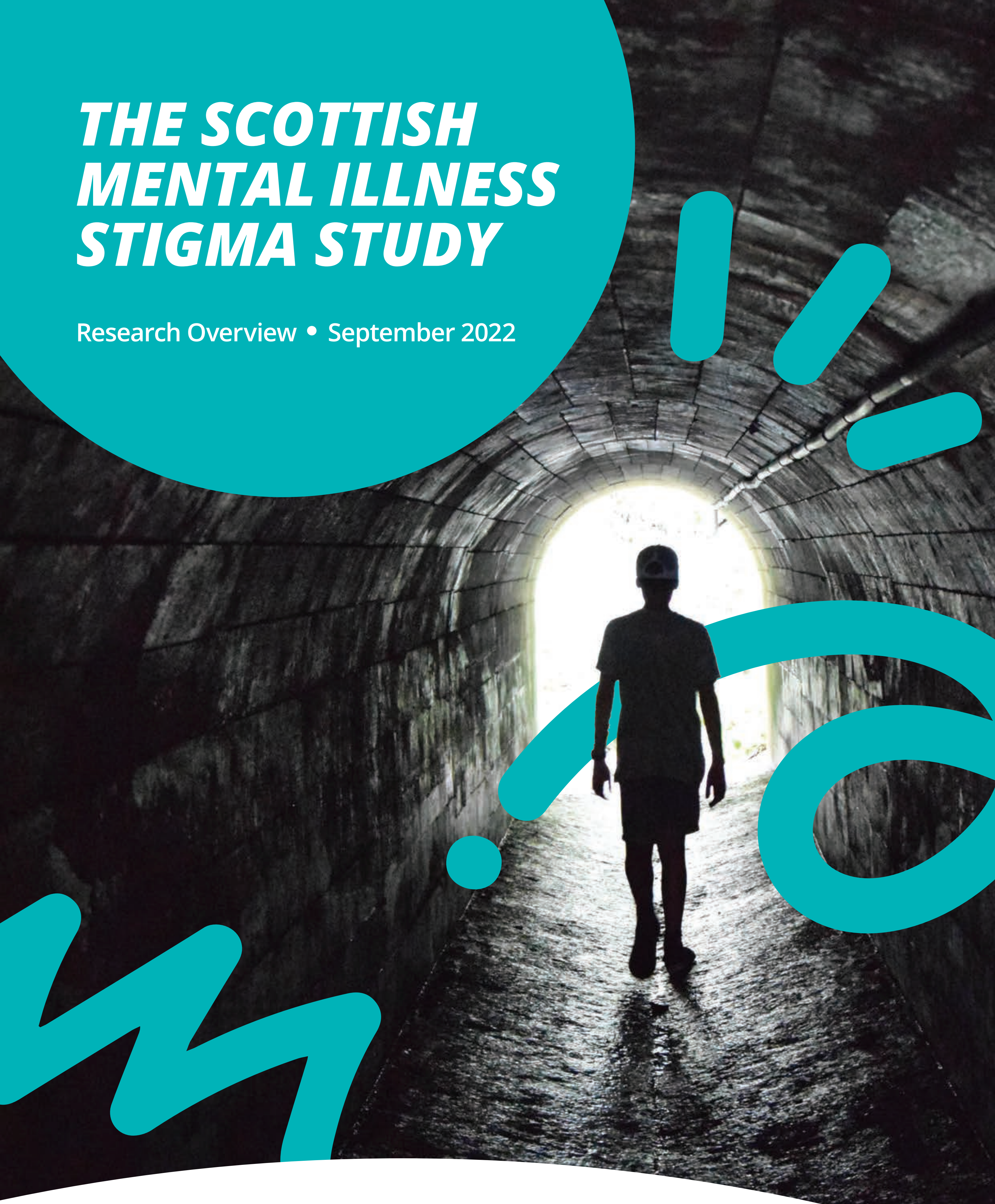
# THE SCOTTISH MENTAL ILLNESS STIGMA STUDY

Research Overview • September 2022



Produced through a partnership involving:

See Me
End mental health discrimination

Mental Health Foundation Scotland

GCU Glasgow Caledonian University

The Lines Between

See Me
End mental health discrimination

See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is for a fair and inclusive Scotland, free from mental health stigma and discrimination. We work to change negative attitudes, behaviours and cultures towards mental health. The programme is funded by Scottish Government, guided by people with lived experience and managed by Scottish Association for Mental Health (SAMH) and the Mental Health Foundation.

