Personality Disorder Improvement Programme

See Me - Reducing Stigma Workshop

Thursday 19 January 2023

12:30 – 2:30pm

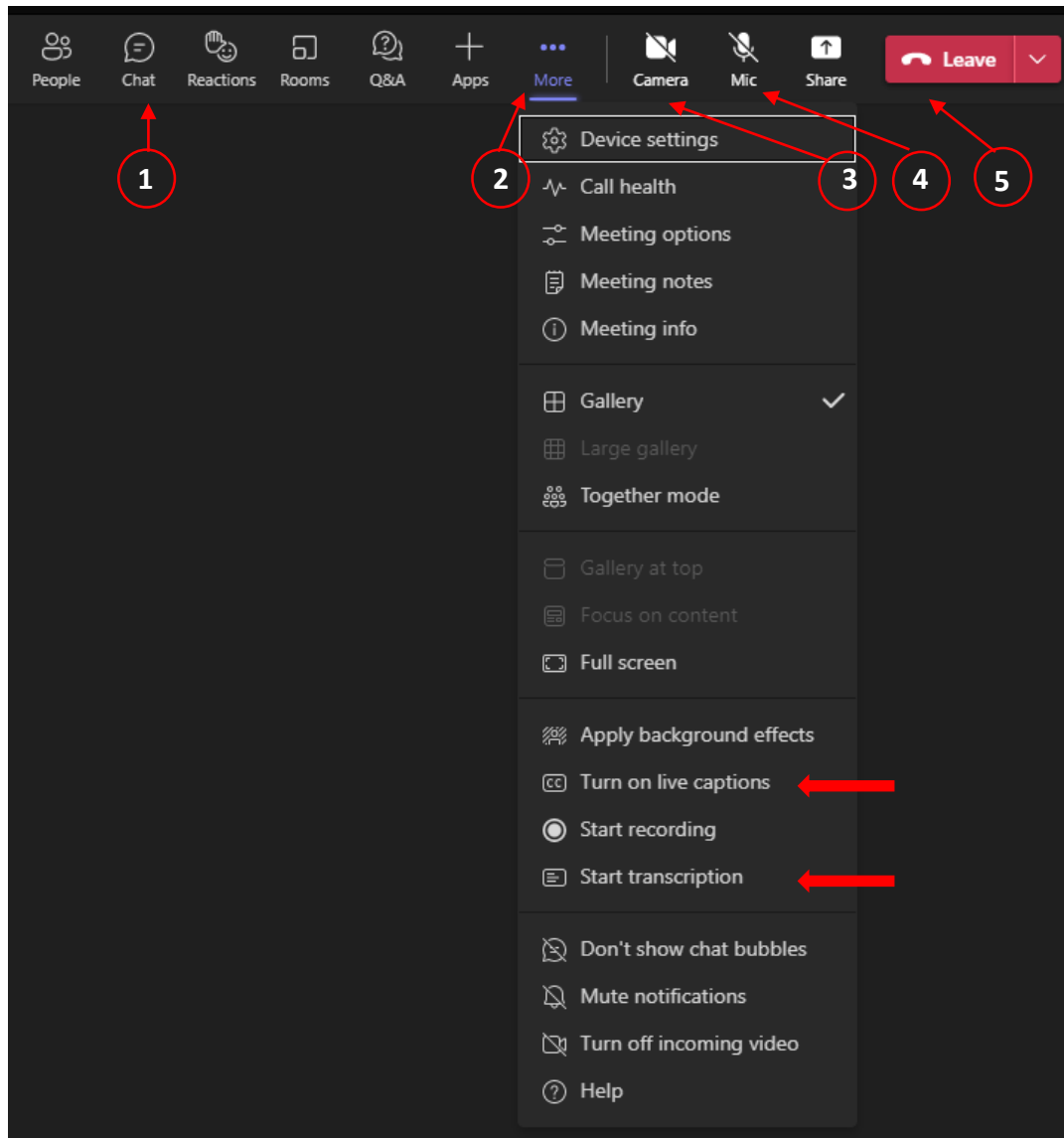#PDIPscot

MS Teams Settings

1. **How to open and close the chat panel** – use the chat panel to introduce yourself, raise any questions you may have for the speakers and also post comments.

