



Interim Mental Health Lived Experience Report – Mental Health Carers Group / Healthwatch Stockport

Report To (Meeting):	ONE Stockport Health and Care Board		
Report From (Board Lead)	Maria Kildunne, Chief Officer, Healthwatch Stockport		
Report From (Author):	Mental Health Carers Group Stockport / Healthwatch Stockport		
Date:	19/07/23	Agenda Item No:	9
Previously Considered by:	Not applicable		

Purpose of the report:

- This is an interim executive summary report to update partners on the progress of the joint Serious Mental Health Engagement work programme from Healthwatch Stockport and Mental Health Carers Group Stockport.
- The focus of this review was to engage people with lived experience of serious mental illness, about mental health services provided in Stockport. People with lived experience engaged with us either directly or via their carers or other local voluntary and community groups who could help them articulate their experiences of using services, either from a community or hospital perspective.

Key points (Executive Summary):

- The aim was to highlight key considerations to the One Stockport Health and Care System for us to work collaboratively in improving quality of care, treatment, and support for people with serious mental ill health.
- It feeds into the Stockpot Mental Health Strategy. The work complements Ambitions 1 and 5 [Putting Lived Experience at the Heart of What We Do and Improving our Mental Health Support to Enable People to Live Fulfilling Lives – Community Mental Health Transformation for Adults and Older People, respectively].
- The strong views expressed by the participants suggest that the current care provided is not always optimal. Many carers supporting their loved ones in feeding back also highlighted the lived experience of being a carer of someone with a serious mental illness. Their experiences highlighted the need for specialist carers support. We have categorised the emerging themes which relate to 12 key areas.
- Three of those areas which were discussed most include:
 1. Communications with patients and carers.
 2. Recognising and raising awareness that serious mental illness is a long-term fluctuating condition and awareness about the debilitating side effects of medication.



<p>3. Specific training and specialist knowledge when undertaking Care Act Assessments and raising awareness of Section 117 Free Aftercare legislation.</p> <ul style="list-style-type: none"> • Primary Care was also raised frequently when listening to participants and we would like to propose a follow up piece of work with primary care colleagues and PCNs early next year. • There are recommendations within the report relating to these key areas which we would like to Board to consider through the proposed Mental Health Partnership Board. 			
Recommendation:			
<p>The Board are asked to:</p> <ul style="list-style-type: none"> • Acknowledge the interim report. • Agree to consider the 3 key areas highlighted in the report through the proposed mental health partnership [if governance agreed] with a follow up piece of work around primary care next year. • Receive the full report later in year. 			
Decision		Discuss/Direction	X
		Information/Assurance	X

Aims (please indicate x)		
Which integrated care aim(s) is / are supported by this report:	People are happier and healthier and inequalities are reduced	x
	There are safe, high-quality services which make best use of the Stockport pound	x
	Everyone takes responsibility for their health with the right support	x
	We support local social and economic development together	

Conflicts of Interests	
Potential Conflicts of Interest:	The chair of the Mental Health Carers Group sits on a range of local, regional, and national mental health groups and has been asked to note their role as a Governor of Pennine Care NHS Foundation Trust.

Risk and Assurance:	
List all strategic and high level risks relevant to this paper	Mental health recognised as a key priority for Healthwatch Stockport.

Consultation and Engagement:	
Local People / Patient Engagement:	This is a report coproduced by people with lived experience of serious mental illness, their carers, and representatives from voluntary and community organisations [Advocacy, Mind, Pure]
Workforce Engagement:	We are working to ensure the feedback from people working in statutory mental health services is included in the final publication.

Potential Implications:						
Financial Impact: Please note - All reports with a financial implication require detail of the level of funding, funding stream and comments from Finance.	Non-Recurrent Expenditure	£				
	Recurrent Expenditure (please state annual cost)	£				
	Funding stream	Yes		No		
	Included in the s75 Pooled Budget					
	GM ICB (Stockport) delegated budget					
	Other, please specify:					
Finance Comments:	This piece of work was co-produced by mental health carers groups Stockport, organisations from the voluntary and community sector and Healthwatch Stockport within their own organisational resources.					
Performance Impact:	n/a					
Workforce Impact:	n/a					
Quality and Safety Impact:	n/a					
Compliance and/or Legal Impact:	Healthwatch Stockport are working within their statutory functions to ensure the voices of local people are made known to those responsible for commissioning and scrutinising health and care services.					
Equality and Diversity: Has an equality impact assessment been completed?	General Statement: Healthwatch Stockport is committed to ensuring all our activities are free from any form of discrimination on the grounds of age, disability, gender, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation, in accordance with the Equality Act 2010. We have developed an equality roadmap that sets out our commitments to addressing equality, diversity and inclusion that runs through all our work.					
	If Not Applicable please explain why	Yes		No		N/A
Environmental Impact: Has an environmental impact assessment been completed?	General Statement:					
	If Not Applicable please explain why	Yes		No	x	N/A

