the treatment approach as they aim to be therapeutic and collaborative, and it is in these meetings that treatment choices are discussed, and decisions made.

Interestingly, in open dialogue, as with the EYE-2 approach, there is a particular emphasis on maintaining this open

communication across community mental health teams AND crisis care teams.

There are a number of papers that suggest that the OD approach has benefits for psychosis service users' mental health and well-being.<sup>9-10</sup> There are as yet no Randomised Controlled Trials that have demonstrated benefits of the OD approach in the UK, but a trial is currently underway. EYE 2 is not about training EIP clinical staff to deliver OD, but to use some of its elements and core components that overlap with the EYE approach, to enhance care.

OD practice is underpinned by **7 key principles**. The 2 most relevant are:

**(i) A social network perspective** – the service user, their family and key member of their social network are involved right from the outset in 'network meetings', where social support is identified and acknowledged. The social network can include neighbours, friends, work colleagues, classmates, employers, teachers, peer support workers, representatives from wider health, social and spiritual support. The aim is to include all of these people in understanding and supporting a young person's mental health. Network meetings are central to the treatment model; they function as a therapeutic space and the key decision-making forum for deciding on treatment options and, where needed, referral to other mental health and other-health and social care services.



**(ii) Promoting dialogue** – effectively this involves an emphasis on communication and listening to the service user in a non-hierarchical, non-judgmental, collaborative therapeutic way, as we described earlier, but in OD this is extended to all relevant members of a service user's whole social network. The aim with this communication (or dialogue), as in our EYE-2 section on communication, is to follow the themes and the way of speaking of the service user, *as well as* their whole network. The purpose of this communication is to get a clear understanding of the service user's perspective and experience and to enhance empowerment, confidence, agency, positive action and collaborative decision making about treatments with the service user and their whole social network.

Other key principles of the open dialogue approach are:

**Psychological continuity** – to create a new, shared process for the psychological understanding and integrated treatment of the service user's problems, involving the whole network.

**Immediate help in a crisis** – through strong links between community mental health, crisis, inpatient services and the social network.

**Flexibility** - to meet in the best place for the whole network, often in the service user's home, and to adapt the approach and treatments to the changing needs of the individuals in the network.

**Responsibility** – to rest with the whole team, who together coordinate the treatment programme.

**Initial Tolerance of uncertainty, with a gradual move towards certainty** in thinking and deciding about treatments, through regular meetings so that everyone feels safe in the process, whilst avoiding premature conclusions or decisions about treatment.

The resource section of this manual includes a consent form for involvement of the social network, and a template invite letters that can be used to invite family and friends to a meeting.

## The social network in Open Dialogue and EYE-2

In terms of the EYE-2 approach, the aim is to

- (i) broaden the use of a collaborative approach with the service user to key members of the service user's social network
- (ii) utilize this network to help support the service user to

- (iii) express and address their needs, identify and reach their goals
- (iii) reach collaborative decisions regarding supportive treatment approaches that aid the service user towards their goals
- (iv) offer regular meetings and / or communication with family, friends, and other key members of the person's social network
- (v) offer social groups facilitated by service user peers, especially where a service user's network is limited.

**The main challenge in engaging the social network**, is that we

are often uncertain about whether and how to engage families, particularly when a service user disagrees with this engagement, and particularly in the context of risk. This is even more complicated when engaging friends and others outside of the immediate family, where confidentiality issues and risk of stigma may be particularly important, and we are often uncertain and unfamiliar in working with friends.



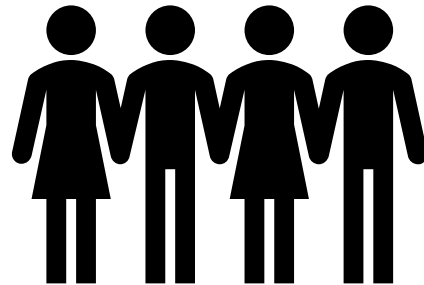
## Guidance for involving family members.

In the EYE-2 model, the main aim is to consider not whether but **how** to include the family. Best practice guidance on working with families<sup>11</sup>, advises that it is important to support families in their own right. With permission from the service user, we can share and discuss information about the service user's mental health and treatment. We can also do so if the service user has refused this permission but does so due to a lack of capacity to make this decision. This lack of capacity may include the service user holding delusional beliefs about the family. If a service user does have delusional beliefs about the family, it is reasonable to continue to have discussions with the family, but to restore openness, transparency and trust with the service user as soon as capacity returns. If a service user refuses permission and does have capacity, it is still possible to provide family members with support, and to listen to their perspectives about the service user and their opinions about treatment. We just can't share information about the service user's mental health and treatment.

A first step in the EYE-2 approach involves providing **the Friends and Family Booklet**.



We can provide the booklet either before or in conjunction with the first family or social network meeting. It can be valuable from the outset to discuss and reach agreements about treatments with the family and key social network to ensure the best engagement and outcomes. Family may also be able to provide important information about the service user's cultural and spiritual background. They may also be able to provide important information about who else to include in discussions. The aim is to identify key members of the service user's social network who are trusted by the service user and respecting of the service user's confidentiality.



