healthwatch Devon

Better services through public involvement

# Experience Summary Report

## Devon Partnership NHS Trust

## Data report for period: April 2016 to March 2017

April 2017

# Contents




This report has been produced by Healthwatch Devon – the independent consumer champion for health and social care in Devon. We would like to thank everyone who took the time to share their experiences.



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# Introduction

## What we do at Healthwatch Devon

Healthwatch Devon is the local, independent consumer champion for health and social care services.

One of the key functions of Healthwatch Devon is to obtain the views of local people regarding their needs for, and experiences of, local care services and importantly to make these views known.

Since Healthwatch Devon was introduced in 2013, thousands of people have shared their views and experiences with us in relation to their local health and social care services.

The experiences we gather are entered (anonymously) into our evidence bank. A summary of this information is then shared with those who commission, provide, regulate and monitor healthcare services in Devon.

## How Healthwatch Devon deals with enquiries

If someone contacts us directly about an experience that relates to a mental health service, we will in the first instance, signpost them to relevant service provider's patient, advice and liaison service so that they can have their enquiry dealt with directly by a member of staff at that service.

Some enquiries are sufficiently serious that we see a need to refer the matter to the Care Quality Commission, or other relevant authorities. We call these "escalations and alerts".

## Devon Partnership NHS Trust

Devon Partnership NHS Trust provides a wide range of NHS services to people with mental health and learning disability needs - in Devon, the wider South West region and nationally.[1]

**The mission**: To become a recognised centre of excellence in the field of mental health and learning disability within the next five years.
**The vision**: An inclusive society where the importance of mental health and wellbeing is universally understood and valued.
**The values**: The values are enshrined in the NHS constitution and underpin all that we do:

- Everyone counts
- Respect and dignity
- Commitment to quality of care
- Working together for 'patients'
- Compassion
- Improving lives

## About this report

The information on the following pages illustrates the nature of the feedback that has been received in relation to experiences involving mental health care and learning disabilities services that relate to Devon Partnership NHS Trust.

During the last fiscal year, April 2016 – March 2017, we have captured a total of 56 individual experiences. This report summarises what those 56 people told us.

[1] information taken from the Devon Partnership NHS Trust website

# Experience Data Analysis

## Fig.1. Nature of the feedback provided

The following shows the number of comments recorded broken down by the nature of the experience.


## Fig.2. Mental health service providers and nature of feedback

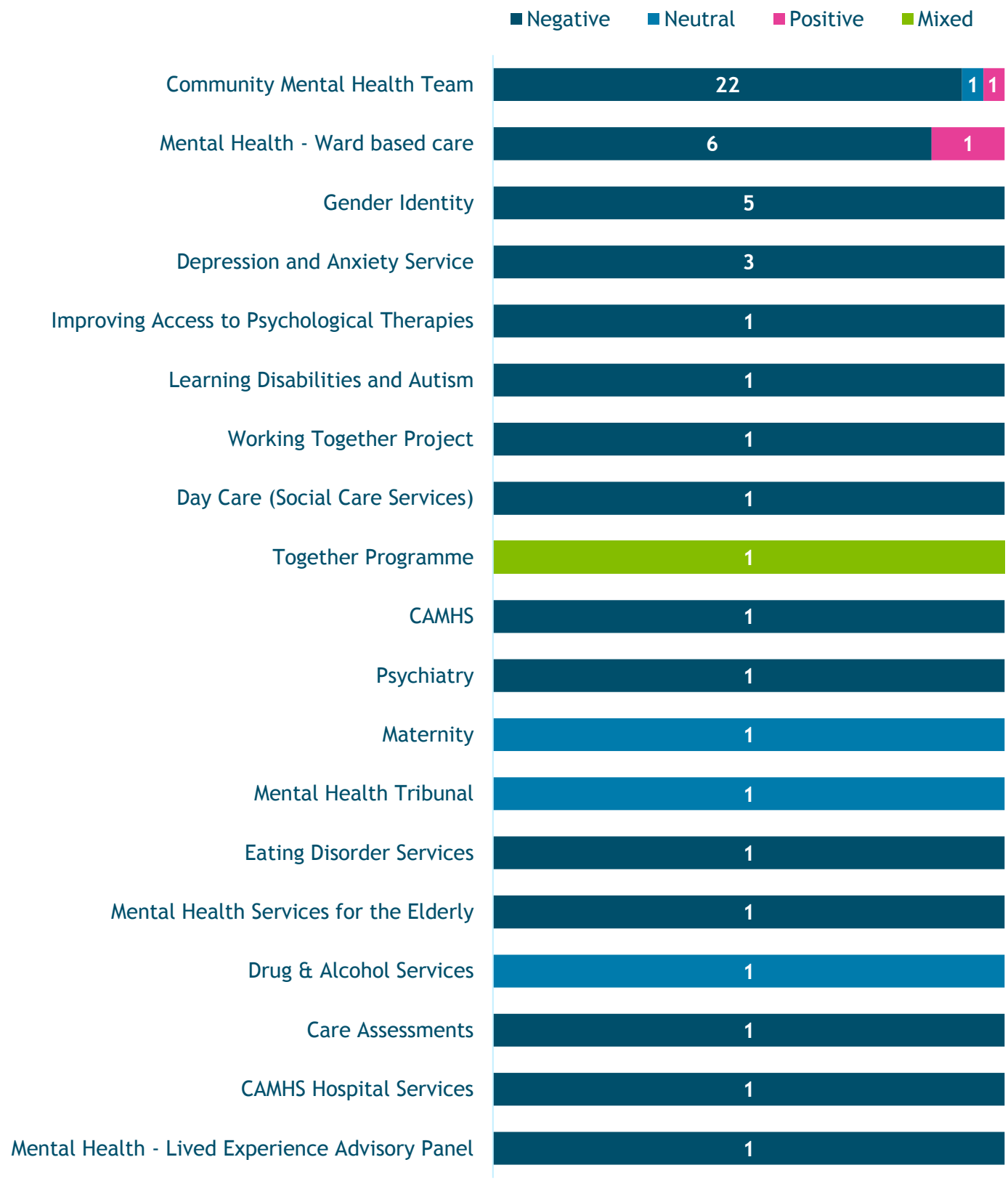
The table below lists the organisations and departments that the feedback relates to and the nature of the experience.

| Negative | Neutral | Positive | Mixed |
|---|---|---|---|
| • Crisis Team<br>• Devon Partnership NHS Trust<br>• HMP Exeter<br>• Ivybridge Psychological Services<br>• Livewell Southwest<br>• Mental Health Services<br>• MIND in Exeter and East Devon Ltd<br>• Rethink Mental Illness<br>• St John's Court<br>• The Cedars Unit<br>• The Laurels Specialist Gender Identity Clinic<br>• Together Project<br>• Torbay Hospital, Haytor Unit | • Devon Partnership NHS Trust<br>• North, East and West Devon CCG | • Devon Partnership NHS Trust<br>• Rethink Mental Illness<br>• Wonford House Hospital | • Devon Partnership NHS Trust |

## Fig.2.1. Mental health services and nature of feedback

The chart below illustrates the mental health services that the feedback relates to and the nature of the experience.

Community mental health team received 44% of the comments 92% of which were negative. Ward based care received 29% of the feedback, 86% of which was negative.



## Fig.3. Emerging Themes

When Healthwatch Devon records an experience, there are a list of categories to which an experience can be themed. Depending on how much information is provided, feedback can refer to more than one of these themes.


The following table shows the breakdown of the themes that the experiences have been categorised and the sentiment.

