



My Story, Our Future

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The McPin Foundation

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My Story, Our future - Outline



- **My story, Our future - Talk outline:**
 - **Study background**
 - **Methods – a life stories approach**
 - **Key messages**

What did we do?



- **Project commissioned by:**
 - Office of London CCGs
 - Lambeth, Southwark and Lewisham CCGs
 - Certitude

What did we do?



- **Back ground – project inspired by an oral histories approach**

Oral histories enable people and communities whose voices might not otherwise be heard and who are often marginalised or invisible within mainstream history to narrate their experiences in their own words, providing first-hand accounts of the past that can enhance, or even challenge, dominant historical accounts (Frisch, 1990)

Why did we do this project?



- **My story, Our future – Aims**
 - **Understand in detail the life-stories of people in London who are using (EIP) services - to explore and understand their experiences of living with psychosis**
 - **To explore the experiences of people who are carers to people in this group**
 - **To ‘give voice’ to people in both groups**

How did we do this?

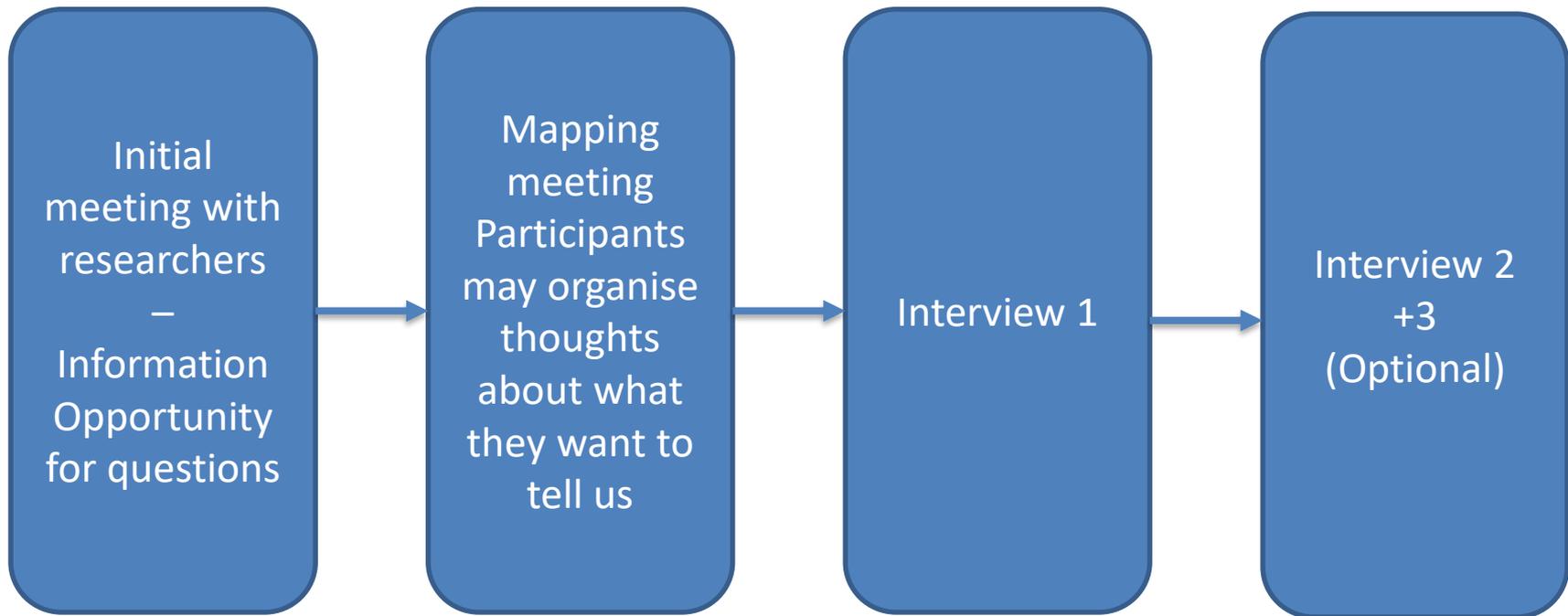


- **Methodology**

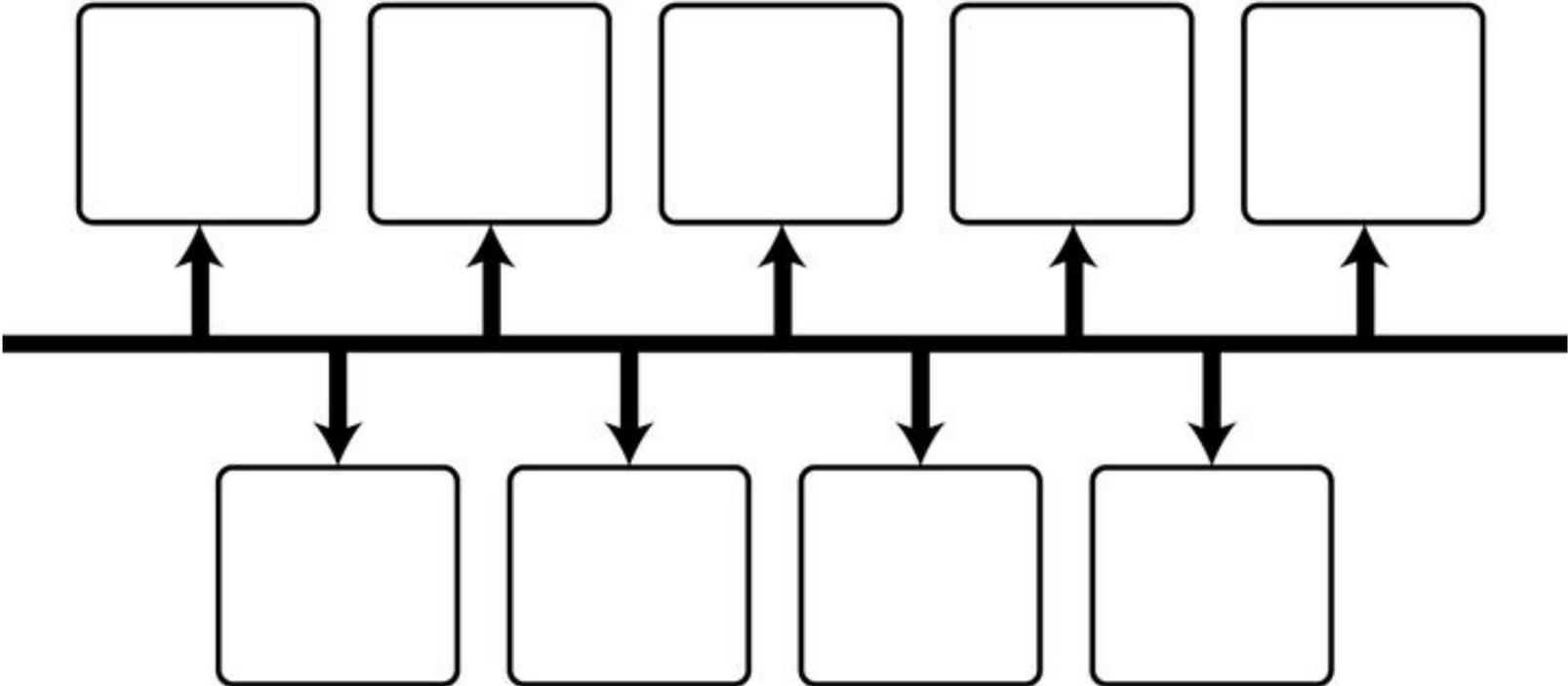
- Peer research approach
 - Three researchers who all had lived experience of psychosis
 - Were involved in all stages of the project
- In depth qualitative approach

How did we do this?

- Multi-stage flexible approach



Mapping tools



Mapping tools



Mapping tools



Analysis



- **Creative analysis process**
 - Inclusive of researchers with lived experience
 - Less formal training in 'academic' analysis
 - Helpful in making sense of a very rich, very diverse set of data
- **Narrative analysis**

Analysis



Analysis



Participants



- **Interviews complete with 9 people who use EIP services**
- **Interviews complete with 5 people who care for people who use EIP services**
- **Diverse sample with respect to gender, age, ethnicity and socioeconomic experiences**

Understanding the value of their own stories: 'The before'



There is always, "What were you like before?" people make reference to. You might have £1m, you might have nothing but people will talk about you before, whether you're homeless or you make it. ***Before is really important.*** In that before time, the teenage years or the young adulthood years, a lot of people take a step the wrong way and it's because of where they're from or just what they have done. So when I said the estate or the environment, it's not the best place and they have to work twice as hard to make sure it doesn't have an effect on their life in a negative way.

