

NCAP –EYE-2

Supporting the Collection of Routine Outcome Data in Early Intervention in Psychosis Services

Prof Kathy Greenwood



Overview



The EYE-2 Project



EYE-2 PROJECT

The Early Youth Engagement in first episode psychosis (EYE-2) study

- Cluster randomized controlled trial of effectiveness, cost effectiveness and implementation of the team-based motivational engagement intervention
- evaluated with respect to disengagement & routinely collected outcome data (HoNOS, QPR and DIALOG) in 950 service users



EYE-2 research team

- National EIP and clinical-academic psychosis leads from around the country
 - Manchester
 - London
 - South of England
- Researchers
 - Patient and Public Involvement
 - Implementation
 - Statistics and qualitative analysis

1. Team values and data collection

Take a moment to think about

- your own and your team's values?
- How do these values fit with collecting EIP routine data?
- Flexible, engaging, creative?
- Empathic, Person-centred?
- Evidence based?



The value of using outcome measures?

Ellie – Manchester

I felt a bit overwhelmed and hopeless. I think the questionnaires can really help you to notice that something has started to get better, even it's just a little bit, on one question.

Ben – London

EIP staff member: how do you feel when we ask you to fill in these really boring questionnaires?

Ben: I don't think they're boring at all – I remember filling some in when I first came to EIP, but no-one shared the results with me. I'd like to do them every month so I can see how I'm getting on.

The value of using outcome measures?

EIP Team Leader

I was pretty skeptical to be honest, but then I was working with someone who kept missing our sessions. I really didn't get it as her housing was really bad and I was trying to help. I had to do the DIALOG, with her and then I discovered that from her perspective, her housing was the best it had been for ages, and her main problem was something completely different. That's why she wasn't meeting me. Outcome measures give us the opportunity to notice something that otherwise we might have missed.

The value of using outcome measures?

Provide additional information for care planning

Ensures service user is heard

Show and improve clinical outcomes

Enhance shared decision making

Improve collaborative practice

Reduce drop-out rates

Improve ability to detect relapse

Service users like them

Inform team development

The Measures



The Measures

The Early Intervention (EIP) Expert Reference Group (ERG) recommend 3 outcome measures:

DIALOG

The Process of Recovery Questionnaire (QPR)

Health of the Nation Outcome Scales (HONOS)

2. What are the barriers?

We have been working with clinicians in teams across the UK, to identify barriers that get in the way of using the measures in practice.



Barrier for you/your teams?

Perhaps note down a key barrier for you or members of your team in using these measures routinely?



Barriers – Time

- Not enough time to complete the measures during the session
- Too much to talk about
- May drop to the bottom of the agenda



Barriers – Clinical challenges



- Collecting outcome measures not highest priority
- Other things to consider in a session
- Too much other paper work
- Feel little value to completing measures
- Feel measures may hinder therapeutic relationship.
- No history of previous scores to compare a patient's progress against

Barriers – Service user challenges

- May not want to complete measures/may be suspicious
- Acute mental health issues – may feel overwhelmed, struggle to concentrate
- Cognitive difficulties may make completion difficult
- May not see measures as useful/valuable
- Language barriers may prevent completion



Barriers – measures themselves



-
- Language difficult to understand
- Some questions less relevant early on ...

3. Strategies to overcome barriers



Overcoming Time challenges

- Start session -completing measures together- let results guide rest of session –
 - less crisis led
 - shows measures are embedded in what we offer.
- Consider placing paper copies in the waiting room or posting out -service users can fill out or at least look through, then complete together.



Set up lots of reminders

- Team meetings
- In-Out boards
- Phones
- Outlook diaries
- Excel spread sheets
- Posters



Overcoming clinical challenges



- Think about how to introduce measures.
 - Remember, in general, service users are positive about these (it's us who may find them boring!)
 - Apologising as you hand outcomes over minimizes value and
 - Bringing the results into session may help
- Use for care planning

Ways to introduce measures

We use these measures with everyone who uses EIP services across the whole country. They've been designed by service users. They can provide some really useful information about you and how you are getting on at the moment.

These are two questionnaires. We might try to complete these about once every 6 months, so that we can keep a track of how things have been going?