Mental Health Foundation
Scotland

The Mental Health Foundation is the UK's leading charity for everyone's mental health. Its vision is for a world with good mental health for all. With prevention at the heart of what we do, we drive change towards a mentally healthy society for all, and support communities, families and individuals to live mentally healthier lives, with a particular focus on those at greatest risk.

GCU
Glasgow Caledonian University

Glasgow Caledonian University is the University for the Common Good, aiming to shape society, influence governments, and transform people's lives around the world.

The Lines Between

The Lines Between is a social research agency with expertise in accessible and engaging research and evaluation activity. We believe robust research and evaluation can achieve powerful positive change, particularly for communities and marginalised groups.

# Acknowledgements

We would like to unreservedly thank the lead researchers of the original Our Turn to Speak study – Dr Chris Groot and Dr Imogen Rehm from the **Melbourne School of Psychological Sciences** (University of Melbourne) – for their support and advice throughout this research. From giving permission to adapt their pioneering research materials for Scotland, to actively participating in the Research Advisory Group and always being available to offer valuable insights and learning, this study would not have been the success that it has been, without their backing. For that we are truly grateful.

We owe a huge amount of gratitude to the members of the **Lived Experience Working Group** that included VOX members and See Me volunteers for consistently feeding into the research process, including development and testing of the survey, support with participant recruitment and openly sharing their own stories of stigma and discrimination, ensuring that the study has involved voices of lived experience. Without their input, this research would not have been as meaningful as it is. Individual members of the Lived Experience Working Group can be found in the final report.

We would also like to acknowledge the contributions of our **Research Advisory Group** and **Project Management Group** members who brought professional expertise and lived experience to the study in abundance, and who provided guidance, insights and direction, supporting us to work through the process of developing and promoting robust research materials by generously offering their time and invaluable perspectives that have resulted in the production of this report. The unwavering support of this group of talented people has enabled us to undertake what we believe is a high quality research study.

Most importantly, we would like to thank all of those who showed an interest and took part in this research. Participation in the study was no small undertaking, and we want to recognise the time and effort of people with lived experience of severe, complex and enduring mental illness who openly shared their experiences of stigma and discrimination through this work. We understand that at times it could have been challenging and distressing for people to relive difficult times in their lives related to their mental health, and we want to express how appreciative we are of everyone who selflessly did that, and who made this research possible.

# Contributors to the research

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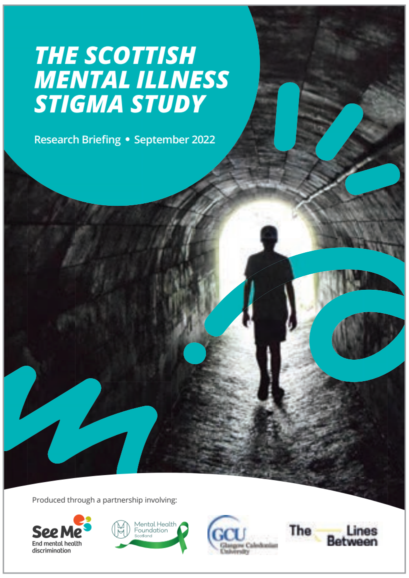

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# Foreword

When preparing our strategy With Fairness In Mind (2021-2026) much of the data available for review described improvements in attitudes and behaviours towards people living with common mental health problems. Whilst this marks good progress for the challenge to end stigma in Scotland, our review also showed that this positive trend is not universal. Data and personal testimony describes that people living with complex mental conditions continue to experience stigma and discrimination. To understand more about the stigma affecting people living with mental illness and to gather views about what actions would make a difference, we commissioned this study. As a first of its kind to take place in Scotland it draws on pioneering research carried out in Australia. Almost 350 people completed the survey and 70 participated in interviews and focus groups, providing us with the clearest picture we have ever had of the types of stigma and discrimination people with severe, complex and enduring mental illness experience.

