

the **Viewpoint survey**

Institute of
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Transforming mental
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Qualitative findings from the Viewpoint study

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Study team



Viewpoint study team at IOPPN and the McPin Foundation:

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Dr Sarah Evan-Lacko

Dr Sarah Hamilton

Dr Claire Henderson

Dr Vanessa Pinfold

Professor Diana Rose

Professor Graham Thornicroft

17 interviewers – most peer researchers

And in particular, the qualitative team:

Katherine Barrett

Lisa Couperthwaite

Jane Matthews

Solveig Warren

Learning objectives



1. To explore stigma construct as a single phenomena, using in-depth interviews from the Viewpoint Survey.
2. To provide a model for understanding mental health discrimination as it is assessed by people who experience it, based on analysis of in-depth interview data by peer and academic researchers
3. To consider the role of peer researchers in stigma research studies.

Study aims



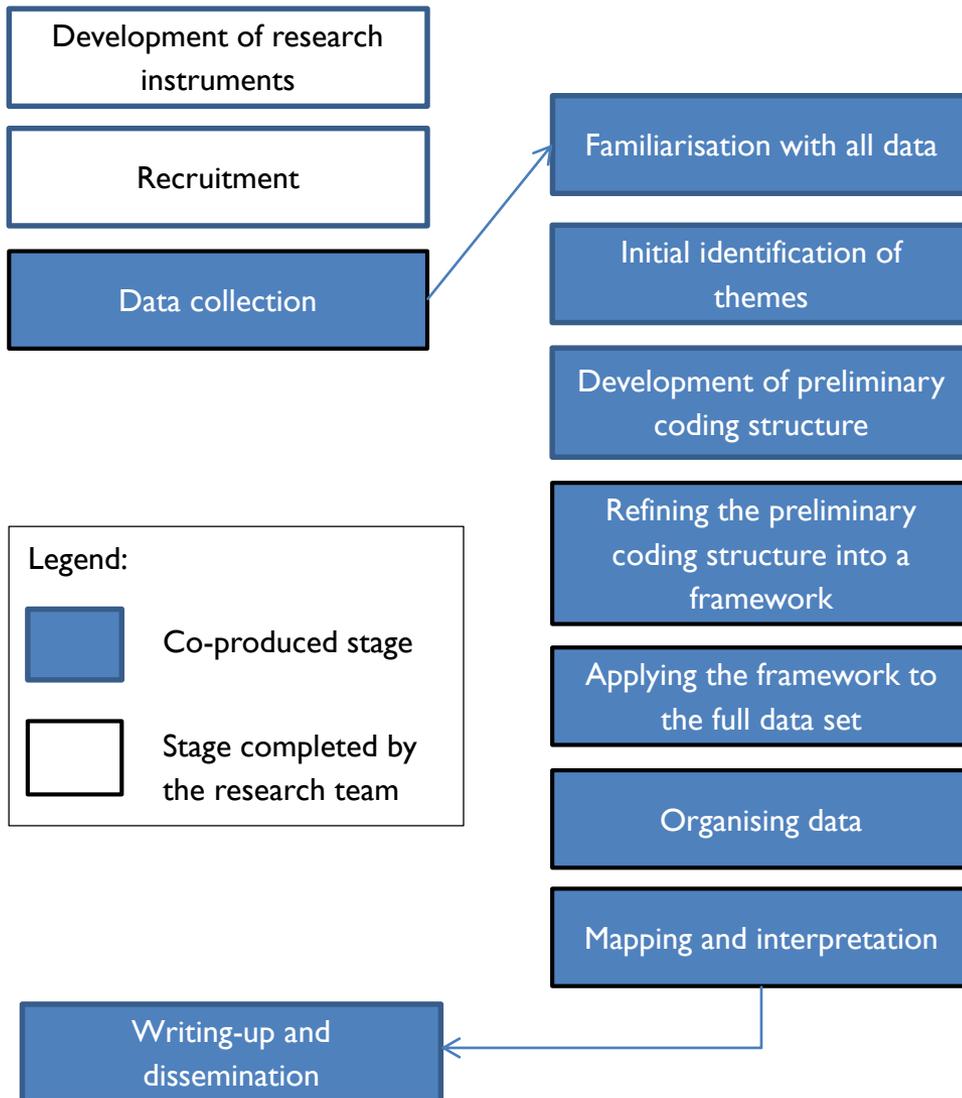
- 1. To understand what types of behaviour are being experienced as discrimination and recorded in the Viewpoint survey**
- 2. To draw out differences in the behaviour experienced in various settings and within various relationships**
- 3. To provide insights that might be used to target future anti-stigma campaigns or explain why some areas may be more resistant to change than others.**

