1 IN 100

The experience of living with schizophrenia and psychosis in Scotland: Results of the Scottish Schizophrenia Survey

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Support in Mind Scotland

- Member led

- Influencing decision makers

- Delivering services
    - Local
    - National

Previous Reports

- Exploring Family Carer Involvement in Forensic Mental Health Services
- Caring is a Journey
- A Safe Place to Be
- Information and advice

Background to Survey

- English Schizophrenia Commission 2012
    - The Abandoned Illness

- People with severe mental illness such as schizophrenia still die 15-20 years earlier than other citizens.
- 87% of service users report experiences of stigma and discrimination.
- Families who are carers save the public purse £1.24 billion per year but are not receiving support, and are not treated as partners.

- Only 1 in 10 of those who could benefit get access to true CBT (Cognitive Behavioural Therapy) despite it being recommended by NICE (National Institute of Health and Clinical Excellence).

Psychosis and Inequality

- Childhood adversity associated with increased risk of experiencing psychosis (Varese et al., 2012)
- Income inequality associated with prevalence of psychotic experiences (Johnson, Wibbels, & Wilkinson, 2015)
- People diagnosed with a psychotic disorder die on average 15 – 20 years earlier than general population
- People with a diagnosis of schizophrenia are up to twice as likely to have two or more physical health co-morbidities (Smith et al., 2016)

Advisory Group

- Frances Simpson, CEO Support in Mind Scotland
- • Carolyn Little, Chair Support in Mind Scotland
- • Graham Morgan, Project Manager, Spirit Advocacy and HUG
- • Dr Paul Cavanagh, Consultant Psychiatrist, Royal College of Psychiatrists
- • Professor Stephen Lawrie, Network Director, Scottish Mental Health Research Network
- • Professor Andrew Gumley, Professor of Psychological Therapy (Mental Health & Wellbeing),University of Glasgow
- • Dr Tom White, Principal Medical Officer (Forensic Psychiatry), The Scottish Government

1 in 100 survey

- Survey was available on Support in Mind website
- Emailed to organisations such as carers organisations and local authorities for distribution
- Available through Facebook page
- Distributed by post and email to 219 current Support in Mind Scotland members and 175 lapsed members

Responses

- 138 responses
- 87 surveys were completed by someone who identified as a family member, carer, friend or supporter of someone who is living with schizophrenia and psychosis.
- 37 surveys were completed by someone who identified as a person with lived experience of schizophrenia and psychosis.
- 14 respondents did not answer this question.

How we looked at the responses

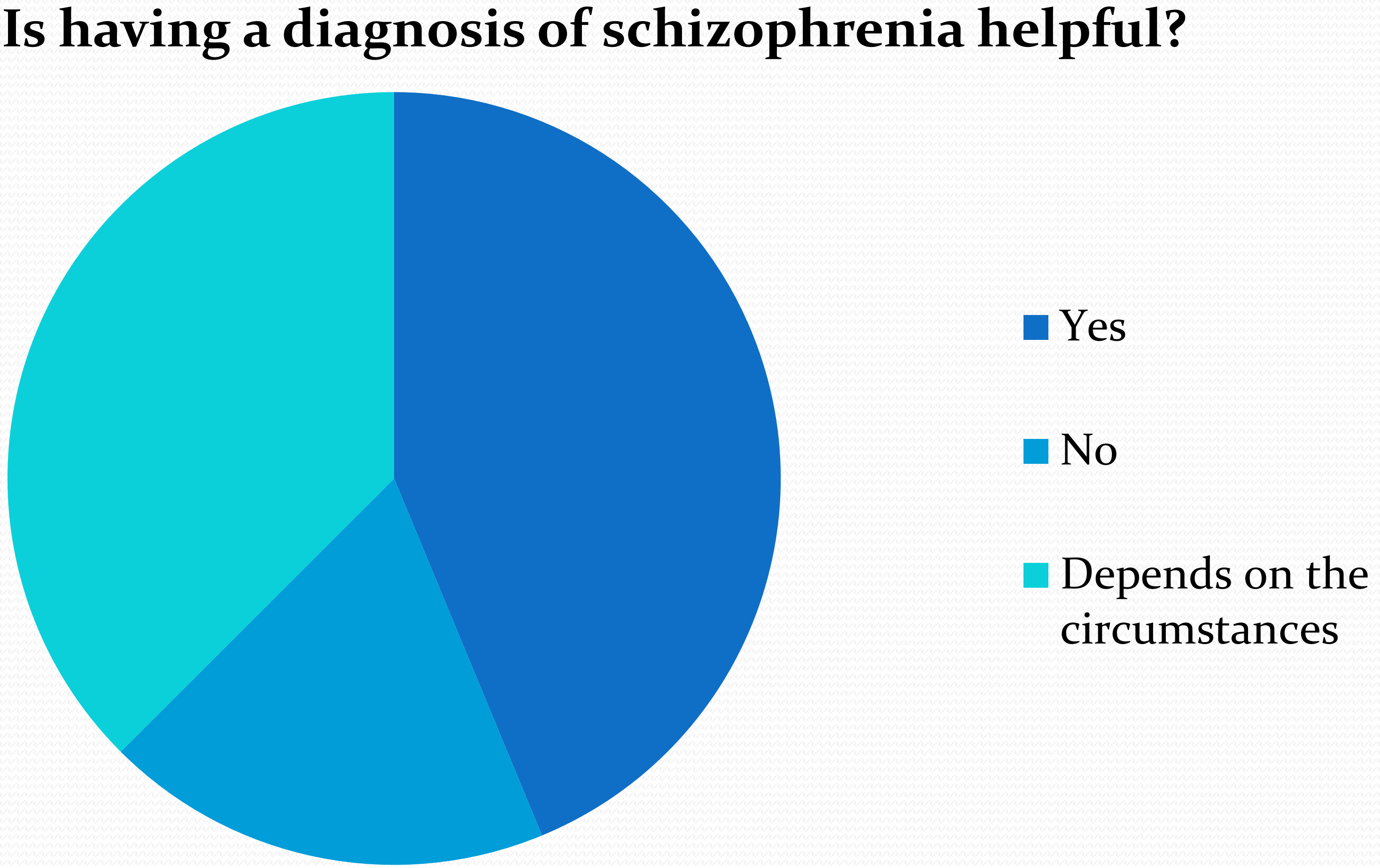
- Responses separated into two groups
    - Carers and supporters group
    - People with lived experience of schizophrenia and psychosis group

