

Sharing your experiences of support for mental health and wellbeing

Survey Report

February 2016



Introduction

Healthwatch Worcestershire (HWW) is undertaking a piece of work to find out the experiences of people who use and try to access mental health services. We are also seeking the experiences of carers. This piece of work takes a whole system approach and looks at the support people receive for mental health from a number of services not just NHS Mental Health Provision.

Why are we doing the work?

Locally

Locally HWW identified our mental health business priority as a consequence of the service user and carer experiences reported to us during our first year of operation (2013), and these reports continue to be made to us. We have identified some key themes:

- Access to primary care
- Access to crisis support, especially out of hours
- Not feeling listened to and taken seriously

We would expect the findings and recommendations to influence the current redesign of Primary Care, Secondary Services and Vocational centres and to give service users a say in how services are run. There is a large piece of work being undertaken to implement the local action plan for the Mental Health Crisis Care Concordat. The findings and recommendations in the report provide further evidence demonstrating the need for improved access to quality support during a crisis.

Nationally

Improvements needed in support for mental health and wellbeing have been recognised nationally by NHS England (NHSE) and the Care Quality Commission (CQC). In March 2015 NHSE launched the independent Mental Health Taskforce to develop a five-year strategy to improve mental health outcomes across the NHS. In September 2015 the Taskforce published the report: The Five Year Forward View Mental Health Taskforce. Prevention, Access and Quality are the three key themes that emerged from this piece of work. The CQC's Right here, Right now

explored people's lived experiences of support during a mental health crisis finding many experienced problems accessing the right help at the right time. This report highlights the inconsistency people experience in the quality of care they receive when accessing help in a crisis and the implications for safety when people do not receive the appropriate care quickly enough. The themes emerging from these reports are reflected in the service user and carer feedback we gathered prior to this survey.

Methodology

Engagement was carried out with service users, carers and representatives at 16 support groups and voluntary organisations from across Worcestershire. The key themes from this engagement were used to form the survey which was co-produced with a task and finish group of service users, carers and representatives from groups and organisations like Survivors Worcester and Speak Easy. The survey used adapted questions from the CQC report Right here, right now. The survey was completed by a total of 68 service users from across Worcestershire. 42% of the surveys were completed online with the remaining 58% being sent in by post or completed face to face with the support of a HWW Engagement Officer.

All survey questions were optional giving people the opportunity to skip irrelevant questions or questions that may have been too difficult to answer.

Results - Access

If you have been diagnosed with a mental illness please tell us what it is.

41 - Depression/Anxiety or both

9 - Personality Disorder

6 - Bi-polar

6 - Schizophrenia

3 - Post Traumatic Stress Disorder

(Many people had more than one diagnosis)

Have you ever tried to access mental health services?

97% - Yes

3% - No

Where did you go first?

89% - GP

5% - Voluntary organisation or support group

6% - Other (Hospital, Out of hours GP, Helpline)

How long did you wait between being referred and receiving an assessment?

31% - Up to one month

25% - 1-6 months

23% - 6+ months

21% - Other (can't remember)

How long did you wait between your assessment and your first appointment/receiving support?

33% - Up to one month

25% - 1-6 months

8% - 6+ months

34% - Other (can't remember)

Quality of care and support

Have you been asked what things would make you feel better?

- 19% - Yes
- 27% - Sometimes/occasionally
- 34% - No
- 20% - Not as much as I would like

What information has been given to you by the services supporting you?

- 55% - A crisis telephone number
- 28% - A named person to contact in a crisis
- 49% - How to access help in a crisis
- 43% - Information about coping skills
- 55% - Information about medication (side effects, how to take, when it will be reviewed).
- 32% - Information about support groups
- 51% - Information about condition/illness

What information would you find helpful that you have not been given?

In order of frequency...

- What to do in a crisis, including who to contact and where to go
- Information about local support groups
- Information about diagnosis and coping skills
- Easy read/easy to understand information
- Information about waiting times and communication during the waiting period

Do you feel the help, care and support you receive meets your needs?

- 19% - Yes
- 46% - No
- 32% - Some but not all
- 3% - Not sure

What would make the help, care and support you receive better meet your needs?