If a service user does refuse permission for us to discuss their care with their family members, we can still use the open, honest, collaborative approaches to understand their decision. They may have a very valid reason for not including their family in their care. At the same time, if there are not strong reasons for excluding family, we may want to consider using motivational approaches to reach a more inclusive decision about how family may be helpful in the service user's treatment.

## Guidance for involving friends, other key members of the service user's social network, including spiritual leaders.

The main issues that need careful consideration when thinking about including friends, colleagues, spiritual leaders and other members of the social network are:

- i) what consent the service user has given us to share information about them and their mental health
- ii) what the value might be to the service user of working closely with different members of their social network
- iii) whether the service user and potential members of their social network understands issues around confidentiality and sharing of information with their social network

### Who to involve

You may find it helpful to refer the service user to the section in the **Mental Health and Help-Seeking** booklet on 'Addressing personal barriers to talk' and 'Involving friends'. This section gives some tips, about who might be appropriate to include.



A key member of the social network may be defined as someone who supports, advises or influences the service user. This could be a family member, partner, close friend, housemate, teacher, work colleague or spiritual support.

Any of these member's involvement may be valuable as long as they are willing and have the service user's best interests at heart – even if their current beliefs or advice seem at times to be contrary to this. People are not always consistent and may well be trying to do their best for the service user.

It will be important to discuss confidentiality and ensure this is understood and maintained.

### How to involve the social network?

The main point here is to be guided by the service user. *Unlike in open dialogue approaches*, the aim is not to gather everyone together for a free-flowing dialogue about treatment approaches and risk management.

Rather, the aim is to think, with the service user, about where there are conflicts or differences of opinion about engagement and treatment, and about who can best support the service user with which aspects of their life and goals.

It might be worth starting with a discussion about

- (i) who are the key people in a service user's broad social network – thinking about family, friends, work, education, health, mental health, risk, difficult emotions, relationships,

- accommodation, spirituality and leisure;
- (ii) who does the service user trust, share information with, get support from and listen to and about which topics;
  - (iii) who would it make most sense to include in discussions about topics such as health and mental health support, treatment, coping, risks, religion and spirituality
  - (iv) who could help them with setting and working toward personal goals about important things in their lives, such as leisure, vocational and occupational activities, housing changes or relationships.



Involvement is then focused on discussing specific agreed topics. Considering the social network member's thoughts and advice on this particular topic, discussing together the impact of this new perspective on the service user, considering this perspective in the context of other perspectives (service user, clinician, team, family etc.), finding a solution or a way forward that is mutually supportive for the service user, and which provides the social network member with some clear sense of how they can help, and when and how their own input can be supported.

### Activity 7: Involving the social network

In pairs, role play a discussion about

- The range of different people that may be involved in a service user's social network
- How to get these individuals involved in the service user's care.

One person should be the care co-ordinator or clinician and the other the service user

### An Introduction to EYE-2 social groups

We know that psychosis can impact on a service user's social network so that they lose their social network or it diminishes over time. They may also lose confidence in meeting friends and colleagues.

**We also know that Peers can provide a normalizing network to enable the service user to reconnect and regain confidence socially**, whilst also sharing experiences and suggestions for coping and support.



We explored different ways of involving peers, as part of the original EYE-1 project. This included having meetings with peer workers, and running social groups, involving peers and peer workers. The consensus from the EYE-1 project was to run a social group in each team randomized to the intervention arm. The plan for these groups is that they are run by and for young

people, as opposed to by clinicians. This is because in the original EYE-1 project, young people and their families said that social groups could be really helpful in supporting them to rebuild confidence and social relationships. However, they also said that service users are more likely to attend a social group if they can attend with an aim to support others, and share what has worked. In doing so, they can also build confidence and meet new people. Young people felt it could otherwise be stigmatising to attend a social group as this implies you have a ‘social problem’.

As much as possible the aim is for these groups to be run by and for service users themselves with support from the patient and public involvement lead, research assistant, other service users involved in the local EYE-2 service user advisory group or service users from the service themselves. The main aim is to encourage service users to support each other, share ideas, and socialise.

The social groups proposed in the EYE-2 intervention are designed to be co-led by people using Early Intervention services. As such the structure of these groups will be flexible and responsive to the ideas and wishes of the people attending them within each local context, the perspectives of the local team and the opportunities available in the local area. However, there are core principles that should guide what happens within these groups to ensure the safety of attendees.



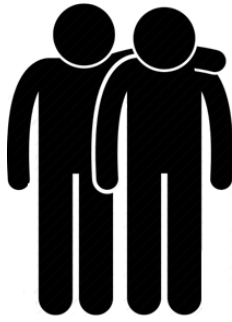
### Set up

The research assistant and PPI lead will work with the link person in each service. This will involve mostly logistical tasks such as locating and securing a venue, making and circulating advertising flyers, making an initial list of cheap or free social activities, and liaising with staff in the services to inform the people using those services about the groups.

**See page 56 for resources to help with setting up the social groups. These can be adapted based on your service user’s needs.**

In the early stages it will also involve facilitating the group to develop a set of mutually agreed ‘ground rules’ around how group members will treat each other with kindness, dignity and respect. The group rules may also determine the way people discuss certain emotional topics such as suicidal feelings, and how decisions about the future activities of the group are made.