These are two questionnaires that can help us get to know you and what matters to you. You can fill them out by yourself or I can help you if you want.

These are two questionnaires that can help us understand about your feelings, about your goals for recovery, about what you want to achieve and how we may be able to support you.

I'm not sure if you remember filling out these measures a while ago? If you could fill them in again now - we can have a look at what's changed for you in the last 6 months, if you're interested?

Use in care planning

How would you use this DIALOG to plan the service user's care?

Please read the questions below and tick one box for each question to indicate how satisfied you currently feel in that area. Please also indicate (Y or N) in the final column whether you would like additional help in those areas.

Use ✓ to indicate your answer	Totally dissatisfied	Very dissatisfied	Fairly dissatisfied	In the middle	Fairly satisfied	Very satisfied	Totally satisfied	Additional help wanted? Y/N
How satisfied are you with your mental health?			✓					Y
How satisfied are you with your physical health?					✓			N
How satisfied are you with your job situation?		✓						Y
How satisfied are you with your accommodation?			✓					Y
How satisfied are you with your leisure activities?					✓			N
How satisfied are you with your friendships?						✓		N
How satisfied are you with your partner/family?						✓		N
How satisfied are you with your personal safety?						✓		N
How satisfied are you with your medication?			✓					Y
How satisfied are you with the practical help you receive?							✓	N
How satisfied are you with consultations with mental health professionals?						✓		N

Use in care planning

The Questionnaire about the Process of Recovery (QPR)

[15/10/2007- Version 1]
[02.04.2014 Version 2]

We developed this questionnaire in order to understand more about the process of recovery; what's helpful and what's not so helpful. Everyone is different and there will be differences for everyone. The items on this questionnaire were developed through a process of interviewing service users about their recovery journeys. We hope that by filling in this questionnaire you will help us find out information that is important to you and your own recovery. Not all factors will be important to you, since everyone is different. This questionnaire is not intended to be used to impose anything against your wishes.

If you would like to fill in the questionnaire, please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements by putting a tick in the box which best describes your experience.

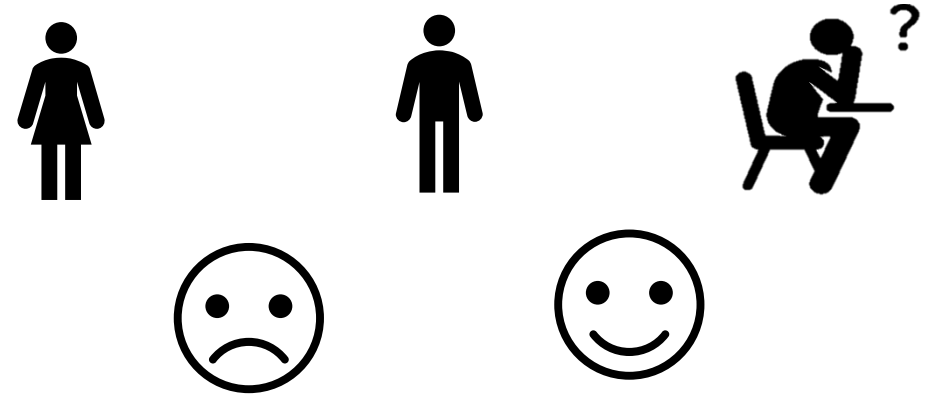
How would you use this QPR to plan the service user's care?

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
1. I feel better about myself		✓			
2. I feel able to take chances in life		✓			
3. I am able to develop positive relationships with other people		✓			
4. I feel part of society rather than isolated		✓			
5. I am able to assert myself				✓	
6. I feel that my life has a purpose		✓			
7. My experiences have changed me for the better			✓		
8. I have been able to come to terms with things that have happened to me in the past and move on with my life			✓		
9. I am basically strongly motivated to get better				✓	
10. I can recognise the positive things I have done			✓		
11. I am able to understand myself better				✓	
12. I can take charge of my life		✓			
13. I can actively engage with life		✓			
14. I can take control of aspects of my life			✓		
15. I can find the time to do the things I enjoy				✓	

