Caring for Young People

Engagement and Help-seeking studies

Intervention - First episode psychosis (MAPS)
And Introducing Dr Rick Fraser - Chief Medical Officer with Board responsibility for Research, Previous CHYPS clinical director,

“I am keen we continue to grow as a research organisation and build research into our clinical programme. I will promote and support our research agenda and engage with our partner organisations to work creatively and to collaborate on delivering our vision for better mental health and well-being for all. We have some excellent projects running presently. I am confident in our team and look forward to working with everyone. I am also committed to working with our service users, families and partner organisations to co-design services.”
Supporting Engagement and Help-Seeking in Young People.

Dr Kathy Greenwood, Iain O’Leary, James Moon
collaboration is everything
Types of involvement

Consultation & Collaboration

- Ruth Chandler was a co-applicant with lived experience provided input to grant applications.
- Ruth Chandler and worker co-designed and facilitated Service user involvement forum (SURF)
- Service user involved in refining design, and recruiting clients with difficult engagement histories to SURF meeting
- Student researchers leading on aspects of the project who both have experience of using CAMHS/young adult mental health services
- Service user researchers and youth volunteers have worked together on project delivery
- Service users involved in staff training, design/delivery of EYE booklets and website
- Service users will be involved in the decision aid design
Background

- Adolescence characterised by significant change in social and emotional function

- Mental health issues most commonly arise in adolescence and young adulthood (50% by age 14)

- Mental health issues cause significant short and long term disruption and negative outcomes in this age group

- A large proportion of young people still do not seek help for psychological distress

- Early intervention is associated with better outcomes but 25-30% of young people disengage from services
What we know about factors that influence help-seeking

- Lack of mental health literacy
- Self-stigma
- Self-reliance
- Lack of knowledge of services
- Negative attitudes towards services
- Negative responses to prior help-seeking
- Negative cultural beliefs towards help-seeking
- Lack of accessible services
Figure 1: Model of beliefs about help-seeking

- Existing beliefs about MHDs
- Beliefs about the impact of experiences on the self
- Perceptions of others' beliefs about experiences as normal or abnormal
- Beliefs that experiences are normal or abnormal
- Beliefs about the process of help-seeking (and that others will respond negatively)
- Perceptions of others' beliefs about the outcome of help-seeking
- Beliefs about the outcome of help-seeking (and that others will experience burden/relief)
- Weighing up costs and benefits of help-seeking

BELIEFS ABOUT A NEED FOR HELP-SEEKING

Glossop, Cooke and Greenwood in prep
What we know about factors that influence disengagement

- Younger Age
- Less Family involvement
- More Substance use
- More mild symptoms
The early youth engagement (EYE) project aims to understand and improve the engagement of young people in mental health services.

- What are the barriers and facilitators of engagement?
- Can services be adapted to be more user friendly?
- Can adaptations be successfully implemented to increase youth engagement?
The EYE intervention

Barrier and Facilitator themes

Communication

Service to service user/carer

Social

Lack of information

Mental health service

Stigma

Mental health service itself

Family

Media facilitator

Social barriers

Medication

Hospital

Service user

Action

Attitude

Behaviour

Mental health Staff

Knowledge

Personal experience

Personal qualities

Social environment
The EYE intervention

Information
- Myth busting booklets
- Treatment choice booklets
- Website
- Help seeking tool
- Carers/schools packs
- Improved GP links

Social
- Family and friends protocol
- Peer workers

Mental Health Service
- Parallel family and service user
  social support group

Mental Health staff
- Transparent, flexible
- Goal-focused engagement
- Using MI principles
- Considering lifecycle
- Service user/carer led

Personal qualities
- Information booklets
- Website and blog
- Help seeking tool
Is anyone else like me?