- Percentages of different responses calculated

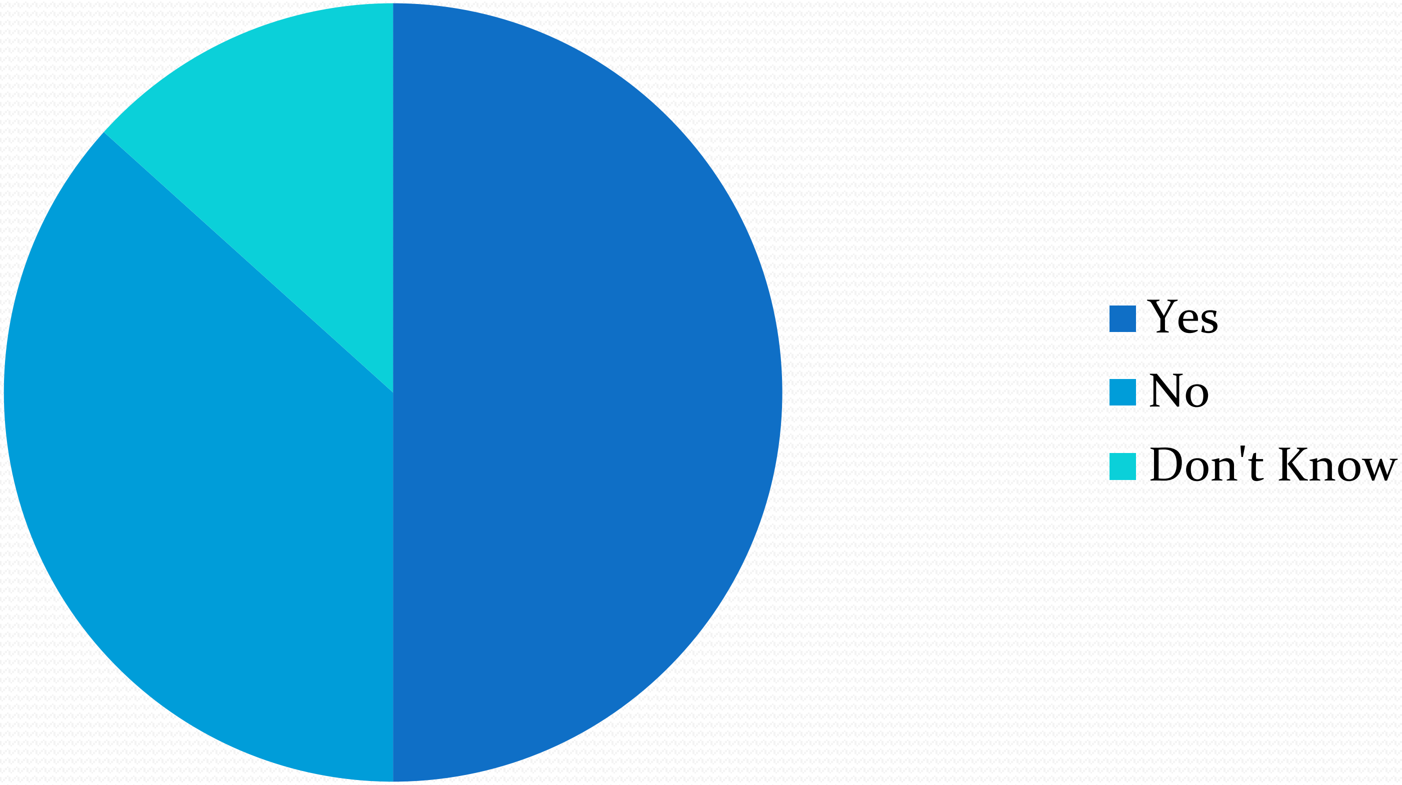
- Longer written answers from lived experience group
    - Looked for patterns of answers and experiences