Thank you for completing this questionnaire

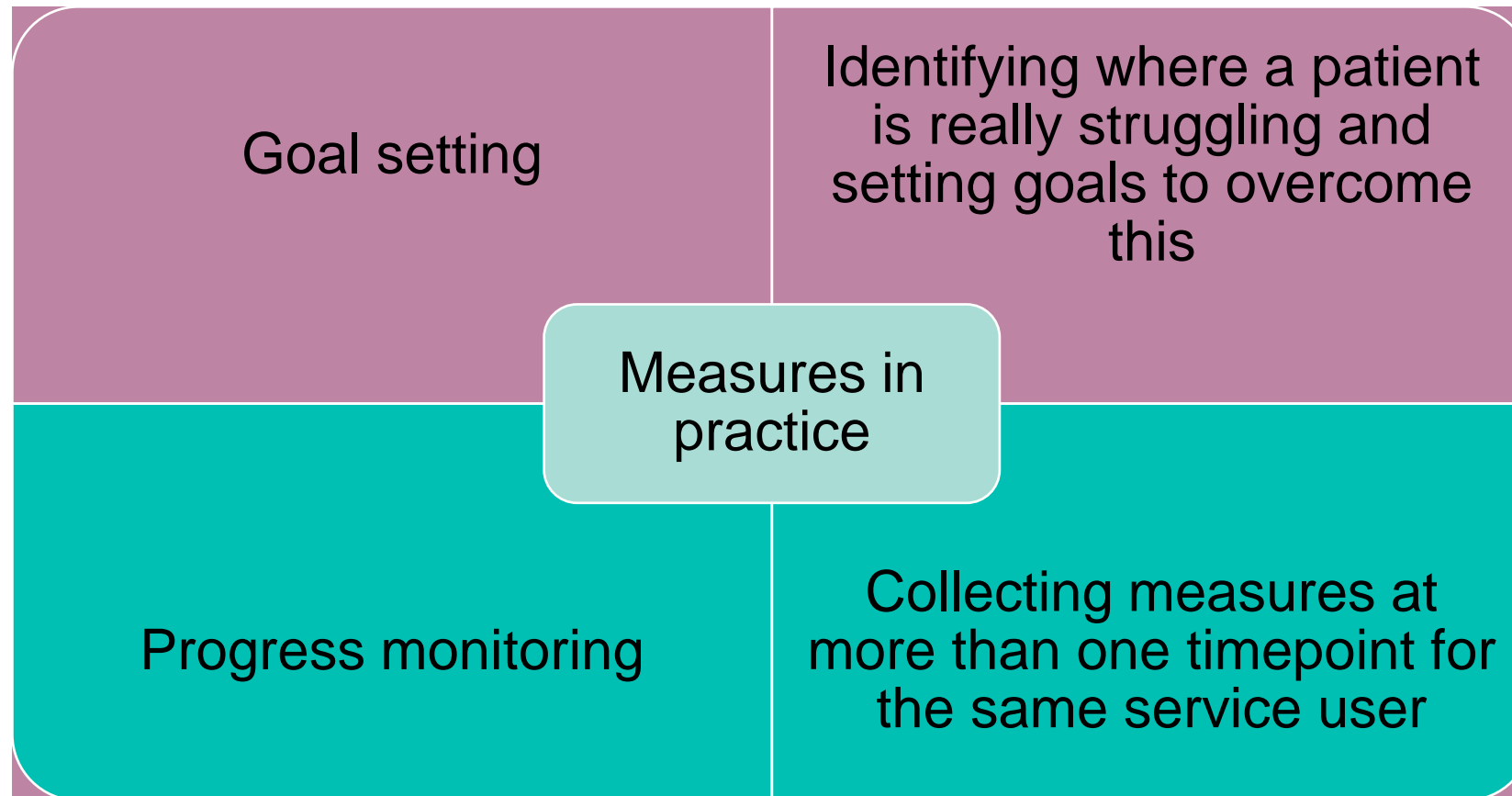
Use QPR and DIALOG to identify goals

The **DIALOG** can help to identify broad areas of dissatisfaction and need such as mental health, physical health, job, accommodation, leisure activities, friend and family relationships, safety and treatments – medication, consultations and practical help.