### Top 3 themes in relation to mental health services

1. Overall we found that 14% of the feedback received was given a theme of **Staff attitudes**. 95% of this feedback was negative.
2. **Access to mental health services** attracted a further 12% of the total feedback of which 89% of the comments were negative and 11% neutral.
3. 12% of the feedback included the theme of **quality of treatment**. 83% was negative, 11% positive and 6% neutral.

| Theme | Negative | Neutral | Positive | Mixed | Total |
|---|---|---|---|---|---|
| Staff attitudes | 21 | | | 1 | 22 |
| Access to Mental Health Services | 17 | 2 | | | 19 |
| Quality of Treatment | 15 | 1 | 2 | | 18 |
| Waiting Times | 11 | | | | 11 |
| Referral | 9 | | 1 | | 10 |
| Safety | 8 | 1 | | | 9 |
| Appointments | 7 | | | | 7 |
| Access to Hospital Services | 6 | 1 | | | 7 |
| Monitoring & Accountability | 7 | | | | 7 |
| Suitability of Provider / Staff | 6 | | | | 6 |
| Dignity | 6 | | | | 6 |
| Equality | 5 | 1 | | | 6 |
| Staffing Levels | 5 | | | | 5 |
| Service Coordination | 4 | | | | 4 |
| Diagnosis | 3 | | 1 | | 4 |
| Complaints Process | 3 | | | | 3 |
| Procurement / Commissioning | 3 | | | | 3 |
| Nutrition & Hydration, Discharge, Access to Social Care Services and Cleanliness (2 negative comments each) | 2 | | | | 8 |
| Fees/Charges, Admission, Privacy, Choice, Confidentiality and Consultation (1 negative comment each) | 1 | | | | 6 |
| **Total** | **150** | **6** | **4** | **1** | **161** |

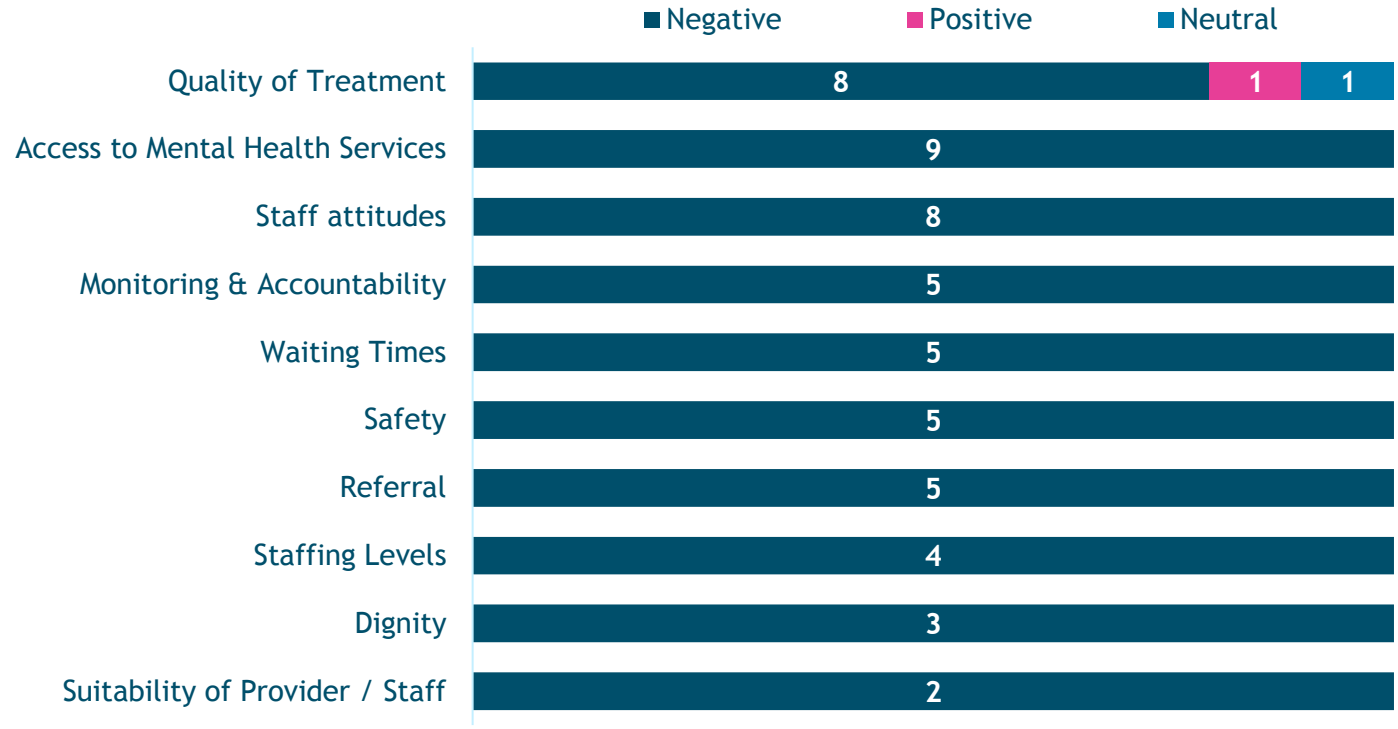
** For more information regarding all themes to which feedback can be categorised see appendix 1.*

## Fig.4. Mental health services, themes, nature of feedback and comments

The following are the top 10 themes and nature of the experience shared regarding community mental health team which was the service that received the most comments.

### Community mental health team

In relation, specifically to community mental health team services we found that 15% of the feedback received was given a theme of **quality of treatment**. 80% of this feedback was negative. **Access to mental health services** accounted for 13% of the feedback and 12% was regarding **staff attitudes**, all of this feedback was negative.




### Community mental health team comments

"I have basically been told that despite suffering from an enduring mental health disorder I am being discharged from my community mental health team. This is despite the CMHT acknowledging I am a risk to myself and have been at risk from others. During the times I am at risk I'm deemed as lacking capacity. Also risks have been reported and ignored. I class this as negligent and that the duty of care that should be afforded to myself has not been met. I strongly dispute I'm ready to be discharged as I'm at my most unstable. I have support workers stating the same. I am beside myself to be honest."

"An individual explained that they had recently had a mental health inpatient stay during the summer. They were allocated an active review care co-ordinator on leaving hospital and then subsequently discharged from mental health services with a rapid re-referral agreement in place. Due to the distress of a friend's suicide their own mental health deteriorated. As part of the rapid referral system they contacted the community mental health team in order to be referred back into the service. They were told that they needed to go via their GP which they did, but over a week later they still had not heard. They felt this was too long. A month later the individual went back to their GP and mentioned the mental health referral again. Their GP said they had sent it. The individual then contacted Exeter Community Mental Health Team who said they had not received a referral. The individual then rang the GP surgery to tell them this and an urgent letter was then written. The Community Mental Health Team have now held a meeting and the individual should receive some support soon they said there was a letter in the post to confirm this. The individual thinks the GP had not made the referral when they said they had and they also felt that they had had to chase it up to make it happen and at such a difficult time too."

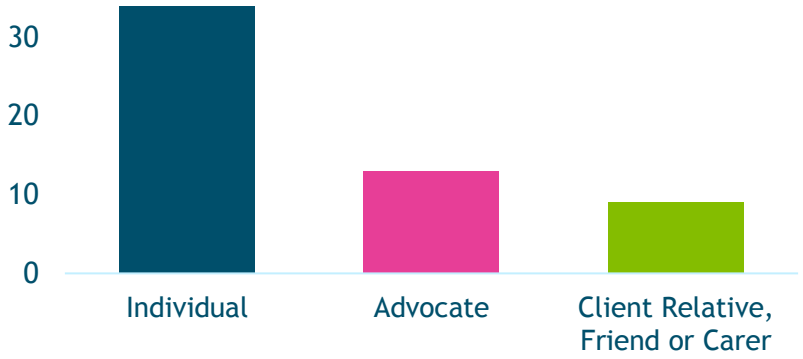
"Client has mental health issues and is often suicidal. She has been referred to mental health team who have not been able to support her and advised that this is because they are short staffed or have not enough staff. GP gives impression of not being supportive. Client has complained by letter."

