People's experience of mental health services in North Tyneside

A report by

Healthwatch North Tyneside

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The views expressed in this report are those of Healthwatch North Tyneside and do not necessarily represent the views of any of the local organisations and people who participated in this piece of work. It is acknowledged that the views shared with Healthwatch North Tyneside do not necessarily reflect those of all service users.

Healthwatch North Tyneside

Healthwatch is the independent consumer champion in health and care. We gather and represent the views of people who use health and care services. We feedback this information to the people responsible for commissioning and providing services so that they can take action to address people's concerns and improve the services in their area.

Local Healthwatch have been set up in each local authority area in England, creating a national network to make sure the voices of people who use health and social care services are heard at the highest level.

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Summary

In July 2015 Healthwatch North Tyneside (HWNT) prioritised gathering the views of local people about mental health services. To help us we set up a project team to steer the work. This had representation from service users, carers, public health and local community groups.

We used a number of ways to get people's views. We invited views from service users, carers, family members, professionals and commissioners. Views of just under 300 people were gathered in the period from 1 October until 16 November 2015.

This report aims to:

Gather, understand and articulate the views and experiences of people who have used mental health services in North Tyneside in order to improve services.

The National Institute for Health and Care Excellence (NICE) has published guidelines outlining the level of service that people using NHS mental health services should expect to receive. We considered this when assessing services in North Tyneside along with national and local documents which set out ambitions to improve services.

We have grouped what people told us about their experiences according to which part of their 'journey' they are talking about.

Entering services

Entering services is a real concern for people in North Tyneside who reported that they find it difficult to find the right service to access in particular if they have specific needs such as personality disorder, learning disabilities or are users of drugs or alcohol.

The length of time that people have to wait to start being supported by services was highlighted as a concern for local people. Some people waited longer than the national standard and some felt that they would benefit from some other kind of support whilst waiting for services.

Though a number of people reported a positive experience of using crisis services, many more felt that this service area requires improvement. In particular the ease at which people can access support in a crisis and the quality of support given.

Likewise, support given to people who feel that they may wish to end their life or have made an attempt to do so, is an area which people feel can improve. People report that it is difficult to find the right place to get support, they may experience lack of dignity in their treatment and may face barriers to receiving ongoing support once an intial crisis response is ended.

Receiving services

In the main, once people are using services their experience is largely positive and they feel that the services they used have supported them in their recovery. Some concern was raised about the types of assessment carried out at the start of their services and how medication was managed by services. Furthermore, people

reported that services could be improved if different professionals involved in their care were working with a more multi-disciplinary approach. Service users also report that they would like to be more involved in decision making about their care. This could include increasing control over their own care and having input into the decisions about how services should be delivered.

Leaving services

People report that when a service comes to an end it is important that discharge is planned and support is in place. This was unfortunately not the experience of many of the people who gave their views. People who transition between services also report that this could be better planned.

Other issues

Staffing was the single most commented issue. People feel strongly that the role the staff member has in recovery is important and they need to have the right skills. Concerns were raised about staffing levels and continuity of care when staff are absent, these are areas that require attention.

Physical health has been identified by some as an area which could benefit from improvement as some have experienced physical illness being attributed to mental health conditions.

Involvement - Family and carers have reported that they would like to be supported to be more involved and supported in their role. They reported barriers to involvement in relation to confidentiality reasons as well as lack of information about who to contact in a crisis.

Austerity - People were concerned about the impact of austerity measures on mental health services in North Tyneside and suggested that this should be prioritised for investment by commissioners locally.

HWNT has made a number of recommendations which will be sent to commissioners and providers for their formal response. Some of these recommendations have already been incorporated in North Tyneside Mental Health Strategy and this will be monitored by HWNT.

Introduction

In July 2015 Healthwatch North Tyneside (HWNT) prioritised gathering the views of local people about mental health services. This was based on data indicating that many people with mental health problems had concerns about the services available in North Tyneside.

North Tyneside Health and Wellbeing Board also prioritised mental health as a key focus of work for 2015/16 and held an action day in December 2015 to contribute to the development of a local Mental Health Strategy. We fed back emerging trends from our work at this event, placing the voice of local people at the heart of strategic decision making.

Aim

This report aims to:

Gather, understand and articulate the views and experiences of people who have used mental health services in North Tyneside in order to improve services.

Our approach

Our primary aim in carrying out this work was to listen to the views of local people. However we also wanted to make sure that we heard from North Tyneside Council (NTC) and Clinical Commissioning Group (CCG) which commission the services and those organisations in the NHS and in social care who provide services.

To help us we set up a project team to steer the work. This had representation from service users, carers, public health, voluntary organisations and local community groups.

We held meetings with the council, CCG with local commissioners and providers of services to get their views on current provision and to map current services. You can see the service map used by the project team in Appendix 1.

We used a number of ways to get people's views. These included:

- A survey (which could be completed off or online. See Appendix 5)
- Six focus groups
- Through our outreach and engagement work. This included both our regular sessions which are open to anyone as well as more targeted with people who use mental health services.
- Through social media (Facebook, Twitter).

We focused primarily on adult mental health service users, however some of the data collected related to transitions into adult services. We invited views from service users, carers, family members, professionals and commissioners. Views were gathered in the period from 1 October to 16 November 2015.