2. **Under 'more' you can access some accessibility features** such as live captions and also a live transcript of the meeting (highlighted with the arrow).

3. How to **turn your camera** on and off during discussion session

4. How to **turn your microphone** on and off during discussion session

5. How to **leave** the meeting

Parts of this workshop will be recorded.

The link will be uploaded to our website, so those who are unable to join us today can listen to the speaker session only.

Therefore please do not record the session.

Agenda for today

Item No.	Title	Lead	Duration	Timings
1.	**Welcome and introduction**	Gordon Hay	5 minutes	12:30 - 12:35
2.	**Scottish Mental Illness Stigma Study: Stigma around personality disorder**	Dr Patty Lozano-Casal	25 minutes	12:35 – 13:00
3.	**Lived experience perspective**	Catherine Watson	15 minutes	13:00 - 13:15
4.	**Breakout room discussion** What are your reflections from what you've heard so far? Has anything surprised you? Is there anything you can do to help address some of the stigma identified?	See Me and Healthcare Improvement Scotland	15 minutes	13:15 - 13:30
5.	**Break**		10 minutes	13:30 - 13:40
6.	**Partner input - NHS Greater Glasgow and Clyde, BPD Dialogues group**	Alison Duncan and Fiona MacNeil	15 minutes	13:40 – 13:55
7.	**Breakout room discussion** What might be the barriers and enablers to adopting more inclusive language in services? How can we support staff in services to have the knowledge, capacity, ability and confidence to offer person-centred, compassionate care to people living with personality disorder? Are you aware of any services or interventions that help reduce mental health stigma around personality disorder?	See Me and Healthcare Improvement Scotland	30 minutes	13:55 - 14:25
8.	**Reflections from PDIP team and close**	Gordon Hay	5 minutes	14:25 - 14:30

Scottish Mental Illness Stigma Study: Stigma around personality disorder
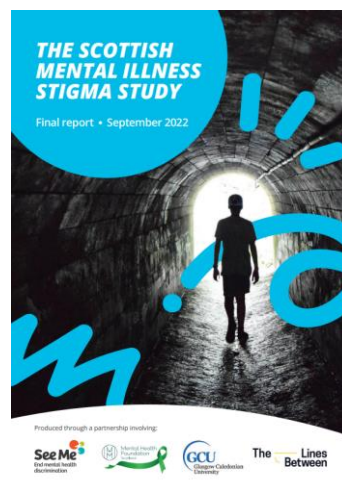
Dr Patty Lozano-Casal
Programme Manager (Settings)

Study by See Me, created with Mental Health Foundation, Glasgow Caledonian University and The Lines Between

Setting the context

- Our volunteers with experience of mental illness speak about the stigma they experienced

What is the Scottish Mental Illness Stigma Study?

- Social gradient for mental health, linked to living in areas of high deprivation

- Lack of data / harder to find

- First of its kind for Scotland

- It explores how people with experience of severe, enduring and complex mental illnesses face stigma and discrimination in various different life areas

- Includes: In relationships, healthcare and mental healthcare services, employment and online

- Created by See Me, with the Mental Health Foundation, Glasgow Caledonian University, The Lines Between and supported by VOX

