

Mental Health Call for Evidence Report 2016

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Healthwatch Warwickshire wishes to thank all the respondents, both service users and carers, for their time and contribution to our report. For obvious reasons service users and their carers are not named.

We also wish to thank, Springfield MIND and Guideposts, Kineton Carers and Making Space for their advice and support with this project.

This report is available to download from our website.

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Disclaimer

This report relates to findings taken from structured interviews that took place between January and June 2016. Our report is not a representative portrayal of the experiences of all service users, only an account of what was contributed by those who took part.

Executive Summary

Healthwatch has been aware for some time of concerns about Mental Health services in Warwickshire. We knew, however, that this was a complex area to look at and also potentially very wide ranging. We wanted to look at the patient experience and did not seek to comment on clinical issues, only on the patient's experiences of them.

We sought to engage with those who had a mental health condition, through a series of one-to-one discussions. We also engaged with those who cared for people living with mental health conditions, usually family or friends.

This Report seeks to give a clear and accessible summary of those discussions, and contains both direct quotes and notes from meetings. There are also a series of recommendations:

Diagnosis - for those referred, or presenting themselves, at the single point of entry there needs to be a clearer explanation of the triage process and what can be expected. The importance of an early and clear diagnosis was stated by those who took part in the survey, for many of whom having a diagnosis was crucial. Following a diagnosis respondents felt that they had a genuine problem and were not 'making it up'. They were also more likely to search out options to help them improve their condition. There is evidence that the time from initial contact with mental health services to diagnosis is taking too long.

Talking and holistic therapies - Respondents were clear that they would all benefit from counselling, or other therapies, yet these had to be sourced independently. Respondents felt that what was offered was wholly inadequate in this respect. If this is not the case, and these services are offered, then there is poor communication between the mental health service providers and service users which needs to be addressed.

Treatment plans - There was a lack of understanding about treatment plans. Two respondents are using private healthcare and felt that they had a good plan and fully understood it. Others felt that they were presented with a plan but were not consulted about it. Mental Health Services should review their care planning with clients and how this is to be best achieved.

Discharge and follow up - Respondents were also confused about 'what happens now' when they come to the end of their treatment schedule. Some felt 'dumped and at sea' and thought there should be better handholding to ease them out of the service. There seems to be little understanding of how or why decisions are taken by the services. This could be reviewed by service providers and, where possible, clearer information given on what to expect following discharge.

Better service coordination - there appears to be poor coordination between mental health services and GP's. Respondents also felt that they were not getting a good service from their GP and that, generally, there was a lack of understanding by GP's

about mental health. There appears to be a silo approach where the patient is passed to the mental health service and then back to the GP depending on the condition.

Carers - Carers feel excluded yet have much to contribute. The case studies presented within the report clearly describe an all too common scenario whereby carers are seen as an obstacle to, rather than a partner in, the treatment process. Healthwatch recommends that mental health services reappraise their relationship with carers and specifically, the blanket use of confidentiality. All carers should be given a support pack with information on relevant local services. Confidentiality issues should be addressed following guidance issued under the ['Royal College of Psychiatrists Guidelines on Carers and Confidentiality'](#) with support from the Carers Trust.

Healthwatch Warwickshire Mental Health Report

What is this report about?

For some time now Healthwatch Warwickshire has been hearing concerns about local mental health services from both service users and carers. We have been told that there are delays in accessing services, that the service is unresponsive to carers who tend to be 'kept out of the loop', that follow up support is inadequate and that those with a mental health condition are left isolated following their discharge from a service. We have also been told that some GP's do not understand mental health services and, as a result, are unable to provide the support that patients and carers say they need.

At national level we know that there is a crisis in mental health service provision. The CQC¹ has stated in the Mental Health Act code (applying to inpatients at mental health hospitals) that;

“Providers are failing to make sure patients receive the support they need to be involved in their care.

The biggest issue we found for patients who were subject to the MHA in 2014/15 was a lack of support to be involved in their care and treatment. This included the information they were given, access to external support such as advocacy, and care planning. We are concerned by this finding, as not supporting patient, family and carer involvement may limit people's recovery and could result in longer stays in hospital, poor discharge or an increase in the potential for readmission.”

What did we want to do?

We wanted to ask service users;

- What services were they currently using?
- Did they have a diagnosis and how important was this to them?
- How did they manage their condition, what strategies did they employ?
- Do they believe that their mental health condition affected their physical health?
- What messages can we take from them to help improve services?

Carers, (these include husbands, wives, parents and children of those with a mental health condition) reported to us that they felt excluded, yet felt that they had much to offer, those health professionals treating their family member. Many stated that they are treated with apparent disdain and excluded from any of the decision making processes in the treatment of those they care for. We wanted to hear more from this

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<http://www.cqc.org.uk/content/mental-health-act-annual-report-201415>

group.

We also wanted to know more about resilience, specifically how do those with a mental health condition manage for themselves? How do they deal with what has been described as the 'hidden illness'? How do they manage on a daily basis? How do they cope with 'stigma'?

How did we carry out the research?

Healthwatch Warwickshire worked with Springfield Mind early in 2015 to explore the issue. It was decided that Healthwatch should hold a 'call for evidence' on mental health services within Warwickshire.

We knew that this was a complex area to look at and also wide ranging. We wanted to look at the patient experience and would not be in a position to comment on clinical issues.

We concluded that the most appropriate way forward, given that we wanted to conclude our initial research by summer 2016, was to take a qualitative approach based on interview rather than relying purely on gathering statistical data. We wanted to engage with those who had a mental health condition, through a series of one-to-one discussions. A structured interview framework (see appendix 1) was designed with the help of Springfield Mind that would be the basis of the interviews.

Interviewees could wander off track if they wished, and they often did. The framework was not rigidly enforced.

We also understood that we could only interview those who were well enough to maintain a discussion and respond with cognitive insight into their condition and experiences.

Service providers, particularly Making Space and Springfield MIND, have been very supportive in facilitating access to those who wished to be interviewed. Healthwatch also visited their drop in sessions with users and carers. Healthwatch would also like to thank Guideposts and Kineton Carers for their support in facilitating access to carers.

Healthwatch also spoke to carers and users who were not involved with any support groups.

Interviews took place in people's homes, the Healthwatch office and cafes. Generally, the interview took about an hour.

