

Information and Psychosis Participant Summary

Why we did it

The Imperial College Health Partners project has developed a psychosis pathway and is working locally to improve outcomes for people with psychosis. One aspect of this project is to look at information provision. Imperial College Health Partners therefore commissioned the McPin Foundation to conduct a qualitative project to gather views from a diverse range of carers and service users about their experiences of information gathering and opinions on useful information provision for psychosis.



Specifically, we wanted to explore:

1. Where people who are experiencing psychosis or their family/carers have tried to access information
2. If they haven't found it, where they would like to access it
3. The type of information they are looking for
4. Whether, or not, they are able to find the type of information they were looking for

What we did

We conducted interviews and focus groups with service users and carers to find out about their experiences of trying to find information about psychosis. After we had collected this data and identified some common themes, we then presented these to people who had taken part in the project at one of two workshops, and participants were able to feedback and help us to identify future actions.

4 focus groups

- 19 service users
- 7 carers

17 interviews

- 8 service users
- 9 carers

2 workshops

- 8 service users
- 9 carers

What we found

During interviews, we asked service users and carers to think of three words which summarised their experience of trying to find information about psychosis. Below is a word cloud which depicts what was reported; those words that are largest are the words that were most frequently cited by participants. These were; difficult, confusing, frustrating and frightening.



What we found

Below are two separate information pathways. The first of these, is the journey to information that people described to us during data collection. The second is the journey to information that people *recommended* or felt would be better than what they had experienced, which was generally negative.

People's experiences of trying to access information

1. Before becoming unwell

- On the whole, people had no understanding of psychosis.

2. First experiences of psychosis

- People did not realise that they / their friend or family member was developing a mental illness.

3. First contact for information

- People approached their GP, but mainly with physical health complaints – some GP's did not recognise their mental illness, others were able to signpost them to specialist services.
- People also contacted the police, religious figures, universities and helplines. Experiences were mixed.

4. Engagement with mental health services

- People didn't receive sufficient information about what the diagnosis meant, and the support or medication that they/their friend or family member were receiving, or about alternative options.

Recommended information pathway

1. Before becoming unwell

- WHAT: Outline of early signs of psychosis
- WHERE: In the media (e.g. television and adverts)

2. First experiences of psychosis

3. First contact with services (GP)

- WHAT: Signposting, information delivered face to face about what psychosis is and leaflets for carers
- WHERE: GP surgery, from their GP or another mental health specialist

4. First contact with mental health services

- WHAT: Information delivered face to face about psychosis, written information about medication
- WHERE: From a CPN / care co-ordinator / keyworker / leaflets on wards

5. When living with psychosis

- WHAT: Information from a lived experience perspective, impact on carers and what they should do to support friend / family member, information about impact on daily life
- WHERE: Carers or service user drop-in or support groups, online (Trust recommended websites)

Overall, the information that service users and carers wanted was quite similar:

Service users	Carers
Symptoms of psychosis	Early symptoms of psychosis
Who to contact for further help plus contact details to give to carers	Who to contact for further help
A detailed explanation of psychosis	A detailed explanation of psychosis
Other service users experiences	Other carers experiences
Living with psychosis – how to get a job, basic rights (benefits), how to get a house	Living with psychosis – how to interact, how to manage violence and aggressions, impact on family
Medication (including side effects and alternatives)	Causes of psychosis

What next?

A report has been submitted to Imperial College Health Partners for use in their psychosis pathway work. We expect you will hear more from the North West London locality about next steps for psychosis services, including improvements in information provision. The McPin Foundation would like to thank everyone for supporting this work, with tight timescales. We enjoyed meeting you all and will incorporate what we have learnt into other work we are involved with. This includes research on collaborative care for psychosis and a life stories project in South London that will explore people's journey living with psychosis and the role of services within that.



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