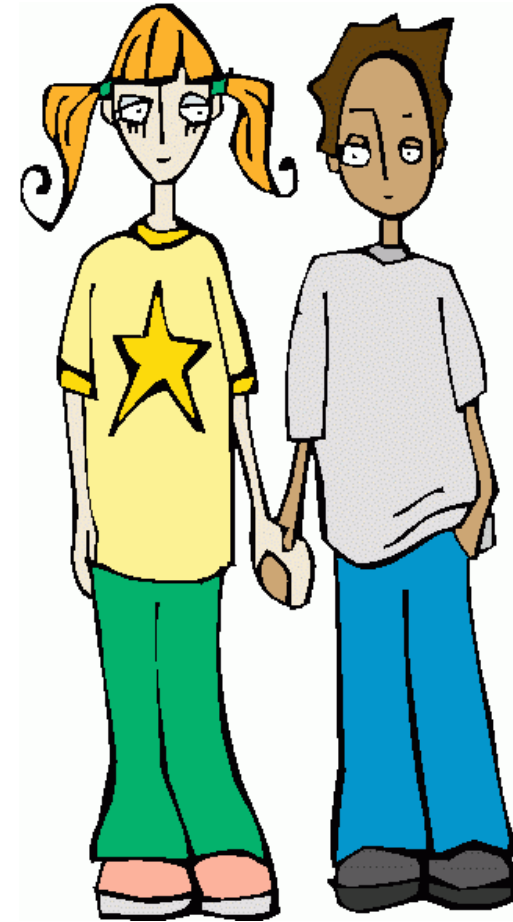
The **QPR** on the other hand, can identify beliefs about life, self and social skills, motivation, outlook, and abilities which may underlie dissatisfaction and get in the way of positive change.