Key findings



- **Storytellers spoke to us about challenges they faced:**
 - **Insecure housing or homelessness**
 - **Stress in school or at work**
 - **Accessing services**
 - **Challenging home environment**

Key findings: Insecure housing or homelessness



“[...] I was going to simple places, like the shop and I’m waiting in the shop and I come back and somebody’s broken in and taken this and taken that. It started with small things. I got myself a [computer games console] after that and finding out that that’s gone and all the games and that’s the first time. The first, second time, third, fourth, fifth, sixth, seventh. It just got to a point where, third time, I said, “It’s someone who lives here.” [...] So, it got to a point where this was happening and I didn’t even care about what was taken but I did at the time because it was sentimental stuff that got taken. [...] So, yes, like all these things added up to a case for me to go to the housing association and be like, “Look, I’m not safe there. Your facilities are not making it helpful for me to deal with things like that.””

Key findings: Stress in school or at work



“In primary school, my teachers knew that I was a young carer, so they looked out for me. In secondary school, my teachers knew that I was smart, so they pushed me. In sixth form, they didn’t give a shit—sorry for the language, but they really didn’t.”

“So, I was studying the equivalent to five A-levels, because that was a BTEC, so it was two A-levels, and I was doing science as well. However, because I didn’t enjoy it, that was even more demotivating, in sixth form, as well, and my teachers weren’t really helpful—They thought ‘you know, this girl got twelve/eleven A-C grades; she is capable of doing A-levels, we don’t need to help her, let her do the work’.”

Key findings: Accessing services



“About six months ago I told my mum [...] She persuaded me to go and see the GP. [...] They seemed very standoffish. You've got your 10 minutes with the GP. I really don't get much out of them anyway. They said that they were going to refer me on to another group somewhere and I went to them. All the time I'm rehashing my story, I'm retelling the same thing and it's stressful. To step out there and communicate and tell the world in the first place is a difficult thing and to be faced with a reaction or feeling that you are not being understood or that what you're saying is a little bit whacky, you're worried about, "How is this going to be perceived? Am I going to be telling some professional, it's going to go down on my notes and before I know it, I'm incarcerated in some hospital because I'm saying something that sounds just really weird and wonderful?" So you're gauging to yourself, "How much do I say? What do I say? Who can I trust?" that kind of thing.”

Gary

Key findings: Challenging home environment



I felt like I was okay as a person. My character was okay. I was a humble person. I didn't make trouble or stuff like that. I felt trapped, I didn't want to be there. I wanted to be in the suburb somewhere. I would prefer that my mum moved away. I would prefer to be somewhere else. Then after some time, yes, it did have an influence on me but I didn't get in trouble so I can't say it took over and it made me a different person but it does change you. The neighbourhood does change you. You see things that change you. You see things that get to you. There's a lot of what you see you don't talk about here. There's a lot of, "No, you can't do that, it won't work out for you."

Key findings



- **Storytellers also spoke to us about things that helped them:**
 - Friendship
 - Creativity
 - Faith
 - Nature

Key findings: Friendship



I: You said you are a good friend and I was just wondering what makes you a good friend?

R: I guess I am always there to listen to other people's problems in a way. I don't really judge anyone because you don't know what they are going through so that's why I feel like I am a good friend. I am not being egotistical about it. I am just saying that I wouldn't hate someone just because they are different from me I guess because they are still the same person really. Nothing really changes.

Key findings: Creativity

I think when we first met you, you also talked a little bit about learning to play the drums on the computer.

R: Which I'm taking very seriously. I've ordered a drum machine. I have one already but it's not very good. It was a few hundred pounds. This one is supposed to be £1,000 but I'm getting it for less off of someone who has probably finished learning with it. I want to buy a different instrument. So I'll be getting it for half price. It should be coming from the States. Really what that is about is giving me something to do at home because I have a lot of time. I'm a bit of a loner sometimes so I want to learn a skill. I want to make it a hobby also. Music is great for someone that sits in their room all the time, like myself, and wants to learn more about music than they have before at school. Music at school and music outside of school is different. I want to probably pursue music if I'm good at it but I don't know whether I am so it's just a hobby for now.

Key findings: Faith

Then I went with her to a local church, which I've been going to ever since and that was quite a big thing for me at the time, being out and being among people, I was quite anxious about that when I started, less so now, but when I started going and I didn't really know anybody, other than who I was going with. So, I managed it and because I was in bed, sort of forgot the time I was going out and I found it useful reading the Bible and gradually I became, partly through reading the Bible and what they'd said to me, I became hopeful that I did have in effect have a future.

Key findings: Nature

So I think sort of part of it was growing up in the countryside and now sort of since having depression, it's nice going... I like going out for walks in the park or such things, which is good for my mental health. And I've become more interested in the trees and also my spirituality, I sort of see it in different, slightly different way now.



Thank you for listening

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