One small and informal focus group took place at Springfield Mind Hub that did not make full use of the interview template due to the fluid nature of the event with clients coming and going throughout the visit.

One respondent visited the Healthwatch office wanting to discuss mental health services and the guided interview template was not used on this occasion, however, their views are incorporated in this report.

Carers were interviewed either individually or in a group setting. No guided interview

template was used.

What did those with a mental health condition tell us?

Healthwatch interviewed 14 people who have a mental health condition. A further 3 took part in trialing the early drafts of the structured interview template. They were not interviewed but they did submit written responses. The comments from these 3 are included where appropriate, however, they are not included in any of the charts.

1) Are you currently accessing health and social care services?

Of the 14 people interviewed 2 stated that they were not currently accessing any health or social care service. One interviewee was desperately looking for support and wandered into the Springfield MIND office during the Healthwatch visit and joined in the discussion. This respondent was unable to identify any health or social care service that they were using.

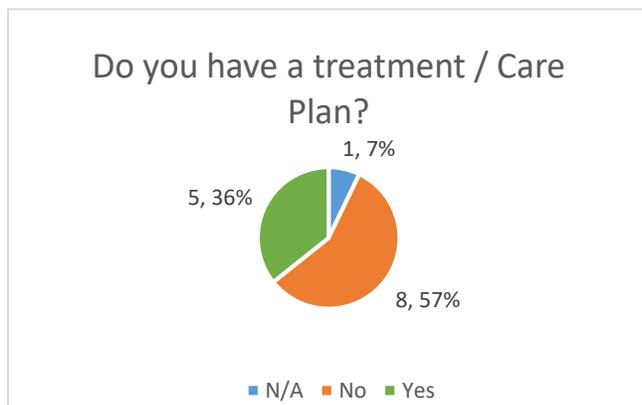
2) If yes, what services are you accessing?

Springfield Mind	4
Psychiatrist (NHS)	4
Psychiatrist (Private)	2
Psychologist (Private)	1
Psychologist (NHS)	1
GP	7
The Railings	2
Making Space	4
Old Bank	1
Bi Polar Support Group	1
RETHINK	1
Specialist social worker	1
Generic counselling	1
Shakespeare Hospice	1
Crisis team	1
St Michaels	1

Although the question was specifically concerned with what services were being accessed now, most respondents also provided a history of their condition and the services that they attended in the recent past.

Both the Making Space and Springfield Mind services were used by most people, however they appeared not to identify these as a 'health and social care service' but as a support service where they acknowledged the huge support they received from attending these organisations. Hence they are underreported in the above list.

3) Do you have a treatment/care plan?



Healthwatch wanted to know how many people had a care plan. By 'care plan' we meant a document of some sort that sets out their care and support needs as assessed by a clinician/healthcare worker and is shared with the patient.

Only 5 people said that they had some form of care plan. Their more detailed response has been picked under questions 9/10/11 below.

Typical responses were;

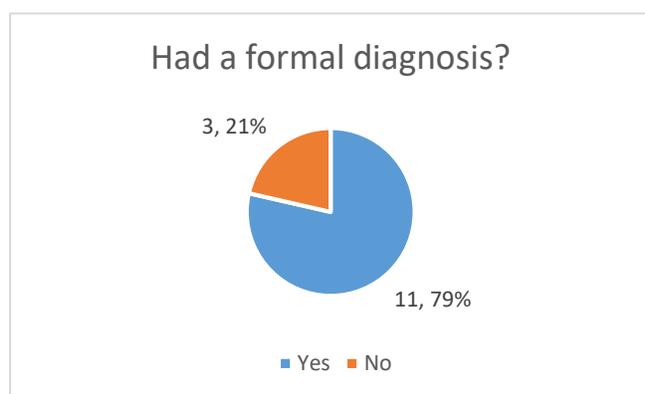
“Care plan - I don't have one, but I need somewhere to go when you start to get funny, somewhere to go when you start to go off the rails and cannot see this for myself”.

“I have no care plan.”

“I don't have one.”

“I have a letter telling me what to do with my medication from the psychiatrist. This is reviewed every 6 months. I also have a copy of letters sent to my GP.”

4) Have you had a formal diagnosis?



We asked if they had a formal diagnosis from a clinician of their illness. 11 reported that they had a formal diagnosis.

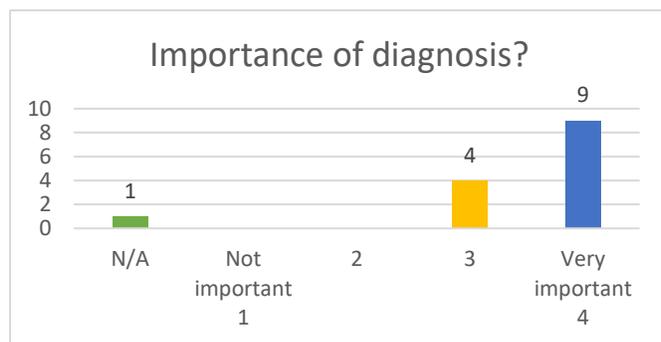
They told Healthwatch that they had the following conditions and these are given in appendix 2 below.

There was also confusion around diagnosis. One person stated;

“I'm thinking of going to the GP for a diagnosis. I was told by my GP that evidence of the condition is needed and then he could do the tests.”

Others stated they had gathered knowledge of their illness but had not had a formal diagnosis.

5) How important is this (a diagnosis) to you?



“It’s been very important. I can look it up and read about it. I can now also connect with others who have the same condition. Also. When the doctor told me what was wrong it gives me confidence that they know what they are doing.”

“It’s been good; it gives it a name.”

“Very important but I do not want to be stuck with a label.”

“I was initially in denial and the label 'mental illness' is something I struggled with and this caused me even more depression. I now recognise that I have an illness that has taken me much longer to deal with.”

“Because I have a mild condition it’s helpful to understand the reality of my situation. Because I have a diagnosis I don’t feel like a fraud.”