Stigma

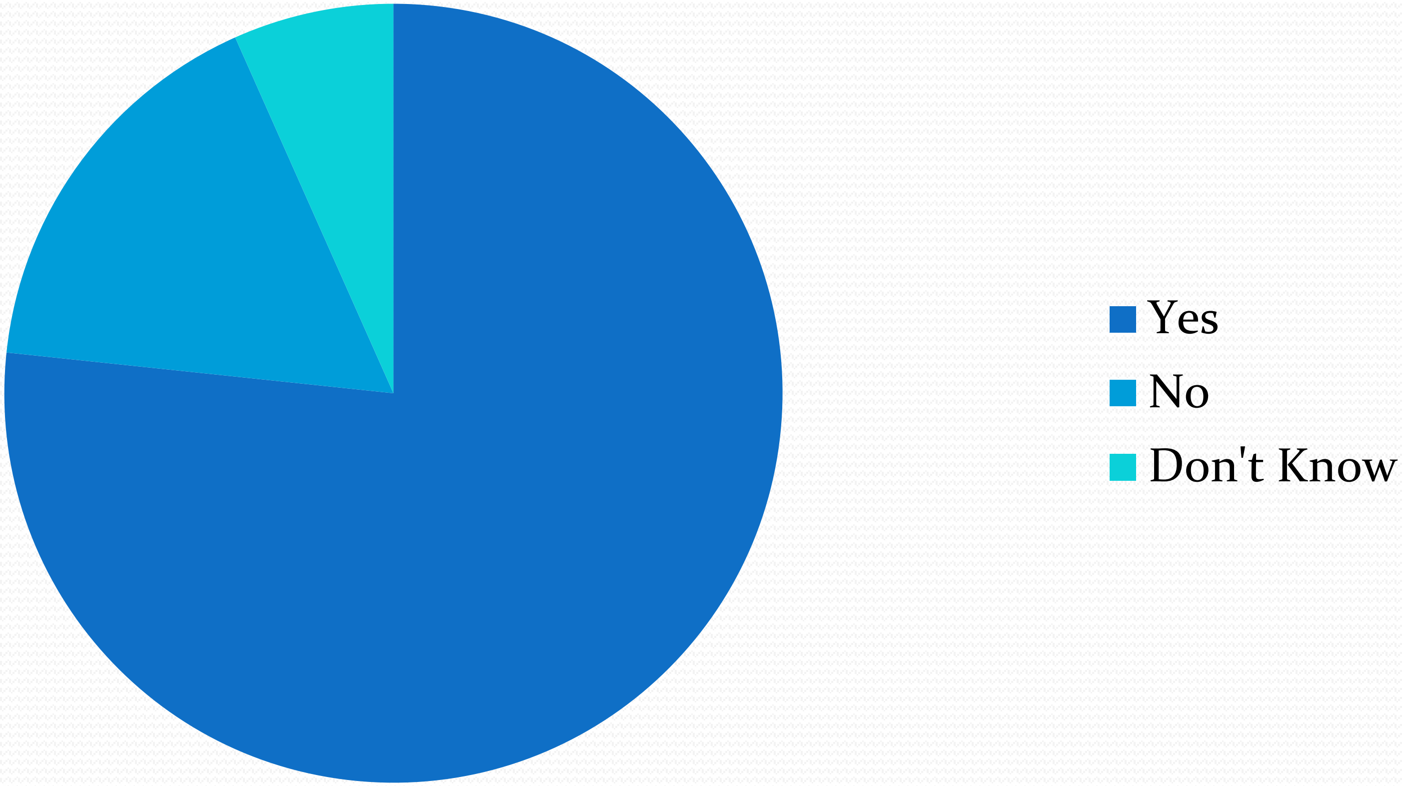
Lived Experience Group



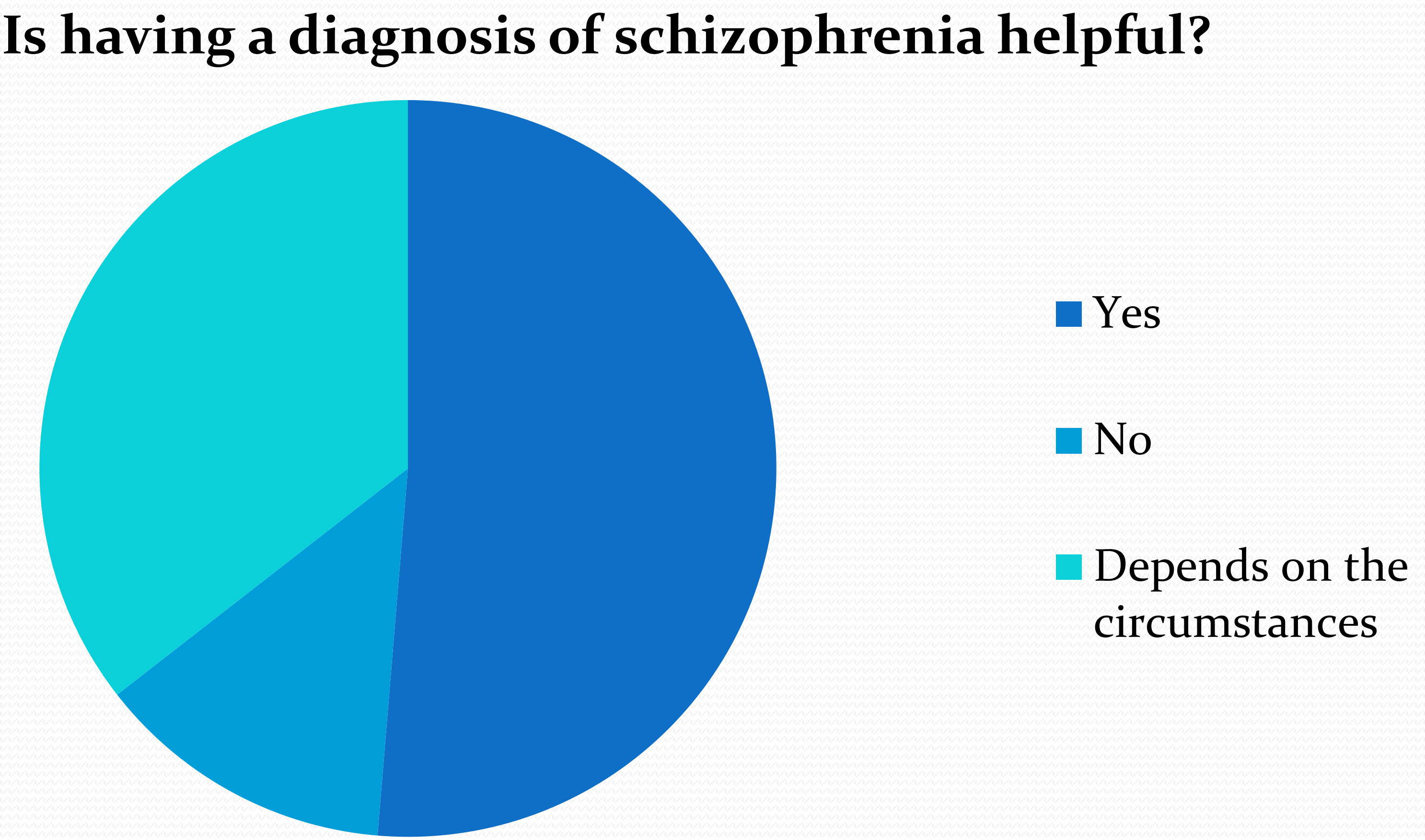
Do you think the word schizophrenia should be dropped and another term found