In order of frequency...

- Someone to talk to
- To be listened to and heard
- Personalised support, not one size fits all
- Peer support
- One point of contact
- Support to extend past 6-8 weeks
- Timely access to the right support
- Information about medication and coping skills

Do you receive help, care and support from anywhere else?

60% - Friends and family

38% - Voluntary organisation

29% - Support group/peer support

10% - Helpline

10% - Online/social networking

19% - None

Why did you choose this support?

The top three reasons...

1. To talk to people who understand/are going through the same thing (71%)
2. Safety and security (42%)
3. Didn't know where else to go (39%)

Discharge

Have you been discharged from mental health services?

50% - Yes, now receiving no support or treatment

10% - Yes, now using the service again

40% - No

Did you feel ready to be discharged?

13% - Yes

69% - No

18% - Not sure

What information were you provided with when you were discharged?

Nearly 60% had received no information.

Other comments...

“That my doctor would monitor me. That didn’t happen which is why I am in the service again”

“Call the Samaritans”

“Lots. All very good”

“Out of date leaflets from another health authority”

Do you know what to do and who to contact if you begin to feel unwell again?

44% - Yes

37% - No

19% - Not sure

What else could have been done to support you in discharge?

In order of frequency...

- More gradual process
- Information about what happens next
- Information about support groups
- How to get help again if needed

There are a wide range of services that might provide help, care and support for people experiencing a mental illness. The percentages represent those people who agree with the... I feel/felt statements for each service they came/are in contact with.

Local Service	Treated with respect	Listened to and my concerns are taken seriously	Treated with warmth and compassion	Not Judged	Given the advice and support I needed	Given help in a timely way
GP	70%	72%	60%	58%	50%	46%
Community Mental Health Team	60%	47%	47%	57%	40%	37%
Home treatment team	75%	67%	58%	58%	58%	67%
Cognitive behavioural therapy	72%	56%	52%	68%	44%	36%
Psychological therapy	75%	69%	62%	69%	62%	44%
Counselling	70%	65%	70%	60%	55%	45%

Crisis

How did you first come into contact with care services or the police?

I, or someone else...

Telephoned/went to a GP surgery	72%
Went directly to A&E	10%
Called the police	5%
Called an ambulance	8%
Contacted a service that specialised in mental health or crisis care	5%
Phoned a helpline/visited a website	0%

How long did it take for you to get the help you felt you needed?

14% - Up to 1 hr

14% - 1-4 hrs

18% - 4-12 hrs

9% - 12-48 hrs

14% - 48+ hrs

16% - I didn't get any help

15% - I can't remember

Where did the help come from?

28% - GP

19% - Crisis Team

11% - Ambulance

8% - A&E

8% - Police

6% - CPN

6% - HTT/CMHT

14% - Other

Do you feel the care you received provided the right response and helped you to resolve your mental health crisis?

30% - Yes

51% - No

19% - Not sure

What do you feel was most important to you in the care you received during your crisis?

In order of frequency...

- To be listened to
- Someone to talk to
- Warmth and compassion
- Not being judged
- Understanding/feeling understood
- Right response received quickly

In your opinion, do you feel anything was missing that you feel might have improved the quality of care you received during the crisis?

63% - Yes

18% - No

19% - Not sure

Additional comments...

“Felt like I was being processed”

“In A&E...I felt alone and afraid and judged”

“To this day I feel misunderstood”

“Lack of communication and support”

“The crisis team could have come quicker and been more sensitive”

Do you feel anything more could have been done to prevent you from reaching crisis point in the first place?

58% - Yes

42% - No

Additional comments...

“Quicker help”

“Immediate practical help”

“Support services when I need anything”

“Not to be told by the crisis team they haven’t got anyone to help”

“I was too ill to ask for help and no one knew how ill I was”

If you experienced a crisis in the future do you think you would know what to do?

58% - Yes

42% - No

How confident to you feel that you would receive a timely and helpful response from your local services?

2% - Very

44% - To some extent

42% - Not at all

12% - Don’t know

There are a wide range of services that might provide help, care and support for people experiencing a mental health crisis. The percentages represent those people who agree with the... I feel/felt statements for each service they came/are in contact with.