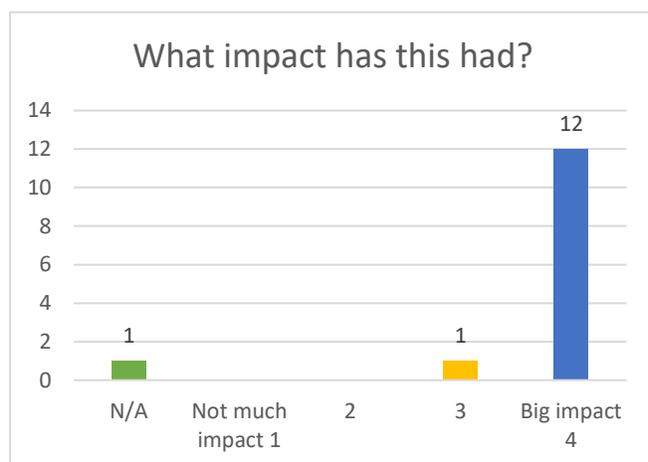
“Very Important to me. I was unable to cope and suffered loss of confidence. I felt like I was in a black hole, felt that this was the end - that’s how I got referred to the shrink.”
 “I’ve been diagnosed with depression. It was good to know what they (the clinicians) were on about.”

“It’s been very important as it gives me feedback and monitoring of my condition.”

Regarding not having a diagnosis:

“It would be really useful to have a diagnosis but because of my other health conditions I was told there was nothing wrong with my mental health. So I don’t have a formal diagnosis. It’s like they can only work with either a physical or mental illness but not both.”

6) What impact has this had?



All but one stated that having a formal diagnosis has had an impact on how they now go about their lives. More often than not the impact was positive and seen to be empowering to the individual.

“It's had a big impact. As I said, I know more about my situation. I now have more confidence I suppose. When I feel high or low I know that this is part of how it is. I now have a personal coping framework because I know what is likely or possible.”

“Yes it's had a massive impact. Others thought I had a condition but I didn't accept it. It made me go home and look for online support and medication. It became my own project, something I needed to do. I need the diagnosis in order to push me into doing something. Some say it is a label but actually this has helped me. Before I had been anti-medication but since the diagnosis I was willing to try. If I wasn't medicated I wouldn't be well now so that's positive.”

“Having a mental illness has changed my attitude towards mental illness sufferers I use to be very negative about them.”

“It has helped my feelings of self-esteem and confidence because when I go 'OTT' I now know why.”

Others were not so positive, particularly in the absence of a diagnosis;

“I tell people that I am really stressed but I am not taken seriously because I have no diagnosis.”

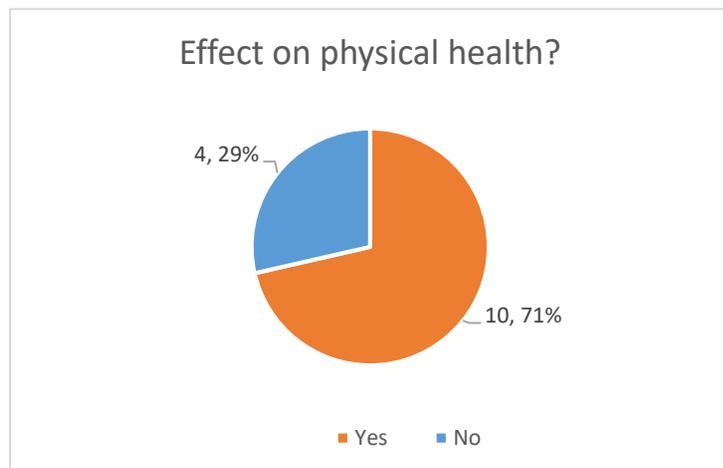
Others felt bad due to their condition:

“Stigma is a problem, mental health is a hidden illness and I feel powerless.”

“I hide my condition behind my smiling face, this is very exhausting and it affects family life and impacts on my relationships. I feel like a robot, that's how I feel.”

“I can’t go shopping or be in a crowded room, I hate lots of noise, get anxious and agitated. I don’t trust people much, I’m annoying, I’m thick, people tolerate me. I feel lonely, stupid and a nuisance.”

7) Has your support service or lack of a support service had an effect on your physical health?



The majority of those interviewed stated that their mental health condition did have an effect on their physical health.

We have tried to break these down into negatives and positives. There may be no correlation between having a mental health condition and the health issues reported. There is insufficient evidence to support a conclusion either way.

What is clear is the majority did believe that their mental health condition has had a negative impact on their health and this is leading to other conditions. For example, where there is a lack of motivation this can lead to poor uptake of physical exercise. Three people reported this and one stated that as a result he uses his wheelchair much more than he should. However, one of the respondents was making a lot of effort to visit the gym in order to deal with stress and depression. Tiredness and stress incontinence and migraines were just some reported conditions.

8) If yes, can you describe this? How has it been dealt with?

Negatives

“Yes if I feel very tired, I get chest infections and vomiting.”

“I don’t get any exercise, I have a number of conditions but mainly suffer from stress and incontinence.”

“I don’t get enough exercise and need to walk more but I tend to use my wheelchair to get about.”

“Yes my condition has impacted on my health, I have cancer and other long term conditions.”

“I have a reduced immune system and chest pain; these are possibly the result of my medications clashing.”

“Since they put me on medication I have put on a stone in weight.”

“I feel very tired; I take a lot of Diazepam to get me through the day. I think that I am addicted to Diazepam.”

“Stress has had an impact on my health. I get a lot of migraines.”

“I’ve had operations.”

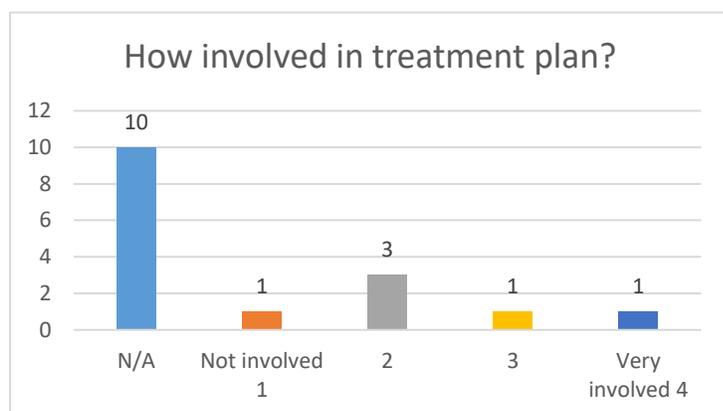
“I get tired, have acid reflux, get indigestion and stomach aches. To deal with it I have been put on medication and try to relax.”