The data that we gathered was analysed at both a thematic and service level. Initial recommendations were developed from this data and these recommendations were presented at North Tyneside Health and Wellbeing Board's Mental Health Action Day in December 2015. The data about services collected during the project was fed back to providers and commissioners prior before finalising this report so that their views could be considered in this final report. This report sets out in sections where providers or commissioners provided comment.

We gathered the views of 272 people as shown in table 1.[1]

Table 1: Who we heard from - number of people giving views by method

Methodology	How many people gave their views?
Survey about local mental health services	72 (service users) 38 (family, friend, carers) 40 (professionals) Total 150
Generic engagement and outreach activities	42 data sets (some people in groups)
Focus group discussions	69
Thematic engagement and outreach	53 (including service users letters)
Estimated total reach	272

66% of service users' views relate to experiences of services within the past two years. Of these, 41% reported that they used a service for less than six months and 59% for up to a year. More information about how this breaks down by service is shown in Appendix 3.

More detailed demographic data on those who gave their views, is shown in Appendix 2.

[1] It is not possible to give an entirely accurate figure as some people may have contributed in more than one way.

Mental health services nationally and in North Tyneside

It is widely recognised that mental health services in England require significant improvement. In February 2016 Prime Minister David Cameron acknowledged mental health as a major problem with many people not getting access to the high quality care that they need. He announced an extra £1 billion a year for mental health care as an important step towards delivering the government's commitment to put mental and physical health on an equal footing.[2]

In addition, North Tyneside faces particular challenges. The North Tyneside Mental Health Needs Assessment (which was not publically available when this report was published) carried out by Public Health, shows that while the percentage of the population reporting a long term mental health problem is similar to the rest of England, the borough faces higher than average rates of attendance at A&E of people reporting mental health problems.

The Mental Health Needs Assessment (2015) also identifies that suicide rates are higher in North Tyneside than for the rest of England[3]. The needs assessment set out that there is possible under-diagnosis of depression in primary care and that rates of recovery for people referred to the Improving Access to Psychological Therapies (IAPT) programme is significantly lower than the rest of England. Carers are also reported to receive significantly lower rates of assessment compared with the rest of England.

In North Tyneside mental health services are commissioned by North Tyneside Clinical Commissioning Group and North Tyneside Council. The main providers of clinical services are Northumberland Tyne and Wear Mental Health Trust and Northumbria Healthcare NHS Foundation Trust. You can see a service map in Appendix 1.

[2] Prime Minister's announcement 15 February 2016, see https://www.gov.uk/government/news/pm-improve-mental-health-treatment-to-get-thousands-more-back-to-work

[3] This data has been queried. However the Office for National Statistics shows that the North East suicide rate is higher than the rest of England. In addition North Tyneside has the highest suicide rates within Tyne and Wear (2013-2015), see www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/suicidesbylocalauthority

What makes a good mental health service?

We have identified the following standards against which local peoples' experiences of services should be judged:

A Vision for Change: No health without mental health (2011) sets out six objectives to improve mental health outcomes for individuals and the population as a whole:[4]

1. More people will have good mental health.
2. More people with mental health problems will recover.
3. More people with mental health problems will have good physical health.
4. More people will have a positive experience of care and support.
5. Fewer people will suffer avoidable harm.
6. Fewer people will experience stigma and discrimination.

The National Institute for Health and Care Excellence (NICE) has published guidelines outlining the level of service that people using NHS mental health services should expect to receive.

Quality Statements: NICE Quality Standard QS14 - Service user experience in adult mental health services. There are 15 quality statements some of which are referred to in this report[5].

Several local documents also define how services should be provided. These include:

1. North Tyneside Mental Health Needs Assessment
2. North Tyneside Mental Health Crisis Concordat Action Plan 2015[6]
3. North Tyneside Suicide Prevention Action Plan

These documents are not all in the public domain, however, extracts will be quoted in this report.

[4] DoH 2011 No health without mental health: A cross-government mental health outcomes strategy for people of all ages
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf
[5]. https://www.nice.org.uk/guidance/qs14
[6] http://www.crisiscareconcordat.org.uk/areas/north-tyneside/