## Fig.5. Commentator Information

The following chart displays a breakdown as to who provided the feedback to Healthwatch Devon on the experiences reported during the year

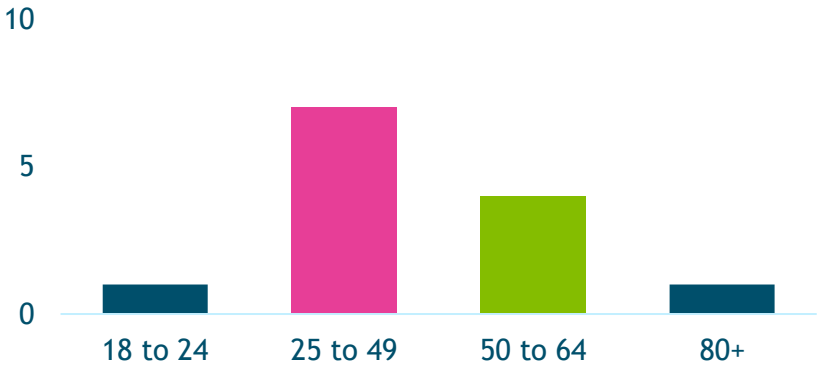
### Who provided feedback

| Commentator | Number |
|---|---|
| Individual | 34 |
| Advocate | 13 |
| Client Relative, Friend or Carer | 9 |
| **Total** | **56** |



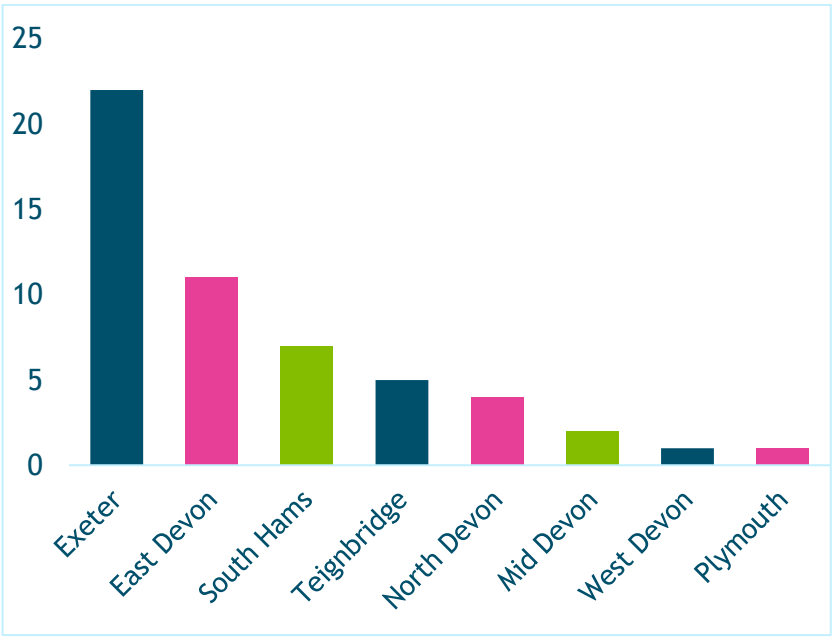

### Age Range

| Age Band | Number |
|---|---|
| 18 to 24 | 1 |
| 25 to 49 | 7 |
| 50 to 64 | 4 |
| 80+ | 1 |
| **Total** | **13** |




### Location

| Location | Number |
|---|---|
| Exeter | 22 |
| East Devon | 11 |
| South Hams | 7 |
| Teignbridge | 5 |
| North Devon | 4 |
| Mid Devon | 2 |
| West Devon | 1 |
| Plymouth | 1 |
| **Total** | **53** |



# Appendix 1: Comments

The following are all other comments received by Healthwatch Devon regarding mental health services during the year April 2016 – March 2017.

1. Individual called us after having been sectioned. They had tried to contact Rethink and Devon Partnership Trust but no one has returned their calls. The individual is very anxious, stressed, upset and frightened at being on the hospital ward. This is not the first time the individual has been sectioned here and was informed that they would not have to return to this ward they would re-admit them somewhere else. They have been told they are not allowed in the kitchen so any food that a friend brings in they are not allowed to heat up and they cannot eat the meals provided because they are allergic to the food they are offering. The individual was in their room and did not realise that there were workmen outside the window and so was walking around undressed and they looked in and laughed. There is drilling and noise all day. There are more patients than there should be. There are no activities on the ward and there is no care plan in place for when they are released from hospital so they end up being re-admitted. The environment makes them feel unsafe, a patient punched a member of staff so the individual locked themselves in their room by putting a table in front of the door as they were afraid. One of the patients verbally attacking them. There are not enough staff on the ward. Individual feels like they are in prison and stated where are my rights under the Section 2 mental health act? When the individual gets upset they just give them medication to shut them up.

2. Individual called whilst in hospital. They are unhappy with the environment of the hospital ward and the food offered. On admission, they were given their medication by the doctor and was told that they would also be given nicotine replacement therapy. They still had not received this a week after admission. This individuals condition means that they require a balance diet and therefore they asked for fresh vegetables with their meals, but again this has not been received. Some of the patients drink out of the milk cartons and then put it back in the fridge, using no cup or glass and the staff do not say anything. The ward is filthy and there are human fluids on the floor that are not cleaned up probably, the staff just use paper towels to wipe and no cleaning solutions. The staff dishing up the food have gloves on when touching the food, however they touch the bin between touching the food. Staff are provoking the patients so they request their drugs to calm them down. The staff allowed one patient to drink cola at night which the individual thinks is neglectful as the staff do not explain that it is not a good idea to drink caffeine before going to bed. The individual has seen patients with sores and cuts on their bodies that have not been clinically looked at and the doctors and nurses say that they are looking after their mental health needs not other healthcare needs. The individual feels like they are in a detention centre not a hospital. One of the staff went to the shops for them, they had asked for fruit which they did not buy and also they never received a receipt for the other shopping. The staff wind the patients up for a reaction. This individual also thinks the hospital has a campaign to disturb their sleep. The staff were opening and closing the door every 10 minutes whilst she was trying to sleep. The individual asked what they were doing and they said that they were observing every 15 minutes and apologised as it should have been every hour. There was also noise from outside her room and so she asked what they were doing and they said they were checking the bathrooms which she thought was strange as patients can only use the bathroom if they have a key from a member of staff.

3. There are not enough beds at the Cedars. While waiting weeks for a bed, my child twice spent a night in a cell because there were no emergency beds. When they had a stroke the bed was taken whilst in hospital for four nights, they couldn't return to the ward on Cedars unit because the bed had been taken. The feeling of security is lost when this happens and the recovery takes even longer. When they started to have days at home the bed was taken when they returned. They were finally discharged when home for a few days, as there was no room for them to return to complete their treatment.

4. I want to share with you something that happened last year with Devon Recovery Learning Community. I was attending a course and one of the other participants made false accusations to the leaders that I was harassing them. I can prove that I was in no way harassing them but I was barred from the remainder of the course and any others. What makes this disgusting, is that no evidence from me was asked for. I asked them if they were going to ask me what happened and if they would investigate but was just told you're barred. Having mental health problems is bad enough in a society of wilful ignorance, stigma and myths, but when you are treated as I was, it makes these problems even worse.

5. With the ending of Be Involved Devon please can you let me know what support is available for people with lived experience of mental health difficulties being involved in service user involvement. Would be very grateful for some advice on how I can continue doing this as I do not feel I can do this alone in strategy meetings etc.