Positives

“I’m very lucky as I am having regular proper check-ups with my GP.”

“I used to have panic attacks. My GP was able to deal with these.”

9) How involved do you feel with decisions about your care/treatment plan?



We asked people to tell us how involved they were in their care plan on a score from 1=not involved to 4= very involved.

“I was presented with my care plan but have no knowledge about the process of the care plan. My support worker tells me what to do. I’m not happy about this.”

“I care about my care plan. I felt like I needed more support and wanted a care plan. I asked for the CPN and was told that I was too highly functioning and don’t need help. I thought it was a strange way of looking at things.”

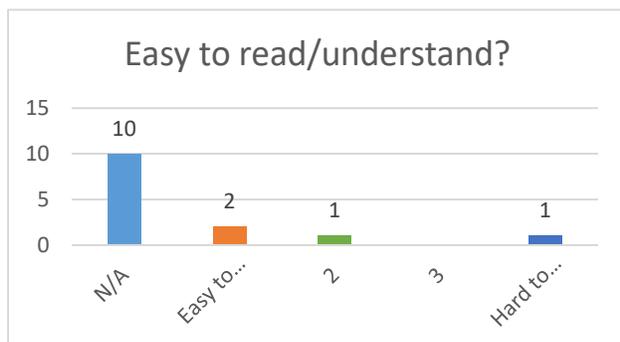
“I didn’t know what was happening or the procedures involved.”

“Some days my mind is not clear enough to deal with things so my psychologist and wife help me with this. My wife joins with me in the psychologist session.”

“Very much so - I make sure that I am involved. I don’t really trust my current GP; my previous GP was useless. The Mental Health specialist care is very good though.”

“Not involved at all. I’ve been funnelled through a medical model.”

10) Was (your care plan) in writing and easy to understand?



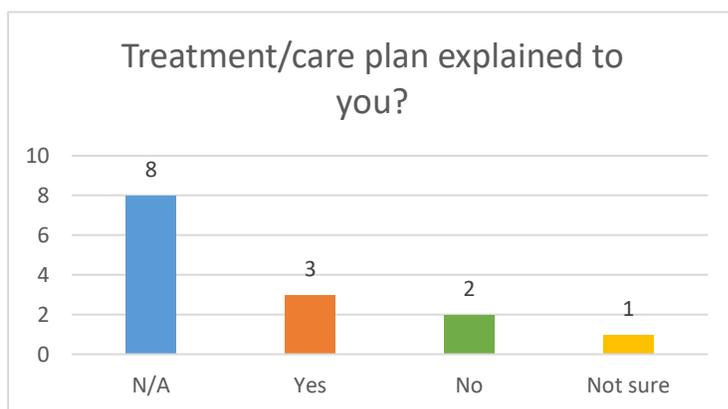
Obviously those who stated that they were not in treatment at the time of the interview would not have a treatment plan.

“It’s easy to understand, it’s in writing. They told me to call if ill and gave me a telephone number, how to react to relapse, appointment times and service access.”

“It was not in writing. My wife has a better understanding of where I should be before each appointment so she takes charge. I have a poor attention span.”

“I have had a letter with all the information that I need.”

11) Has your treatment/care plan been explained to you?



“I need help with my condition. I get a review with a support worker but do not get any emotional support targeted at the right area.”

“I only saw the psychiatrist but I’m not sure that he was helpful I think it helped him but it left me ‘triggered’ and I have to deal with that. I felt like I was his pet

project. For a year I got nothing out of it and it was not good value for money regarding National Health Service spending.”

12) What’s worked well/ not so well from your care/treatment plan?

“The Psychologist was helpful but I had limited appointments and then I was out the door - I saw the psychologist 8 times approximately.”

“All I get is my repeat prescription for diazepam and nothing more.”

“I last saw the crisis team over 2 years ago they were not good. They were not taking me seriously, I was just given an activity plan and told to carry on.”

“It's working well I have the support of the psychologist and I am also attending Making Space and it gives me a massive focus and I feel like I'm putting something back. I'm currently with the best GP I've ever had I'm very lucky to have the medical insurance but I have paid into it for a long time. It helped me jump the queue.”

“It's working well - at last someone who knows what they are doing (psychiatrist) and I no longer feel like I am in the wilderness. I just need objective, informed opinions. My GP is not so good but remember I am paying for private help.”

“What's working well? Not being dismissed, referrals to supportive voluntary organisations, not being told what I think. What's not working well? Waiting times, poor GP service, not being diagnosed, not having an action plan, not being told who appropriate mental health GP is, not having the services connected.”

“The Medication Management Team (MMT) at the Partnership Trust are excellent. I had a bad reaction to my medication but the MMT looked this up, no messing about, and they call you back with information.”

13) What would you like from your care/treatment plan?

“Crisis Team - seem quite good. Home treatment side - need them to be around much longer and continuity of hand holding i.e. they need to keep contacting patients to check up on us, confirm arrangements etc. GP's are hopeless at this.”

“Home Treatment Team (HTT) - there is no follow up care. HTT very sparse - no regular visits, they vanish within three weeks of discharge from St. Michaels. Why did my GP not visit me when I was in St. Michaels and upon my discharge?”

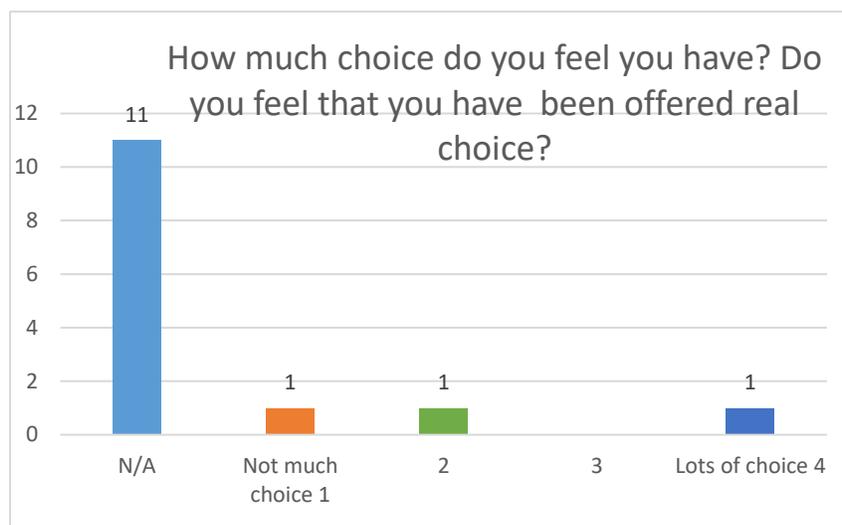
“I need more interventions.”