- Inspired by Australia's National Stigma Report Card and Our Turn to Speak survey (Canada also completed a similar study)
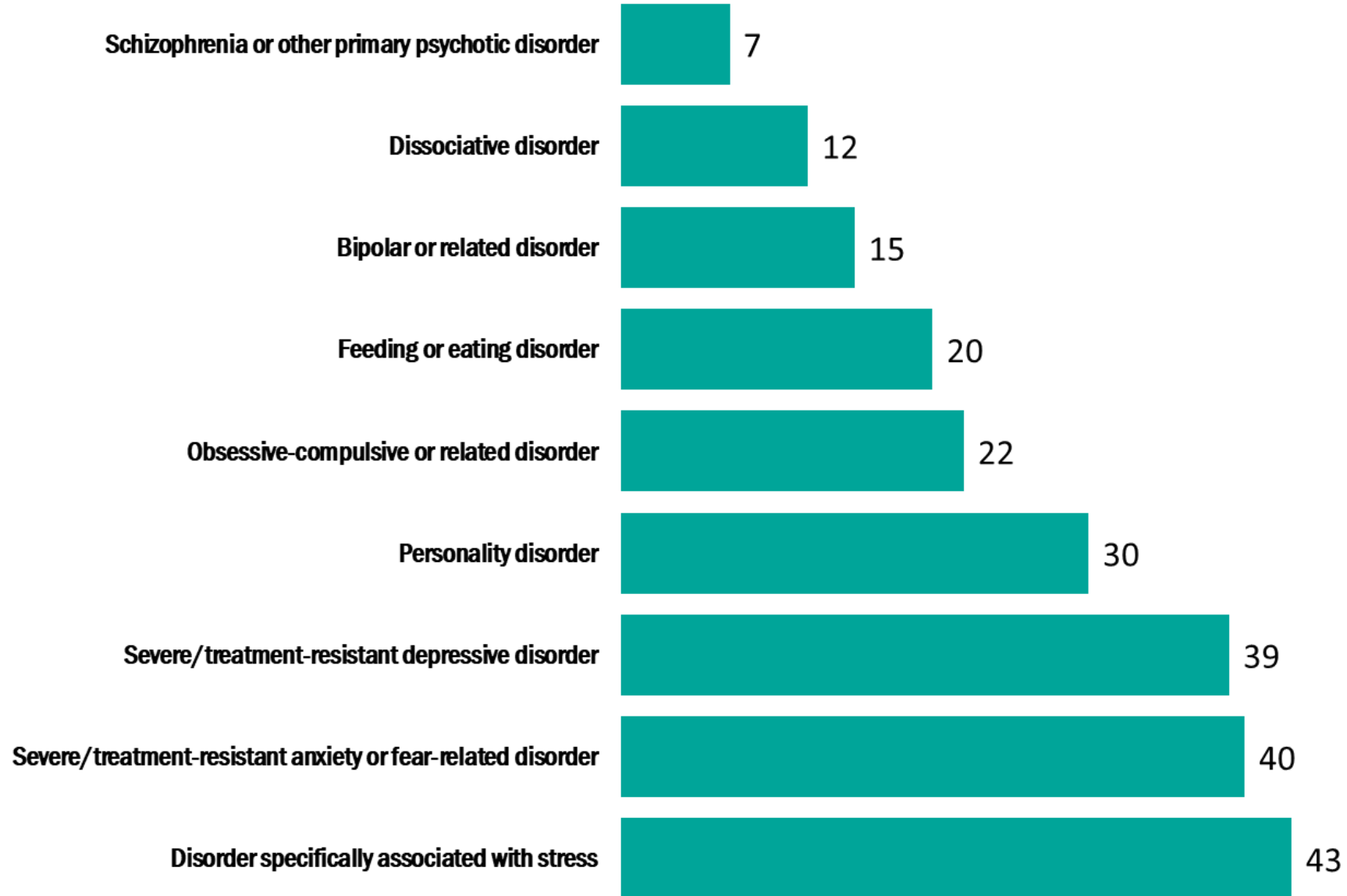
Methodology

- Mixed methods: Survey, small groups & interviews

- 416 Participants (346 survey participants, Nov 2021-Mar 2022)

- Adults living in Scotland with severe, complex and/or enduring mental illness/es

- 14 life areas incl. relationships, employment, mental/healthcare services, housing, welfare, education and training, recreational spaces, etc.

- Experienced stigma and discrimination in the past 12 months

Research questions:

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?

2. What is the nature of the stigma and discrimination people experience?

3. Which groups experience the most mental health stigma and discrimination, and in what life areas?

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

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?

Mental illnesses in past 12 months

Disorder	Value
Schizophrenia or other primary psychotic disorder	7
Dissociative disorder	12
Bipolar or related disorder	15
Feeding or eating disorder	20
Obsessive-compulsive or related disorder	22
Personality disorder	30
Severe/treatment-resistant depressive disorder	39
Severe/treatment-resistant anxiety or fear-related disorder	40
Disorder specifically associated with stress	43

Perceptions and attitudes

- Years of stigma and discrimination have left people feeling ashamed and assuming that the public, and people in positions of power think the worst of them, including that they are dangerous and to blame for their conditions.