6. My son is in his twenties and suffers with an ASD/probably Aspergers. I visited my GP for support with him only to be told there are no services other than diagnosis available in Devon. This means that we get no support whatsoever and it also makes claiming benefits extremely difficult for him. What happened to the Autism Bill?

7. Individual has been involved as a service user to the Trust with interviewing and decided to become involved in the Together Project. However, this has been a disappointing experience as the individual feels no time was given to launch the project, one meeting was cancelled altogether. The Trust have spent money on free merchandise e.g. pens, mugs etc. where there was no extra money for the actual project. A follow up meeting was held which I felt had no service user input and the facilitator was rude. All I wanted to do was help improve the service and I thought the Together programme would be the way forward.

8. The individual states that a survey on mental health care in Devon was sent out on 9 December 2016 and closure date of 16 December 2016. Very unhappy with the timescale to complete the survey. If serious due consideration was intended to be given to service users concerns at a time when budgets are being more and more restricted Devon Partnership Trust and LEAP would have circulated and followed up the results long before now. I think this last-minute request is somewhat disgraceful and an indictment of how little service users concerns and experiences impact on strategic planning and monetary governance. Oh to have long term needs and patient continuity. Shame quick fix solutions and prevention does not always win long term. It is a shame it is not cancer or some such other immediate physiologically understood ailment. Please could you pass this onto Devon Partnership Trust for research purposes. From my point of view sending this out on 9th December for such an important consultation is totally unacceptable and I would like my thoughts and complaint to be passed on. This is typical historic Devon Partnership Trust service user engagement procedures regarding consultation processes. I would like to know what your process is for referral of these matters CQC in order to try to achieve PROPER user service input and consideration. I'm lucky that GPs are very good and been referred to specialist now for medication. Mental health taking a dip at the moment. Struggling to find support. Rethink no longer offer the support they used to and the Womens Network no longer exist in my area. Feel that so many cuts have been made that the support for people with mental health issues is no longer out there. I will use this survey to highlight these issues.

9. Our therapist painfully reminded us today we only have another three sessions left and there are no plans for future therapy even though it is needed. When is someone going to realise we really can't cope anymore? When are we going to be told what is happening when our treatment ends? No one knows, which is just despicable and causing unnecessary pressure when we are already at breaking point. My sibling is sick of explaining all of her anxieties and so has simply decided to paint a happy face. She is good at that. That's why no-one realised our abuse over the years. We put on a good front. We are told to keep writing to each other, we can't do therapy alone. We all need help. If we had been allocated therapy in the first place (5 years ago) maybe we wouldn't be in such a mess. The long and short of it is that every so called professional body have let us down badly. I am forwarding all other emails begging for treatment. So one of the people who decides our fate can hear our plight.

10. Client came to the Citizen Advice (CA) office very distressed and wanting to commit suicide. CA Advisor rang the client's GP who arranged for the Crisis team to visit/ring. Crisis team stated they do not come out to clients, client is in another part of Devon, crisis team seem to be situated in Exeter and they had no other advice to give, other than to ring the police. The advisor rang MIND for further advice to help client. MIND advised them to ring for an ambulance, if client will go and take them to A&E. It seems that there is no process for managing mental health patients in crisis or otherwise. The police do not have to visit as the client was not violent. CA are upset that advice by the professionals is that it is the role of the police to manage mental health patients. Whilst their training is excellent in this field, they are not healthcare professionals. The Devon Partnership Trust's response is insufficient and unhelpful to this client, who was even more distressed. We have advised the client to speak to their GP again advising what has happened and requesting that their doctor contacts DPT for treatment.

11. Individual has called HWD before about the waiting times at West of England specialist gender identity clinic (the Laurels) for the first appointment after the referral from their GP. They have called again as they have now had they first appointment, after waiting over a year, and felt it did not go well. The individual thought they were going to be having their appointment with a psychotherapist and this was not the case the member of staff called themselves an assessor. The appointment was not helpful and the assessor would not let the individual speak. He told the individual to shut up and stop talking and was not given the opportunity to ask any questions. The assessor spoke for around an hour and said they were finished. The appointment should have been for 2 hours. At the end of the session the individual was given out of date leaflets. The individual does not know what is happening next and if there is another appointment.

12. Mental Healthcare not always very easy to get help.

13. Client went missing and was brought to Accident and Emergency by Police for check up. Client was referred by A&E to RETHINK. This agency could not see her and advised she wait for the consultant appointment - was also referred by A&E. NO appointment made and GP is not overly concerned. Client suffers with psychosis and has had her medication taken from her by the A&E department at RD&E. Client has no visible means to support health without GP input.

14. I have a complaint about my care co-ordinator. She put me on a four-month waiting list for 'psychology' and made another appointment to check in with me. My care co-ordinator offered to write a letter of support for Employment and Support Allowance. I knew she was going away so I rang the week before to ask if she or someone else could write this letter so I could get some money. My care co-ordinator apparently didn't get the message. I rang several times to ask if anyone else could help me. I spoke to another member of staff who was very understanding and said she can stand in for my care co-ordinator in future if she is unavailable. However, I still couldn't get the letter. I asked twice for a duty call, waited and no one rang. I went into St John's Court and spoke to three receptionists. I was increasingly upset and went out twice to cry and scream privately in my car. I clawed at my face and pulled my hair and screamed in frustration. I went back in to speak to the receptionists again, to ask please could someone help me? They all said no, and told me to come back the next day when my care co-ordinator would be in. When I saw my care co-ordinator, almost a month had passed since I asked for the letter. She took me into a room and one of her colleagues was there. I asked them to clarify why this other lady was in the room with us and who she was but the answer was vague, just that 'colleagues sometimes pop in'. As it turns out, HMRC have told me I'm not eligible for ESA anyway, so all that stress was for nothing. I received a letter a week later saying that my 'care' was to be transferred and to attend a meeting. Half an hour before the meeting, I received a phone call saying one of the members of staff was ill and the meeting was cancelled. I said I was supposed to see another member of staff as well, but the receptionist said this person was away on holiday. 15 minutes later, another receptionist rang to tell me that the member of staff was ill, and the meeting was cancelled. They are not communicating with each other, again, and again, trust is damaged. Again, I stood in front of a glass panel asking for help and was told to go away. This is my experience with the NHS. It's been nearly a year now that I have been asking. There have been other negative events with the NHS, like being told by a member of the crisis team that I was too upset and she wouldn't talk to me. Another time, a doctor told me that because I don't have bipolar disorder, there is nothing wrong with my brain and I'm not ill. It seems like an obvious choice to kill myself because I've felt so bad for so much of my life. Waking up at 3am to writhe, shudder and convulse with emotional pain is not normal. Spending six months of the year, every year, battling with overwhelming suicidal urges is exhausting. Not being able to maintain any kind of consistent life without having breakdowns is just a pointlessly painful existence. When the meeting with the two members of staff did take place, they didn't want to talk about how my care co-ordinator and the NHS have already failed me, nor explain any of the communication breakdowns. They said now I will get help, it's a new leaf. I asked how long would I have to wait to get Dialectical Behaviour Therapy (DBT) or any kind of constructive help, she doesn't think they do DBT in this part of the country. So why was I told that I would get it by other members of staff and my care co-ordinator? The member of staff who said she could stand in for my care co-ordinator said she has read my notes and knows about me. I found out from her that three very important things were not written in my notes: my mum's suicide attempts, my hallucinations and something else that I don't want to write here. I asked again when I could get help. She asked me if I had been assessed by 'psychology'. I said I don't know, I've been assessed so many times I don't know who they all were any more. She said she would find out. They should know this! She said she had read my notes! What do I have to do to get some help? I phoned the crisis team again and spoke to a man who was audibly eating his supper throughout the phone call. I had been so desperately suicidal that I had almost gone to A&E to ask to be locked up. I have become a people-phobic recluse so being locked up is a desperate measure which I would absolutely hate. I wanted reassurance that they would respond in time to stop me next time I got in a panic suicidal state. I want to be given some drugs that will calm me down when I'm panicking and seeing things. He told me that they don't like to give drugs or put people in hospital. He said 'just stay positive' which is like telling someone with no legs to just keep on walking. I rang my surgery and spoke to a doctor. I explained that I am not well, I have been seeing things which frighten me, and I am still suicidal and unstable. The doctor said they didn't know what to do but would refer me to the psychiatrist for a medication review. A month later and I still haven't heard from anyone. A duty worker left a message saying my new care co-ordinator had to cancel our meeting, this was scheduled for a few days ago. I sent my care co-ordinator two messages asking if they knew when I might get some help or if the psychiatrist had gotten the message about medication. No answer. I asked if they could pass my questions on to someone who could help me. No answer. I asked my GP to help me get some help. They said they would try to find out what was going on. Nothing has happened but a series of let-downs and failures.