“I wonder if the care plan would have helped? I asked for counselling but had to find this for myself?”

“I need compassion understanding and time out. the Caludon Centre offered me none of this and I really thought I would get help there.”

“The first 10 to 15 minutes of each appointment we set goals and objectives and look at where the blocks are to achieving these.” (Respondent in private treatment)

14) What is most important in your care/treatment plan?



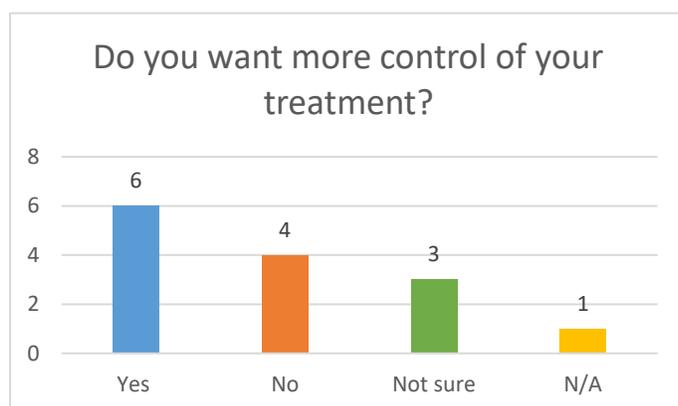
“I need a holistic Safe Space but now I'm wondering about what else to do or try?”

“Knowing that I have an appointment always 2 months ahead and then I get to see a psychologist. Starting that wait is easy at first but as the end of the 2 months approaches it gets harder.”

“My medication is very important to me.”

“It needs to be easy to understand and not too clinical.”

15) Do you want more control of your treatment?



“I don't know? I'm quite happy with the way it's going now, I feel good.”

“I already have full control - don't need more.” (Respondent in private treatment)

“I don't want to be doing something I didn't understand. I put a strong medication into my body that I didn't want I tried to talk to the Mental

Health Pharmacy but was told I need to go back to the Railings, that would take a month. I need to understand medication better, why should I have to research this?”

“I'm scared to go back to my GP because of poor continuity. I just don't get supportive treatment; I don't know who else I will see when I go there.”

“I have as much control as I need - I didn't feel in control until I got to see a psychiatrist.”

“There is no choice in Mental Health!”

“I feel that I'm in control of my treatment but had a problem with my GP over Christmas. Wanted to increase my medication but I didn't want it increased. I won that argument!”

16) What would enable you to manage your condition yourself?

“My cat is very important to me as he makes me happy.”

“I look at mindfulness stuff etc. I'm trying very hard to do the right thing. I have put time into a part time job and I volunteer but I'm not getting anywhere. My GP has no experience, IAPT can't help me, I keep getting fobbed off.”

“I feel very depressed and suicidal when I wake up but practice positive affirmation techniques to get my mind into gear. Having a focus for the day or even for the week ahead, I need to know if people are friends or foe. I've been looking forward to coming to this interview for over a week!”

“What I really want is someone to help me sort out my priorities, maybe CBT treatment, and the stresses in my real life - I'm getting old and less resilient.”

“I wanted a review - my GP told me to go to IAPT. I was given an interview that was thorough but IAPT couldn't help my condition and they referred me to the Mental Health Team 'Single Point of Entry' stating that I would not require another interview. After a few weeks of not hearing from the MH team I called them. They had no information from IAPT! I then went to my GP to find out what was happening. It was very confusing, no one knew how long the waiting list was to see a psychiatrist. It also turned out that nothing, no notes, had been forwarded from the IAPT team so nothing had been done. In the end I went private.” (Respondent in private treatment)

“It's about having coping strategies. I think my GP should be able to give me coping strategies on point of entry i.e. go for a walk, have a bath etc”.

“St. Michaels provided a chaplain - she did more for me than the entire 18 days spent in St. Michaels.”

“I am currently actively managing my condition by ‘driving myself’ and not taking meds’. I have sleep problems and wake very early in the morning - so I get up and start cleaning. I try to lengthen my day so I can sleep better. I am trying to keep positive and am currently on benefits. I want to avoid stress and feeling suicidal. It's ok the psychiatrist saying ‘avoid stress’ but how do I do this? What does stress look like? I'm looking to my own positive activities now to get me through the day. Tranquilising drugs don't help this - they deaden reactions and feelings. I Need to avoid negative brooding - I dust my coffee table every day and grow plants on my window sill - all this is a positive. I need to keep busy.”

“I find just talking about what's going on in my head to be of great benefit, however, friends and family don't want to know and don't want to hear, they don't understand. I need good listeners. On my second visit to hospital I had a long talk with a doctor there and that really helped me. It takes a lot of courage - Needs space and time. Also I go to events, meetings, Making Space - something to take me out of my house.”

“I go to Mind every week. It would have a lot of impact on me if it no longer existed. I like to look after my step daughters and grand kids and do gardening.”

“I have a back bedroom and I often like to wake up there, particularly when the sun is streaming through the window. It feels safe, comfortable and very quiet.”

“I live in a care home. I’m the youngest in there and lots of them have dementia. I don’t know how much the manager knows of my illness? Things take a long time to get done as I have to go through them (care home team). I want a new prescription for glasses - it’s taking forever. I would like to have my ear syringed at the GP’s but I can’t arrange this myself because in the home I can’t do my own appointments. This doesn’t give me any independence. It’s a bit lonely there. I attend Springfield once per week and on Friday I go to a café. I would like to go and see the new (RSC) Theatre but I couldn’t get there.”

“Getting up in the morning is difficult. I tend to be methodical, don’t like meeting deadlines. It took me 2 weeks to contact you for example. I need to know how to go about things and get things done, I need support. I also care for my son who has various conditions - that keeps me occupied.”

“Learning French and Italian makes me feel good but the courses have now stopped. I don’t do a great deal now; all the support services seem to be closing. I used to stay in a group home about 20 years ago but that closed. I liked it there as there was plenty of activities.”