One consideration is whether to run several consecutive groups each for a fixed period or whether to run a single open ended group, that service users can join and leave as they please. An open ended group provides continuity and flexibility, such that there should always be some longer standing members with more confidence to take lead roles, and there is less effort in re-advertising and starting a group from scratch every few months. However, some clinicians have said that it may be easier for service users to join a group if they all start together and get to know each other. If the latter model is adopted there will need to be a plan regarding whether members can join multiple consecutive groups.



### Ongoing support

Once the ground rules of the social group are in place the leadership of the group should be transferred as much as possible to the group members themselves. Group members may take on organisational roles and responsibility for running aspects of the group as it progresses over time. However, group members are not required to stay in these roles if they find it doesn't work for them, and it may be that the people in these roles may change regularly.

The group will continue to be supported organisationally by the PPI lead and research assistant at each site. This support may be in the form of practical or logistical support, for example ensuring a venue is reliably available on a regular basis. The overarching conduct of the group will be overseen by (i) the clinical link person in each team; (ii) the local research team and (iii) the lead of the central PPI programme for the project, who is an experienced service user researcher from the McPin foundation.

### Emotional support within the group

The group should make joint decisions on the kind of activities that they would like to do, keeping in mind that these activities should be low cost, or free if possible. While these groups are not explicitly peer support

groups, it is likely that group members at times will wish to talk about their experiences. How these experiences are spoken about should be thought about within the setting or by updating ground rules. For example, the group may decide it is ok to talk about issues relating to self-harm, but not to talk about specific methods, graphic details of particular incidents or equipment. This is to help group members to feel safe when talking about potentially emotional or 'risky' subjects.



### Risk management within the group

This group is intended to be run by service users for service users as opposed to being led by local clinicians or used as an additional group therapy. For this reason, it is unnecessary for clinicians to be physically present, however mechanisms should be in place to support group members who become distressed during the group or who arrive at the group in obvious difficulties. The date and time of the groups should always be known by the local PPI lead, RA and a nominated EIP link clinician. A named member of EIP staff should be available during the group sessions to respond to any issues that arise – preferably someone who is on site at the time. However, some groups may choose to meet in community venues after the group becomes

established – in this case a member of EIP staff should be available by phone.

### Challenges in implementing this social network approach

We can learn about some of challenges to working with a broad social network, from the work on open dialogue<sup>12</sup>. Previous research on open dialogue has suggested that clinicians and service users view it as a highly valued approach, because it is person centred (focused on transparency, openness, empathy, warmth, active listening, recovery and empowerment) and systemic (involving collaborative relationships and meaningful involvement of the social network), much like EYE-2.

However, despite the popularity of OD, and its consistency with familiar and desired ways of working, implementation was still low<sup>12</sup>. Professional challenges to implementation included

- being unprepared to take risks,
- challenges of working within legal frameworks,
- working with difficult and unsupportive elements within a social system, and
- limited resources.

There were also

- cultural challenges, in moving to a more holistic treatment approach, that is collaborative.

This was difficult even when clinicians were willing, due to

- challenges of overcoming fear of change, and
- varied staff attitudes and commitment.

**The EYE-2 approach provides a more contained social network model. EIP services are ideally placed to implement this, as it is consistent with many EIP values.**

### Activity 8: Engaging the social network barriers

Group Activity: Consider the challenges in offering this engagement approach across the broad social network

What might the barriers be:

- For you, and your own way of working
- For the team’s ways of working
- For the trust’s ways of working

How could you overcome these barriers at an individual, team or trust level?

### Barriers for you in engaging a broad social network

-----  
-----  
-----  
-----  
-----  
-----  
-----  
-----  
-----  
-----



review and call to action. *Early Interv Psychiatry*. 9(4):269-78.

<sup>8</sup> – Bowman S et al. (2017). The positive and negative Experiences of Caregiving for Siblings of Young People with First Episode Psychosis. *Frontiers in Psychology*: 8; 730.

<sup>9</sup> – Seikkula, J. (2011) Becoming Dialogical: Psychotherapy or a Way of Life. *The Australian and New Zealand Journal of Family Therapy*, 3, 2, 179-193.

<sup>10</sup> – Seikkula, J., Trimble, D. (2005) Healing Elements of Therapeutic Conversation: Dialogue as the Embodiment of Love. *Family Process*, 44, 4, 461-475.

<sup>11</sup> – best practice guidance for working with families

<sup>12</sup> – Razzaque R, Wood L (2015). Open Dialogue and its Relevance to the NHS: Opinions of NHS Staff and Service Users. *Community Ment Health J*. 51(8):931-8.

## Personal Barriers

The final key issue that service users said impacts on their engagement was personal barriers. These included:

- past experiences with mental illness, through family and friends
- past experiences with mental health services, and especially negative experiences of hospital
- personal issues with trust, and specific preferences regarding engagement, sometimes as a result of past life-experiences

There are a number of ways in which to work with these personal barriers. The first of these is through the provision of open and honest, myth-busting information about services and what we do. At the first or an early meeting we should aim to

- **Provide the Mental Health and Help seeking booklet.**

This booklet covers issues for a potential service user such as how to seek or make use of help, in the context of personal barriers and trust issues. It provides a link to the website which has a discussion forum, and positive and reassuring stories and videos that encourage the service user to reach out. It also provides general information about mental health and help-seeking.