We found that people who experience mental illness face some of the most pervasive forms of stigma and discrimination in nearly all areas of their lives, and the impact of this can be devastating. The study shows the impact of self stigma, where people describe how they withdraw from the things most of us take for granted and need to feel happy. It highlights the negative impact of public stigma, and describes how stigma within relationships can adversely impact on intimate and family relationships and friendships. It brings into stark focus the impact of structural stigma and discrimination in work, mental health, health care and other life areas.

Although the study reinforces some long standing exclusion and social justice issues, I believe it gives us all an opportunity to take stock of what has been achieved, share learning from what works (or doesn’t), share what is in place to address some of the issues raised and agree what steps we need to take now to make a lasting difference. It is time for concerted, collaborative action; with lived experience at the centre. We need to raise awareness of the ways that the stigma experienced creates a social, economic and health divide for many people who live with mental illness; and drive forward change to address this inequity.

Through combining our efforts, we can directly challenge the negative attitudes and prejudice that many people in Scotland continue to hold. We can raise awareness, understanding, and empathy surrounding mental illness and work to create environments, services and sources of support that are welcoming, compassionate, inclusive and fair.

Special thanks go to everyone who took part in this study; it can be challenging to talk about personal experiences of stigma and discrimination. We all have a duty to act on what people have told us. This is our time to come together, to act and make a difference towards ending stigma surrounding mental illness.

**Wendy Halliday**
Director, See Me

# Overview

There is a growing appreciation that mental health exists on a spectrum, that mental health fluctuates, and anyone can experience mental health problems. Despite this, the findings from this research indicate that stigma toward those living with mental illness endures across many areas of life.

The Scottish Mental Illness Stigma Study (SMISS) aimed to identify the experiences of stigma and discrimination faced by people who reported living with severe, complex and/or enduring mental illness in Scotland. It was inspired by the Australian National Stigma Report Card.

SMISS was commissioned by and carried out on behalf of See Me, Scotland's national anti-stigma programme, in partnership with the Mental Health Foundation (MHF) Scotland, Glasgow Caledonian University (School of Health and Life Sciences) and The Lines Between.

**This first-of-its-kind research in Scotland aimed to answer the following questions:**

- In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?
- What is the nature of the stigma and discrimination they experience?
- Which groups experience the most mental health stigma and discrimination, and in what life areas?
- How does the awareness, experience and anticipation of stigma and discrimination affect the lives of people living with severe, complex and/or enduring mental illness?
- What needs to change to improve people's experiences of living with severe, complex and/or enduring mental illness, and to reduce stigma and discrimination?

Adults in Scotland who identified as living with severe, complex, and/or enduring mental illness were encouraged to participate in the survey to describe the ways in which they experienced stigma and discrimination in the last 12 months. The survey ran between 26th November 2021 and 7th March 2022 and received 346 eligible responses. Most responses were submitted online; and there were ten supported telephone/video call survey completions.

This study draws from the Our Turn to Speak survey developed by SANE Australia's Anne Deveson Research Centre, the Melbourne School of Psychological Sciences (University of Melbourne) and the Paul Ramsay Foundation. Ethical approval for the study was obtained from Glasgow Caledonian University's School of Health and Life Sciences Research Ethics Committee.