Interim Executive Summary Report for ICS Stockport Locality Board

Lived Experience of Mental Health Services

Introduction

“In Stockport there are 3,040 people registered with a Stockport GP with a severe mental health disorder.” [Stockport JSNA, 2022]

This is an interim executive summary report to update partners on the progress of the joint Serious Mental Health Engagement Review from Healthwatch Stockport and Mental Health Carers Group Stockport

Health and care services for serious mental health are complex and covers a broad range of provision from community-based services to secure hospital admissions. In this review we drew on people’s experiences across the system including primary care and housing.

In Stockport there are over **3,040** people registered with a Stockport GP with a diagnosis of a severe mental health disorder. This includes people with schizophrenia, bipolar affective disorder, other psychoses, and other patients on lithium therapy (Stockport JSNA 2022). This is up from 2,400 people registered with a Stockport GP in 2016 [Stockport JSNA, 2016](#).

There is a clear deprivation profile for mental health, with rates of poor mental health in the most deprived areas higher than those in the least deprived [double]. There are significant inequalities, having a mental illness is associated with lower employment, social isolation, poverty, homelessness, increased physical health risks and conditions, and worse health outcomes. It is unacceptable that a person with serious mental illness faces a life expectancy many years shorter than that of the general population.

In 2019 NHS England published the [Long Term Plan](#), which laid out its ambitions for health and care for the next ten years. The [views of over 34,000 people](#), told Healthwatch across the country that they wanted mental health support to improve, helped informed the plan.

It can be difficult to understand serious mental illness, how it presents, how it can affect an individual, carer, and/or family on a daily basis. For several years people with serious mental illness and their carers have reported poor experiences of care to local groups such as Mental Health Carers Group Stockport, SPARC, Stockport Mind, Stockport Advocacy and Healthwatch Stockport.

For example, it is often difficult to get help and support for a loved one with a serious mental health condition if the person lacks insight, as one of our carers who participated in the review illustrates:

My son will often say 'I'm not ill, I don't need help'. This causes problems on many fronts as the cognitive problems he has had since he became ill means that his memory is poor and he often forgets to order medication, forgets to pick it up and take it.

He is 34 and for the most part has managed various volunteering jobs, however people often think that because they see him on good days that he is capable of much more, like paid work and/or college course – which he is capable on those good days – when he is bright, intelligent and caring, however his paranoid schizophrenia and bi-polar means he can't sustain a job or course for long, which excludes him from getting far down the recovery path and causes him to despair further...

There doesn't seem to be anyone who can work with him to keep him well and in a good routine to stop him relapsing, health and care services can't seem to grasp he has a long term condition and needs consistency..

Review Focus

The focus of this review was to engage people with lived experience of serious mental illness, about mental health services provided in Stockport. People with lived experience engaged with us either directly or via their carers or other local voluntary and community groups who could help them articulate their experiences of using services, either from a community or hospital perspective.

The aim was to highlight key considerations to the One Stockport Health and Care System for us to work collaboratively in improving quality of care, treatment and support for people with serious mental ill health.

It will also feed into the Stockport Mental Health Strategy. The work complements Ambitions 1 and 5 [Putting Lived Experience at the Heart of What We Do and Improving our Mental Health Support to Enable People to Live Fulfilling Lives – Community Mental Health Transformation for Adults and Older People, respectively].

Who was involved.

The review was undertaken and co-produced in partnership with [Healthwatch Stockport](#) and the [Mental Health Carers Group Stockport](#). We also collaborated with local voluntary and community organisations who support people with serious mental illness and invited them to take part and provide feedback about services from people they regularly support.

We were able to capture over 35 personal accounts of people with lived experience, service users and carers and further feedback was gathered from the organisations we contacted who subsequently submitted feedback.