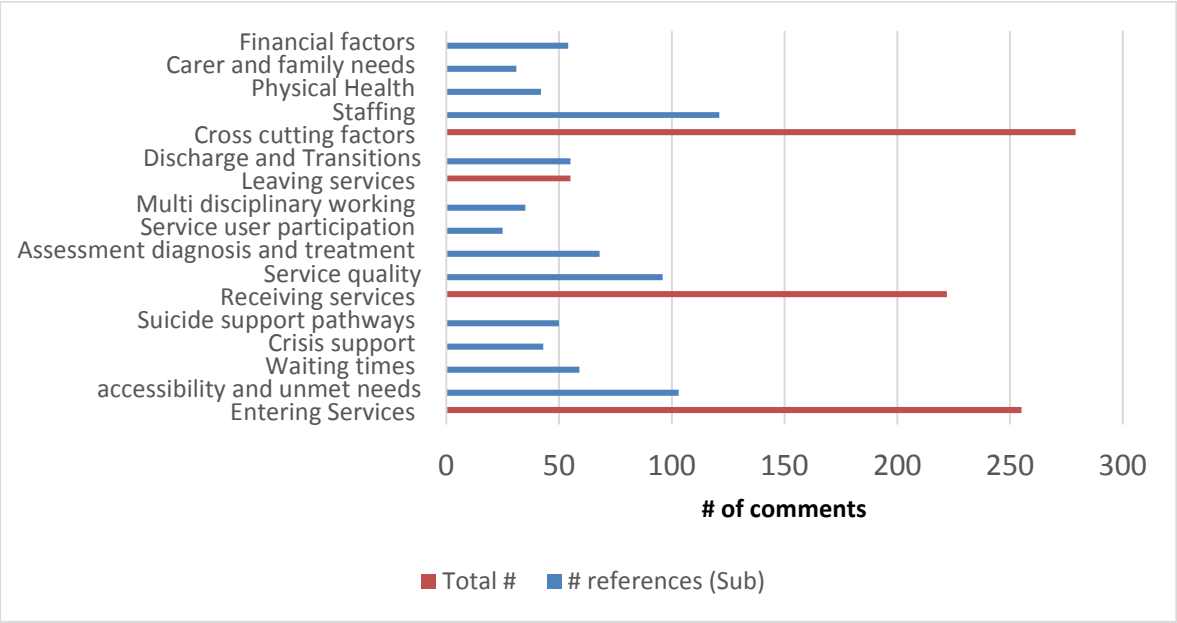
What people told us about their experience of using local mental health services

We have grouped what people told us about their experiences according to which part of their 'journey' they are talking about:

- Entering services
- Receiving services
- Leaving services

As table 2 shows below, most of the comments related to people's experience of entering services.

Table 2: Number of comments made by issue



There are a three factors which impact across all service users' experiences:

- Staffing
- Physical health
- Carer's and family needs

Of these three factors the most commented on were issues with staffing.

We describe the trends in what people have told us under each of these headings below.

We have also explained which service areas the experiences relate to where we feel that this is significant and warrants further attention.

Where we have been provided with supporting evidence from service providers or commissioners we have provided this alongside people's stories.

Entering services

People shared their experience with us of accessing or entering services. We have categorised these experiences under four headings:

- Accessibility and unmet needs
- Waiting times
- Crisis support
- Suicide support

Accessibility and unmet needs

Standards

NICE Quality Standard QS14 Statement 6 states that people should be able to "access mental health services when they need them"

The people we spoke to had strong views about entering services. The majority of comments relate to Community Mental Health Teams (CMHT), Improving Access to Psychological Therapies Service (IAPT) and Child and Adolescent Mental Health Services (CAMHS).

Only one person reported a positive experience of accessing services:

> **"They were easy to access and well run" (service user)**

20% of comments related to general concerns about how **difficult it is to access services**:

> **"Access as in how and where should be clearly made visible in every GP surgery." (service user)**

> **"Self-referrals difficult, people pushed from pillar to post. As a charity we often have to advocate for people wanting to access NHS." (professional)**

52% of comments in this area relate to needs that were not being met by existing services. People with some specific needs told us that they felt their needs were not currently being met properly. These included survivors of sexual abuse, users of drugs or alcohol, people with learning disabilities, personality disorders and those who are socially isolated.

Survivors of sexual abuse and violence

People who had experienced sexual violence or abuse told us they found it difficult to get support through mainstream mental health services. In some cases people were told that they were too vulnerable for counselling through IAPT but the waiting list for specialist support through Rape Crisis is over 6 months, leaving them without support in the meantime.

> **"There needs to be a resource available for survivors of sexual violence who have mental health issues and for self-harmers." (professional)**

Users of drugs or alcohol

People told us it is difficult to access mental health services if using drugs or alcohol. In particular there is an issue that often it is not possible to address substance misuse issues without first addressing a person's mental health needs.

> **"Not all substance misuse is the cause of a mental health issue, it is often used to cope. Young people struggle to access IAPT if they use alcohol to self-medicate". (professional)**

> **"Having a drug and alcohol label is a barrier to interventions". (professional)**

The North Tyneside Mental Health Crisis Concordat acknowledges the need to improve access to services for people who are users of drugs or alcohol, especially when there is a crisis.

"Develop a process around assessment of people under the influence of alcohol to ensure that no-one is excluded from a place of safety or assessment due to intoxication". (3.6)

"Strengthen pathways between Northumberland Tyne and Wear (NTW) NHS Crisis Team and NTW Consortium for Drug and Alcohol provision to ensure joint crisis planning". (5.1)

But it is not just when there is a crisis that people need support. Access to mental health services for this group is a broader issue.

Learning disabilities (in particular Autistic Spectrum Disorders)

We heard from a number of sources about the difficulties people who have a learning disability face in accessing mental health services, especially when they have an Autistic Spectrum Disorder. Long waiting times and a lack of specialised provision were cited as specific concerns.

> **"Support for autistic spectrum disorder- I was diagnosed two years ago but have no other support in the regard". (service user)**

> **"My mental health practitioner has referred me to have an Asperger's assessment but again waiting times are extreme (at least 6 months)". (service user)**

Personality disorder and borderline personality disorder diagnosis

People who have been identified with a personality disorder (PD) or borderline personality disorder told us they had difficulty with accessing both mainstream mental health provision (which in some cases they felt couldn't meet their needs) and specialist provision.