for the symptoms that you experience?



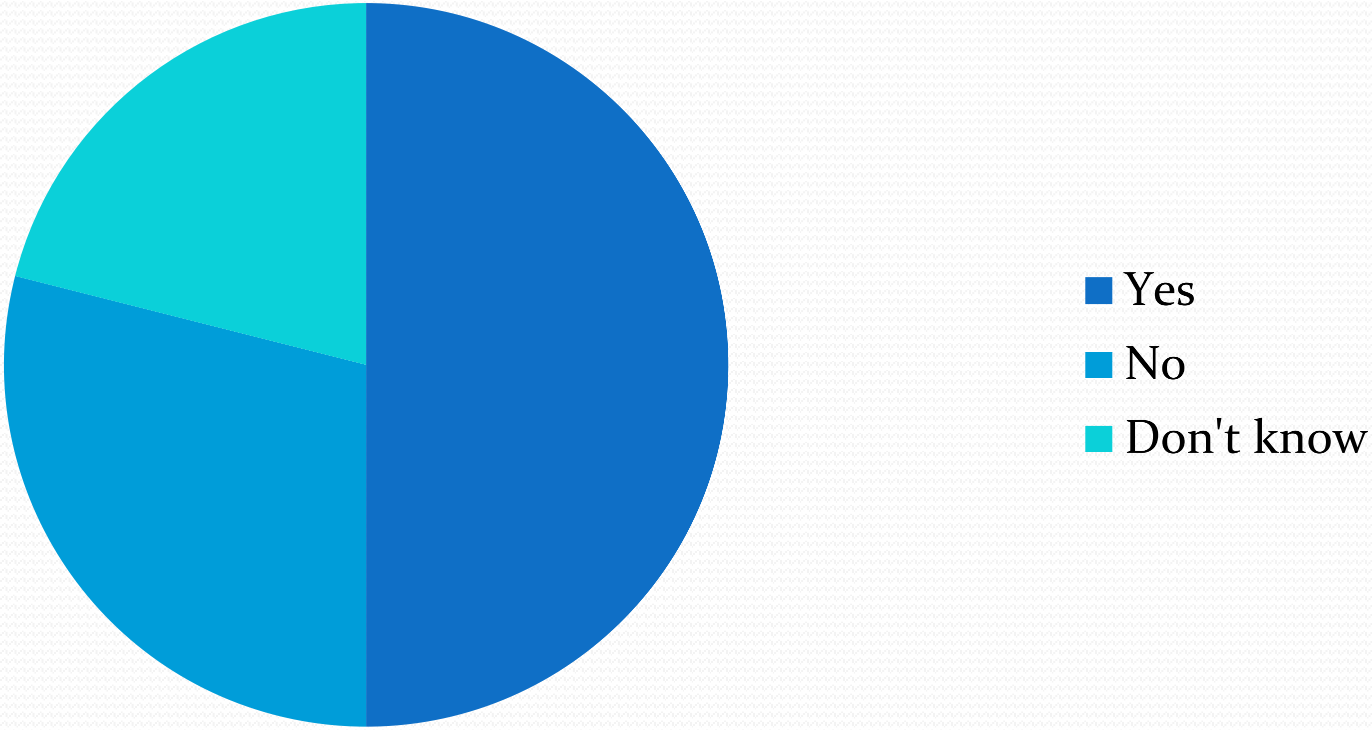
Have you experienced discrimination from any source - the public, people you have met, friends, family?