What we did

The Review began in 2022 with Healthwatch Stockport and Mental Health Carers Group Stockport. We spoke to people living with mental illness, carers, organisations, and groups from the VCFSE Sector.

The engagement spanned 12 months attending several meetings to raise awareness of the review, building trust to ensure people felt comfortable in sharing their experience and encouraging participants to come forward emphasising the importance of hearing the voice of local people. This was intensive as many people although would voice opinion and concern found it hard to articulate or write down their experience, so building up trust in the process was an important factor.

Results

It is apparent from the strong views expressed by the individuals that the current care provided is not always optimal. Many carers supporting their loved ones in feeding back also highlighted the lived experience of being a carer of someone with a serious mental illness. Their experiences highlighted the need for specialist carers support. We have attempted to categorise the views/concerns and actual case reports into 12 themes:

Emerging Themes

1. Lack of care coordination for patients and families
2. The importance of the role of carers and their health and care needs
3. Communication between services and patients and carers and across services
4. Inconsistent primary care liaison, knowledge, and expertise
5. Lack of access to dental services
6. Medication and understanding/awareness of the complexity of SMI
7. Hospital Care and Discharge
8. Lack of understanding of Section 117
9. Lack of brokerage / direct payments support for mental health
10. Lack of adequate housing for people with SMI
11. Risks associated with cuckooing
12. Employment/voluntary work opportunities / access to and support with financial support.

Within each of the themes we have identified the key issues for people, with potential solutions, recommendations, or areas for further clarification and discussion. These are contained within the full report (which will be published in September 2023).

We acknowledge that to work simultaneously on all twelve themes would be resource intensive and therefore unachievable. Initially we propose **three key areas** to begin work on, followed by a bigger piece of work with primary care later on.

Three KEY areas to be considered:

Having a reliable care coordinator who frequently spoke directly with them as well as their family members/carers has repeatedly been raised as a starting point for person centred care.

However, as Care Coordinators are being phased out under [The Community Mental Health Framework for Adults, and Older People](#) and being replaced by Key workers, multi-disciplinary teams (MDTs,) and the Living Well Framework.

Therefore, we would like the following three areas and recommendations be considered and put in place:

1. Communications with patients and carers.

Communication methods between the Community Mental Health Team (CMHT) and mental health patients/ carers is poor and is in real need of updating.

At the moment carers of working age adults have to ring a receptionist on a land-line at CMHT if they need to speak to the Care Coordinator and rarely get to speak to the coordinator straight away. The care coordinator may then ring them back at any time.

Recommendations:

- a. Safe and updated ways of contacting relevant staff should be developed for appropriate purposes e.g., email, text or use of mobiles.
- b. Use of the [2021 SHARE documentation](#) developed by the [Zero Suicide Alliance](#) for safer information sharing between staff and mental health carers and encouraging service users to share information should be followed by all staff working with people with serious mental illness. (Dept of Health & Social Care update – 2021).
- c. Pennine Care Foundation Trust continue to be part of the [Triangle of Care developed by the Carers Trust](#) and deliver training around carer awareness, be disseminated to Adult Social Care, voluntary sector and all staff working with people with serious mental illness and mental health needs.

2. Recognising and raising awareness that serious mental illness is a long-term fluctuating condition

Carers need quick, direct access to educated, skilled support for the mental health condition of their loved one in the community, when they recognise the signs that their loved one is becoming ill.

This must include quick access to appropriate clinical staff when the service user is deteriorating quickly/having difficulty with taking and/or experiencing the side effects of prescribed medication.

Recommendation

The new community service for people with serious mental illness in the community (Living Well Team) provides this “**assertive outreach**” link and we have access to rehabilitation support staff to guide us in our caring, and that appropriate (and recurring if needed) respite is developed.

3. **Care Act Assessment and Section 117 Free Aftercare legislation**

Individuals and carers can access on-going personalised, social care support via [the Care Act assessment](#) and [The 117 Free Aftercare](#) following a section under the Mental Health Act and receive help when required.

Recommendation

The Care Act assessors should have specific knowledge of our loved ones’ mental health condition and the effect it can have on their daily lives (e.g., how changes to their **executive functioning** means they need support in some daily living skills, such as making decisions, completing tasks, memory etc. even though they don’t recognise this).

