

**The Lived and Living experience of restrictive practice from a patient, family and carer perspective across Scotland**

**April 2022**

**Carers Trust Scotland**

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Our vision is that unpaid carers count and can access the help they need to live their lives.

Learn more: <https://carers.org/our-work-in-scotland/our-work-in-scotland>

**Support in Mind Scotland**

Support in Mind Scotland works to improve the wellbeing and quality of life of people affected by serious mental illness. This includes those who are family members, carers and supporters. We are a national charity particularly concerned with serious mental illness. We achieve our mission though campaigning, education and provision of practical help, support and information.

Learn more: <https://www.supportinmindscotland.org.uk/>

**Mental Health Network (Greater Glasgow)**

Mental Health Network (Greater Glasgow) is a network of people and carers with a lived experience of mental health issues.

Learn more: <https://www.mhngg.org.uk/>

**Scottish Patient Safety Programme for Mental Health**

The Scottish Patient Safety Programme (SPSP) is a national quality improvement programme that aims to improve the safety and reliability of care and reduce harm. Since the launch of SPSP Mental Health in 2012, the programme has worked to ensure people are and feel safe in adult mental health inpatient settings.

Learn more: <https://tinyurl.com/yc5mc9xe>

**Foreword**

The aim of the SPSP Mental Health Programme is to ensure that patients admitted to an Adult Mental Health Ward are safe and feel safe. It is crucial that this experience is shared by carers who are supporting loved ones through an episode of illness. The use of restrictive practices in mental health settings can be important in ensuring safety, but there is always a cost in terms of autonomy and human rights.

As such, our aim must always be to reduce the use of practices such as restraint and seclusion wherever possible. Where this is not possible, the aim should then shift to the least restrictive practice being used for the shortest length of time and delivered with care and compassion. The patients and carers who have contributed to this report provide clear insights into how these two aims can be achieved with common themes emerging around person-centred care planning, improved communication as well as practical suggestions to share information in a clear and transparent way.

Those who have contributed to this work all have first-hand experience of restrictive practices either as patients or carers. They offer a unique insight into the issues involved which will be central to identifying opportunities for improvement and developing change ideas for wards to test and implement.

On behalf of the Scottish Patient Safety Programme, I would like to thank everyone involved for taking part in the work which will help shape the programme over the coming years.

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Dr Jane Cheeseman

National Clinical Lead, SPSP Mental Health

**Thank You to the Participants**

The information in this report has only been possible because people with lived and living experience, their families and carers who volunteered their time to share their stories with us.

**Introduction**

The Scottish Patient Safety Programme for Mental Health (SPSPMH) continually seeks to engage people with lived and living experience to help us understand their care experience and inform the future direction and content of the programme. Specifically, SPSPMH wished to understand their perspective on restrictive practice, their experiences, and how we can move to a culture of least restrictive practice in mental health inpatient settings. The aim of these interviews was to inform the development of [new improvement resources](https://ihub.scot/improvement-programmes/scottish-patient-safety-programme-spsp/spsp-programmes-of-work/spsp-mental-health/spsp-mh-20212023/) being developed by the SPSPMH co-design group for use across Scotland.

A collaborative relationship has existed between Carers Trust Scotland, Greater Glasgow Mental health Network, Support in Mind Scotland and SPSPMH since the programme began in 2012, it was natural they would seek our help to engage with the people in our networks on this important issue.

We are delighted to present the findings of the interviews we carried out, with support from SPSPMH, and continuing to ensure the voice of lived and living experience is at the heart of improvements to care and treatment across Scotland.

**Key insights and suggestions related to improvement**

Key insights included opportunities for improvement in:

* transparency in communication and documenting and sharing information about factors related to restrictive practice for patients and carers
* level of access to appropriate activities and advocacy for the patient
* staff time and support available for communication and interaction between staff, patient, and carers/family to support efforts in preventative practice

Specific suggestions included visual communication of ward rules, production of a welcome pack detailing activities and expectations, taking time to elicit and document carer insights about the patient, and appropriate documentation and communication of attempts to prevent restrictive practice/ to debrief on any restrictive practice carried out may offer increased opportunities to identify any issues and further suggestions related to improvement.