Core survey questions covered participants' sociodemographic characteristics, attitudes towards mental health and experiences of stigma and discrimination across 14 life areas (detailed in full in Appendix 1), including employment, relationships and mental healthcare services. Respondents were asked to select the three life areas in which they had experienced the most significant impact of stigma and discrimination and asked detailed questions on:

- Perceived experiences of past stigma and discrimination.
- Anticipated future experiences of stigma and discrimination.
- Withdrawal from opportunities relevant to that life area because of stigma about mental illness.
- Experiences of positive treatment relating to living with complex mental illness.
- Intersectional experiences of stigma and discrimination.

Qualitative research was undertaken to add depth to the survey findings. This involved engaging with a sample of people who responded to the survey to gather additional insights into key aspects of the survey findings and with groups that were under-represented in the survey to explore their experiences of stigma and discrimination and understand the extent to which they aligned with the overall survey findings.

Themes explored through the qualitative research included gaining additional insight into key survey findings and further understanding of the experiences of groups under-represented in the survey, including people aged over 65, people from Black, Asian and minority ethnic communities, and men. People were offered the opportunity to take part in focus groups or individual discussions, either in-person or online.

# Key findings

## Research question 1: In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?

Experiences of stigma and discrimination span every life area explored in the survey, including personal, public and professional spheres. While each person's experience is unique, and the frequency and impact of stigma and discrimination related to mental illness vary by individual, the findings demonstrate that stigma and discrimination are found across many aspects of a person's life. The life areas where stigma and discrimination were reported to be experienced most frequently were relationships with family and friends, physical healthcare services, social media, mental healthcare services and mass media.

The five life areas where stigma and discrimination were reported to have the greatest impact differed slightly from the life areas where they were experienced most frequently. The life areas where stigma and discrimination were reported to have the most impact were relationships with family and friends, employment, mental healthcare services, healthcare services and social media.

Examples of stigma and discrimination respondents shared included:

- Rejection by family members and romantic partners.
- Being made to take early retirement or redundancy.
- Being made to take medication against their will.
- Feeling ignored and/or having views and opinions dismissed in GP and mental health settings.
- Facing barriers to accessing welfare and housing support.

While the research paints a stark picture of stigma and discrimination being experienced across every life area explored in the survey, respondents also reported having positive experiences of living with mental illness in each of the life areas, to varying degrees. Life areas with the highest proportions of positive experiences included: seeing, reading or hearing social media that portrayed people living with mental illnesses in a positive way, having positive experiences in their relationships, seeing, reading or hearing entertainment or creative mass media that portrayed people living with mental illnesses in a positive way and positive experiences in culture, faith, religious or spiritual practices and communities.

## Research question 2: What is the nature of the stigma and discrimination people experience?

Aspects of stigma and discrimination were more prominent in some life areas than others but cut across every life area explored in the survey. Stigma and discrimination spanned interactions with individuals, bias within systems and processes, and broader systemic issues. The nature of the stigma and discrimination described by across life areas was often severe and included:

- Being treated unfairly.
- Denial of access or opportunity.
- Being made to end or exit participation.
- Feeling pressured into unwanted decisions or actions.
- Exposure to hurtful, offensive and/or upsetting attitudes, views and portrayals of people living with mental illness.
- Dismissal of their thoughts, views and opinions.
- Being excluded from decision making.
- Having needs ignored, or preferences disregarded.
- Receiving inappropriate or inadequate service, care and/or support.

## Research question 3: Which groups experience the most mental health stigma and discrimination, and in what life areas?

We urge caution in drawing conclusions about which groups experience the most stigma and discrimination about their mental illness based on the research findings. The data is not to be interpreted as statistically representative of all people with mental illnesses in Scotland.

Stigma and discrimination may also extend to life areas not covered in the survey and is also likely to be experienced by, or affect, individuals and groups impacted by severe, complex and enduring mental illness, including partners, children, carers and friends.

Evidence of intersectional elements of stigmatisation and discrimination related to other aspects of identity was also gathered. This may compound adverse experience and impacts for people with lived experience of severe, complex and/or enduring mental illness. Often, experiences of stigma and discrimination about other aspects of individual identity were intertwined with stigma and discrimination about their mental illness.