Hamilton, S., Lewis-Holmes, E., Pinfold, V., Henderson, C., Rose, D., & Thornicroft, G. (2014). Discrimination against people with a mental health diagnosis: qualitative analysis of reported experiences. *Journal of Mental Health, 23*(2), 88-93.

Methods

- Three interviewers recorded all their interviews in the final two months of data collection – total 84 interviews
- Same interview (DISC-12) but probed for further detail on examples where discrimination had been reported
- Regular feedback from researcher on interviews
- Selected 50 for transcription and analysis - clarity of recording and number of examples
- Collaborative approach to thematic analysis across 4 peer researchers and 2 non-peer researchers

Co-production ...



- Involvement in conducting the interviews was crucial – additional insight into participant meaning; able to draw on hundreds of previous (non-recorded) interviews.
- Involved throughout the analysis, including refining the codes, and revisiting the data iteratively.
- Explicit discussion of how lived experience was used.

Analysis

- Collaborative analysis started throughout the interviews
- Interviews were transcribed and peer interviewers familiarised themselves with each others' interviews
- Through discussion, drew on codes developed in the previous paper and developed own codes – expanded and adapted
- Tested these codes with some of the data
- Revised the codes
- All researchers coded transcripts – put into NVivo
- Produced report summarising the data and codes
- Selected five most common codes from Nvivo
- Looked at each coded section as a story – pulled out the meaning; looked at similarities and differences

Coding framework

1. Mistreatment	1.1 Verbal stigma	
	1.2 Physical abuse	
	1.3 Tormenting	
	1.4 Taking advantage	
2. Social distance	2.1 Social distance by others	
	2.2 Social distance by self	
3. Judging	3.1 Judging competence	
	3.2 Judging character	
	3.3 Judging credibility	
	3.4 Over-protectiveness	3.4.1 <i>Exclusion from decisions</i> 3.4.2 <i>Intrusive questioning</i>
4. Organisational decisions	4.1 System-based	
	4.2 Individual-based	
5. Lack of understanding	5.1 Lack of understanding/empathy	
	5.2 Not being heard	
6. Lack of support	6.1 Lack of support	
7. Dismissiveness	7.1 Dismissive of MH	
	7.2 Silencing of MH	

Discrimination sources

Making and keeping friends	Religion
Neighbours	Social life
Dating	Police
Housing	Physical health
Education	Mental health
Marriage	Privacy
Family	Personal safety
Finding a job	Having children
Keeping a job	Being a parent
Public transport	Avoided or shunned
Benefits	Other

Findings 1: friends

Behaviour

- a) Friends 'shy away' or 'turn their backs' – stop actively socialising
- b) Friends react badly to the mental health condition itself – refuse to talk about it, assume they are over-reacting, not being there when needed
- c) Friends continue to be there but behave differently – more distant, no longer trusting them

Expectations

- a) Friends should be a source of support around the mental health problems
- b) Friendships should be unaffected by the mental health diagnosis

Rationale

- a) Lack of understanding of mental health or appropriate reactions
- b) Friends struggle to 'cope' with them – assumption that friendship is more difficult with someone with a mental health diagnosis

Impact

- a) Isolation and loneliness – effect on wellbeing
- b) Loss of an important source of mental health support
- c) Additional distress exacerbating mental health difficulties

