

the **Viewpoint survey**

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Psychiatry  
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# Qualitative findings from the Viewpoint study

**Together Against Stigma conference,  
San Francisco, 18<sup>th</sup> February 2015**

Vanessa Pinfold

# Study team



## **Viewpoint study team at IOPPN and the McPin Foundation:**

Liz Corker

Jess Cotney

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



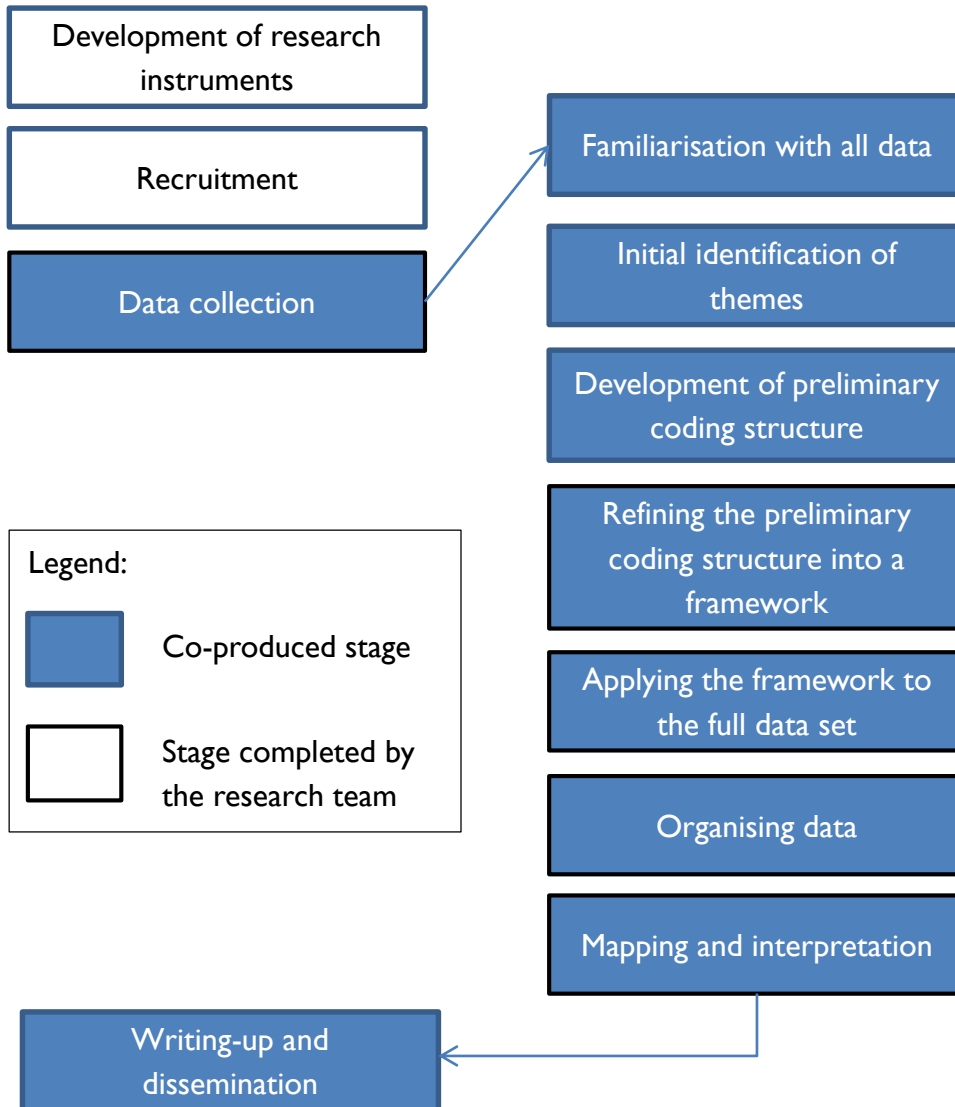
- 1. To understand what types of behaviour are being experienced as discrimination and recorded in the Viewpoint survey**
- 2. To draw out differences in the behaviour experienced in various settings and within various relationships**
- 3. To provide insights that might be used to target future anti-stigma 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

<b>1. Mistreatment</b>	1.1 Verbal stigma	
	1.2 Physical abuse	
	1.3 Tormenting	
	1.4 Taking advantage	
<b>2. Social distance</b>	2.1 Social distance by others	
	2.2 Social distance by self	
<b>3. Judging</b>	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>
<b>4. Organisational decisions</b>	4.1 System-based	
	4.2 Individual-based	
<b>5. Lack of understanding</b>	5.1 Lack of understanding/empathy	
	5.2 Not being heard	
<b>6. Lack of support</b>	6.1 Lack of support	
<b>7. Dismissiveness</b>	7.1 Dismissive of MH	
	7.2 Silencing of MH	



# Discrimination sources

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