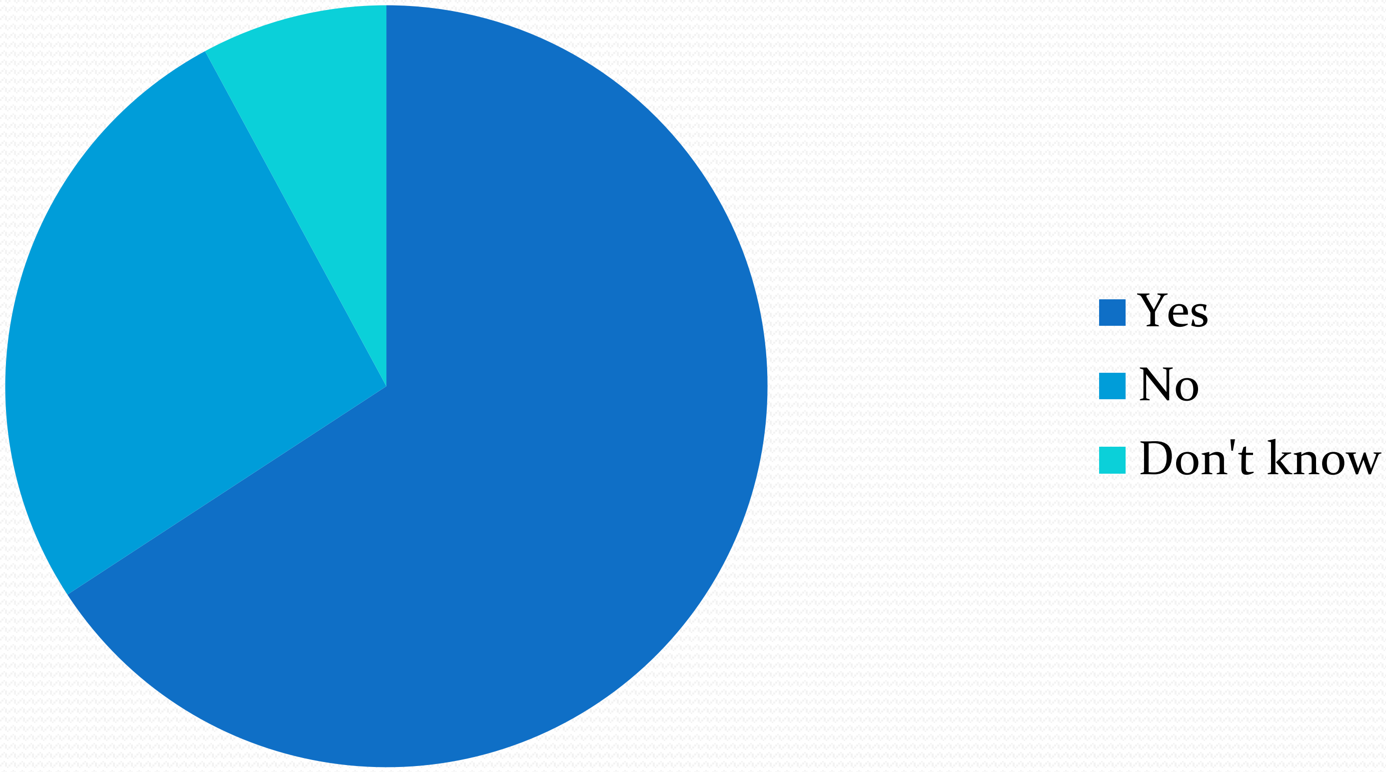
Carer and supporter group



Do you think that the word "schizophrenia" should be dropped and another term found for the symptoms that the person you support experiences?



Have you experienced stigma or discrimination from any source - the public, people you have met, friends, family?