As soon as possible after determining that someone has experienced a psychotic episode. We should also aim to

- **Provide the Early Intervention in Psychosis booklet.**

This booklet is important in the context of personal barriers as it addresses issues such as hospital admissions, medication and diagnoses. A service user may be concerned about these, especially if they or their family have had previous service experiences. It also provides information about why engagement matters, what the early intervention service aims to do, and how it can help.

It may be helpful to engage early with the service user's family or social network, if there are early personal barriers and challenges to engagement. However, we should be aware: trust issues and suspiciousness may be an indication to tread more cautiously and listen more carefully to determine who in the service user's network they trust, who they don't and why. At the same time, we should also be aware that their mental state may also impact their current thinking and decisions.

**Openness, honesty and sincerity are critical when dealing with service users with trust issues. The more we can share information, our thoughts, what we put in notes and letters, the better. We should also be clear about what we will do with information that they tell us and be clear that the service user doesn't need to tell us anything they don't want to. It may take time for them to trust us, and we can tell them that this is OK.**

If a service user is admitted to hospital during their treatment, or our first contact with them is in hospital, we should aim to

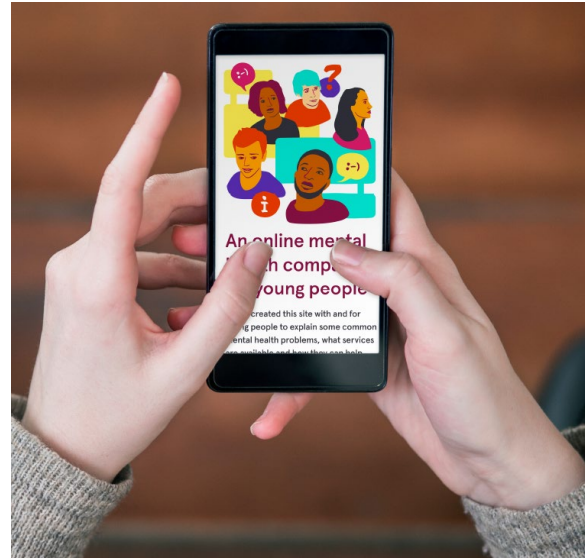
- Provide the **Getting the most out of hospital booklet**

It is worth going through the booklet with our service users who are in hospital at least once. Service users have said that hospital can be an unsettling and confusing experience. Many routines, rules, practices and jargon go unexplained. They may struggle to understand why they are there, how long they will be there, and how and when they might be discharged. Being honest and open and giving explanations can be helpful.

The stressful nature of the hospital environment; and cognitive difficulties due to current mental state and medications; can affect memory and attention processes. It is worthwhile therefore, to visit this information more than once.

### **Introductions to the website**

If our service users are in the right frame of mind, it may be helpful to show them the video '**Simon says ... psychosis**' from the EYE-2 website. It was made by service users, about their experiences of early intervention in psychosis services.



We should also aim to introduce our service users to the website forum. If their suspiciousness and distrust is related to people and services, as opposed to technology, they may find it valuable to speak to others online who have used or delivered services.

They can use this site anonymously to gain a set of opinions. They can also create a profile, if they want to, so that they can easily track responses to their questions.

Finally, by being open and honest with a service user, we can gradually encourage them to be honest with us. Sometimes, a service user might find us hard to get on with, through no fault of our own. In this case, where the option exists, it is worth being flexible and enabling the service user a change of care co-ordinator.

## A Psychoeducational Approach- The EYE-2 Booklets – How and when to use them, based on illness phase.

Below we introduce each of the 5 EYE-2 booklets. We can introduce these as developed by and for service users.

**The content of the website and all the booklets are based on extensive consultation with service users and their families.** They focus on what service users and families need to know to support them to engage with services. **Service users said that they value using these booklets most in discussion with their clinicians, and that the discussion has the greatest impact.** Resources use is designed to be adapted to a service user's illness phase.

### 1. The Mental Health and Help-Seeking booklet – For use at first or early contact.

*When to use* - This booklet is designed to give to young people right at the beginning of their EIP journey when we first meet them. Some services have also said that it is helpful to post this booklet out with the first appointment letter.

It is especially designed for young people who are:

- harder to engage initially,
- reluctant to talk about their difficulties
- using drugs and struggling to separate mental health problems from drug use

- experiencing an 'At Risk Mental State' or where there is diagnostic uncertainty
- have limited insight
- prior to a discussion about psychosis.

*What is it for* - The aim of this booklet is to give young people some general information about mental ill health, to address potential barriers to engagement, and to encourage them to talk to someone.



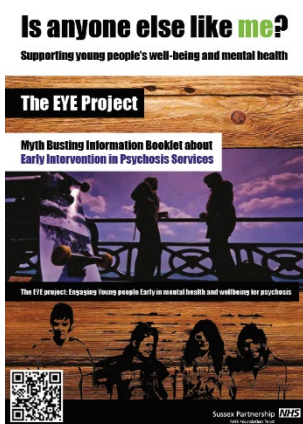
### 2. The Early Intervention in Psychosis booklet – For use as soon as possible after a decision has been made that someone is experiencing psychosis.