Use measures in practice



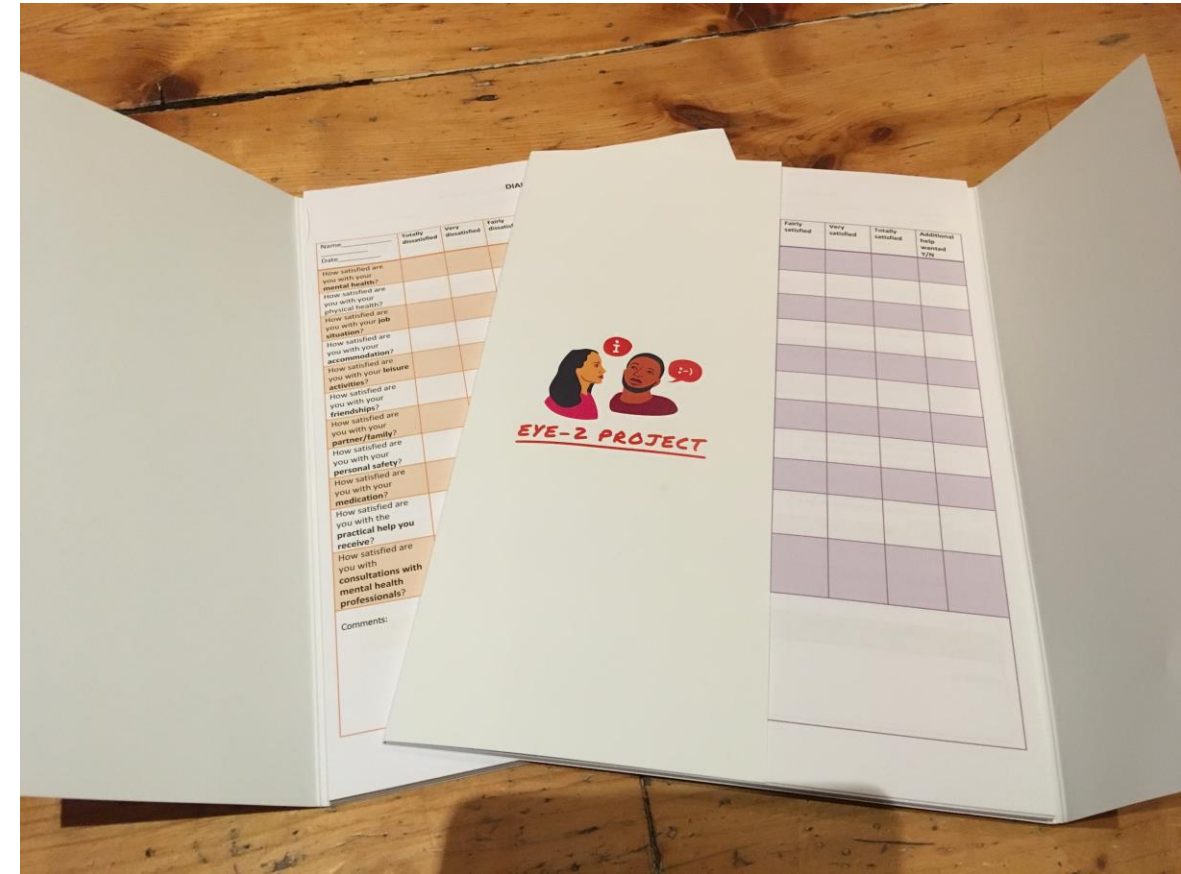
Overcoming service user challenges

- Be flexible – don't complete in crisis
- Be engaging, provide opportunities - do return to them
- Be empathic - Talk through with service user to aid completion
- Be collaborative - Explain importance of questionnaires for supporting service user goals
- Be open/transparent – Provide feedback with scores - discuss together in session
- Be creative – how to collect and use measures



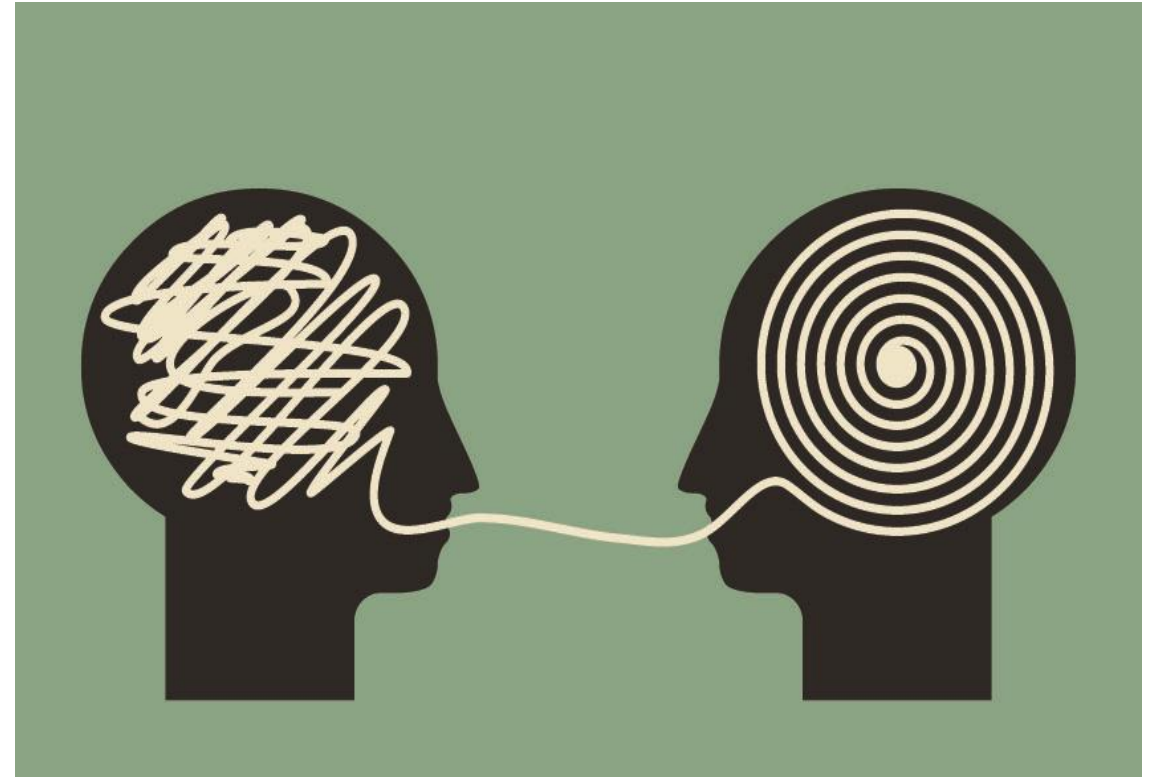
Simplify measures – make them accessible