15. There is a bit of a theme emerging about peoples scepticism and despair that their views are not taken seriously and nothing ever changes as a result of providing feedback. This is what is being said. When do recommendations ever transmit into actions? Anything I ever say can be ignored as a sign of mental instability. Please pass this on if it helps, I doubt it somehow will. I feel worn down and on the verge of just walking away as I will not be included as a tick box exercise.

16. My daughter is on medication for depression and anxiety. She had 16 weeks CBT through depression and anxiety service last year and then no follow up from GP. She had made several attempts to make appointments and finally saw a GP who told he to just stop taking the medication after four years. She didn't. I have spoken with practice manager who assured me a GP would manage this with weekly in person or by phone support and refer to DAS or other for therapeutic support. The GP has not done this, instead telling my daughter to return in three months. My daughter has made several attempts to make appointments and has been told different information by receptionists. This makes her feel powerless and stuck, it makes me feel angry that the GP is not keeping to an agreement. My daughter has given up again on the idea of trying to get better and is too afraid to push for appointments or challenge the GP.

17. A lot of older people still use more traditional methods to look for help. This person and another Crediton contact used their phone book to try and find a way of contacting Devon Partnership Trust. There was one number for the Trust which they both rang on separate occasions, but the number was no longer available with no message to signpost you to another number. The person said there was a dearth of information available from Devon Partnership Trust. For example, the Trust were unable to respond to a request asking how many people in the Crediton area have Alzheimers. There is no regular support service for older people with mental health issues in the Crediton area. People have one-off appointments with their psychiatrist or worker, but no opportunity to come together.

18. About two months ago, things really got on top of me both physically and mentally and I ended up in Torbay hospital. My care was great, but some things just were not. I had a psychiatrist come to see me one evening, I think the second night and I noticed the smell of drink on him and felt unable to share the thousands of fears in my head due to my feeling that he had had quite a lot to drink. I mentioned this to a staff member but nothing was made of it. Some days later a Community Psychiatric Nurse (CPN) came to see me. I liked her and talked and was quite upset. She promised to return that afternoon, she did not return and some days later she came back. This time with some other lady who made me feel uneasy, she refused to sit and I could not talk again. The CPN said she would return, but I never saw her again. I spent 3 weeks in hospital. After I came home I was told I was having a care review. Two people from mental health turned up who I had never met before, an Occupational Therapist and a trainee. I was not asked if it was ok for the trainee to attend; I was told they had stopped my funding for my Personal Assistant and all other mental health funding. I was so upset I just sat and silently wept, but they kept talking for ages not wanting to review how I was getting on or what had happened to me. I ended up saying I do not want to say or do anything I might regret so please leave. They walked out and I have not had anyone check on me to see if I am ok. Prior to my admission, I had asked two GPs for mental health support, but instead I am abandoned, if a friend hadn't come to visit me this week and shop for me I would have gone hungry as I was too afraid to go out without support. I am not opening mail and I feel like there is no point any more no one cares. I have spent 25 years trying to get help from mental health services but now find them lacking, they don't want to visit people in their homes they treat us with distrust and I feel scared. Please pass this on if it helps, I doubt it somehow will.

19. I have put together a precis of my recent experiences and ongoing problems that I have experienced within the mental health service locally. If this is not the type of information you are looking for please disregard and dispose of it. Being Bi-Polar I frequently have episodes, these are normally managed with some interventions from the primary care and mental health teams. I became ill approximately 18 months ago and was referred by my GP quickly and got a timely and prompt appointment with a locum consultant. There were changes to my meds and a follow up appointment was scheduled, also I was assigned a Community Psychiatric Nurse (CPN). During approximately 14 months I saw eleven different locum consultants. My meds were changed several times which I believe added to my fragile mood disorders and lack of confidence in my treatment. There was no continuity of treatment for which my CPN apologised, they referred to the consultants by number (i.e. 16 and counting) rather than name. I have a cardio condition and once had to refer to my cardiologist to check if my prescribed medication was suitable to take, it wasn't and could have resulted in severe side effects. I also Googled an alternative medication and suggested it to my consultant which he accepted and asked me if there were any contra-indications to current meds, I at least thought he would check. All in all, I firmly believe that my condition has deteriorated due to the number of well-meaning consultants I have seen and the frequent changes of medications and associated side effects. At one point the Crisis Team were involved. My current condition is being managed by a locum consultant in whom I have confidence and am hopeful that this intervention will stabilise my condition. I feel that my family life has suffered due to the many changes in meds and believe my experience has had severe repercussions on my recovery. I must add that I believe everyone acted in good faith and I was treated politely at all times, my CPN is excellent, I wonder how the lack of continuity has affected my colleagues who are in a worse place than me.

20. This gentleman said he had a learning disability as well as mental health issues. He had direct experience of a Mental Health Tribunal. He said it was a very scary experience and felt that the process should be made easier for people with mental health issues who also have a learning disability.

21. It is a frightening process, being taken to a police station, especially for people with a learning disability and/or mental health issue. These people should not end up in prison.

22. An individual called in at the beginning of December as he is really worried about his son. His son has been suffering with mental health issues for 15 months and needs intervention for getting better again. The son finished his studies in September 2015 and has not been able to look for a job since as he has been too poorly. He has had some treatment at the RD&E where he has seen his psychologist, this treatment was early in the year. The individual's son has had no follow up appointments and no further treatment. The individual called as he feels his son's treatment has not been completed and is looking for help for his son. The family's GP has been involved and the son has visited the GP on occasions.

23. My friend has a 20 year history of paranoid schizophrenia. They became non-compliant with their meds and started self-medicating with alcohol and legal highs. They then became homeless and moved to Exeter. I had to inform the Crisis Team and impress upon them their responsibility to my friend. After being on the streets for 2 months with me as their only support; occasional baths, change of clothing, meals etc., they were offered a place at a hostel. But they could not cope with hostel life and moved back to east Devon to live as a homeless person. In a rare window of insight and vulnerability they asked to be hospitalised and was refused. Given the mental health diagnosis, being homeless, their poly pharmacy life threatening habits, the potential risk to others, the fact that benefits had been stopped I was shocked, appalled, and very angry. My friend was devastated. I believe that the team should have assessed, and admitted them to hospital. I believe that they have a culture of 'door keeping' limiting access to inpatient services. Eventually after repeated calls my friend was sectioned but only after they had become very angry, abusive and exploitative to myself and another woman living locally. I out of desperation had to file a case against them with the police due to their behaviour in the hope that this would trigger police knowledge and involvement. Three days later they were sectioned. They are still in hospital eight months later. Had they been hospitalised when they first became homeless or when they asked to be assessed maybe they would not have become so ill that they need eight months plus to recover. I have made a complaint but am unhappy with the result.