*When to use* - This booklet is designed to give to people as soon as possible after a psychosis diagnosis has been made. Staff have also given this booklet to people who are in hospital, and are reluctant to talk. It is easiest to use this booklet when

- we first talk about the service and what it does,
- when we first talk about psychosis experiences or diagnoses

**The EIP booklet is important because young people have told us that they are more likely to engage with an EIP service if they understand what the service is and how it might help them. Some young people told us they thought EIP was a charity, or that the service was about having a cup of tea every once in while!**

*What is it for* - The aim of this booklet is to support a conversation about psychosis experiences, to dispel myths and barriers that might put people off engaging, like medication, hospital and diagnosis. The booklet also covers things that might encourage engagement like what an EIP service does, what knowledge and skills the different team members have, and what treatments might be available. There is some discussion about different cultural, religious and spiritual preferences. The booklet encourages service users to tell their care co-ordinator about their needs, goals, and preferences. This should make it easier for us to engage as effectively as possible with the young person.



*A barrier to use?* Some care co-ordinators have said that it's difficult to use the EIP booklet when someone doesn't accept a psychosis diagnosis. Others have said we **can** use this booklet when service users have no insight or don't agree with a psychosis diagnosis, provided we are thoughtful with our language use, and the way we present information. The EIP booklet has a section on what an EIP service is, which gives ideas for how to explain psychosis in a non-stigmatising way.



### **3. The Treatment Choices booklet – For initial treatment choices and all treatment reviews**

*When to use it* - This booklet is designed to use with a service user, family and other members of the social network, to introduce and discuss treatment options, and provide choice. It can be used when

- Discussing a treatment that someone is already receiving, after they have started it, when initial symptoms and distress have settled.
- Discussing new treatment options
- Collaborative care planning
- When things are feeling 'stuck' and we are looking for new ideas or ways to engage
- When a service user or their family want to know
  - What other treatments are available – and as a checklist of what's been offered
  - What else they can do that might be helpful
  - The evidence that a particular treatment works

**Service users have told us that the treatment choices booklet is particularly helpful when they have memory problems. The booklet helps them to remember what they've discussed with their care co-ordinator or clinician. It helps them to feel more involved and able to make choices about their treatments.**

*What is it for* - The aim of this booklet is to support discussion and provide choices about treatment for service users, their families and key members of their social network. It has sections on

- mental health service support
- peer support
- vocational interventions
- physical health interventions
- psychological therapies
- medication treatments

It also provides the most up to date evidence for these treatments for our own knowledge, based on research and government guidelines. It has been written with the help of service users, to make sure it is honest and trustworthy, and with the help of clinicians and experts in all disciplines to make sure it is accurate.

**Treatment choices are critical to engagement. Young people have told us they are more likely to stay engaged with EIP services if they have choices about their treatments, and if the treatments consider their health, wellbeing and goals, and are not solely medication focussed.**

Service users specifically asked that peer, vocational and physical health interventions were at the front, and more traditional psychological therapies and medications were at the back. This was specifically to raise the profile of the former interventions as psychosis treatment approaches.

*A barrier to use?* Some clinicians have said that the treatment choices booklet is too long for some service users and that it is difficult to use when people are unwell. It is possible to use parts of the booklet, as a reference with a service user. For example, we might present

- (i) a choice between 2 treatment options, or
- (ii) a personalised proposed treatment plan

Sections can be photocopied from the booklet, or downloaded as single treatment sections from the website.

We can then return and provide more choices, or the whole booklet later, when the service user is more able to take it in.

Some clinicians also expressed concern that their service may not be able to offer every intervention that is in the booklet. It is possible to steer a service user towards the treatments that *are* available. However, all treatment choices, also have additional information on how to access each treatment.





4. **The Family and Friends booklet – For giving to family and friends at first contact or as early as possible**

*When to use it* – This booklet is designed specifically to be given to friends and family. It can be used at

- The first meeting with each key family member or friend
- A family night, or family group session.

Some teams have also posted this booklet to family members with the first invitation letter to a family meeting.

**The Family and Friends booklet provides specific advice on what to do, and what not to do, to support a family member or friend, as well as themselves. Family and friends have said that they have felt less isolated, and more reassured and empowered by this information.**

*What is it for?* The aim of this booklet is to support families and friends of EIP service users. The booklet contains myth busting

information about psychosis, recovery, early warning signs and where to get help. It addresses a common concern of parents, that they, or someone else, is to blame. It covers challenges such as differences of opinion on hospitalisation and treatment, and stigma, and provides advice for friends and family on how best to work with EIP services, in support of their service user. It provides information about what to expect from the EIP service, and the limits of this. It also provides important information for family members on how to look after their own mental health and well-being.