As might be expected, issues sometimes overlapped in people’s responses and appeared in relation to different questions. It appeared there may be an underlying insight about transparency and clear communication in particular around making any implicit (verbally implied) plans or expectations *explicit* so that all involved are equally informed and potentially then able to understand/consider/reflect on any incidents as part of an ambition of least restrictive practice.

It appears that many of these insights and suggestions align with a number of the existing Scottish Patient Safety Programme [From Observation to Intervention](https://ihub.scot/media/5508/spsp-iop-from-observation-to-intervention.pdf) nine strands, for example:

* involving carers and families in treatment, wellbeing and recovery
* supporting early recognition of and response to deterioration
* improving communication around clinical needs, deterioration and risk
* promoting least restrictive practice
* supporting personalised care and treatment
* creating an infrastructure to support learning and improvement

**Methodology**

A number of consultative interviews were carried out with people with experience of restrictive practice from a patient or family/carer perspective in Scotland. The consultation process was led by Support in Mind, Carers Trust Scotland and Mental Health Network (Greater Glasgow) working in partnership with SPSP Mental Health. This followed a joint communication campaign by the three organisations to recruit possible interview candidates, appendix 1.

A total of eight interviews were carried out using digital platforms. A safeguarding process was put in place to offer support to anyone disclosing information that may result in revisiting trauma. The ‘conversation guide’, co-designed by the facilitator’s, was used at the facilitator’s discretion to avoid potential safe guarding issues.

The most frequently asked questions were developed by the co-design group of the improvement programme and took the form of a ‘conversation guide’, appendix 2. Where eventual interview questions differed the data was grouped where appropriate in to the Q1- Q5 format set out below.

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| Question | |
| 1. | Tell us what happened when you/someone you care for was on a mental health ward? |
| 2. | Each ward has rules around acceptable behaviour. Were these explained to you/ the person you care for and to you? |
| 3. | There are supports (care plan, advanced statement, activities) we can provide to avoid a situation getting out of control. Were these explained/offered to you/the person you care for and to you? |
| 4. | If you/the person you care for experienced restraint or seclusion, would you expect staff talk to them, or you, about it afterwards? |
| 5. | From what you have seen/experienced, what could have been done differently? |

The ihub’s Evidence and Evaluation Team was asked to analyse the data resulting from the interviews.

**Summary of Findings**

This document represents a pragmatic summary of the information gathered, in order to identify insights and suggestions for improvement from the gathered data.

* It appeared that some transcripts represented multiple perspectives of a single incident, for example recall from both patient and carer/family perspectives. If this was the case, both were considered.
* The level of detail shared in the transcripts varied and an informal approach to analysis was taken to summarise the content. The transcription was not presented verbatim.
* For this summary, only transcripts where data were recorded in the first person (for example, where the transcript was written from the “I” perspective) were considered.

**Findings**

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| 1. | Tell us what happened when you/someone you care for was on a mental health ward? |

*One of the nurses saw me at ward door and took me into a small office. He got me tea and a juice for the wean and told me he’d be right back. All I could hear was an alarm going off and people running. I was so scared…About 20 mins or so the original nurse came back and told me what had happened. He said it would be best if we went home and called later to see if my son wanted us to visit. I asked what my son had done and was told he had got involved with an argument with another patient and it had turned violent and my son needed to be sedated to calm down. I don’t think it could have been handled any better, the nurse was really nice and just kept asking if I and my granddaughter were ok. (Carer interview).*

*I know the staff have a hard time but really these folk are ill and probably terrified. My daughter just wanted home as she was scared it would happen to her. Seeing it made me feel powerless and very angry, what about the rights of these patients? It would have helped if staff had come back to make sure the patients, and visitors were alright after [witnessing restrictive practice on another patient] but they didn’t. My daughter says when it happens patients are asked to go into their rooms if possible but no one comes to see if they are ok. I think seeing something like that needs follow up to make sure the other patients are ok (Carer Interview).*

A number of different personal accounts were shared of experiences, which appeared to be mostly on adult hospital wards.