24. My views are based on experience both of the service and of some bodies that have proliferated around the fringes of mental health. I suppose I now believe in individuals and their power- that was always the only positive for me and when I see bodies like e.g. MIND more concerned on their office well-being than on those they are supposed to help or even their front-line staff, I'm afraid I'm not surprised by anything. When do 'recommendations' ever transmit into actions? You can change the rules but the human heart is more impervious. On the cheerful side, anything I ever say can be ignored as a sign of mental instability. Good old 'Catch 22'!

25. It still feels as if Devon Partnership Trust (DPT) are paying lip service to any development of service user/carers involvement. It troubles me to see pens mugs and wall charts produced promoting TOGETHER but nothing seems to have changed and since the proposed launch at the AGM was aborted no further date has been set. DPT staff running the project have not come through with their personal promise to include me, all I have had is a couple of holding emails and no response at all to a direct question. It is exhausting and depressing trying to make a positive contribution to the development of a service when it feels as if there is no genuine belief in the premise that service users and carers can play a positive role. This is backed up by the negative experience I have had both in the past and currently. If the Lead in the Together project, ignores my emails and doesnt arrange opportunities for involvement how can we expect those below him to embrace this new way of working. I feel worn down and on the verge of just walking away as I will not be included as a tick box exercise.

26. Referred by GP for post-traumatic stress disorder, bi-polar, chronic anxiety, for CBT, anxiety management and medication review. Went for assessment (appointment) the letter confirmed that appointment would last between 1 and 2 hours to complete a detailed assessment of need and risk. When they arrived, and introduced themselves they asked the patient, what do you want? Patient was stunned and asked for EMDR - eye movement desensitised reprocessing. Psychiatric nurses then said they would refer to psychology department and it would be about a 7 month wait and they would close her case. Patient and GP astounded. GP referred this as an urgent case. The GP has lodged a complaint.

27. I have recently had a care review and since then my mental health support has been stopped with immediate effect. I had been receiving this support for several years and I now find I am struggling to cope. The funding I lost was for my funded Personal Assistant. I used to talk to her about my worries and she would often help me put things into a better perspective, so I could cope better. Prior to having her, I used to self-harm and overdose regularly, but in all the time she was supporting me, I did not need a single hospital admission. She also enabled me to go shopping, cope with fears I had and would help me bring my purchases back into my home and put them away and dozens of other little things others might take for granted, all things I find it very painful to do for myself.

28. My care plan is written in the first person but most of the information looks like its been copied and pasted. Its not personalised it just looks like its been imported and plonked in my care plan to cover their backs.

29. I have an interest in young peoples mental health generally and in particular in eating disorders. I have volunteered with eating disorder charity and with Young Minds and have been involved with NHS England. I know that every CCG got 2 pots of money and had to submit a plan for how it would be spent. I also work within the NHS and over the last 10 months have looked forward to seeing developments in CAMHS across the south west as a result of the guidance and monies. Sadly, in Cornwall, the response to the monies coming down was disappointing and I believe the CCG have not used the money in purchasing services but have used it to offset their deficit. Which makes me furious! In Torbay I think provider services have adverts out and are talking about change so it looks like the money in Torbay may have been passed on. I have no idea what has happened in Devon. CAMHS and eating disorder services in the South West were some of the worst in the country (National Confidential Enquiry into eating disorder services). My experience and the experience of other families reflected the need to improve. It is so rare that spending in anything goes up so when nationally I saw a commitment to CAMHS such as there was, I got excited. So I am livid that those monies could have been swallowed up in a big black hole. When they came out they were ring-fenced apparently so how can they not spend it where it is needed? It was small sums to help desperately neglected services but it was something positive. I have shared my frustrations centrally that they are sitting there thinking it is all sorted when the CCGs in the middle are scuppering improvement, that I come from a part of the world where it was bad and it still is tough for families. Things have to change! I know centrally they are cross but can only put pressure that they would like it spent as planned by CCGs. Can you help? Can the 3 CCGs in Devon and Cornwall, under the freedom of information act be asked how they have used those monies. And can they be pressured from this end to spend them in the way the money was intended. The money and interest centrally for eating disorders and CAMHS is coming to an end, the new NICE guidance for eating disorders comes out next year, with the work they have done for the last 2 years the department of health feel they have sorted it and they will move on. I know for a fact, NHS England actually put 2 new sums of money to each CCG last autumn (labelled eating disorder services, CAMHS Transformation). So, where has the money gone? I really think the CCGs have to prove how they have spent the money. To demonstrate how they have improved eating disorder services, and are transforming CAMHS!

30. A gentleman gave feedback that the Ivybridge interview rooms are not sound proof and there is no longer a white noise machine to help provide some level of privacy.

31. Two people (person 1 and person 2) arranged to meet with the Be Involved Devon worker to talk about their concerns regarding the recent suicide of a friend. They said their friend had taken an overdose and called an ambulance. Whilst waiting for the ambulance the friend had rung person 1 to tell them what was happening. The friend was taken to the RD&E and person 1 was eventually able to contact them by phone at the hospital. The friend intimated that they might be admitted to the mental health ward and was awaiting a psychiatric assessment. Person 1 did not hear anymore from the friend for several days and assumed they had been admitted to the mental health ward. However, in following up with the friend's close relative they discovered that the friend had been discharged home from the RD&E and two days later was found hanged at home by the same relative. Person 2 questioned the decision to discharge this person instead of providing inpatient mental health care. They felt their friend might still be alive if the decision to admit had been made. They were also concerned that there was apparently no follow-up support post discharge from the RD&E by mental health services. They strongly thought that the systematic contraction of mental health services meant that people no longer had a comprehensive 'safety net' and their friend's death was a consequence of this. An update followed this feedback: Person 1 was able to get confirmation from the deceased friends mother that the friend did not receive a follow up visit once they had been discharged from the RD&E after an overdose and then shortly after had taken their own life.

32. My health became seriously bad due to depression and I was admitted to Wonford House Hospital for 2 weeks. The care provided was excellent and they took care of my needs. This care continues at my GP surgery.

33. Telephone call from an individual who is having a very difficult time. They are waiting for a first appointment for gender reassignment. This person was referred to a clinic from their GP. Their GP has written to the clinic several times and the clinic has ignored all of these letters. The person asked their MP for help, their MP wrote to the clinic and the letter went astray so individual then had to ask the MP's office for a duplicate copy to forward on. The individual found this rather embarrassing. When the individual has telephoned and the receptionist has been very rude and has told the individual to not keep ringing as they will have nothing further to report. The person raised a formal complaint with Devon Partnership Trust and has not been satisfied with the response. DPT Pals have informed the individual that they still need to wait 5 months (18 weeks) from now after waiting a year already. The individual thinks the clinic does not have the capacity to deal with all the referrals. he individual's complaint is now with the Ombudsman.

34. I am a patient at the Laurels Clinic in Exeter because I am transgender and am undergoing gender transition. I have been a patient for a couple of years and have consistently presented as male each time I have attended an appointment at this clinic. I have been refused gender confirmation due to a disability and throughout my treatment there have been delays with getting therapy in addition to my gender confirming treatment. Throughout my treatment at this clinic there have been delays with seeing the doctor and with getting therapy in addition to my gender confirming treatment. Also, there has been contradictory information and vague and misleading information being said to me. I wish for awareness training to be given to the staff at the Laurels to remove the mistaken idea that people with this disability are unable to give consent for treatment. The Laurels should be provided with awareness training as a frontline NHS service.