5. **The Getting the Most out of Hospital booklet – for use with service users who are inpatients**

*When to use it* - This booklet is short and is designed to give key information to service users who are currently in hospital. It is especially helpful when,

- a service user has *not* previously been in a mental health hospital
- a service user does not understand why they are in hospital
- a service user wants to know when they will get out of hospital

*What is it for?* - The aim of this booklet is to briefly explain some of the practices, routines and jargon that are used in a mental health inpatient unit. It also provides advice to service users to help them to find out and understand why they were admitted to hospital; and to help service users to make the most out of their time in hospital. It is anticipated that this information will help service users to feel more calm and in control, to reduce their inpatient stay and to return home more quickly.

would like to discuss. The resources are best used in discussion with the service user and their family and wider social network.

### **Activity 9: Introducing the EIP booklet**

Take a few moments to look at the content of the EIP booklet. Imagine you have recommended the booklet to a service user.

In pairs, role play a discussion about the content of the EIP booklet

- one of you is the care co-ordinator, introducing the content
- the other is a service user

What is helpful and what is less helpful?

**All of the booklets and the website can be used by service users and their families as a reference throughout their time with the service.**

Service users and their families can dip in and out of the booklets. They can read them in their own time, in between appointments. They can pick out issues they

## The EYE-2 Website - How and when to use it

**How to find the website** – You can find the website at [www.isanyoneelselikeme.org.uk](http://www.isanyoneelselikeme.org.uk)

**From a computer**, click on the google chrome (or internet explorer) icon. Type the phrase 'isanyoneelselikeme', with no gaps, into the search space in the middle of the screen, or type the whole 'address' – the part in blue above - into the search bar at the top of the screen.

**From a phone**, click on your internet link and then type the phrase into the search bar. You can also hold your phone camera over the QR code on any of the booklets, and this will take you directly to the website.

**Care co-ordinators and other clinicians have said that they like the EYE-2 booklets and website because all the information they need is at their fingertips, and all in one place. They feel more pride and professionalism in their service because the EYE-2 resources support the core EIP work.**

**When to use it?** – The EYE-2 website can be used at any stage, but is probably best accessed

- when there are personal barriers to engagement
- immediately after the initial crisis or psychosis phase has receded
- early in the recovery phase
- with families and friends

The reason for providing the service user with details of the website early in the recovery phase, is that they may be more likely at this stage to be actively trying to make sense of their experiences. Some people may 'seal over' and not wish to discuss or make sense of their experiences at later stages. This frequently makes the early phase of recovery an important opportunity for information to be shared and support given to help the service user make fullest sense of their experiences. Promoting hopefulness and understanding are key activities.

**What is it for?** – The aim of the website is to provide a source of support and information for service users and their families, helping people to feel less stigmatised and alone. It includes

**Service user stories** – that describe different individuals' experiences of psychosis and recovery. These stories include the service user's perspectives on the factors that helped them. Some stories are narrated by the service user themselves

**A moderated discussion forum** - for service users and their social network to post stories, ask questions, and seek advice and recovery support from others

**A short film** - that follows 3 service users' experiences of psychosis and the support they received from the EIP service

**Treatment and wellbeing advice** - about a range of issues such as drugs, spirituality, and self-help steps.

**Downloadable Resources** – including the booklets and other materials.

**Some service users have said that reading the stories made them feel less isolated, and less convinced that their fears were real as they read about other people with similar experiences who 'recovered'.**

## Facilitators to implementing the EYE-2 Approach

We have conducted interviews with clinicians from all disciplines who were involved in the original EYE-1 project. This helped us to find out what else would help to support clinicians and teams to use the EYE approach effectively and sustain its use with service users and families. Below is a summary of the learning from these interviews and what we have introduced for EYE-2 project.



### 1. Memory prompts and having all the resources easily accessible

This was critical. Clinicians told us that they sometimes found it hard to remember to use the EYE-2 approach and resources. Other clinical demands can push the EYE approach down the agenda. They said it helps to have:

- an EYE-2 team champion/link person
- checklists to record what's been done and what's been shared with the client and family

- memory prompts and reminders from researchers in the team
- embedding the EYE approach within the team by bringing discussions about it into supervision meetings and into team meetings.
- having the booklets visible in team offices and in waiting rooms and keeping them stocked up.
- staff carrying copies of the booklets with them
- some teams found it helpful to have an EYE display board available, which showed all the resources.
- including all the resources in EIP introductory packs for service users and families.

### 2. Booster training and training for new staff

Clinicians said that that it would be helpful to them to have regular EYE booster and refresher training, as well as opportunities for new staff to access the core EYE training. Staff also asked for a training booklet. Team leaders and managers said it's hard to keep reminding their staff to use the resources.

The new EYE-2 approach therefore includes

- checklists
- newsletters
- training updates with new information that we learn during the study.
- 6-monthly booster training
- training for new staff drawing on video materials.
- the EYE-2 manuals for all staff

### 3. Access to written materials and handouts to take away

Clinicians wanted more written handouts to take away. We have therefore developed a

- Comprehensive implementation tool kit with manual and resources.

### 4. Introductory vs advanced MI training.

Some clinicians wanted more introductory MI training, while others found the training given to be too basic.

- We have therefore provided initial book references to the MI approach in the section on page 4, and
- Tailored the MI training to be more specific to the EYE-2 approach.