There may be people in Scotland who have severe, complex and/or enduring mental illness who have not encountered stigma in the last 12 months; but have experienced it previously, with lasting impacts. The findings from the supplementary qualitative research suggest that there are also those with historical experiences of stigma and discrimination in a particular life area, which has led to them withdrawing from participating in those life areas, as well as others, to protect themselves.

## Research question 4: How does the awareness, experience and anticipation of stigma and discrimination affect people living with severe, complex and/or enduring mental health problems?

On awareness of stigma, there are stark differences in how respondents viewed themselves because of their mental illness, how they perceived those in positions of power, and their perceptions on how the public view people with mental illness; and their views of others living with mental illness. Most respondents seemed to expect that people in positions of power and members of the public have negative views with feedback from the qualitative research indicating that this is influenced by past experiences of stigma and discrimination.

Respondents held more sympathetic beliefs about others with mental illness than they hold of themselves. The qualitative research highlighted that experiences of stigma and discrimination can have significant influence on a person's view of self, but also that other factors contribute to this. In terms of viewing others more sympathetically, the qualitative research found that instead of holding negative views about others, respondents empathised, identified with, and understood their experiences. For some, supporting or being kind to others seemed important to their own sense of self or was felt to benefit them too.

The data gathered through this study suggests that experiences of stigma and discrimination can lead to heightened anticipation of future stigma and discrimination. The combination of experiences and anticipation of potential stigma and discrimination can contribute to withdrawal from opportunities as a pre-emptive, protective response.

The research suggests that withdrawal from opportunities and participation in different aspects of everyday life as a result of experiences of stigma and discrimination can have a significant negative impact on people. It can impact on social connectedness, access to support and services, housing, employment and education. A small number of the wide and varied examples evidenced through the study include:

- People choosing not to start a family, withdrawing from relationships with friends or stopping themselves from getting close to others to avoid rejection:

> ***"It has actually made me not have friends. Because I'm scared of explaining myself... I'm the one with the weird character. So it's easier, to try and not explain myself."***

- People stopping themselves from applying for jobs or promotion opportunities, or leaving employment before they were ready or wanted to:

> ***"I've had to leave jobs because of stress – managers have told me they would push me til they broke me – they would make up presumed diagnosis – mental health was used against me – this has impacted my confidence and makes it hard to go back."***

- People stopping themselves from calling 999 for an ambulance or going to hospital for urgent medical care (mental and physical health):

> ***"I try to keep away from mental health services in recent years because I find them to be damaging – the constant invalidation and poor responses – in terms of timeliness and effectiveness."***

- People withdrawing from education or training courses when they didn't want to:

> ***"I dropped out of my MSc because it felt impossible to access support I needed and it was nearly impossible to access flexible learning ."***

**Research question 5: What needs to change to improve people's experiences of living with severe, complex and/or enduring mental health problems, and to reduce mental health stigma and discrimination?**

This study gave people with lived experience a direct opportunity to identify what changes are needed in Scotland to reduce mental illness stigma and discrimination. An extensive range of changes were suggested and these fell into four overarching, inter-related areas that social values; understanding and inclusion; work and education settings; identity and representation; and provision of services and support.

Cutting across each of these areas will require change in culture, policies, systems and practices and a move towards greater education, collaboration, accountability, inclusion, respect and empowerment.

## Social values and understanding

The need for greater knowledge of, and understanding about, mental health issues in society was a recurring theme. This was seen to be fundamental to achieving increased inclusion and acceptance, with the importance of being treated with kindness, empathy and compassion being highlighted.

## Socio-economic inclusion

The need to reduce social inequality and address exclusion in employment, education, welfare, financial support and relationships was seen as a critical enabler of reducing stigma and discrimination. This included reflections and suggestions relating to social policy and areas of systemic change that are needed to reduce discrimination, improve legal rights and representation, increase access to finance and resources and shift social values and expectations.