Stigma Themes

- Identity
  - Finding information and others who understand
  - We're just people it's not the whole me

- Misunderstanding and Misinformation
  - Perceived dangerousness
  - Hiding, concealment and vigilance

Finding information and others who understand

- *“For years I had problems that I could not get to the bottom of, then when I was diagnosed it all became clear”*

- *“With a diagnosis I have access to information and support services and can understand my experiences”*

We’re just people, it’s not the whole me

- *“Some of “us” are able to work, raise a family and be actively involved in our community. Many people think the illness is due to some personality defect rather than the biological, psychological and social issues that can cause the medical condition.”*

- *“(Want) people to still see you for who you are and not the schizo person.”*

Perceived dangerousness

- *“When the press write about cancer they write with admiration or sympathy when they write about schizophrenia, we’re always chopping someone up with an axe.”*

- *“When I reveal my illness although some understand others still immediately have the impression of me as the serial axe murderer that is often portrayed in the media.”*

Hiding, concealment, and vigilance

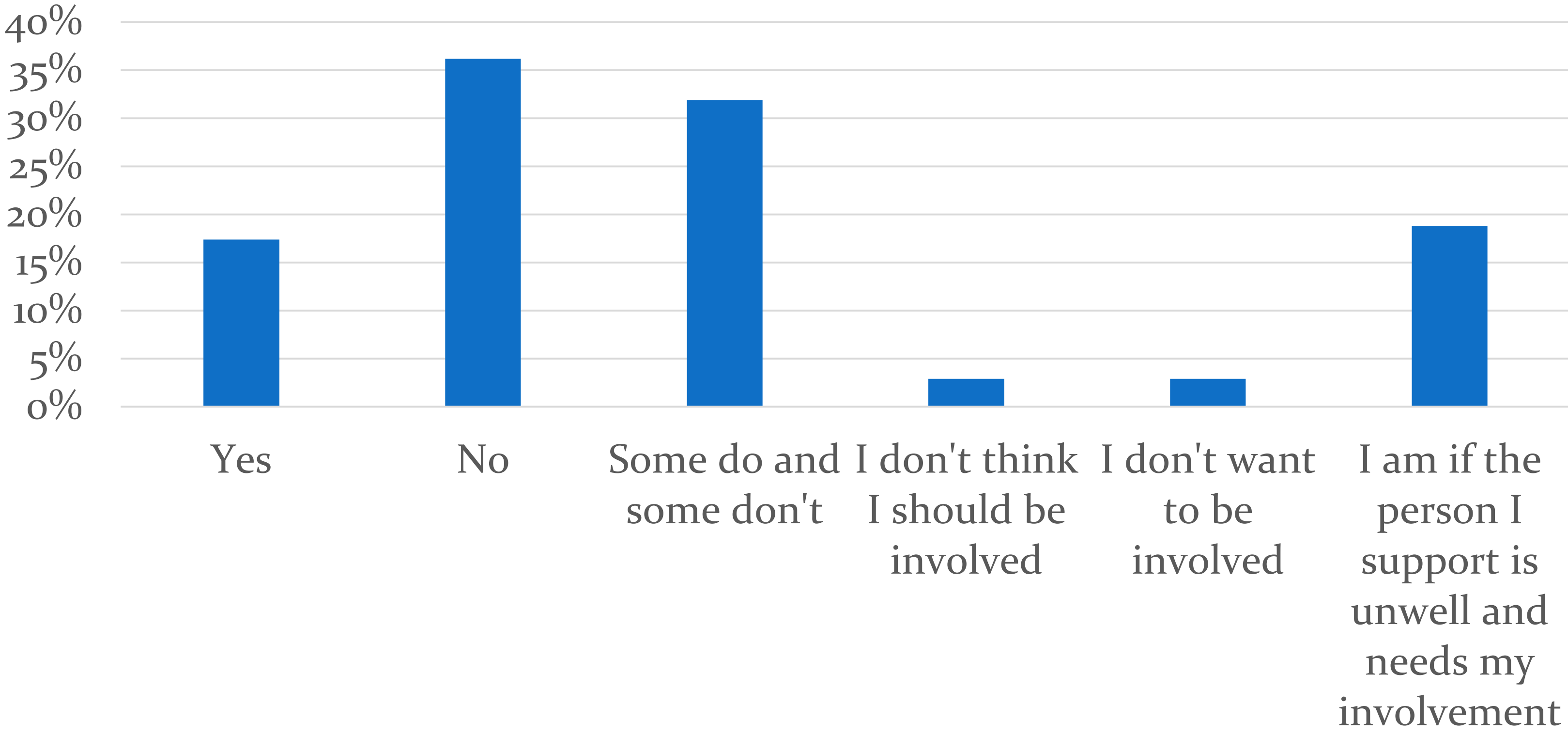
- *"I have to gauge people and calculate how they will react before telling them. Workplace reactions to mental health problems are bad enough without mentioning schizophrenia at times."*

- *"You hopefully learn to read faces but this can be difficult so I guise my feelings and tend to avoid talking."*

Care, Treatment and Services

Services	Carer / Supporter report Percentage (N)	Lived experience group Percentage (N)
Medication	90.6% (58)	96.2% (25)
CBT	9.4% (6)	23.1% (6)
Other talking therapies	9.4% (6)	26.9% (7)
Resource centre / day service	20.3% (13)	19.2% (5)
Help to access community facilities	14.1% (9)	7.7% (2)
Community Mental Health Teams / CPN	71.9% (46)	65.4% (17)
Advocacy	21.9% (14)	19.2% (5)
Employability or skills support	12.5% (8)	7.7% (2)
Art, music, walking or social support groups	20.3% (13)	26.9% (7)
Housing and / or benefits	56.3% (36)	61.5% (16)
Inpatient / hospital care	25% (16)	19.2% (5)
Other	10.9% (7)	23.1% (6)

Do you feel that professionals involve you enough in helping to make decisions with the person you support about their care and treatment?