- Colourful
- Double-sided
- Pads of 25
- Space for notes
- Flap to obscure half the scale
- Smiley face scale
- Explanations for QPR items



Overcoming challenges with measures themselves

- Take more time to explain QPR items if needed
- Ask items in different order if needed
 - People may prefer *not* to start with rating – Satisfaction with mental health (DIALOG) or ‘I feel better about myself’ (QPR)



Manual for download*

EYE-2 Manual – Supporting routine EIP data collection

The EYE-2 Project Supporting the Collection of Routine Outcome Data in Early Intervention in Psychosis Services Manual



Dr Rebecca Webb, Vicci Smallman, Danielle Wilson, Professor Kathy Greenwood, and the EYE-2 team

4. Implementing the measures



Setting team targets



- Start with achievable target in timeframe.
- Target increase of around 20-30% of the caseload over a 12 week period is realistic.

Other helpful implementation strategies



Print outs

- A poster for office
- A poster for meeting/waiting rooms
- Goal setting sheet
- Service user feedback forms

Standard Outcome Measures in EIP Services

The Access & Waiting time standards for EIP services state the HONOS, QPR and DIALOG should be collected at least every 6 months.



Don't forget to take the QPR and DIALOG with you!

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Examples of printouts



Your EIP service aims to collect questionnaire data about your experiences of the services and how you feel about your own mental health.

These questionnaires are the Process of Recovery Questionnaire (QPR) and the DIALOG (your experience of the service).

The service aims to completed these with you **approximately** every 6 months.

Routine EIP outcome measures

The questionnaires can really help you to find out more about yourself. They can also help your lead practitioner of care-coordinator to understand you better.

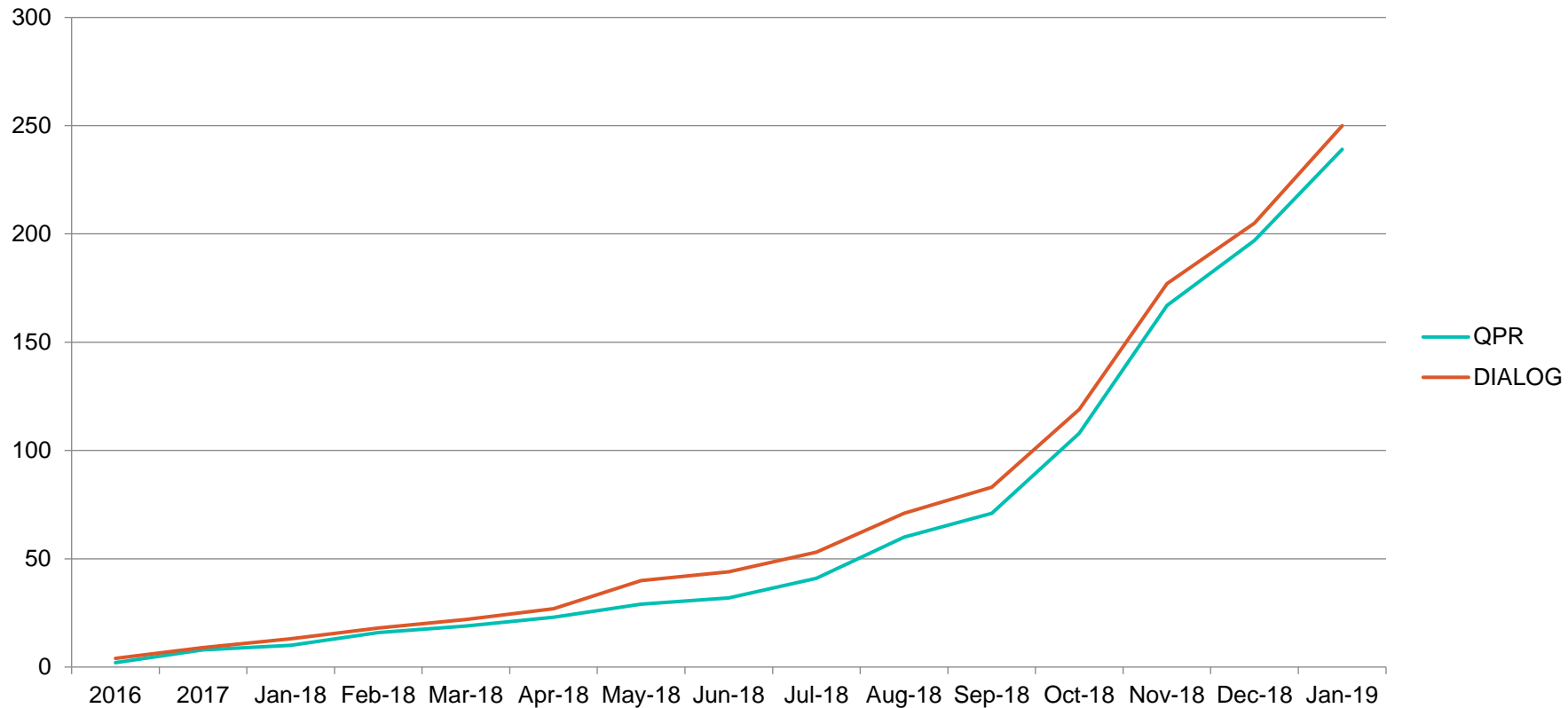
Ask your therapist or care coordinator about the QPR and DIALOG today!