People described varied experiences, but where words were used to describe emotions within the transcripts these included:

* Upset
* Terrified
* Powerless
* Angry
* Scared
* Frightened

Where a carer had experienced that a restrictive practice incident was handled well, they described constant empathetic communication from a staff member on the ward throughout the experience.

One piece of data transcription in bullet point form appeared to potentially describe a historical safeguarding concern – reassurance was sought that this had been addressed as per appropriate existing policy.

Suggestions for improvement included:

* A follow up wellbeing check for all involved in the incident including staff and patient witnesses
* More time for integration of nursing staff and patients
* Gather information from the carer - context and advice about the individual person’s needs and triggers, what has worked to calm in the past
* Create a safety plan which details the preventative approach
* Systematically record and report the incident including prevention attempts and share this with the person and carer

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| 2. | Each ward has rules around acceptable behaviour. Were these explained to you/ the person you care for and to you? |

*I can’t remember seeing anything about behaviour, other than violence towards staff is not acceptable, but that’s been there for ages. I wasn’t told anything about rules of behaviour etc. and didn’t even know I could ask about such things*. (Carer interview).

*Why can a mental health patient be restrained in this way? There is clear guidance and formulation for health and social care staff who restrain young people. Measures are documented by staff and recorded. Yet in mental health there is a grey area as restraint is not regulated and in my case not even recorded. (Patient interview).*

It was notable that many of the transcripts described not ‘seeing’ anything – whilst some expectations around behaviour may have been verbally explained – they were not *visually* displayed either in ward signage or on paper.

Suggestions for improvement included:

* More time for staff to talk to the person
* Improved staff communication with carers
* Improved staff documentation and recording – and that this should be on a par with that expected for children’s services – and patient and carer ability to access these reports
* Include rules around acceptable behaviour in a ‘Welcome Pack’ for the person which would include an introduction, orientation, clear daily timetable, the times staff are available, medication, meals and so on.

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| 3. | There are supports (care plan, advanced statement, activities) we can provide to avoid a situation getting out of control. Were these explained/offered to you/the person you care for and to you? |

*Staff should get an insight into the unwell person, you can feel what is going on – you are pushed to the side. No one asks what your perception of how things are, how have we got to here. Sometimes I feel a lack of interest in my perspective. I have wanted to offer more information to how things have got to that stage.* (Carer interview).

*Never heard of an advance statement and never heard my son talk about one. He has given permission for me to be his named person and to be given information but no one has ever mentioned this. I don’t really know about his care plan as I’ve never been involved so don’t know if he is doing any activities. I’ve never asked him about his care plan... Sometimes it would be better if I could speak my concerns to doctor privately. I hate to say anything I am worried about when my son is present as it feels as though I’m getting at him.* (Carer interview).

There was little description of a care plan being explained or offered, but transcripts of discussions with carers described that it would be helpful to access this.

Suggestions for improvement included:

* Staff having time to involve carers in ongoing discussion about the care plan with the person
* Documenting the care plan and making this accessible to the person and carer and that this could include a ‘Who am I ‘ as well as a picture of the person: what they prefer to be called, what they are being treated for and any specific needs
* Having increased activities on the ward and staff being involved in these

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| 4. | If you/the person you care for experienced restraint or seclusion, would you expect staff talk to them, or you, about it afterwards? |

*There were no notes at all to explain that I had been denied medication, sectioned or restrained – as no doctor had been present to authorise these measures. As there were no records, no explanation was ever given to my husband.* (Patient interview).