> **"Referred by GP to CMHT (Community Mental Health Team) psychiatrist but the psychiatrist specialises in psychosis and schizophrenia and says he (the patient) needs to be seen by the specialist services. NTW specialist services would not see him". (professional)**

"The Personality Disorder team only work through the community psychiatric nurse CPN and I don't have direct contact with them" (service user)

We have been provided with the criteria for the specialist PD service which makes it clear when a person will receive direct specialist services and when the PD team will support the mainstream services (referred to a 'scaffolding service'). Therefore whilst professionals may be clear as to why direct specialist support is not deemed appropriate, it may not be clear to those who access services.

The feedback we have received shows there is a need to ensure that these referral pathways are strengthened and cases regularly reviewed to escalate to specialist provision where appropriate. There is also a need to clarify under what circumstances 'mainstream' mental health services may not be accessed by people with a personality disorder diagnosis and what alternative will be offered.

People who are socially isolated

People told us there is a lack of services for people who are not 'unwell enough' for support from mental health services but who are at risk of their mental health deteriorating due to being socially isolated.

"It would be helpful if there was support for people who are on their own with depression and mental health issues. Organisations often say talk to your family or friends, some people don't have family or friends". (service user)

Falling through the gaps

14% of comments relating to access, were about people feeling that they are **'falling through the gap'.** People believe it is getting more difficult to meet the criteria for services and therefore harder to get support. This particularly applies to people with mild to moderate mental health problems.

"Eligibility criteria to gain access to mental health services seems to be going up all the time making it impossible for someone with a moderate mental health need (i.e. not yet at the point of crisis) to get any help." (carer)

People raised concerns that there are people who are deemed too unwell for some services but not unwell enough for others:

"Difficult to find the 'right place' for people. Too high risk or needs for IAPT not high enough for CMHT." (professional)

Waiting times

Standards

NICE Quality Standard QS14 Statement 6 says that there should be evidence "that people with non acute referrals to mental health services have a face to face appointment that takes place within 3 weeks of referral"

Some people reported a positive experience of waiting:

> **"Often able to offer support to client and support workers at short notice." (professional)**

> **"At NSECH (Northumbria Emergency Care Hospital) I was seen within 5 minutes." (service user)**

> **"Mental health reablement- Fast response to referrals." (professional)**

However, an overwhelming majority of comments about waiting times (81%) express dissatisfaction. Most of these were about the IAPT service.

> **"Took months to see a psychiatrist and get a correct diagnosis and medication. Almost a year later, I am still waiting for OT referral and talking therapies which were suggested in my first appointment over a year ago." (service user)**

This is a particular issue in times of crisis and immediately after crisis. The NICE Guidance states people should be seen within 4 hours.

> **"Waiting list was 8 weeks to see someone following hospital discharge and suicide attempt." (service user)**

A few people pointed out that there is no interim support available for people who are on a waiting list

> **"I have been on the waiting list in excess of 200 days and nobody helping me to cope with this." (service user)**

Data from the Clinical Commissioning Group shows that for the year to November 2015, 91% of people referred to the service had their first appointment within 6 weeks and 94% of people were seen within 18 weeks.

This data compares favourably to the new national standard which is to be implemented in April 2016. This is that 75% of people should be seen within six weeks and 95% of people should be seen within 18 weeks.

However some people reported recent waits of longer than the reported timescales to HWNT.

> **"The waiting list, very long!!!! Awaiting a referral for 8 months now." (service user)**

> **"I fear for my future, without the talking therapies that I believe can help me to understand and work with my condition. However have been on the waiting list in excess of 200 days." (service user)**

On the basis of this not matching the performance reported to the CCG it is worth considering if those who are reporting longer waits are perhaps subject to some failure in referral pathways.

Others expressed general dissatisfaction with waiting times.

> **"IAPT was really useful to talk to someone you don't know. They waited a long time for it to start." (carer)**

"IAPT Services high waiting lists since service retendered. It's too long." (professional)

This indicates that there is a need to communicate the standards to service users to help manage their expectations.

People also raised concerns about the waiting times for being seen by CMHTs. The actual wait complies with local standards of eight week waits, but is perceived to be too long.

"Waiting list was 8 weeks to see someone following hospital discharge and suicide attempt." (service user)

"Actual appointments can be up to 2 months" (service user)

The expectations of service users about what is a reasonable wait appear to be different from the standard set by the CCG, which is longer than the NICE Quality Standard. Waiting times for local services should be reviewed to ensure they meet national standards and are in line with what patients need.

Crisis support

Standards

The NICE standard QS14 Statement 6 states that crisis and home resolution teams should be accessible 24 hours a day, 7 days a week regardless of diagnosis. Statement 9 also sets out that people at risk of crisis should be offered a crisis plan.

26% of the comments relating to crisis support were positive:

"Crisis team - expert, considerate, positive." (professional)

"Coming off meds I could phone up during withdrawal and information and advice was brilliant." (service user)

However, 74% of the comments came from people who feel that, based on their experience, improvements are needed in several areas.

Increase the resources available to the Crisis Teams.