- The impact of discrimination, is that more than half of people with mental illness respect themselves less because they think they will never get better.

  - **69%** think people in positions of power think that people with mental illness are dangerous
  - **78%** think the public think that people with mental illness are dangerous
  - **87%** think the public think that people with mental illness are to blame for their problems

Perceptions and attitudes

"I really feel like I'm a burden. And I don't want to be, I don't want my daughter to remember me as 'oh gosh I had to go up and look after my mum today' or… 'instead of spending time with the kids, I had to go look after my mother'. So that's why I sort of try and keep myself in my wee box and do what I can for myself… I do get up in the morning and stick the smile on. I know I do that."

"Aye, I'm negative about everything…because (of) experiences like this I'm pure negative about trying new things, trying to access things… I'm scared of everything…when I go outside is when I had panic attacks… That's down to prior experiences trying to get help out there in a big wide world."

What do respondents think can help change things?

- Embedding mental health education across all parts of our lives
  - School curriculum
  - Improved student or workplace education,
  - Public campaigns, etc.

  to encourage more open dialogue at home
- Education should include how mental illness may present, or be experienced, to encourage people to seek help and support each other
- In society, reduce social inequality and address exclusion in employment, education, and relationships

Frequency and impact of stigma and discrimination experienced

Position	Frequency (based on proportion of respondents reporting occasional, frequent or very frequent stigma and discrimination)		Impact (based on proportion of respondents selecting in their three most impactful)	
1	Relationships	92%	Relationships	56%
2	Social media	78%	Employment	36%
3	Healthcare	78%	Mental healthcare	35%
4	Mental healthcare	74%	Healthcare	32%
5	Mass media	73%	Social media	21%
6	Employment	72%	Education & training	15%

Stigma and discrimination in life areas

Experience	Anticipation	Withdrawal

- Participants were asked questions about the type of stigma and discrimination they faced in each of the three areas of highest impact:
  - Their experience of stigma and discrimination
  - What stigma and discrimination they anticipated experiencing
  - Where they had withdrawn from things due to stigma and discrimination

Relationships with friends and family

Experiences

- **49%** Have been rejected or estranged from family

- **72%** reported having been treated unfairly when making or keeping friends

- **54%** have been treated unfairly by intimate partners

- **61%** have had positive experiences in this area

"I had a friend who didn't want me around her children anymore as I was 'probably dangerous' because I have a mental illness diagnosis."

Anticipation

- **67%** expect that people will not want to start a family or have children with them

- **82%** expect that people will not want to be friends with them

- **76%** expect that people will not want to date or have intimate relationships with them

"This makes me very depressed as I want nothing more than to find and be with a partner."

Withdrawal

- **45%** stopped themselves from starting a family/having children

- **90%** have withdrawn from relationships with friends

- **93%** stopped themselves from getting close to people to avoid rejection

- Appreciative relationships, connections and valuing lived experience were highlighted as positives

"I wouldn't be here without my family; I'm incredibly lucky and my heart goes out to those struggling without that support."

n=133-186

Relationships with friends and family

- "I feel my conditions are a significant barrier to me being open and honest with partners or in pursuing potential partners as I believe there is significant stigma attached to BPD."

- "In the past family members have said things like 'I was having a good day until you phoned'. In another situation, when I spoke to family and they said 'why can't you not just be normal'. I think they try to help but don't understand what they are saying is so hurtful."

- "If social opportunities arise, I feel inadequate because I have never had children or care dependents. I feel like a useless member of society with nothing to contribute. Being diagnosed with a mental health condition 30 years ago and living in cramped housing means having a family isn't an option."

What can help change things?

Education across society can help with understanding, consideration and compassion to improve relationships.

Employment

Experiences

- **57%** have been unfairly denied employment opportunities

- **77%** have been treated unfairly at their place of work

- **30%** agreed to some extent that they had been unfairly asked to leave employment

- Those who had positive experiences had their lived experienced valued in work

"My manager has been very judgemental of one of our sales assistant's mental health struggles, and as a result I haven't told anyone about my specific diagnosis/symptoms."