Personal Accounts

Three case studies¹ have been chosen to illustrate the key areas outlined above, they are personal accounts that highlight issues being raised about communication, provides insight into the fluctuating nature of serious mental illness, how it affects both patients and carers and provides examples of where a care act assessment or 117 Free Aftercare can make a difference.

(These are direct extracts taken from personal accounts of participants, these are their views, about their situation, and they do not necessarily reflect the overall views of services. Wording has not been changed to retain the feeling and sentiments of the individual)

My wife has been seriously ill over the last five years and over the last two years she has been admitted to the Oasis Mental Health Unit at Stepping Hill on several occasions. She has now been diagnosed with Bipolar II and she is at home, and I continue to be her carer 24/7.

My wife does not get regular home support visits. I recognise that resources are constrained but the main reason is that my wife finds her allocated nurse to be very difficult to liaise with. A couple of years ago she liaised with a care worker who visited weekly, and she was very helpful and supportive.

The Mental Health Services are not co-ordinated with GP services at all. I have asked for joint reviews to discuss my wife's illness, but these never happen. The Mental Health Team do not seem to want to know about non-mental issues, and my GP doesn't want to know about mental issues. But mental issues affect physical health and vice-versa.

I have found, over the last five years, that there is very little support for carers. I am her sole carer 24/7 when she is ill. Last summer I had to leave home (on doctor's advice) as I was exhausted and needed immediate respite. I cannot understand why carers are not supported more. If carers can't cope, then this leads to more problems for the health services.

Unless the general situation improves, I cannot see how I can continue to provide support on my own. This is because I am continually exhausted, have had no holidays for years and hardly get out at all. I'm trying my best but cannot continue like this."

Personal Account 2:

¹ Full permission has been obtained from participants to allow us to include and share experiences.

Our Son suffers with schizophrenia and bipolar disorder. He was placed for some time under the Section 3 mental health act² within a placement in Stockport. Heathfield House³ was an excellent placement and met his needs perfectly as he permanently needs an element of control in his life. Previously, he had been placed back in the community which resulted in disastrous outcomes on at least 3 occasions.

Despite this previous history, a decision was made that he could be moved to a supported living accommodation and placed on a Community Treatment Order⁴ (CTO). After 6 months his CTO was cancelled by his Approved Mental Health Professional (AMP), on his own, despite objections from his parents, care workers and psychiatrist. He has since almost died of a drug overdose.

His care package included a social worker who seemed to look after both his social and mental wellbeing. However I think it was in April 2021, this service, for some unknown reason was split so all he had was social support with no mental health support, It took us 9 months to eventually get a care coordinator allocated to him, in which time he has decided to reduce his own medicine intake spiralling into chaotic erratic behaviour.

our son reduced his Clozaril by over half each It was HIS decision, because he could do, and there was nothing his psychiatrist could do, even though everyone knew it would result in disastrous and potential life-threatening consequences.

The problem to us seems to be that people with mental illness can be placed under a Section 3 to protect both themselves and others. The system then seems to want to get them into the community as soon as possible which is all very well. However, you then have people with mental illness, unable to make rational judgments and decisions allowed to care and make decisions for themselves. There is no in between support and care from a Section 3, to being released in the community.

My Summary of my experience:

- I felt the AMP was given too much control to cancel the Community Treatment Order*
- No cognisance of previous issues, concerns and history when reviewing Community Treatment Order. The stance seemed to me - "let's not bother with what's happened in the past, it's the future that matters. People can change".*
- There are times where some people need constant control in their lives, and they cannot survive without full support in the community.*
- More resources needed as care co-ordinators to support mental wellbeing.*

² [Section 3 Mental Health Act Explained](#)

³ [Heathfield House](#)

⁴ [A Community Treatment Order \(CTO\) explained](#)

- *I feel there is a gap in mental health support between hospital section 3 placement and in community placement"*

Personal account 3:

My son's last care plan which he was shown was in January 2020. Since leaving his supported accommodation in January 2021, he has been living at home with our family of 5. We brought him home from the supported accommodation as he was being evicted. He was being cuckooed and being blamed for the actions of others who he thought were his friends but weren't.

He is entitled to section 117 Aftercare and is very vulnerable, but during Covid he was only having 1 hour per week support instead of the 6 hours he had on his support plan. It was in the morning and his medications make him drowsy in the mornings.