## Identity and representation

The need to erase negative representations of people living with mental illness, particularly personality disorder diagnoses, was raised. Many urged an end to the dehumanised and stereotyped identities they felt ascribed to them, and greater use of more thoughtful and inclusive language. The media was discussed as both problem and solution to better representation, with a call for less stigmatised, more accurate or more celebratory representations of mental illness experiences by media platforms and outlets, while also recognising that all parts of society had a role in this.

## Services and support

Improved services were identified as another important step. While NHS and mental healthcare supports were most repeatedly mentioned, physical healthcare, crisis support lines, welfare support, job centres, housing supports, policing and legal aid services were also discussed. Suggestions for improvement included broad comments relating to organisational and cultural change and service reform, through to specific changes related to accessibility and availability, resourcing and investment, staff training and greater coordination across services.

# Conclusions and recommendations

The research indicates that many people in Scotland living with complex, severe and/or enduring mental illness experience stigma and discrimination across every life area explored in the survey. It has gathered a significant body of evidence and revealed hard-hitting findings about the extent, impact and nature of stigma and discrimination experienced by people with lived experience of complex, severe and/or enduring mental illnesses.

This is the first large scale piece of research undertaken in Scotland. Some of the examples of stigma and discrimination identified in this research are likely to have profound and enduring impacts for those who experienced them. Many of the examples in the full report are distressing and bring into sharp focus the need for ongoing improvement in systems and services that aim to engage and support people who live with mental illness.

The findings make a clear case for the continued investment into and focus on tackling stigma and discrimination in Scotland, with particular emphasis on how they impact on experiences and outcomes of people living with mental illness. The findings also illustrate the scale of the challenge, and the change that needs to take place if stigma and discrimination are to be genuinely tackled and reduced.

Those seeking to tackle stigma and discrimination will need to acknowledge these calls for change, identify any gaps through reflecting on the findings ‘of this report, and prioritise which steps to take. Achieving change will involve extensive engagement, buy in and commitment from a wide range of stakeholders and partners. This work should agree timescales, identify leadership and implementation roles, guide implementation and monitor desired changes, and generate resources. This must be a collective and collaborative effort across partners and stakeholders if the change required is to be achieved.

There is a need to consider where efforts to tackle these may have the greatest effect. For example, whether to prioritise reducing incidences of stigma and discrimination, or to focus on addressing aspects of stigma and discrimination which are reported to have the greatest impact.

## Strategic recommendations identified in response to the findings from this study include:

1 Sharing the research in tailored ways with key stakeholders and generating engagement with, and acknowledgement of, the findings amongst people with lived experience, policy makers, funders, researchers, those leading and delivering public services and others with an interest and responsibility for reducing stigma and discrimination.

2 Allocating and rallying resources which reflect the scale, scope and long-term nature of the work required to tackle stigma and discrimination. This may include achieving commitment to action on challenging stigmatising cultures and behaviours, redirecting or expanding services and drawing on the skills, experience, expertise, influence, connections and resources of stakeholders and partners.

3 Developing an action plan to address the issues set out in the report, demonstrating and covering ownership and accountability, resourcing, timescales, monitoring of progress and impact.

4 Repeating the survey on a larger scale to generate data which is representative at population level. This will require support from NHS Health Boards to reach people supported by mental health services.

5 Generating evidence to answer some of the questions raised during this research, such as:

- Does mental illness stigma and discrimination extend to life areas not covered in the survey?
- In what ways is stigma and discrimination experienced by, other groups impacted by complex, severe and/or enduring mental illness, including partners and children?
- Are there people with complex, severe and/or enduring mental illness who have not encountered stigma in last 12 months; but have experienced it previously, with lasting impacts? If so, what are those impacts and what effect do they have on the person's life?