The EVE Project: Engaging Young people Early in mental health and wellbeing for psychosis

Myth busting Information about mental health, unusual distressing experiences and early intervention

Are you a young person who is worried that there’s something wrong with you? Have you already been referred to or seen someone from a mental health service? Or an early intervention in psychosis service? Want some advice or answers? Then this website is for you. It has been produced with and for young people.

Why bother with this website?

Young people have mental health problems too! Did you know that 1 out of every 10 teenagers will have some sort of early mental health problem and as many as 2-3 people out of 100 will develop psychosis? Imagine thats as many as 3 or 4 people in a college class having one problem or
Young people have mental illnesses too!

“I think knowing that other young people have it as well, really helps, because a lot of people think ‘oh I’m really unusual’ and kind of shy away from it. But I think when you do realise how many other people can have the same problem it helps.”

Cassie aged 19

“I was hearing voices. I thought there was someone trying to get me out of the house. I thought I heard my neighbours walking past and I thought they were talking about me. Then they went round the corner and I could still hear them. I looked out and I thought I saw some guy in like a van trying to contact me and I thought well that’s my next door neighbour or whatever cos I’ve seen him going in the house once.

“At first I thought it was my brother actually, and his girlfriend round there trying to get me out of the house, and then when the people knocked at the door, I went outside, just to check, and like a leaf fell from the tree and I thought I heard the leaf like saying something or something and then I knocked on this van and then I heard them say, ‘oh she knows we’re in here.’

Ben aged 20
Common myths

‘They put everyone on medicines’

Certainly one of the main treatments for psychosis is medication, but over half the people who are seen in EIP services don’t end up having psychosis.

If you don’t have psychosis, you might just have a few meetings to reassure you, or you might be recommended to a different service that will suit you better. If you do have some of the unusual distressing experiences we’ve been talking about (psychosis), remember it’s quite common, and doesn’t mean you’re ‘weird’!

Someone will probably talk to you about medication because some people find it really helpful to deal with stuff that’s happening and to stop it coming back again! After all, we take painkillers for headaches, coffee to wake up - so what’s the difference? Generally speaking you don’t absolutely have to take medication, and someone will also talk to you about other things that might help, like talking therapies, support for getting back to school, college or work, help with money and housing, and help with diet and exercise.

Our ‘Informed Choice in Treatments’ booklet tells you more about all sorts of things that might be helpful.

‘They put you in hospital’

EIP services definitely don’t want to put you in hospital. In fact, EIP services were specially set up to do the opposite! They try to make sure that things never get that difficult. They try to help you recognise ups and downs so that you can deal with issues early. Only if things are impossible to manage, very distressing and you or the EIP team really think things are unsafe will you end up going to hospital... and that doesn’t happen often because it also costs the NHS lots of money (e.g. about £2500 per week in 2013)! If you do end up going into hospital, there’s a booklet to help you with that too. It’s called ‘Dealing with hospital: getting on with life’. 
What are EIP services? - ‘It’s what you do next that counts’

EIP stands for Early Intervention in Psychosis.

You might think the word psychosis is a bit unsettling and maybe it's putting you off reading anymore? Unfortunately, this may well be because of stigma! We can blame some of that on the media but we can feed into it too. What do you imagine when you think of psychosis? Would you be surprised to know that half of the people pictured in this booklet have psychosis?

Psychosis is not a diagnosis, it's just a description of a set of experiences. They include things like being paranoid, thinking someone's following you or out to get you, having other strange or upsetting thoughts or indeed real experience of hearing, seeing, feeling, smelling, and tasting things that other people don’t. It can be scary at the time, but you can get over it, have a life, a good job, a relationship and a family. Even psychosis is quite common. Some people think that psychosis is just an extension of anxieties that we all have.

Different people respond to it differently though and some people struggle more and have a harder time and more long term problems. It’s what you do next that counts!

If you think you have psychosis, or someone has suggested this to you, choosing to work with early intervention services is a first step to doing the best you can for yourself. EIP services try to meet and support young people with psychosis as quickly as possible so that they have the best and fastest recovery that they can. Your decisions are important here and they matter.