### 5. Familiarity with the content of the booklets and website

Clinicians said they were more likely to use resources if they had read them and were confident and familiar with the content.

- We have therefore provided a summary of the content of each booklet, including how and when to use it, and how it was developed.



KARLY'S STORY

I was surprised by how much support and understanding I received

### 6. Managerial support and supervision

Clinicians said that receiving regular support and encouragement from their manager and team leader helped them to embed use of the EYE approach in their routine clinical practice.

- We have aimed to ensure that all EIP team leaders and managers are able to join the training sessions.
- We have produced checklists that can be used in supervision, in case these are helpful

### 7. Keeping a record of engagement and disengagement

Clinicians said that it would be helpful to know how many people do disengage.

- We will aim to keep teams up to date on engagement outcomes



### Benefits of the EYE-2 Approach

In addition, to suggestions to support implementation, clinicians also reiterated some of the values of the approach.

#### 1. Noting the value of booklets and resources

The booklets and resources provide

- Helpful information for new and existing EIP staff
- Summaries of NICE guidelines for psychosis
- Reliable resources from a trusted source
- Information all in one place, that is accessible and easy to use
- Resources that guide clinical work and the process of relationship building and goal setting
- Resources that can be used in Introductory packs for service users and family members or used to shape and inform psycho-education or support groups run by EIP teams.

Some staff also said that using the approach helped them to manage the pressures of their work.

#### 8. Noting the perceived benefits to service users

Clinicians described potential benefits to service users including

- Engagement and collaboration
- Empowerment and Control
- Containment and reassurance
- Reduced fear and anxiety
- Hope and Motivation

## Barriers and Solutions to implementing the EYE-2 Approach

Our interviews with clinicians also told us about some of the additional barriers to delivering the EYE-2 approach, and how to overcome these.

### 1. Challenges to using the website –

Some clinicians didn't feel confident in using the internet to find the website or to guide others to find and use it. Others found it practically hard to use the website in a session as it needed a computer and an internet connection. There was some concern about possible risks involved in using the forum on the website. Some staff also said that it was hard to find information on the website, and it was hard to navigate.

- We have provided detail about how to access the website
- We have produced EYE-2 business cards with the website name, QR code and information about how to use the website that can be given to service users
- We have redesigned the website, based on clinician and service user feedback to be easier to use.
- The website is now mobile friendly so that it can be accessed on a mobile phone or a tablet.
- The forum is a moderated discussion board. No post will be uploaded until it has been approved. It will be overseen by trained clinicians and researchers.
- Specific advice on the website will state that the forum is not the place

to express risk and that any serious concerns should be discussed with an EIP clinician or the care co-ordinator.



### 2. Challenges to using the booklets

Some clinicians were concerned about giving service users and family members too much information, or giving 'worrying' information about psychosis and treatments. There was concern that service users and staff might ask for treatments that are not available. Some staff found it hard to remember what was in the booklets, and when to use them and this made them less confident in using them. Some staff were worried that service users may be too unwell or too agitated to use the booklets, and families may be too stressed to take in the information. Sometimes service users may refuse or avoid using the booklets. There was also some concern that the booklets are not available in other languages.



- Information can be given in stages, as appropriate based on clinical judgement, and in discussion with the care co-ordinator/team members.
- Initially when a service user is less well, only a short booklet or a section of a booklet may be used. More information, and whole booklets may be used as a service users' mental state improves.
- Treatment choices information can be given as individual sections as appropriate.
- Service users have said that they often do ultimately want the information so they can make informed choices.
- Clinicians can direct service users and family to the treatments that are available.
- There is a section in the booklet that explains that non-core treatments aren't available everywhere.
- There is a summary of the booklet content, including when and how to use them, in case this is helpful.
- Service users who don't want booklets, may use the website, or may want some but not all booklets.
- The website content can be translated into other languages.
- We will produce a shortened introductory leaflet in a range of languages.

- We aim to include spoken sections of the website in different languages



### 3. Resources need to be up to date, and localised to each team

- We have updated all the resources for the EYE-2 project
- We have included local information and images from each team where possible
- Recent updates, team specific information and events are available on the website which will be regularly updated.



### 4. Considerations for social groups

Social groups may not work in some geographical regions and may work better in collaboration with care co-ordinators. There may be concerns about how to manage risk issues.

- Social groups can be shaped flexibly to match the context of each individual team.
- Social groups can even be offered as an 'on-line' group on the forum at a specific time and day if preferred.
- Social groups, and indeed family groups, could be run as 'pop up' events in different locations where there is a large rural geography.
- We have provided guidance on how to manage risk issues within a group but each team, PPI lead and RA, should decide on the final protocol for risk management based on local policies.



#### 5. Service users may be reluctant to involve friends; friends may be wary; and we worry about confidentiality

Service users may not want to involve friends, and friends may be wary due to stigma and related issues. The critical issue here will be to

- Consider how to explain the involvement to friends in a normalising, non-stigmatising way
- Consider who to involve and why
- Consider carefully the pros and cons of involving friends based on the social network section

- Agree what to share and how much friend can be trusted with confidential information
- Arrange a friends meeting in a neutral non-NHS environment like a college or community venue.