*The nurse on the day it happened did speak to me and I have to say I found it a real comfort. He told me my son was fine, and I remember him saying something like “it sounds horrible to say your son was restrained but we are all trained in how to do this in as safe a way and for as short a time as possible and I can assure you that this was what was done.”…I felt relieved that the nurse talked to me, I would have hated to have been sent away and then hear nothing from them, my mind would have thought all sorts of things were happening. (Carer interview).*

One carer reported that this had happened and it had been helpful. Carers advised that they would expect staff to talk to them about an incident such as a person being cared for being restrained and they would like to know what had been tried before restraint was used. Some also suggested they would expect it to be recorded in addition (and therefore a report would be available). A person who had directly experienced restraint advised they would expect a different staff member to the person who carried out the restraint to talk to about the experience.

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| 5. | From what you have seen/experienced, what could have been done differently? |

*I was being treated in a (physical speciality ward) and I was prescribed pain medication and other medication at high dose. On admission to (specialist mental health ward) there was no doctor available to carry out physical health checks or write up my medication. This meant I went without any medication the other ward had prescribed for me for over 4 days. A GP came to the ward but said he could not prescribe any of my medications… (Patient interview).*

*In my case I don’t think they could have done anymore, the staff were great. I suppose it could have been different if no one spoke to me, but that’s what most of the issues are, lack of communication and trying to cover things up. I hear from other [families] some awful stories about them being left in the dark about things, guess I am just lucky that hasn’t happened to us. … (Carer interview).*

Suggestions for improvement included:

* Sharing information with patients and carers about standards relating to restraint – what is permitted and what is not, what de-escalation means
* Pro-active work involving patients and carers, respecting communication with them
* Use ‘Who am I’ and safety plan documents
* More time for staff and patients to interact
* Inform patients at admission if there are staffing issues or absences, give a clear explanation of ward rules, as well as the possibility of the practices of seclusion and restraint and how these are used and monitored
* Access to an independent advocate (details could be included in a welcome pack)
* Accountable process so staff are not left to manage restraint individually
* Joined up physical and mental health care – consider patient’s physical needs including medication and pharmacist involvement if necessary
* Least restrictive practice in a respectful manner- risk of reduced trust in the clinical relationship

**Scottish Patient Safety Programme for Mental Health Response**

We are grateful to our colleagues in Carers Trust Scotland, Support in Mind and the Mental Health Network (Greater Glasgow) for collaborating with us to understand the experiences of people with lived and living experience and the opportunities for improvement they have identified.

**How have we responded?**

SPSPMH has taken the findings of this report along with an [evidence scan](https://ihub.scot/media/8776/2021108-spsp-mental-health-evidence-scan-v10.pdf) and staff survey and developed a new suite of [improvement resources](https://ihub.scot/improvement-programmes/scottish-patient-safety-programme-spsp/spsp-programmes-of-work/spsp-mental-health/spsp-mh-20212023/) to support inpatient teams across Scotland.

The new [SPSPMH change package](https://ihub.scot/media/8781/20211012-spspmh-change-package-v10.pdf) reflects a significant number of the improvement opportunities identified above, such as

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| Opportunities for improvement | Change ideas in our change package |
| Systematically record and report the incident | [Measurement framework](https://ihub.scot/media/8778/20210706-spspmh-measurement-framework-v10.pdf) that includes recording incidents of restraint and episodes of seclusion |
| Create a safety plan which details the preventative approach | Aligned person-centred clinical needs assessment, risk assessment and safety planning |
| Improved staff documentation and recording | Person-centred care planning |
| Improved staff communication with carers | Improve communication between staff, families and carers |
| Having increased activities on the ward and staff being involved in these | Introduce staff led group activities |

We will also share these findings throughout our networks to allow services and teams to independently identify and address improvements identified in this report that may be required in their area.

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| Appendix | |
| Appendix 1 |  |
| Appendix 2 |  |