Services accessed by carers	**%**	**N**
Generic carers support group for emotional support	29.2%	14
Specific mental health carers support group for emotion support	56.3%	27
Groups for arts, music, skills, interests	8.3%	4
Groups for social contact	18.8%	9
One to one support from statutory services	16.7%	8
One to one support from voluntary sector services	22.9%	11
CBT	8.3%	4
Other talking therapy	8.3%	4
Advocacy	10.4%	5
Information - helpline or use of info sheets/packs/websites	39.6%	19
Other	25.0%	12

Care, Treatment and Services Themes

- Whole life, not just one aspect
  - Distinctions between physical and mental health
  - Benefits and other life stresses

- Effort and Time

Distinctions between physical and mental health

- *“I am unable to access many day services. Mobility problems with my chair – not accessible – mental health / physical health.”*

- *“Because I now suffer – toxic meds on central nervous system, staff had no experience to support me. Physical challenges ignored by mental health staff – no knowledge lacking in empathy.”*

Benefits and other life stresses

- *“Having enough money to live on is a big priority because financial insecurity can really rock the ship.”*

- *“Sometimes I feel that a wider sense of being a person is obscured by a superficiality from case notes that are medical.”*

Effort and Time

- *"There isn't always time for professionals to get into the nub of what can affect my wellbeing. I just don't always have that insight myself."*

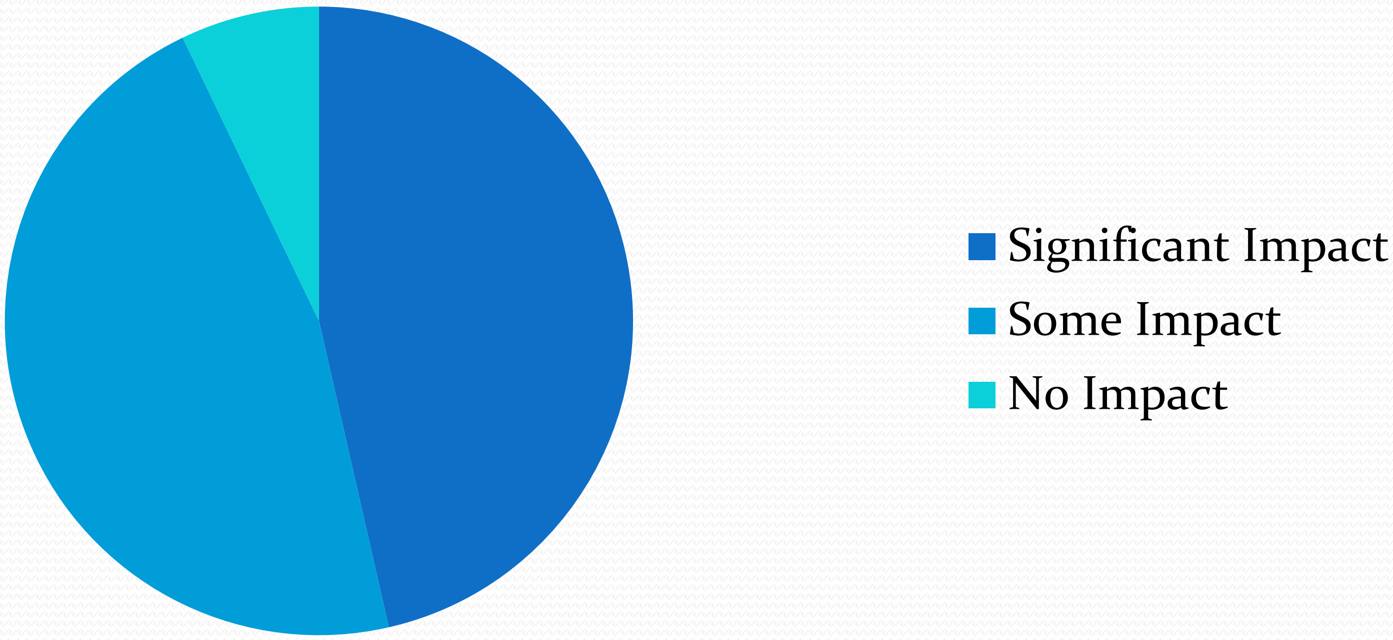
- *"Not having a chance to sometimes get down to the nitty gritty of my worries can be very frustrating. In the time available, it may not be possible. I can sidetrack. I also may have a bad or good day and I suppose that can influence others."*

- *“I can’t access employment because I’ve been off sick too long and have no references – it’s not through lack of trying.”*