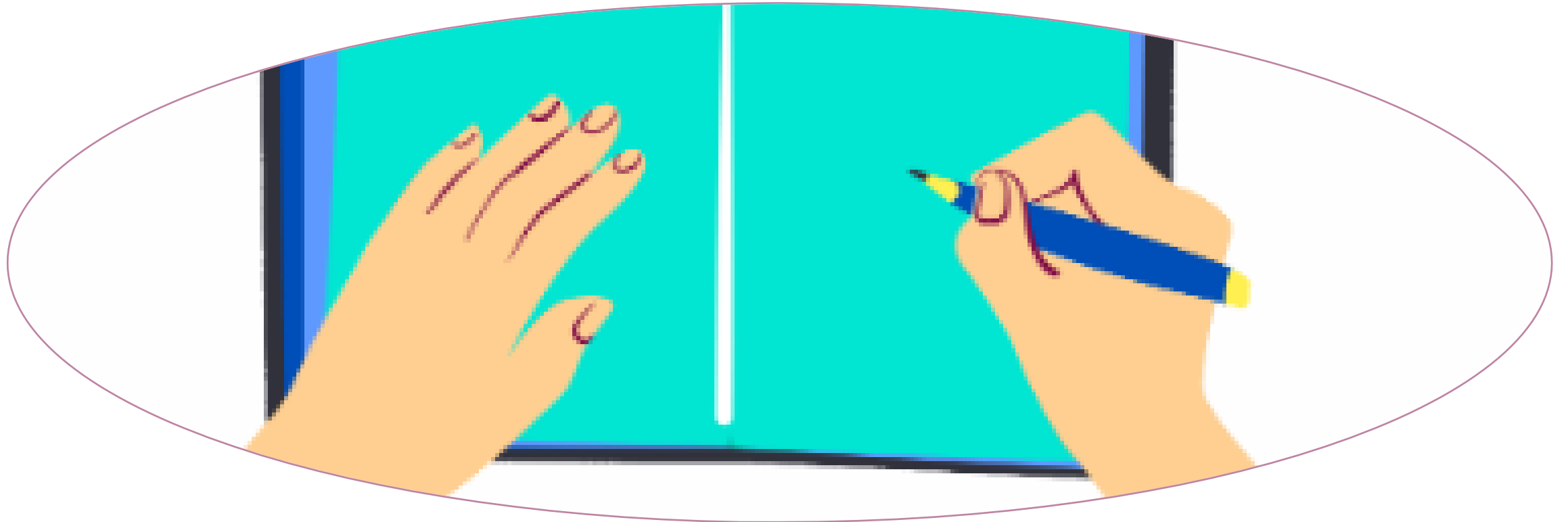
DIALOG and QPR Goal setting form

QPR/DIALOG Item	Goal
QPR/DIALOG Item	Goal
QPR/DIALOG Item	Goal
QPR/DIALOG Item	Goal