35. Devon Partnership Trust want to close one of their facilities using government guidance on relinquishing properties which are too expensive and/or underused. However, before this occurs, they should engage with the public but this has not been done as they have seemingly ignored a group of users and some staff. Last year they agreed to supply reasons for the closure and to seek alternative accommodation but this has not been fully completed. Despite a year passing, with a meeting where promises were made, this group has not been consulted. There are plans to move some of the services to Exeter. I feel that any ideas put before the Board etc. are dismissed and basic information is not provided. Exmouth hospital does not have enough space with limited parking. St John's Court is purpose built and has had a vast amount of money spent on it to refurbish, is ideal in its quiet solitude and has plenty of parking for all clients and staff. Exmouth has excellent transport links and it seems absurd to have people going to Exeter where there is little or no parking and a two step journey if relying on public transport; DPT is on the same site as the RD&E, this site is very busy and possibly disturbing to those suffering from mental health conditions, notwithstanding getting yourself to the site which is distressing in itself.

36. SUMMARY; I have had mental health problems since I was 11 years old. I left mainstream school at 12/13 and went to a pupil referral unit. I was having such severe hallucinations that it broke every one of my friendships down and everyone said I was a freak. I then started to have delusions. I had multiple possible diagnosis including Borderline personality disorder. I was in and out of a psychiatric unit from age 14. I have tried to kill myself in multiple ways. I've been on different medications through the years and Ive had multiple therapies. I was in a lot of trouble with the police when I had manic episodes and would hallucinate. I had a baby in May 2015 and I struggled so badly with paranoia and anxiety that my mum has been looking after him for the past year over night. I tried my absolute hardest to get help so I can be the mum I desperately want to be but I'm having no luck. I struggled with my GP to get medication after my psychiatrist told me he would not prescribe anything for borderline personality disorder, and the only way is talking therapy, which could take many years away from my chance at motherhood and feeling normal, and maybe not even work, after all I have been talking for 8 years. Recently my GP prescribed me venflaxine because I was having paranoid thoughts of my baby being killed. The psychiatrist wrote to my GP and discouraged him from prescribing me anymore medication. Now I have no medication, no therapy. Nothing. I am alone. And I am scared. I have battled so hard. The adult mental health service is shocking, I feel neglected. When I told my psychiatrist please, I need medication that will help me. I have been medicated before and been a whole new person. How would you feel if I ended up dead after begging for help?. He responded by saying that's your choice. My new psychiatrist held a medication review last week, I was explaining that at night I have traumatic thoughts about something happening to my son. This was hard for me to tell him as it upsets me deeply. He went on to tell me that being a young mother is hard and asking if I was angry with my son for trapping me. I said that sometimes it was hard of course because I have missed my teenage years in a way. He then went on to ask if I ever got angry with my son and I said absolutely not. As soon as I look at his little face, how could I be angry? He then went on to tell me yes, I understand it's hard to admit that you get angry with him. I went on to tell him I was not angry, nor have I ever been angry, with him. He carried on, saying that the scary thoughts and anxiety were caused by me being angry with my son, and feeling trapped. This is totally untrue, I had said many a time how I was not angry with my son, and how I could never be angry. I am a vulnerable teenage parent, I have been suffering from anxiety and borderline personality disorder from 11 years old, so I stress to you that this was all happening before my son was even born. This psychiatrist is a danger to his patients. He is planting things into people's heads that weren't previously there and has caused a big problem for me. How did he know I was not suggestible? I could have come home thinking I really was angry with my son. If I was a suggestible person he could have really made me believe I felt anger towards my son. Also a few months back, I was suffering badly with depression/anxiety. I went into my appointment with him to ask if he would consider medication as I was struggling to cope. He laughed and said so, what you're basically saying is give us a pill? Haha. I am not sure how this is acceptable as a psychiatrist. To make patients feel you are mocking them, not listening to them, and to plant ideas and thoughts that were never a problem. Nobody should be treated like this. Please don't let someone else give up on their life because of negligence of mental health patients, and because of tick boxes that nobody will ever fit into. Please, please help me. For me, for my son and for my family. It has been 8 years. And that is 8 years too long.

37. There is now new guidance from the government for people on medication who also drive. There seems to be a certain amount of leniency if you are on certain medication.

38. My 17 year old daughter has gender identity issues and was referred to a counsellor. She went along to the specialist session but is was full of older transgender people who she didn't have anything in common with; it wasn't what she expected. I was given contact details for Mermaids and GIRES support groups, and the address of the Laurels.

39. I've been referred to you by the Department of Health. I am not being given support at all from the mental health service and have been struggling for a long time to get some help! The latest care coordinator allocated to me only met me for 10 minutes in the entire six months they held their post for. They, cruelly and harmfully, left a voicemail to tell me they were leaving right away, so I had no warning and am back to square one. Even though I try and communicate with the mental health team I get nowhere. The manager should be doing something I would have thought, but hasn't. I'm left feeling isolated, at risk of harming myself and unsupported. Is there anything you can do?

40. Client referred herself to the Depression and Anxiety Service the local mental health services team. A few weeks after the referral the client was assessed as needing further treatment. They were told they would receive a letter offering a further appointment. The letter when it arrived stated that someone would be in contact in 2 weeks to arrange a follow up appointment for CBT on a one to one basis. Client heard nothing, so rang a month later wherein was told that an appointment could not be offered for 3 months and there were several people ahead on the waiting list. The GP intervened after the individual was admitted to hospital the second time, when they had threatened to commit suicide, but no emergency appointment was offered.

41. I am contacting you in regards to my gender identity therapy. I have come to terms with being trans (male to female) for a few years now and have only within the past year received therapy. My therapist has made several suggestions that my gender identity is linked to my racial background although I have had no concerns regarding this throughout my life. They have also claimed that further treatment should be done through their private practice which I cannot afford. I have also been informed that they have been in contact with my mother who is not completely happy with my transition although I am unsure of the validity of this. I am uncertain as to what action I need to take next to proceed with the lifestyle I know I need to be able to lead a happy life, these recent problems have left me with strong feelings of depression, despair and self-harm. Feelings that I had made my therapist aware and has only subsided since coming to terms with myself and starting therapy. Any help or advice that you could give me would be highly appreciated as I am left extremely uneasy about my future.

42. Individual has an ongoing complaint with the ombudsman with regards to Devon Partnership Trust. Individuals child has severe mental health issues and is on medication but individual says this is set too low. Child has been sectioned on many occasions and this individual has told HW Devon that DPT just do not listen or discuss any of their adult child with them. The child denies that they have a problem and so the help needed is never given. The parent has contact all the PALS team and nobody ever helps. They are worried that their child is fixated with a number of people and is emailing and contact these individuals, but no health professional seems worried about this.

43. I think I mentioned to you I was going to see the Depression and Anxiety Service. Well they referred me to a mental health assessment team and I had an appointment a few weeks ago. Because I'm not critical I'm entitled to no help from them but they are referring me to the Community Care Trust for support so I've just got to wait for that. She did tell me though that DAS won't treat anyone with Bipolar which I think is really bad and discriminating so I am contacting PALS about this and making a complaint. I had a conversation from a man from PALS yesterday. He's taken it to the top and spoken to the operational manager and is going to get back to me when he has some news. They have changed things now with mental health support and you don't get any help unless you're at crisis point which is bad.

44. I feel there is little provision for people with dementia and their carers in Crediton. There is only the dementia cafe which is insufficient and I'm not sure there are any professionals there. We used to have a much better provision.