Anticipation

- **70%** expect to be unfairly denied employment opportunities

- **74%** expect to be treated unfairly at their place of work

- **48%** expect to be unfairly asked to leave

"I put extra pressure on myself and work much longer hours than anyone else to prove that I am worthy/able to be employed. I fully expect to go in most days to be fired or pulled up for issues with what I'm doing in my job."

Withdrawal

- **85%** have stopped themselves from applying for employment opportunities

- **75%** have stopped themselves from discussing their mental illness needs and experiences at work

- **45%** have resigned or left employment before they were ready

- **64%** stopped themselves from asking for flexible work arrangements or other reasonable adjustments

"The end result was that I lost my job, confidence and self-respect."

n=116-119

Employment

- "Due to my bipolar disorder diagnosis, I failed a workplace medical for a teaching role, despite never having an issue related to my mental health throughout my teaching career…. They subsequently quoted the Glasgow bin lorry tragedy as their rationale, implying that my condition made me dangerous. I was certain that they felt I was unfit for work, so withdrew. I was without pay for four months as a result of this experience."

- "Being told repeatedly I don't have to share details about my mental health because it might make others uncomfortable means I, by existing, make others uncomfortable, which is an incredibly depressing thought."

What can help change things?

The study findings suggests we should aim to remove the barriers which stop people gaining and maintaining employment.

Reasonable adjustments, such as part time & flexible working, working from home, more regular breaks, and mental health leave can help.

Better workplace cultures to address bullying, judgement and stigmatising attitudes are important to the participants.

Mental healthcare services

Experiences

- **81%** reported having been unfairly denied help for my mental illness(es)
- **66%** unfairly referred or discharged out of mental healthcare services
- **63%** have been unfairly excluded from having a say in decisions about their care and treatment planning
- There are great and supportive health care staff across Scotland, and people have felt listened to, validated, collaborated with, and treated with kindness, compassion, understanding and respect

"I do not reveal how much I am struggling at times as I have had previous experience of forever hospitalisation."

Anticipation

- **81%** expect to be treated unfairly when trying to get help for their mental illness
- **80%** expect to be unfairly denied help for their mental illness
- **68%** expect to be unfairly excluded from having a say in decisions about their care and treatment planning

"I have only received discrimination since I received my diagnosis of personality disorder. I have been treated unfairly, dismissed and told to go away when seeking help from Crisis teams at the hospital."

Withdrawal

- **80%** have stopped themselves from getting help for their mental illness
- **58%** have stopped themselves from calling 999 for an ambulance or going to hospital for emergency mental healthcare
- **75%** have stopped themselves from revealing the severity of their mental illness when getting help from mental healthcare professionals

"I feel like treatment is done to me rather than with me and I am not involved in any decisions around / about my care......I have no autonomy or control or power in my own care."

n=114-118

Mental healthcare services

- "The stigma that prevails around personality disorders is horrible. I have had mental health professionals tell me 'I can kill myself if I want to, I can hurt myself and they won't help me or stop me because that's just how people with personality disorders are.' It's so bad."

- "Because of my BPD diagnosis, I have had crisis team staff hang up on me even when I'm feeling as though I couldn't keep myself safe. I was discharged from my CMHT by a psychiatrist who never spoke to me once but decided to discharge me anyway. I have been called "attention seeking", "manipulative" by services. I feel as though mental health services don't take me seriously because of stigma around my diagnosis."

What can help change things?

Supportive relationships, being treated with kindness, compassion, or understanding; helpful services and improvements all helping people in this area.

According to the data, to overcome stigma in the mental health care system, there should be more timely mental health support with reduced waiting times, increased crisis supports and earlier intervention, as well as improve long term support and planning.

People being treated as individuals, and getting the right care and support for them will make a difference, according to participants.