Getting the right amount of support and advice at the right time can make a big difference to your life in the long term.

This booklet is here to give you some advice on how to find someone you can talk to.
Addressing personal barriers to talking

“I don’t talk about my past, I don’t talk about how I feel, I don’t talk about the emotions and all that because it makes me feel vulnerable.”
Tom aged 17

“I can’t say ‘oh you know, I’m being haunted by spirits’ or ‘I got attacked by demons’ to a doctor, because they’ll just think ‘oh he’s crazy.’”
Joanne aged 16

It’s hard enough to talk to people anyway when you’re a teenager or young adult. Then add to that talking about mental health with someone you don’t even know. That can feel like a nightmare, but it doesn’t have to be.

Your worries about talking to someone may be similar to lots of other young people’s worries (and adults too!).

For sure, it can be scary talking about difficult stuff for the first time, but it can be really helpful to share our worries with other people. What about with friends, family, boyfriends or girlfriends? What would be the easiest way to start talking? Why not try writing things down first?

Then you could try talking to the easiest person you can find to talk to. You don’t have to tell them everything at once but it may help. You could ask someone to come with you to help when you talk to someone, and you could try choosing a comfortable place to meet. Even professionals are flexible and some will meet outside, in a café or in your own home!

If you’re still finding it difficult to talk, have a look at the ‘Where to get help’ page for more ideas.

“You might have good reasons not to trust people, but things change, and there really might be someone you can trust, you just need to find them!”

“I was completely the opposite of strong, you know I was literally just a dead… like a zombie, you know, and so I needed someone to step in and be like, you know, my voice.”
Jack aged 19
Study aims

- To design a novel help seeking decision aid

- Through exploration of:
  - Participant recognition and understanding of mental health difficulties
  - Attitudes and past experiences to help-seeking, and how these fit with current models and help seeking literature.
  - Ideas relating to creation of a specific help-seeking tool for YP.
The Diverse Voices of the Project

- 37 young people with and without MH concerns
- NHS mental health services and youth services
- Diversity of Service ->
  Early Intervention, CAMHS, Adult CMHT, Crawley Pathfinder;
  YMCA, Positive Placements, Hastings Youth Council
  -Age- -> ranging from 15 to 28, average under 20
  -Location- -> all across Sussex
  -Experience- -> of MH, help-seeking, services and broader life experience
Setting Up

- Collaborating with teams, Young People, and Families across Sussex

- Topic guide developed by research team and Service User Research Forum (SURF)

- Focus groups of 2-12 or one-to-one interviews

- Choice:
  - Where to meet to ensure participants feel comfortable and safe
Coming Together
The Conversations

What we explored

Personal Experiences
- Exp. of early health and mental health
- Recognising the problem
- Exp. of first seeking help

Screening Tool
Perspectives and ideas on a MH screening tool for Young People

Help-Seeking Aid
Information to facilitate help-seeking
The Conversations

What we heard

- Willingness (to contribute)
- Openness (in disclosing)
- Lasting impact (of isolation; not being heard)
- Frustration
- Peer support/comradery
- Creativity
- Enthusiasm for change
Reflections/Lessons

- Ask, don’t assume

- Young people are an essential part of the solution
Methods

- Thematic analysis (Braun & Clarke, 2006)
  - Familiarise with data
    - 16 interviews conducted, listened to and transcribed
  - Generate initial codes
    - Each transcript analysed line by line
  - Search for themes
    - Initial long list grouping
  - Review themes
    - Further discussion, re-grouping, renaming,
  - Define and name themes
    - Start to develop headings
  - Produce the report
    - Describe each theme and highlight with quotes
### Results - Barriers to recognition