In the 14 months he's been at home we have never seen a care plan, (or assessment or support plan). We believe he was having an assessment over the phone, but we never heard back the results.

Since his care coordinator left soon after he left Heathfield Rehab in October 2019, he had no care-coordinator, for months, then a locum, (after we complained) and then months with no-one.

Similarly, with the social workers – he's had two or three who left after one phone conversation. When I phoned to ask to speak to one who had been allocated a few weeks before – they said he'd left that day.

He has not been given a personal budget – we don't know why as we haven't seen his Care Act Assessment.

Recently he has been given an excellent care worker who takes him to an activity twice a week. However, he can only do this when he is on duty; when he's not on duty, I have to take him, or he can't go. There is just no consistency.

I work full time and my son is home all day with no routine which he desperately needs.

Three weeks ago, my son was given a new care coordinator. She came to our home to see him, and I had the morning off work to meet her. My son had wanted to come off his medication for some time and we were pleased

that he could talk to a care-coordinator about the side effects of his medication and how he was feeling.

From the start she tried to exclude me and said I didn't need to be there. I explained that she was in my home, and I had never met her before, and my son was happy for me to be there. My son wanted my support as he finds it stressful meeting a

new people and answering questions and usually just wants to get it over with quickly.

When my son tried to explain about his medication, she wouldn't listen and dismissed what he was saying. I supported his explanation about the meds and tried to explain about the difficulties at home and the support he needed. She dismissed this as well and said it seems like he doesn't need our (ie the CMHT's) support any more.

My son and I wanted a copy of his latest care plan. She only had a copy of the Jan 2020 one and went through it quickly with my son. When I asked for a copy, she just asked my son if he wanted one – he said he wasn't bothered, (as he wanted to get the meeting over with asap), and so she didn't give us a copy.

As his carer, I really need a copy of his most recent care plan to help me with his care. The communications were not in accordance with the Triangle of Care, and I am very worried about his care after this first meeting.

On the positive side, we arranged a meeting with my son's consultant who spoke with both of us and explained his difficulty with his meds. She has listened and is changing his meds and keeping me fully informed – as I need to be as his carer."

Next Steps

Continual conversations are taking place about the recommendations within each of the themes with people who took part in the review and system leaders to ensure we work towards balanced and achievable outcomes which will improve the quality of life for people with serious mental illness, whilst we continue to work towards publication of the full report in September.

We are currently working with system leaders in mental health, health, social care, and public health in setting up a Mental Health Partnership Board, which will be co-chaired by someone with lived experience* ⁵

Whilst this Board will work towards supporting the delivery of the mental health strategy, we believe the mental health strategy in its current form needs to be strengthened on delivering good outcomes for people with serious mental illness in Stockport. We hope that this board will also oversee some of the proposals set out within this and our subsequent reports.

⁵ * Format, membership, and name yet to be decided

Appendix i

About Us

[Mental Health Carers Group Stockport](#) (MHCGS)

MHCGS is a constituted community group, launched in 2011, and run by a committee of mental health carers.

The group is for people living in the Stockport area who care for or support family members or friends of working age living with a serious mental health condition. The group also includes carers who live outside Stockport, but who's loved one lives in Stockport, and people who were members but have been bereaved by suicide.

Their motto is "**One Size Does Not Fit All in Mental Health**" and they campaign for better treatments and care for loved ones with severe mental health conditions.

Activities of the group includes self-help, information, speakers, peer support, networking, campaigning, fundraising, advocacy, representing the group at local and national planning meetings. They challenge attitudes to mental illness, share knowledge and expertise about treatments, policy and cutting-edge research, making a difference locally and to mental health services.

The group hold monthly meetings, both face to face and via Zoom and regularly invite expert speakers and/or researchers to discuss various topics such as how the Care Act is implemented for people with mental health conditions in Stockport.

Irene Harris Is the co-author and Chair of MHCGS and is a member of many other bodies locally, regionally, and nationally such as being a Governor at Pennine care FT.

[Healthwatch Stockport](#)

Healthwatch is your health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services, we want to hear about your experiences.

As a not-for-profit independent organisation who carries out statutory functions, we have the powers under legislation to ensure NHS leaders and other decision makers listen to your feedback and improve standards of care. Last year we helped nearly a million people across England like you to have your say and get the information and advice you need.