#### 6. MI, openness and social network approaches may not be possible when working with acute risk

- We have focused more specifically on how to use MI approaches in the context of risk, and the OD approach is specifically designed for delivery in crisis teams.
- However, openness may need to be used sensitively, and all of these approaches should be used in the context of our good clinical judgement regarding what is appropriate and when.

#### 7. Staff might struggle to use the EYE approach when they are too busy

- There are lots of suggestions for how to support the EYE approach in the previous section in case any of these are helpful.
- Clinicians from the original EYE-1 study said that the EYE approach actually saved them time, as they sometimes gave information, and allowed service user to read it and discuss it within their social network.



## Resources

# Certificate of Achievement in Best Practice

This certificate is presented to:



---



For showing good collaborative practice by:

---

---

---

---



I .....[name] have identified

**The following key family members who I would like to be involved in discussion/support with EIP**

**Family members name/s** .....

- Any aspect of my life
- Health, mental health treatments, risks and coping only
- leisure and social life, work college and day-to-day activities only
- religion and spirituality only

**The following key friends who I would like to be involved in discussion/support with EIP**

**Partners/Friends name/s** .....

- Any aspect of my life
- Health, mental health treatments, risks and coping only
- leisure and social life, work college and day-to-day activities only
- religion and spirituality only

**The following people (e.g. teachers/work colleagues/spiritual guides) who I would like to be involved in discussion/support with EIP**

**Names of other people who are important to me**.....

- Any aspect of my life
- Health, mental health treatments, risks and coping only
- leisure and social life, work college and day-to-day activities only
- religion and spirituality only

**Signature** ..... **Date** .....

**Template letters**

**[Service/Trust logo]**

**[Service address]**

**[Date]**

Dear ..... [name]

Your relative/friend/student [delete as appropriate] .....[name]

has suggested that you may be able to support him/her in some work that we are doing at the moment, around their mental health/day-to-day life/education/work life/spiritual life. [delete as appropriate]

This work and your input would be confidential. We would only discuss this between ourselves and others who are working with ..... [name]. The only exception to this would be if a risk issue arose that affected someone else.

I hope that you might be willing to help. If you are happy to be involved or would like some more information, I wonder if you could give me a ring on the number above so that we can discuss this further and, if you are happy to go ahead, to arrange a time to meet. We can meet at a time and place that is convenient for you and ..... [name].

Yours sincerely

..... [name]

## EYE engagement checklist

## Social Group Resources

### Ideas for Social Groups

We have listed a few ideas for the social groups here. You don't have to use all/any of them. It is entirely up to you how the social group is run.

- Cheap Eats – identify a list of places that do cheap food/special offers
- Social foodies – you could each volunteer to bring in some of your favourite food/ a food associated with your culture/a family recipe for others to try
- Open Spaces – visit a park, a garden, go for a walk in the woods, have a picnic during the warmer months
- Growing and eating your own fruit and veg – identify a place where this can be done for cheap, or do it in your own garden/kitchen windowsill and discuss the progress
- Leisure/Sports facilities – find a local outdoor gym, go for a jog together, hire a cheap room and follow some online YouTube tutorials.
- Movie Group – identify a list of movies you all want to watch – watch them together or separately and then discuss them.
- Book group – identify a list of books to read, aim to read one every couple of months and discuss them.
- Galleries/museums – some galleries/museums allow free entry. An opportunity to socialise and learn!
- Go to cheap cafés
- Online group/Whatsapp group chats – if meeting in person is difficult this may be the best way to socialise
- Board games – meet up to play a board game together
- Go to a free community event – check your local area's website (as well as that of your local library, any local colleges or universities, any local newspapers, and Meetup) and see what kind of free events are going on in your community.
- Volunteer as a group – for example, spend a Saturday together working at a Habitat for Humanity house or helping a food pantry restock their shelves or planting flowers at a park.
- Start a fantasy sports league – e.g. sign up for fantasy football and see who picks the best team!
- Host a clothes swap day where everyone brings clothing and accessories they no longer want, and everyone goes home with something new!
- Photography/Art/Creative writing – work together to create an art piece, take some photographs, host a session to show off some of your talents.

With thanks to Chris Shoulder (PPI Lead for London) and "The Simple Dollar" for these ideas (<https://www.thesimpledollar.com/cheap-and-social-15-inexpensive-and-very-fun-things-to-do-with-friends/>)



# Social Group – Ground Rules

Use this to write down the ground rules for your social group.

1)

2)

3)

4)

5)

6)

7)

8)

9)

10)



# Want to spend time with people with similar experiences?

**WHEN?**

XXXXX

**WHAT TO**

**EXPECT?**

XXXXXX

**WHERE?**

XXXX

**CONTACT?**

XXXXX

Please join our social group, run by and for people who are receiving  
Early Intervention services.

Access e-versions of the social group resources by following this link:

[https://www.dropbox.com/sh/tgrr8a79rx1c357/AACgBZ\\_GGNo\\_c8VTnA-RGufBa?dl=0](https://www.dropbox.com/sh/tgrr8a79rx1c357/AACgBZ_GGNo_c8VTnA-RGufBa?dl=0)