Health and Wellbeing

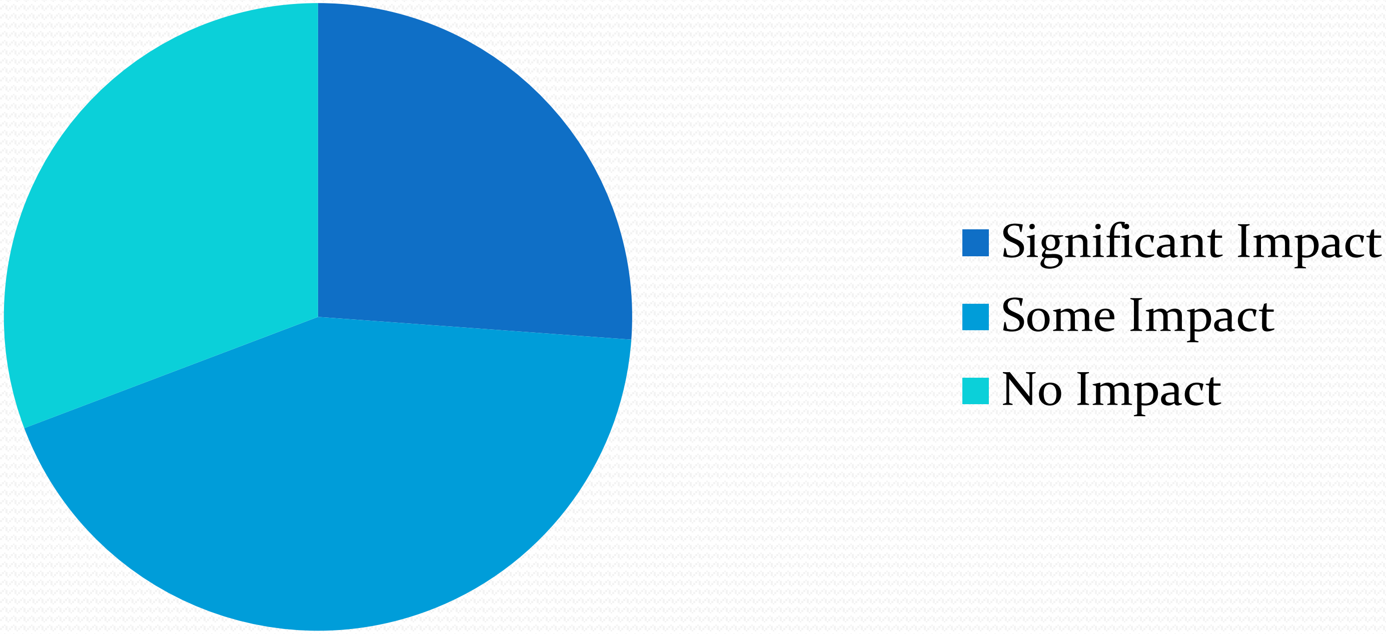
Lived experience Group

What impact has living with schizophrenia/psychosis had on your physical health?



Carer / Supporter Group

What impact has supporting someone living with schizophrenia/psychosis had on your own physical health?



Health and Wellbeing Themes

- Impact of medications

- Balance between physical and mental health
  - Prioritising one or the other
  - Continuum – one affects the other

Impact of medications

- *“I have many physical health problems. Many are due to the medication I take for my schizophrenia.”*

- *“The medication for schizophrenia (antipsychotics) helped to destroy my physical health with its side effects.”*

Prioritising mental health or physical health

- *“My mental health comes first. I have to keep on top of that.”*

- *“Being off medication would balance my appetite, but I won’t do that until I’m told.”*

Continuum – one affects the other

- *"When feeling apathetic I eat more so-called convenience/junk foods which are detrimental to my physical health. I do try to cook from scratch so I know what's in my food but regularly I falter – I put it down to my illness."*

- *"Taking part in sport and going to the gym makes a difference to my mental health."*

Quality of Life and Recovery

Quality of Life and Recovery Themes

- Others understanding and accepting

- Managing not curing
  - Self awareness, routine and structure
  - Ups and downs to be expected

Others understanding and accepting

- *“Friends certainly. There is an element of compartmentalisation. I do value what friends I have. Good friends – not many just a few.”*

- *“I am lucky my family have stuck by me all of the time and some other people.”*

Self awareness, routine and structure

- *"I think recovery is a journey – you will always be aware that you had an illness, and be aware of your triggers. I think mental illness can make you more compassionate and understanding towards others."*

- *"I work full time so I am always tired, but having a routine keeps me focussed."*

Ups and downs to be expected

- *“Recovery does not go in a straight line and there are downs as well as ups. For some people recovery is limited because their illness is a constantly disabling reality. I hate the crap about everybody supposedly having hope and the right to a positive experience of recovery. It’s just not feasible for some people and setting up this overwhelmingly positive view of recovery risks stigmatising those who cannot “measure up”.*

Implications of report

- Support for the findings of The Schizophrenia Commission in England
- Stigma and discrimination are still common experiences
    - See Me campaign
- Importance of integrated physical and mental health care

- Involvement of carers
- Recovery means different things for each individual
  - Importance of social support and relationships
- Importance of continuing to highlight the experience of people living with schizophrenia and psychosis
  - Government strategies
  - Media influence

- Thank you!
- Any questions?
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