Standards

NICE Quality Standard 14 Statement 6: Access to services states that in order to meet the standard there should be evidence of a local 24 hour helpline staffed by mental health and social care professionals.[1]

Some people described their difficulty with accessing trained professionals when in crisis. Some people said the waiting time for support was too long.

"Crisis team are also excellent. However, there are not enough staff available at night time (when things are a lot harder) and you end up having to leave a message with the night guard, asking for a phone call

back, and if the team are responding to an emergency and are out of the office, it can take hours to get a response from a trained mental health worker. This HAS to be improved as vulnerable people are being left un-supported". (service user)

The North Tyneside Crisis Concordat sets out an ambition to "implement a multi-agency single point of access for mental health services which provides expert advice and support for external agencies, services users and carers."(2.6) It is not clear if this will be a 24 hour service.

The response in A&E needs to be improved

Several people told us about problems they had experienced accessing support at A&E when they were in crisis.

"A&E terrible, they don't listen or care why you did it. Poor care makes you not want to go back" (service user)

The Mental Health Crisis Concordat set out a goal to:

"Implement liaison psychiatry services at acute hospital sites and in wards, aiming to provide seamless referral into appropriate mental health services where emergency/urgent needs are indicated and to avoid unnecessary hospital admissions." (3.4)

Discussions with the CCG confirm that psychiatry is now being delivered from the Northumbria Specialist Emergency Care Hospital. Initial feedback shows this has had a positive impact and the service has improved.

Improve skills to deal with crisis across providers.

Some people told us that, in their view, the staff who they came into contact with during a crisis did not have the necessary skills or knowledge to support them. Some of these staff were from the crisis team, but others were in other services such as GP or hospital reception staff, A&E staff.

"They felt under trained and lacking in first-hand experience of such problems" (service user)

"I am not convinced the training that staff have gives them an understanding of how human beings behave in especially crisis and traumatic situations." (service user)

The following quote illustrates that the North Tyneside Crisis Concordat Action Plan recognises that training needs to be improved:

"Review training needs of all agencies to develop a multi-agency framework of training to improve understanding of mental health, relevant legislation and the roles and responsibilities of each partner agency. This will include training to police staff and to ambulance staff regarding mental health". (1.5)

A date of April 2016 was set to deliver this target. We believe that some progress has been made but more funding is needed to implement it fully.

This plan also states that commissioners and providers will:

> "Ensure that staff who encounter people experiencing mental health crises will develop an evidence based understanding of mental health crisis from the perspective of people with mental health needs, carers and families". (1.5)

It is important that progress is made to deliver this.

Suicide support

Some people (22%) reported positive experiences of accessing support when they were considering suicide.

> **"The best support I found was family and friends" (service user)**

> **"When I have wanted to harm myself in the past the most helpful thing has been the support of my CPN during office hours, or her coming out to see me straight away the next morning." (service user)**

> **"MIND saved my life after this incident. They called the ambulance which took me to NTGH." (service user)**

However the majority of comments identify a need to improve support for people when they feel they want to end their life. Improvements required include:

Ensuring it is easy to find the right place to go

> **"Had called number of places today trying to get help as feeling suicidal and isolated but not able to get help from CMHT, Crisis Team, MIND or other VCS." (service user)**

> **"Too much of a rigmarole to get support asap." (service user)**

Treating people with dignity and respect

> **"She attended NSECH and was discharged with more drugs. She thought this was a bit stupid as she now had more ways to end her life". (carer)**

> **"What happens is, I go to A&E in the evening, they offer no support, they keep me in a small room with two chairs until 9am the next morning when they contact my CPN and she picks me up and has a chat with me. If it is a weekend then I am released from A&E with no support what so ever because someone from the crisis team tells them I am well known to services and there is nothing they can do for me at that time." (service user)**

> **"My GP told me to go and commit suicide." (service user)**

> **"Some doctors and nurses don't give you respect. They think that if you cut your arm that it's your fault. Sometimes it's not avoidable, you don't do it for fun. Sometimes you heart aches so much you need to cut yourself to get the pain away. They think we do it for attention. Sometimes we do but it's because we are desperate. We need attention, we need services. I want to live but everything I am going through hurts**

so much that sometimes I just want to die. I need help. I need respect and I need understanding." (service user)

Data provided to HWNT from Public Health shows that 64% of people in North Tyneside who ended their lives had no previous record of attempting suicide and the majority had not accessed mental health services previously. This highlights the need to improve access to support in a crisis and when someone feels that they wish to end their life.

Follow up support

22% of comments about suicide raised concern about the follow up support available once an initial response is over. Some people said that follow up was not forthcoming in a timely manner:

"At hospital I was discharged straight after my suicide attempt with no follow up which led to a second attempt at home." (service user)

"After discharge there is no continued support for patients through referral to other more informal services." (service user)

In some cases follow up support was promised but not delivered or was subject to significant delay:

"Waiting list was 8 weeks to see someone following hospital discharge and suicide attempt." (service user)

"When sent home from Hospital I was told that the CAT team would be there for support and help but I am still waiting to hear from them months later!!!!" (service user)

Public Health data shows that 19% of people attempting suicide had made a previous attempt and 17% of these had made an attempt in the past year. 35% of people had accessed mental health services at some point.