“There should be better information and proper support. I need externally safe support. Medication is very important, most important is an online community and I use that a lot. Bipolar UK is a community that is well moderated with lots of users and good information, I’ll be sometimes there 24/7 and I get good advice it was this group that encouraged me to prepare an ‘advanced statement’ for the medical and mental health team. I think that talking therapies are very important and these need to be developed.”

“Don’t know. I’m quite happy with the way it’s going now. I feel good. I go to support groups and get involved. MIND are just down the road. I can talk to them about anything and it’s important to talk because I’m by myself most of the day.”

“RETHINK is a release and I do practical work for them.”

“I keep to a routine if I have nothing to do I stay in and do things that help me to be happy, such as play computer games, but outside my house I always have music with me. It helps me to process information.”

“It’s working well. I have the support of the psychologist and I am also attending Making Space and it gives me a massive focus and I feel like I’m putting something back.”

“When I was given help via my psychologist who mentioned the women’s group at Springfield Mind. This really helped my depression and has given me a lot of confidence.”

“Taking care of my mother and coming to Springfield once per week.”

“I try to manage it myself by going to social groups and distractions i.e. games, walking, gardening and going to social groups and friends (when they can be bothered).”

17) What is stopping you managing the condition yourself

“More support to show me how to use a microwave, washing machine and help me get through the day.”

“Pessimism, low self-esteem and too emotional.”

“Lack of professional knowledge.”

“I want a proper health assessment at the job centre so I can get employed. I failed the assessment, you never meet the assessor, it’s always done by a form.”

“Too stressed and not having the support that I need.”

“Not feeling well.”

Carers Interviews

Healthwatch wanted to hear from carers about their experiences with local mental health services.

Unstructured interviews were carried out between January and June 2016 with both individual carers and in 2 focus groups hosted by Guideposts.

Interview with Carer A

Carer A approached Healthwatch in 2014 with serious concerns about her ex partners (M) care at St Michaels. The interview for this report took place in January 2016. Her ex-partner was still under treatment at that time. The comments raised seem to be a common thread in carers complaints.

“I have a have a longstanding complaint with St. Michaels and this has not been resolved. I have found myself providing support for my ex-partner and I am extremely concerned with the treatment and care that is being provided. Specifically:

A. Nursing care/cleanliness / basic care - M has spent months in the same underwear

B. Atrocious record keeping - the hospital can’t even tell how many admissions M has had

C. Coordination between inpatient and outpatient teams is very poor

I originally started my complaint in 2013 - and was working with Pohwer. I did meet with senior management to discuss issues. It proved virtually impossible to get a meeting with some senior managers. I eventually made a presentation at a meeting set up to investigate my complaints however nothing has happened as result. I did eventually receive an acknowledgment letter but this didn't indicate any apparent changes to my partner's treatment and care."

She states that St Michaels provides no therapy: "it is all medication based, patients are left to rot. Basic care is missing - he was dirty, not washing himself and lying in a wet bed."

"He was moved next to a patient who threatened to kill him, he was terrified!" She feels that the ward staff refused to acknowledge M's concern and "didn't believe him."

When she went through the complaints procedure but felt the hospital is "on the defensive and always believed the staff."

"In August 2015 St. Michael's care coordinator let M walk home unattended. He got drunk and this resulted in a confrontational meeting with his care coordinator - the police were called - he was sectioned and kept in the police station without clothes. Eventually he was 'shipped back to St. Michaels without clothes."

"If I wasn't there he would have no one. Probably be dead by now."

It appears to the carer to be a catalogue of errors and indifference.

"M was sent home and he went from 24-hour care to zero-hour care."

Regarding continuity of care - he never sees the same consultant twice. There is NO therapeutic relationship.

Regarding email - I very rarely have a direct response to my letter.

St. Michaels is part of the problem - they're defensive they operate in a blame culture.

St Michaels might benefit if they had a buddying system so that tasks that are large can be broken down i.e. small working groups including advocacy, Staff, Warwickshire County Council etc. rather than being alone in providing a service.

Interview with Carer B

In November 2015 Healthwatch Warwickshire was contacted by a concerned mother Carer B. Her son had been sectioned earlier in 2015 and was admitted to the Caludon Centre and from there to St. Michaels, Warwick.

Carer B raised a complaint concerning St. Michaels stating that she and her partner had serious concerns both over her son's care and how she and her partner had been treated by the staff at St. Michaels.

B believes that there has been a failure to act by the clinical staff at St. Michaels and by not including herself and partner into her son's care plan his "diagnosis was completely missed during his first stay in St. Michaels and that this may have been prevented if we had been tactfully engaged with in the first place."

B has been in contact with St. Michaels since May 2015 and formally entered in a complaints procedure. This was resolved in early summer 2016.

Details of the complaint:

Carer B's complaint focused on the communication between the hospital staff and herself. These included; failure to involve her in decisions and consult with her about her son, lack of support and guidance, lack of a safe space for her to meet with the clinical team that resulted in damage to the relationship between herself and her son, as a result of the handling of the family situation.

1) Following admittance to the Caludon centre B's son J was subsequently moved to St. Michaels however B and partner were not informed of the move.

2) At no time did clinical staff ask B and partner for any background information on her son J, Information that she feels would help the clinicians. B has expressed the view that whatever her son J said was taken as 'the truth' when it was not.

3) There was a lack of proactive involvement with the J's parent. B stated that she had to ask to attend ward meetings, there was no proactive invitation from the clinical team.

4) Not being informed that a meeting attended by carer B was actually a discharge meeting.

5) Discharging J to home without a support package and with no consultation with B. J turned up on the doorstep with only a phone number in his pocket. As a result, B and husband had to find the number for the Crisis Team themselves and call to get someone to visit J. J wanted to get a train to London which would have breached the terms of his home release yet no one mentioned this to B or her partner.

6) No advice, support or guidance given to B and partner on how to support J on his return home. No investigation as to home circumstances was made. For example: were there children or frail and elderly at the property? This could have presented safeguarding issues.

7) Failure to communicate even basic information to B and partner. For example; No information or leaflets provided to B - she found out about 'Carer Support' /assessments through a visit to Guideposts. Carers Support information should have been given to B from the outset by St. Michaels.