Healthcare services
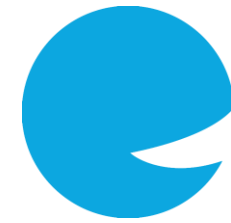
Experiences

- **85%** have experienced unfair treatment when trying to get help for physical health problems

- **85%** have experienced unfair treatment from health professionals

- Being listened to, validated, collaborated with, and treated with kindness, compassion, understanding were all highlighted in positive experiences

"My doctor's ignored my repeated calls about various debilitating symptoms for 9+ years , it turned out I was very close to dying due to severely low iron."

Anticipation

- **32%** anticipated being pressured into receiving physical healthcare treatment they did not think was necessary

- **81%** expect to be treated unfairly when trying to get help for mental heath problems

- **68%** expect to be unfairly referred or discharged from physical health services before being ready

"I dread going to my GP about a physical health issue because often I am not taken seriously."

Withdrawal

- **85%** have stopped themselves for asking for help for physical health problems

- **51%** had avoided calling an ambulance or attending A&E in relation to their physical health

- **49%** have stopped themselves attending general health check-ups

"I am not heard. I am simply mentally ill, incapable, deranged."

Healthcare services

- "After I disclosed my mental illnesses, I was told I 'wasn't sick enough' to be admitted to the gastro ward… I was so upset by these comments and genuinely felt it was due to being discriminated against, as the Dr was fine with me until I told them about my personality disorder. I was later admitted to the gastro ward despite being told this, and had to undergo a procedure of which I was told I would be sedated for. I was… denied a sedative at the last minute for unknown reasons. I cried throughout the full procedure."

- "It seems to come up over and over again that GPs and physios and anyone with any access to my NHS records can look at a diagnosis I received about eight years ago (that I consider to be completely inappropriate to my history and symptomology, and also inappropriate to apply to human beings in general – that'd be Borderline Personality Disorder) as a reason to treat me as hostile or hysterical or dangerous."

What can help change things?

- Maybe change to: Considering the person as a whole and making better links between physical and mental health services

- Taking physical health concerns seriously and ensuring equality of access to physical health treatment for those living with mental illness

- There needs to be improved public and third sector services, including mental and physical health care, and the funding in place for it.

- Addressing those who act in a discriminatory way can be done through more effective complaints procedures, greater accountability and a "zero tolerance approach" to staff who discriminate.

What needs to change

- **Societal values and understanding:**
  - Education and awareness
  - Inclusion and acceptance across society
  - Kindness, empathy and compassion
- **Identity and representation:**
  - Removal of negative representations of people living with mental illness
  - The need for thoughtful and inclusive language
  - Greater visibility of those living with mental illness
- **Socio-economic inclusion:**
  - Reducing social inequality and address social exclusion
  - Social policy and systemic change
  - Reasonable adjustments and considerations
- **Services and support:**
  - Removing barriers and making services accessible
  - Timely mental health support
  - Greater variety in therapy and approaches
  - Staff training in services

Thank you!

Dr Patty Lozano-Casal

Patty.Lozano-Casal@seemescotland.org

Study report(s) and further details

www.seemescotland.org/stigmastudy/

Breakout room etiquette

- We all have the same aim
- Respect confidentiality – it's okay to discuss issues raised outwith the event, but be mindful not to use names or anything personal which could be related back
- Be supportive
- All voices matter
- Respect people's opinions
- Don't dominate the conversation

Stigma around personality disorder: group discussion

1. What are your reflections from what you've heard so far? Has anything surprised you?

2. Is there anything you can do to help address some of the stigma identified?

Stigma around personality disorder: comfort break

Stigma around personality disorder: BPD Dialogues Group

Alison Duncan and Fiona MacNeill

Stigma around personality disorder: Group discussion

1. What might be the barriers and enablers to adopting more inclusive language in services?
2. How can we support staff in services to have the knowledge, capacity, ability and confidence to offer person-centred, compassionate care to people living with PD?
3. Are you aware of any services or interventions that help reduce mental health stigma around PD?

See Me
End mental health discrimination

Thank you for your time and input!

Polls

Next steps

Follow up email circulated soon. Slides and recording will be uploaded to website which can be accessed here

Next webinar will take place on 7th March and will focus on crisis and unscheduled care

Get in touch with the team on his.mhportfolio@nhs.scot or on twitter by visiting @SPSP_MH