The North Tyneside Suicide Action Plan sets out the following actions required to improve services:

1. Reduce the risk of suicide in key high risk groups
2. Tailor approaches to improve mental health in specific groups including children and young people, men, people with a history of self-harm, LGBT, people in contact with the criminal justice system and supporting those with existing mental health conditions.
3. Provide better information and support to those bereaved by suicide.
4. Support research, data collection and monitoring,
5. Support the media in delivering sensitive approaches to suicide and suicidal behaviour.
6. Reduce access to means of suicide.

The suicide rate in the North East continues to be above the rate for England as a whole. The data for 2012-2014 does show that for North Tyneside the rate has reduced and is now similar to England. Nonetheless based on what people told us we believe there is still a need to improve services further to deliver these objectives.

Receiving services

This was the area where the largest levels of satisfaction were reported. We have analysed comments in the following categories;

- Quality of services
- Assessment and diagnosis
- Treatment and medication reviews
- Service user participation
- Multidisciplinary working

Quality of services

Standards

NICE Quality Standard QS14 Statement 1 states that people using mental health services, and their families or carers should "feel optimistic that care will be effective".

80% of comments about the 'quality of services' highlighted good quality services

> **"I think the mental health unit at North Tyneside General Hospital for people over 65 is very good and very tranquil." (carer)**
>
> **"They are a valuable and much needed solution to the many vulnerable people whose lives are affected on a daily basis. They provide outstanding help so that many people, such as myself, very much depends upon." (service user)**
>
> **"I lead a normal life now. I do manage a flat of my own and a reasonable independent life." (service user)**

Most comments were about Community Mental Health Teams

> **"I used to attend community mental health services periodically. When I was better I saw psychiatrist 2 to 3 times annually. I have attended various groups for depression or anxiety. These were fabulous! I realised I wasn't the only person on the planet like me. Learned coping strategies and relaxation."(service user)**

Assessment and diagnosis

Reports of people's experience of assessment and diagnosis were mixed.

> **"One carer reported a quick turnaround by NTRP (North Tyneside Recovery Partnership), but this was due to a referral by a CPN who co-ordinated the care and supported the service user into (community rehab)." (carer focus group)**
>
> **"I was at St Georges Hospital for a month and it was a quick admission and well organised." (service user)**

Some people raised a concern about the time available to carry out a full assessment:

> **"The length of time waiting for initial assessment then initial appointment is too long." (service user)**
>
> **"Some people might need more time to explain how they feel" (service user).**
>
> **"The GP saw her for 10 minutes and prescribed medication!" (carer)**

Others raised concerns about the appropriateness of the assessment such as the use of telephone assessments or the level of information requested:

> **"Assessments should be done in person" (service user)**
>
> **"You often do not see the most appropriate person for your condition first as they seem to assume that the self-help services are best even when your GP advises them that this is not the right level of service. You can waste a lot of time seeing the wrong people and this can make people stop accessing services altogether." (service user)**
>
> **"Adult Mental Health services fail to recognise the importance of taking as full a social/developmental history prior to diagnosis." (carer)**

Getting a diagnosis is important to many people to help them understand their illness and access the right treatment:

> **"Gave me an understanding of my illness and helped to create my own coping strategies to manage them" (service user)**

However others felt that a diagnosis was not helpful as labels impaired the person centred approach to treatment and brought stigma:

> **"The medical model is not helpful. It puts people in impossible boxes which are very self-limiting and the names themselves i.e. the diagnostic label are frightening to hear and say that you have this diagnosis to others. Having mental health problems is challenging enough with much prejudice towards you without the added difficulty of cruel labels." (service user)**

Some people said there was a delay in getting a diagnosis.

> **"Did not get a diagnosis from his GP 8 years ago, has now been diagnosed with bipolar" (carer)**
>
> **"After many years of unusual behaviour a diagnosis was given." (carer)**

Treatment and medication reviews

Standards

NICE Quality Standard QS14 Statement 7 says states that people using mental health services should understand the treatment options available to them.

The majority of comments in this area relate to Community Mental Health Teams and General Practice.

Some people reported that medication reviews resulted in changes in medication being made without their involvement or understanding of decisions or proper support being in place. In some cases this resulted in a crisis:

> **"They wouldn't give a repeat prescription of Temazepam and took my off my meds and put me on other medication without support." (service user)**

> **"My previous GP took me off medication I have been on for 15 years instead of weaning me off slowly. I therefore had a massive breakdown and had to change my GP as a matter of urgency. I lost trust in my GP as she was negligent in my care." (service user)**

Other people said that medication reviews do not take place often enough:

> **"More follow ups on people needing or may not needing medication and who still take them because they have been prescribed for them." (service user)**

> **"I get my medication delivered 3 monthly and no mention of reviewing my symptoms or medication I am taking." (service user)**

Concerns were raised that people were not being offered treatments beyond medication:

> **"Dr XX doesn't seem to think that talking helps as much as medicine." (service user)**

> **"Choice of therapies. More trauma focussed therapists. Less CBT coaching and telephone work." (service user)**

Prevention

People told us that there is a lack of investment in preventing of mental illness (including relapse) and promoting emotional wellbeing:

> **"There is a definite need for community based outreach services, to monitor and help people maintain mental well health. It appears to me that more people are living in the community with mental health issues, so I hope there is the provision to give them the support they need to enjoy a healthy, fulfilling life" (professional)**

> **"More inclusive mental health offering that allows people to access before they become chronically ill." (professional)**

More integrated services

Standards

NICE Quality Standard QS14 Statement 4: "People using community mental health services are normally supported by staff from a single, multidisciplinary community team, familiar to them with whom they have a continuous relationship."