Findings 2: mental health professionals



Behaviour

- a) Inaccessibility of appropriate mental health care
- b) Lack of support, particularly inpatient
- c) Not being listened to or understood, including inappropriate remarks

Expectations

- a) Good understanding of mental health needs and appropriate support
- b) Prompt, efficient, specialist help when required
- c) Support delivered with dignity and respect

Rationale

- a) Lack of understanding of mental health or lack of caring
- b) People were often understanding around cuts in services and over-worked staff

Impact

- a) Detrimental impact on mental health through delays and added distress
- b) Additional distress exacerbating mental health difficulties
- c) Drop out from treatment

Findings 3: benefits

Behaviour

- a) Systems too rigid to accommodate individual needs
- b) Detrimental decisions (e.g. loss of/reduction in benefits, encouraged to seek work)
- c) Poor practice – communication, loss of decisions overturned at tribunal

Expectations

- a) System should be applied flexibly based on individual mental health needs
- b) Individual staff members should demonstrate understanding of mental health
- c) Efficient, supportive service

Rationale

- a) Rigid system perceived as ill-suited to mental health
- b) Lack of understanding of mental health among benefits staff
- c) Perceived stigma of being a ‘benefits scrounger’ – scepticism around mental health needs – government cuts

Impact

- a) Several experienced stress as a result of appeals, tribunals, temporary or prolonged financial hardship - exacerbating mental health difficulties

Findings 4: finding a job

Behaviour

- a) Not being offered interviews or jobs (even voluntary)
- b) Being given only menial tasks – not trusted with skilled work
- c) Discrimination is rarely explicit, mostly inferred

Expectations

- a) People compared job application results with those prior to illness
- b) Expectation of reasonable adjustments and flexibility

Rationale

- a) Very difficult for people to assess – multiple discrimination (age, religion and sexuality also mentioned)

Impact

- a) Impact on confidence and self-worth

‘It’s made me question myself and my own abilities, my own abilities to understand or recognise when I wasn’t well, or that... it just takes all your confidence away completely and utterly.’

What does discrimination look like?

Behaviours:

Includes:

- Subtle, behavioural changes within complex relationships (friends)
- Poor standards of service (benefits, mental health)
- Being treated 'the same' instead of taking mental health into account (benefits, employment)
- Legal definitions (employment)

Expectations:

Includes:

- Providing practical and emotional support (friends, mental health)
- No change (friends, employment)
- Accommodating individual, mental health support needs (benefits, employment, mental health)

Rationale:

Includes:

- Lack of understanding (friends, benefits)
- Lack of resource (mental health)
- Stigmatising attitudes (benefits)

Impact:

Includes:

- Additional stress and distress (all)
- Loss of sources of support (friends, mental health)
- Loss of confidence and self-worth (employment)

Lessons from the qualitative approach

- Highlights limitations of *only* quantitatively captured data on discrimination experiences:
 - Unclear that the types of experience captured are ‘of a type’: variation in behaviours; variation in expectations; variation in impact.
 - Highlights the difficulty participants have in assessing discrimination experiences.
 - Problem of terminology – reluctance to use the term ‘unfair’ but *feels* like discrimination.

“It’s a difficult one that one because I think sometimes you get, you have your expectation of what you’re going to get and they don’t meet that expectation, so it feels like you’ve been treated unfairly.”

Lessons from the qualitative approach



- Caveat: there are limitations to qualitative data collected through a structured survey: time restrictions; specified categories; number of questions
- Allows more complex understanding of discrimination and its impacts
- Can inform more targeted approaches to reducing discrimination
- Collaborative approach – drawing on personal experiences

Lessons from coproduction approach



- Really very rewarding to work in this way – for everyone in the team
- Takes time to co-produce well and this has resource implications in projects
- That not everyone finds it easy to engage in this way – involves lots of compromises, sometimes on points individuals feel passionate about
- We have found co-producing knowledge outputs is particularly challenging – but we are working on this!
- **We recommend – try it!**



Thank you

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