# Appendix 1: Life area definitions

## Housing

This life area relates to experiences of accessing and sustaining housing and homelessness services. Housing includes private rental, and local authority, housing association and social housing. Homelessness services include emergency and temporary accommodation and other homelessness support options.

## Employment

This domain relates to experiences of applying for, finding, participating in and sustaining paid employment, which includes casual/zero hours contracts, part-time, full-time, and fixed- term temporary and permanent employment contracts.

## Education and training

Education and training includes secondary education, college and university education, vocational qualifications and modern apprenticeships, short courses, continuing professional development and work-related training/qualifications.

## Relationships with friends and family

This life area relates to experiences of developing, participating in and maintaining relationships with people considered to be friends, biological, adopted, fostered and chosen family, relatives and children, and intimate partners (e.g., dating, married, civil partner, co-habiting, casual relationship).

## Healthcare services (excluding mental health services)

This life area relates to accessing and using healthcare services (excluding mental health services which are considered separately) for a range of physical health issues, across public and private sectors. Healthcare services include but are not limited to: GP surgeries, dental services, pharmacies, community healthcare teams and other primary and community care services. Healthcare services also include hospital services including A&E, in-patient and out-patient services.

## Mental healthcare services

This life domain relates to experiences of accessing and using mental healthcare services for a range of mental health issues and illnesses, across public, private and third sector providers. Mental healthcare services include, but are not limited to:

- Crises helplines, community healthcare teams and other community-based services.
- Hospital-based services (in-patient and out-patient).
- Residential and rehabilitation services.

## Sports, community groups and volunteering

This life area relates to experiences of accessing, participating and sustaining involvement in sports, community groups and volunteering activities. These group include, but are not limited to:

- Local sporting teams and clubs.
- Arts, crafts, music groups, book clubs, or other social/community groups.
- Volunteer (unpaid) work or committee positions.

## Public and recreational spaces

This life domain relates to public and recreational spaces, including public transport. It considers experiences of accessing and using public and recreational spaces, including but not limited to:

- Public transport (e.g., buses, trains, trams).
- Public spaces for gathering, events, recreation and fitness (e.g., parks, shopping centres, libraries, museums, music venues, theatres, pubs, cafes, restaurants, community festivals, sporting grounds and facilities).

## Banking and insurance services

This life area relates to experiences of accessing, using and maintaining banking services and insurance products, which include but are not limited to:

- Bank accounts (e.g., savings or everyday current accounts).
- Credit cards.
- Loans (e.g., personal loans, business loans, mortgages).
- Insurance cover (e.g., health insurance, life insurance, home insurance, car insurance).

## Welfare benefits and financial support

This life area relates to experiences of welfare benefits and financial support, such as accessing, using and retaining welfare benefits and state financial support, including (but not limited to): Universal Credit, Jobseekers Allowance, Employment and Support Allowance, Personal Independence Payments, and Child Benefit.

## Legal and justice services

This life area relates to experiences of accessing and using legal and justice services, which include but are not limited to:

- Police service (including the use of 101 and 999 calls).
- Civil and criminal courts of law (including accessing legal representation and advice.
- Family courts (including child protection).

## Cultural, faith and spiritual practices, and communities

This life domain relates to experiences of participating in cultural, faith, religious or spiritual practices and communities. These include but are not limited to

- Customs and traditions.
- Prayer and meditation.
- Regular services.
- Celebrations.
- Any other important rituals, practices or spaces of cultural, faith, religious or spiritual significance to you.

## Mass media

This life area relates to experiences of engaging with mass media content, which includes (but is not limited to) mass news media (such as televised news programmes, radio, newspapers, magazines, online news sources) and mass entertainment or creative media (such as films, music, books, televised entertainment programmes).

## Social media

This life area relates to experiences of engaging with and using social media websites, applications and forums. These include but are not limited to:

- Facebook.
- Instagram.
- Twitter.
- WhatsApp.
- Reddit.
- Pinterest.
- Snapchat.
- Tik Tok.
- YouTube.

See Me

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