Many people referred to a perceived lack of care coordination and multi-disciplinary working:

> **"People (professionals in mental health service) don't talk to each other like they should." (service user)**
>
> **"I have found the link between GPs and mental health services tenuous at best." (service user)**
>
> **"I think there is a gap in service between primary care and secondary care mental health services." (service user)**
>
> **"CMHT don't talk to each other and all have different views." (service user)**

26% of comments in this area referred to pathways to services not being clear or well understood by the professionals who signpost or refer people:

> **"Doctors have no clue where to signpost you to and say don't go to the groups." (service user)**
>
> **"Who really knows how to get this and what I can have?" (service user)**

The need to improve how services work together is acknowledged in the North Tyneside Mental Health Needs Assessment which calls for services to "Improve the interface between services and signposting across settings e.g. primary and secondary, primary and community (including social prescribing and voluntary sector services), social care and health care, recovery and treatment".

This is also acknowledged in the Crisis Care Concordat which states that this will be achieved through "implementation of New Models of Care in North Tyneside to provide multi- disciplinary specialist support for a specific sector of the North Tyneside population…. This includes provision of mental health services and will aim to prevent mental health crises arising".

However, it is clear that there is still work to do to improve integration of services.

Service user involvement

Standards

NICE Quality Standard QS14 Statement 5 states that there should be "evidence of local arrangements to collect and use views of service users to monitor and improve the performance of services" and "evidence of local arrangements to have service user monitoring of services; for example, using exit interviews undertaken by trained service users".

Some people expressed the view that service users should have a greater involvement in **making decisions about** services and that the involvement of service users and carers needs to improve:

> **"This person uses services 3 days per week and it is closing in September. They feel that their voice has not been heard in the decision making process and they want to request that this decision be reviewed. They would like to know who to access support from to have their voice heard." (carer)**

> **"Services say they listen but they only pay lip services when we do raise our voices, they become defensive and don't take constructive criticism on board." (service user)**

> **"Launchpad North Tyneside has been wonderful in bringing service users and carers together to allow them to have a voice. Service users and carers have been invited to join MH planning day." (service user)**

One respondent suggested greater engagement of service users in feedback and participation in decision making at a service level:

> **"More reflective reviews from inside and outside organisations - not in a threatening way but to give perspectives back to these teams in order to create something that is perceived to be more worthwhile by all." (service user)**

Standards

NICE Quality Standard QS14 Statement 3 states "that people using mental health services are actively involved in shared decision making and supported in self-management".

One person reported that they had a positive empowering relationship with service staff:

> **"My GP listens and that is what I need. He takes notice of what I say" (service user)**

However more people said they felt that decisions and control over their own treatment was taken out of their hands:

> **"A service user accessed specialist services from a VCS organisation. The CPN contacted the VCS organisation (which was not contracted by the CCG or council), the referrer and the service user and told them to stop**

treating/accessing the service as it was not in their best interest". (service user)

"Reading things about mental health doesn't make it gospel....please be mindful of patients thoughts as some professionals dismiss patient or service users as knowing nothing." (service user)

"Meaningful consultation with service users and their carers. Don't take the attitude that you know everything and the service user knows nothing. Listen to needs." (service user)

The North Tyneside Mental Health Needs Assessment also identifies this as an area for improvement: "Strengthen engagement of service users in service developments and collect service user experiences more systematically. Improve engagement and learning from service user and carer experiences".

This acknowledges that there is a need to ensure that the involvement of service users at all levels of decision making is enshrined in commissioning cycles, contractual expectations and involvement is monitored and improvements delivered.

Leaving services

People shared their experience with us of leaving services. We have categorised these experiences under the headings below:

- Discharge
- Transition

Discharge

A small number of people reported positive experiences of being discharged from services:

"I feel that services and in particular my CPN have been supportive in guiding me back into community activities, hobbies and voluntary work. I now feel more able to attempt activities and hopefully put to good use some of the skills I have picked up in the past." (service user)

"I am still currently in CMHT, though when I have left previous services such as CAMHS and IAPT I have always felt ready to leave." (service user)

However 95% of comments about discharge highlight areas where there are concerns.

22% of comments in this area related to people being discharged too early. People thought that services were quicker to discharge than in the past and many felt they were not ready to leave.

"People being moved through services quickly. Creating lots of stress for individuals who feel their support is being taken away." (professional)

"I felt like I was pushed out." (service user)

"They discharged me and they have not finished the job." (service user)

Other concerns were that people were being discharged because they had not attended some appointments. Though they appreciate that 'DNAs' (Did Not Attend) are difficult to manage in the context of limited resources, they feel that there is a lack of an appreciation of the complexities of the conditions that some people are dealing with and the barriers to accessing support:

> **"Do not discharge people from MH services for missing one or two appointments." (service user)**
>
> **"Missing 3 appointments means no longer having access to the service, which is difficult to do when struggling with depression and anxiety." (service user)**
>
> **"The most needy do not attend and are discharged" (professional)**

Some people stated that discharge planning is inadequate and that the support people need is not put in place.