Outcomes in Sussex



5. Scoring



QPR- Scoring

- For each question rate the response as follows :

Disagree strongly	= 0 point
Disagree	= 1 points
Neither agree nor disagree	= 2 points
Agree	= 3 point
Agree strongly	= 4 points

- Add the scores for all questions together to form:

QPR Total score

The lowest possible score is 0, the highest possible score is 60



QPR- Scoring

Higher scores indicate greater recovery

- Mean score for a sample of 399 people with psychosis (average age 44) = **38.7** *
- QPR total good internal consistency (.89), reliability (.74), convergent validity (.73) sensitivity to change (.40).
- We are now looking at scores in a sample of FEP and will be able to report this shortly.



* Williams et al. 2009

DIALOG Scoring

- Each item is scored
- Totally dissatisfied = 1 point
- Very dissatisfied = 2 points
- Fairly dissatisfied = 3 points
- In the middle = 4 points
- Fairly Satisfied = 5 points
- Very satisfied = 6 points
- Totally satisfied = 7 points



DIALOG Scoring

- Scores on the DIALOG can be clustered into 2 mean scores:
 1. Quality of life: Items 1-8. You can find out a service user's score by averaging these 8 items
 - total score \div 8 = **Subjective quality of life score**
 2. Satisfaction with treatment. Items 9-11. You can find out a service user's score by averaging these 3 items
 - total score \div 3 = **Treatment satisfaction score**
 - Lowest score = 1, Highest score = 7



DIALOG Scoring

- **Higher score average score indicates greater satisfaction**
- Scores below 4 reflect dissatisfaction
- Scores above 4 reflect satisfaction.
- Scores of 4 are neutral
- Mean score for 271 people with schizophrenia spectrum (average age 43)*
 - Subjective QOL = **4.8**
 - Treatment satisfaction = **5.5**
- Good internal consistency (.71/.57), convergent validity (.94/.33) and sensitivity to change
- We are now looking at scores in a sample of FEP and will be able to report this shortly.



HONOS Scoring



- Each item on the HONOS is rated on a five-point scale:
- 0 = no problem
- 1 = minor problem requiring no action
- 2 = mild problems but definitely present
- 3 = problem of moderate severity
- 4 = severe to very severe problem

HONOS Scoring

- **HoNOS Total Score = sum of scores on all 12 items**
- **Higher score = greater problem**
- Minimum total score is 0, Maximum is 48.

- **HoNOS subscales scores can be clustered into 4 groups:**
- **Higher score = greater problem**
- Behavioural problems (Items 1-3; Max score of 12)
- Functional Impairment (Items 4-5; Max score of 8)
- Symptoms (Items 6-8; Max score of 12)
- Social problems (Items 9 – 12; Max score of 16)

- HoNOS good internal consistency (.59-76), fair-moderate reliability and sensitivity to change*

*Jacobs 2009



Preliminary HoNOS outcomes for EIP

Baseline EIP EYE-2 Data – mean age 25.4 n = 740

HoNOS total =	13.2	(25 th -75 th % 9-17)	Max = 48
• Behaviour	2.6	(25 th -75 th % 1-4)	Max = 12
• Function	1.1	(25 th -75 th % 0-2)	Max = 8
• Symptoms	5.5	(25 th -75 th % 4-7)	Max = 12
• Halluc/del	2.3	(25 th -75 th % 2-3)	Max = 4
• Social	4.1	(25 th -75 th % 2-6)	Max = 16



Preliminary comparison of outcomes for EIP

Published Data – mean age 44-43

QPR (n=399)

mean = 38.7

DIALOG (n=271)

Subjective QOL = 4.8

DIALOG treatment satisfaction = 5.5

Baseline EIP EYE-2 Data – mean age 25.4

QPR (n=419 – 56% of whole sample)

mean = 38.5 (25th-75th% 30-46)

DIALOG (n=420 – 56% of whole sample)

Subjective QOL = 4.6 (25th-75th % 3.8-5.4)

Treatment satisfaction = 5.2 (25th-75th % 4.3-6)



EYE-2 PROJECT

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