8) B wanted to share information about J with the psychiatrist at the hospital yet was shown to a room on the ward in full view of her son who, as a result, burst into the meeting and was aggressive.

9) General response from St. Michaels to offers of information or queries was “well he’s an adult and it’s confidential.”

10) Calls were not returned to B and when she asked when she could expect a reply to her letter she was told “we do not reply to letters.”

Following a meeting held with B and her partner with St. Michaels in August a letter was sent to B outlining the nature of her complaint and the initial findings. This response was not received by B until 2nd October.

The letter found that:

A) There had been a failure to record “within the admission checklist documentary confirmation that a Carers Information Booklet had been provided to you as carer on admission”. This had been left blank and not completed.

B) There is “no recorded documentary evidence to confirm that a carers assessment was either explained/considered or offered at that time.”

C) There is “documentary evidence within the health care records, to confirm that you (Carer B) had initiated significant/almost daily telephone contact with the clinical inpatient ward team. It is not clearly recorded that the carer’s views had been considered or reasons why this did not take place.”

D) Two letters to St. Michaels from B were acknowledged as being held on their system.

E) ‘Care Programme Approach and Risk Planning and Working with Risk’ documentation should be updated and recorded. St. Michael’s state that this was done however there is further learning and action “to be taken forward to look at sharing of information with relatives when the patient has withdrawn consent. Especially when leave is with the specified relative/carers.”

St. Michaels stated in their letter that steps would be taken to redress these complaints.

A further letter dated 24/10 was sent to Carer B from CEO of St. Michaels with an official response to the complaints raised.

The letter outlines recommendations and organisation learning points. These are:

- Carer support leaflets need to be provided to family members at the point of admission
- Staff to be reminded of the importance of engaging with families when patients are discharged and given leave
- Staff to be reminded of their responsibilities to patient and carers when complaints are raised directly with the service

- Ward information packs need to be available and given to service users on admission.
- Carer B's final complaint letter was to be shared with ward manager for discussion at Governance meeting to reflect on the issues identified in the complaint.

Interview with Carer C

“I care for D he has a dual diagnosis (mental health / drugs). His mental health issues are anxiety, OCD, depression. D masks this by using drugs - Street drugs.”

He has been the assigned a psychiatrist.

They always want him to give up illegal drugs before prescribing MH medication, they say that he needs to be clean before they will treat him. They don't understand that his drug use is because of his mental health problems. If you don't fit in the right pigeon hole you don't get treatment, they don't join up the dots and the mental health team have an old-fashioned view of things.

Why don't they just go to America or Sweden and find out new ways of doing things?

Where does this leave him now? I thought to get him into rehab, currently he is using legal highs but D doesn't think that these are the best things for him, he's really unwell and he cries a lot.

He's my son and he's not getting a service.

Last year there was overkill from the police and the Medics whilst he had a seizure, they had to hold him on the floor and he was bleeding; it was very upsetting.

D has never had a proper key worker with the Mental Health Team. I need support myself now. I did have contact with one of the Mental Health Team, it was good to talk but she has now left. She promised to assign someone for me but no one has come, no one ever stays in the service very long and there is no cover. D had one visit from his key worker, he didn't even know D's address. He wouldn't talk to me because he said that I didn't have D's permission. D said this was rubbish as he gave permission.

Because he has a dual diagnosis the mental health team are passing it over to Recovery Partnership.

How am I coping? I'm on anti-depressants as is my husband. Mental health and drug addiction is pigeon holed; there is no support for D. I'm in despair, no one chases up appointments made, but if someone doesn't turn up they never call to say see why, there's no cover, there's not contingency.

I'm concerned over the inflexibility. Service users and carers make suggestions but these are never acted upon. Confidentiality this is always used as a block.

The original plan was to give D some voluntary work. It never happened
There is the problem of inappropriate medication. This causes problems especially when it is used with alcohol - I am talking about Fluroxine. This causes behaviour to change and I had to get the police to arrest him for our safety.

I asked if they could give him some psychoanalysis but they said no it would not be beneficial.

D was admitted to xxxx House' where he made good progress. The doctor suggested things that should be in place on discharge i.e. a voluntary work placement, but there was nothing in place when he left.

The consultant neurologist at UCHW requested admission and detox but this was never offered. I wrote to the mental health team in April 2015, I got a very bland response on the 30th of May; my questions were not answered. Response was very 'airy fairy' and 'pass the buck' - it wasn't joined up and I can't get a support worker.

I know about Carers Support but I don't think they are appropriate in my situation.

I feel that I have done as much as possible to help but D needs now to engage with what little services are on offer. The dual diagnosis and mental health teams need to join up. Why is there not more support?"

Interview with Carer D

"I've been the carer for my son for 15 years. I have also been a carer for a lady with a degenerative alcohol condition including anxiety and depression. I did become involved with the drug and alcohol team for a while. She started out fine and acupuncture and group sessions were offered however nothing was done to assist with her financial or social problems.

She also attends a pain clinic who appointed a clinical psychologist, she sees this person once a month. The psychologist refers her to the Partnership Trust for further assessment. Referred in May 2015 and offered an appointment in August 2015. I visited her in July 2015 and saw that she was in a bad way, so I called the new Central Point of Contact who said that she has been triaged and does not need further help. I challenged this and they eventually agreed that she hadn't had triage. She was then offered an appointment in September, however she was then sent to the wrong place.

The Psychiatrist saw her twice - the last time was in November 2015 and offered a further appointment in February 2016. Her medication was changed with the addition of a new drug. No other psychological interventions offered, she was considered 'not

stable enough'. When she turned up for her February appointment the psychiatrist was away on holiday. No one bothered to tell the client. Complaint made to PALS but they never got back to her. This person has complex problems that the Partnership Trust cannot seem to pick up and run with, instead there is lots of mucking about.”

Carer D then described her experiences supporting her son.

“My son has psychosis and is under a Community Treatment Order. He used to have carers come into his home to observe that he is taking his medication.

He has been involved with mental health services for about 20 years. The first 8 years were good - there was a day hospital then so he went there during the day as a voluntary patient.

He is currently chronically disabled and living in his own flat we (his parents) provide social care.

He got a new psychiatrist 2 years ago however because he missed appointments he ended up sectioned and sent to St. Michaels. Because I was an ‘appointee’ I was able to be more involved.