45. Client is very distressed that many services are going to be cut and no longer funded from April 2017. This client and many other service users are trying to support the most unwell in the group out of their own money and on a voluntary basis as they are so concerned about what might happen to the most seriously mentally ill users without the regular cafe groups. This client does not recall getting a letter that all service users should have received explaining the changes i.e. that only those referred by Devon Partnership Trust will be able to access the services from April 2017 but it seems the users are not clear about this.

46. Individual called and feels they are now ready to make a formal complaint with regards to the treatment received at the Cedars Unit. The experience was over a year ago but only now feels they are strong enough to raise their complaint.

47. I went to a Rethink peer support group today that recently started. The group seems helpful and I am meeting in between for coffee. I have a good doctor and I am helping myself by achieving small goals.

48. Originally diagnosed with depression by my GP, about 18 months ago. In order to block out the way I felt, I would drink excessively for several days which I later found out was a symptom of Borderline Personality Disorder. Referral was made to the Plymouth Options Team. I was told to expect a long wait. After a few months I received an appointment to be assessed. The person I saw was rude and showed no empathy at all. I came out of the assessment and cried. I was told that I would receive a letter telling me the results of the tests and what the next step would be. Several months later and still no response. This was despite many calls to them. Calls remained unanswered, or messages left were simply ignored. If you were lucky enough to get through, the person you wanted to speak to was never there, but would get back to you as soon as possible. Call backs were not honoured. Eventually, after a particularly angry message left on their voicemail, a letter arrives telling me they cannot help me. I then had 6 private sessions with a clinical psychologist. These sessions were paid for through my Mother's private healthcare insurance. I feel that the sessions helped me, but they had to stop as the funding was only for 6 sessions and further ones were available at a cost of £95 a time. Further referral by my GP, this time to Mount Gould Hospital. Again, I was advised that there may be a long wait. I finally received an appointment and tests were done. I am now diagnosed with Borderline Personality Disorder, but they are unable to help me and I need to be referred to someone else. Further waiting. Yet another appointment is made for me, this time at River View. More tests are done, and BPD is confirmed. However, I am now diagnosed with another symptom - avoidance disorder. I am now told that River View cannot offer the specific treatment I need, and I therefore need to be referred back to Erme House. I feel that I am being passed from pillar to post and just going around in a very vicious circle. Part of my condition is that I feel no-one cares and that I am terrified of being alone. This is an abysmal 'service' offered to the most vulnerable of people who are desperate for help. This needs to be investigated as to why the service is so bad and what can be done in order to improve and speed up the referral process. The delays in waiting for appointments and treatment is certainly not acceptable.

49. I am extremely concerned and annoyed about threatened cuts to mental health support, all across the county. It will lead to long term and more expensive treatment in the future. Can we have some long term funding/planning please.

50. An advocate wanted to know who would be able to provide support and give assistance to an individual who was based in Exeter Prison and suffering from severe depression and anxiety, and due to the prisons policies, with no medication. The advocate was very worried about this individual as it was coming up to a bank holiday weekend and the individual had been transferred to Exeter from another prison that should have been helping him with his healthcare needs, instead they just transferred him to a prison that could not give him the medication he needed.

51. We should have a mother and baby inpatient unit in Devon. People from Cornwall have to go to Bristol! Also they would be lucky to get in. I used to work in this field.

52. Individual called as they are worried about the services for mental health sufferers. The individual suffers with Bi-polar disorder and was admitted in hospital. Wonford House did not have enough beds so they were sent to Torbay Hospital and stayed on the Mental Health Ward for 3 days. They cut their stay short as they felt terrified being there as the other patients were worrying people to the individual. So they told the hospital they were going to stay with a relative. This individual has found the whole process a nightmare whilst being poorly. They had to wait 6 months to just see a consultant. Their comment; Would you wait 6 months to have a broken leg looked at? The consultant at the hospital produced a treatment plan for the individual. The community mental health team did not like the plan. The Crisis Team gave no support and the individual found there was no support care in community after seeing the consultant. The individual did not go out for 3 months and feels without the support of their family they would not be here today. When their community psychiatric nurse went on leave the individual was told there would be support from if they needed it. Called for help but no one answered and the crisis team was not available. The waiting list to see a psychotherapist is 2 years.

53. Question to Healthwatch Devon. Would you be an organisation who could help me with some concerns we have encountered with RISE recovery service in Devon?

# Appendix 2: Healthwatch Themes

When an experience is recorded there are a list of categories to which the feedback can be themed. The table below shows a list of all those themes and the definition of each.


| Theme | Definition |
|---|---|
| Access for people with a physical disability | Access issues due to physical disability (e.g. wheelchair access) |
| Access for people with a sensory disability | Access issues due to sensory disability |
| Access to Dentistry | Other access issues regarding dentistry |
| Access to GPs | Other access issues regarding GPs (e.g. Availability) |
| Access to Hospital Services | Other access issues regarding hospital services (e.g. layout) |
| Access to Opticians | Other access issues regarding opticians |
| Access to Pharmacy | Other access issues regarding distribution of medicines (e.g. repeat prescription) |
| Access to Social Care Services | Other access issues regarding social care services (e.g. availability of social worker) |
| Admission | Entry to a treatment pathway that is appropriate and timely |
| Appointments | Easy access to appointments |
| Car Parking | Ability to access the service via parking |
| Choice | Providing alternatives and allowing them to be picked from |
| Cleanliness | A clean environment free of hazards |
| Complaints Process | Having a system which allows for the raising of concerns, and also feedback and action in relation to those concerns |
| Confidentiality | Keeping personal details safe and undisclosed unless permission has been given for them to be disclosed |
| Consent | Asking permission before performing an action which affects another |
| Consultation | A meeting with an expert, such as medical doctor, in order to seek advice |
| Diagnosis | Understanding the need that needs to be met in an effective way |
| Dignity | To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals |
| Discharge | Exit from a treatment pathway that is appropriate and timely |
| Equality | Treating everyone the same regardless of any perceived difference |
| Fees / Charges | Issues with services that require payment (e.g. dental treatment/ sick notes) |
| Monitoring & Accountability | That the performance of the service is being monitored, poor performance is addressed and it is clear where responsibility lies |
| Nutrition & Hydration | Easy and appropriate access to proper nutrition and water |
| Opening Hours | Access to services at appropriate times |
| Patient Transport | Ability to access the service via patient transport |
| Privacy | Not undermining a person's self-respect, including respecting a right to a private life |

| Theme | Definition |
|---|---|
| Procurement/Commissioning | The buying and contract management of services |
| Quality of Treatment | High quality procedures, the right medication etc. |
| Records Management | Systematically controlling the creation, distribution, use, maintenance, and disposition of recorded information |
| Referral | The act of referring someone for consultation, review or further action (e.g. the directing of a patient to a medical specialist by a GP) |
| Safety | Being protected from danger, risk or injury (including health and safety issues) |
| Service Coordination | A seamless link between health and social care services so that if more than one service is involved in meeting a person's health and social care needs, they work together in a joined-up collaborative way |
| Service Monitoring | That the performance of the service is being monitored, poor performance Is addressed and it is clear where responsibility lies |
| Staff Attitudes | Members of staff having a friendly and helpful manner |
| Staffing Levels | Availability and capacity of staff |
| Stigma | Stigma is a perceived mark of disgrace that sets a person apart, which can bring about feelings of shame, blame and distress |
| Suitability of Provider Staff | Staff who have the skills, time and resources |
| Waiting Times | Easy access to timely appointments |

The data included in the experience summary reports are for the recipients to utilise and to help inform service design, delivery and improvement.

In addition our database is set up so that we can filter these themes allowing us to identify emerging topics. We will then look in more detail and extract feedback regarding these topics and feed them into specific commissioner/trust reports and sometimes look to produce a specific report.