<table>
<thead>
<tr>
<th>Mental health difficulties are hard to recognise &amp; categorise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition occurs by comparison self &amp; others</td>
</tr>
<tr>
<td>Mental health difficulties are individual</td>
</tr>
<tr>
<td>Physical symptoms easiest to recognise</td>
</tr>
<tr>
<td>Serious problems involve crisis, self-harm, constancy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Young people with mental health difficulties struggle to express selves</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young people hide mental health from themselves</td>
</tr>
<tr>
<td>Young people self-isolate and ‘put on a mask’</td>
</tr>
<tr>
<td>Young people struggle with emotional literacy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>External validation required for invalidated teenagers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural narratives invalidate ‘teenage’ experience</td>
</tr>
<tr>
<td>External messages are a powerful prompt</td>
</tr>
<tr>
<td>Diagnoses legitimise experience and reduce isolation</td>
</tr>
</tbody>
</table>
## Results - Barriers to recognition

<table>
<thead>
<tr>
<th>Mental health difficulties are hard to recognise &amp; categorise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition occurs by comparison self &amp; others</td>
</tr>
<tr>
<td>Mental health difficulties are individual</td>
</tr>
<tr>
<td>Physical symptoms easiest to recognise</td>
</tr>
<tr>
<td>Serious problems involve crisis, self-harm, constancy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Young people with mental health difficulties struggle to express selves</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young people hide mental health from themselves</td>
</tr>
<tr>
<td>Young people self-isolate and ‘put on a mask’</td>
</tr>
<tr>
<td>Young people struggle with emotional literacy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>External validation required for invalidated teenagers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cultural narratives invalidate ‘teenage’ experience</td>
</tr>
<tr>
<td>External messages are a powerful prompt</td>
</tr>
<tr>
<td>Diagnoses legitimise experience and reduce isolation</td>
</tr>
</tbody>
</table>
Help should be transparent, increasing agency, control and trust

- Young people don’t know who or what information to trust
- Young people want control over help-seeking process
- Clear information needed on options and what will happen if seek help

Help-seeking is easier where there is knowledge and understanding of young people

- Best help is youth specific - adults can struggle to relate to young people
- Only people that can understand you are people like you, your peers.

Help should be holistic, understanding, and listening to the individual

- Listen, don’t assume
- Contextualise problems and solutions within life story
Creating an engaging questionnaire to promote help-seeking

- Access and confidentiality important for completion
- Something that helps you talk to someone in your life or a professional about your concerns
- Questionnaire needs to be brief yet thorough and easy to fill out. Possibility of a long and a short version
- Need balance between normalising mental health concerns and promoting help-seeking
- Language needs to be clear, not patronising, positive and not transparently diagnostic
- Content based on areas of life and difficulty not diagnosis
- Feedback needs to state that mental health problems are common and they are not alone

‘Something that implies and sort of pushes you to sort of go and talk to someone without implying that, you know, you have a mental health issue’ – Focus group participant

Figure 1: Emergent themes from the focus groups related to questionnaire development
Format of a help-seeking decision aid?

- (i) information to support and give people the mental health literacy and language to ask for help
- (ii) information to validate distress, effects of experiences on function, and justification to seek help
- (iii) information to support social comparison between current self, past self and peers who are not struggling
- (iv) clear 'external' messages and prompts (from influential people?) to encourage early help-seeking
- (v) guidance on how to seek help whilst maintaining control/agency, prompts on rights and what to say?
- (vi) guidance on where to find local appropriate and flexible youth focused support
- (vii) information on the likely process and outcomes of help-seeking
Next steps

- Validation and further development - Kirsty Labuschagne
- Delphi consultations with participants
- Creating and piloting the decision aid
- Research into how we understand, talk about and respond to youth health concerns? The EYE-2-I project
- Thinking about the bigger picture - how can we create environments that facilitate help seeking? The Teams project
Thank you

SPRiG
Sussex Psychosis Research interest Group

www.isanyoneeelselikeme.org.uk

www.sussex.ac.uk/spriglab