At St. Michaels there was dirty food on the floor, they wouldn’t let him do clothes washing and wouldn’t let me take his clothes home. His stinking clothes just piled up. St. Michaels took my son’s side and wouldn’t intervene.

I rang St. Michaels to ask if my son was eating and sleeping ok. The nurse stated that this information couldn’t be disclosed without asking my son first. My son didn’t give a view so I couldn’t get that simple information.”

Carer D then described the post discharge experience.

“He was given a good CPN and Occupational Therapist. St. Michaels stated that he would be going home for a day and then returned to hospital. I then received a call to say that he discharged home. However, at that time we were on holiday and not available. My son and his CPN said that he was not ready for discharge. There was no care plan in place and he was returned to his house alone.

My son eventually got a ‘community treatment order’. Both his CPN and Community Support Worker never got into his home to assess his living conditions. He was taken out to lunch and to play pool. His house was filthy and chaotic. Eventually it got so bad that I called for a review with the psychiatrist and the CPN. We were only invited to some of the reviews. St Michaels stated that they would take control of the cleaning issue and told me not to go in and clean. The situation got worse but St Michaels stated that he was getting better because he is no longer being bullied by aggressive people. We assume that they meant his parents. They always take the side of the client even when delusional.

St Michaels tried to get my son to do things by ‘prompting’ I feel that with St Michaels you have to constantly push or make suggestions, they never came to me or my husband.

Notes from Guidepost Carers Rugby 26th May

“We need family therapy, something to help us manage within the context of the family member’s illness.”

“Why not offer coping strategies within the family unit? Provide more help and support also, see where the problems are within a family.”

“Notes take forever to be circulated.”

“We never get things.”

“Reports from our meetings with the mental health team are not what actually happened.”

“Carers views are missing from reports.”

“Reports say what the professionals want to say rather than what has been said.”

“There is a problem caused by limited ‘drop-in’ and support available across the county.”

Recommendations

Diagnosis - for those referred, or presenting themselves, at the single point of entry there needs to be a clearer explanation of the triage process and what can be expected. The importance of an early and clear diagnosis was stated by those who took part in the survey. Having a diagnosis was crucial. Following a diagnosis respondents felt that they had a genuine problem and were not ‘making it up’. They were also more likely to search out options to help them improve their condition there is evidence that the time from initial contact with mental health services to diagnosis is taking too long.

Talking and holistic therapies - Respondents were clear that they would all benefit from counselling, or other therapies, yet these had to be sourced independently. Respondents felt that what was offered was wholly inadequate in this respect. If this is not the case, and these services are offered, then there is poor communication between the mental health service providers and service users which needs to be addressed.

Treatment plans - There was a lack of understanding about treatment plans. Two respondents are using private healthcare and felt that they had a good plan and fully understood it. Others felt that they were presented with a plan but were not consulted about it. Mental Health Services should review their care planning with clients and how this is to be best achieved.

Discharge and follow up - Respondents were also confused about ‘what happens now’ when they come to the end of their treatment schedule. Some felt ‘dumped and at sea’ and thought there should be better handholding to ease them out of the service. There seems to be little understanding of how or why decisions are taken by the services. We think that this could be reviewed by service providers and, where possible, clearer information given on what to expect following discharge.

Better service coordination - there appears to be poor coordination between mental health services and GP’s. Respondents also felt that they were not getting a good service from their GP and that, generally, there was a lack of understanding by GP’s about mental health. There appears to be a silo approach where the patient is passed to the mental health service and then back to the GP depending on the condition.

Carers - Carers feel excluded yet have much to contribute. The case studies presented within the report clearly describe an all too common scenario whereby carers are seen as an obstacle to, rather than a partner in, the treatment process. Healthwatch recommends that mental health services reappraise their relationship with carers and specifically, the blanket use of confidentiality. All carers should be given a support pack with information on relevant local services. Confidentiality issues should be addressed following guidance issued under [the 'Royal College of Psychiatrists Guidelines on Carers and Confidentiality'](#) with support from the Carers Trust.

Appendix 1: MH call for evidence - Guided Interview

Are you currently accessing health and social care services?

Yes No

If yes, what services are you accessing?

Do you have a treatment/care plan? *(Pick up on treatment/care plan later do not discuss here - ask for simple yes / no)*

Yes No

Have you had a formal diagnosis?

Yes No

How important is this to you?

Not important 1-----2-----3-----4 Very important

What impact has this had?

Not much Impact 1-----2-----3-----4 Big Impact

Has it changed how you feel?

Has it changed attitudes / perceptions?

Positive / negative impacts?

Has your support service or lack of a support service had any effect on your physical health?

Yes No

If yes, can you describe this? How has that been dealt with?

If the interviewee does not have a care plan, go to Q13/14/15

How involved do you feel with decisions about your care/treatment plan?

Not involved 1-----2-----3-----4 Very involved

Was it in writing? Easy to understand?

Easy to understand 1-----2-----3-----4 Hard to understand

Has your treatment/care plan been explained to you?

Yes No Not sure

What has worked well /not so well from your current care/treatment plan?

What would you like from your care / treatment plan?

What's most important in that care/ treatment plan that makes it work for you?

How much choice do you feel you have? Do you feel that you have been offered real choice?

Not much choice 1-----2-----3-----4 Lots of choice

Do you want more control of your treatment?

Yes No Not sure

What would enable you to manage your condition yourself?

What is stopping you from managing your condition yourself?

What makes it difficult for you

Can you say why you can't do more yourself

Appendix 2: Mental Health Conditions

The patients and/or carers reported are living with a range of conditions including:

- Depression
- Bi-Polar
- Dysthymia (a chronic mood disorder characterized by depressed (feeling sad, blue, low), loss of interest or pleasure in one's usual activities, and other symptoms typical of depression but tending to be longer in duration and less severe than in major depressive disorder)
- Post-Traumatic Stress Disorder (PTSD) that triggers anxiety and depression
- Hypomania (A mood state characterized by persistent disinhibition and pervasive elevated (euphoric) with or without irritable mood but generally less severe than full mania)
- Schizophrenia
- Delayed onset of grief and anxiety
- 'Neurodiversity' and ADHD as an offshoot
- Clinical Depression, anxiety and OCD