Local Service	Respected	Listened to and my concerns taken seriously	I was treated with warmth and compassion	I was not judged for what I had done or how I felt	The advice and support I was given was right for me	I was given help in a timely way
GP	60%	67%	55%	60%	50%	50%
Community mental health team	50%	45%	41%	50%	45%	45%
Accident & Emergency/Minor Injury Department	33%	44%	33%	33%	33%	39%
Mental health liaison in hospital	64%	54%	45%	54%	54%	45%
NHS 111 phone line	36%	27%	36%	36%	36%	36%
NHS Ambulance	50%	58%	50%	58%	42%	50%
Social Services	30%	30%	30%	30%	10%	0%
The Police	64%	57%	43%	50%	50%	57%

Summary

The findings of this survey suggest that whilst some people have positive experiences of support for mental health there is an inconsistency in the quality of care received. Key themes can be identified as:

- Not feeling listened to and/or taken seriously
- Not being treated with warmth and compassion
- Timely access to the right support
- People do not have confidence in the services supporting them

Additional comments

“I had a series of 8 appointments, I just felt it wasn’t long enough”

“I have never received a review of my medication which I have been on for 14 years”

“I have a great GP...he referred me to other support and when I go there I feel I am not being listened to or like a bat and ball being bounced around all areas”

“It feels like a one size fits all approach. Individual needs are not listened to. Felt I needed to fit a tick box”

“I don’t really understand about my tablets and if I’ll get better”

“Sometimes I feel they don’t know what I’m on about”

“All the while you’re under a mental health worker they think about discharge”

“I feel I have been left to cope, only help from voluntary services”

“Not taken seriously enough”

“Nobody has any sort of compassion or understanding what it’s like to live with mental illness”

“Not to be told a lot of medical jargon which can be a lot to take on”

“Timely support”

“Not to be treated like an idiot. Not to be asked to fit into a box. Not to be treated like a waste of time”

“I understand I was only suffering from mild depression but I felt I was low down on the list of priorities and would not be inclined to go to my GP in future.

“My GP was extremely understanding and saw me 3 times in one day”

“All the treatment in the psychiatric wards and by my psychiatrist and CPN was excellent. I felt the staff in A&E were not very caring or understanding of my illness. I was left alone for long periods of time...I felt I was being judged a nuisance because I had harmed myself”

“Great care, lovely people, very timely”

“The care by the ambulance crew was good”

“Crisis teams also need peer support workers”

Recommendations

Based on the findings in this report, Healthwatch Worcestershire feel that these recommendations need to be addressed by the current and upcoming redesign of Enhanced Primary Care Mental Health Services; Secondary Care Mental Health Services and Vocational Centres.

Those responsible for implementing the Mental Health Crisis Care Concordat should use these recommendations to improve the patient experience before, during and after crisis.

Other non-mental health professionals such as GP's and acute hospital staff should consider these recommendations to improve the quality of care they provide to those needing support for mental health and wellbeing.

Access

1. Waiting times for mental health services to be reduced and the evidence for this to be monitored.
2. Consideration of how services might communicate with those on waiting lists in order to keep the patient informed.
3. Consideration of risks to ensure that people are not at risk of suicide or self-harm as a result of waiting times or lack of appropriate support
4. Services to provide service users with accurate easy to understand information about how to access help in a crisis

Quality of care and support

1. Co-produce the design and delivery of mental health services with service users to ensure they are personalised and not 'one size fits all'.
2. Consider how all services can ensure consistency in the quality of information provided to patients relating to their mental health needs.
3. Ensure that professionals involve service users in decisions about their care in order for services to better meet their needs.
4. Commissioners and providers to consider how they might monitor patient experience in a meaningful way to improve services.

Discharge

1. Consideration by providers about how the discharge process can be improved.
2. Providers should consider improving the quality and consistency of information given to service users on discharge.
3. Involve service users in decisions around discharge.

Crisis

1. Continued work by those involved in the mental health crisis concordat to improve access to help in a crisis to ensure a 'no wrong door'
2. Consideration by providers on how crisis support can be person centred and not a one size fits all approach.
3. Mental health training for non-mental health professionals who come into contact with service users