> **"I was discharged last year with no support whatsoever as they were reorganising their services." (service user)**
>
> **"Would be nice for a few check-ins to see how I was doing, maybe a follow up after a year" (service user)**
>
> **"On discharge just gave me helpline numbers." (service user)**

Linked to this some people pointed out that discharge to GP care was inappropriate when access to GP appointments can be difficult:

> **"Been discharged recently with a WRAP plan back to GP and hard to get an appointment with them unless you phone at 8.30 and 1.30." (service user)**

Transition

Transition from Child and Adolescent to Adult Mental Health services was highlighted as an area where the system needs improvement:

> **"When referred to adult services in Wallsend, I felt like my CBT coach didn't care. I got little helpful advice, like they couldn't relate in any way to my problems. It made my move to university particularly challenging." (service user)**
>
> **"Found the handover service from adolescent to adult mental health services belittling as he was asked to fill in forms and repeat all his answers at interview when he was referred to Saint Nicholas Hospital. He found this challenging because of his ADHD." (carer)**

The recently developed CAMHS Transformation Plan refers to a plan to "review transition arrangements between children and adult services" by April 2017.[7]

[7] North Tyneside CCG, Northumbria Healthcare NHS Foundation Trust, Northumberland Tyne and Wear NHS Foundation Trust, North Tyneside Council: North Tyneside Transformation Plan 2015 - 2020 Promoting, Protecting And

However, there is relatively little detail about who will lead this process and what form the process will take. It would also be useful to have clarity on short term measures which can be taken to make 'quick wins' on how to improve people's experience of this transition.

Cross cutting factors

People shared their experiences with us about issues which cut across their journey through services. They talked about issues relating to:

- Staffing
- Physical health
- Family and carer needs
- Financial factors

Staffing

Comments relating to staffing within services were the largest area of comment indicating this is an area of great importance to service users. Issues included training, attitudes and approaches

Positive experiences

People commented that finding the right person to support them could make all the difference:

> **"Overall it is so much down to the person that you are given and both how good they are at what they do and how able they are to put aside all their prejudices and work with you rather than against you." (service user)**

Some people had a good experience of relationships with staff and felt that they had the skills to support them:

> **"Hard working staff. More recognition of positive work needed." (service user)**
>
> **"Finding the right GP is a life saver. They listen and are proactive in your care. You feel like they are there for you" (service user)**
>
> **"They were there for me when I was in crisis and in providing personal and practical support with the benefits system as I recovered" (service user)**

Improving staff skills

However, 42% of comments in this area identified a need for staff to improve their skills.

Improving Mental Health And Wellbeing Of Children And Young People In North Tyneside

"They felt under trained and lack in first-hand experience of such problems." (service user)

"She was still at university part time and was obsessed with talking about 'psychosis' and nothing else." (service user)

People felt that primary care staff in particular would benefit from a greater understanding of mental health, referral pathways and community services:

"GPs often don't show an active interest in mental health unless the patient raises it." (service user)

"GPs not know about mental health areas, virtually nothing about what the charitable third sector do for mental health." (service user)

"The problem for me has been that my surgery have been nothing short of useless in their signposting of me to services better equipped to help me with my mental health." (service user)

Other comments were that training was needed for people who are working with service users diagnosed with an Autistic Spectrum Disorder:

"It was difficult to find a therapist with experience of helping those with ASD." (carer)

As suggested previously dealing with people in crisis was also an area where better training is required.

"They are inadequate when problems are complicated and challenging. Too often cases end up being dealt with by the policy instead of being properly treated." (carer)

"I am not convinced the training that staff have is understanding of how human beings behave in especially crisis and traumatic conditions." (service user)

The North Tyneside Mental Health Needs Assessment recommends improvements to training: **"**It is recommended that all frontline staff (statutory and voluntary sector) in contact with people with physical health conditions and long term conditions should be given mental health awareness training to be able to respond appropriately to the mental health needs of these groups".

Staff - dignity and respect

Standards

NICE Quality Standard QS14 Statement 2 states that "people using mental health services should feel they are treated with empathy dignity and respect".

19% of comments about staffing were from people who said that they hadn't been treated with dignity and respect. Most of the comments received relate to the Community Mental Health Teams and A&E settings:

"I have tried to overdose twice and my experience of A&E was diabolical. I was treated with indignity and disrespect." (service user)

"Questions and remarks about my illness can be laden with value judgements and limiting the sufferer to a set of labels which obscure the whole individual beneath." (service user)

"If you are free thinking you are seen as hostile and uncooperative and are treated with feels like prejudice." (service user)

Continuity of care

Standards

NICE Quality Standard QS14 Statement 6 calls for "local arrangements to ensure that service users are seen within 20 minutes of the agreed appointment time"

A number of concerns were raised about challenges of continuity of care at the Community Mental Health Team.

"Holiday provision is unsuitable as case details are not passed on to other staff and appointments are missed rather than someone else keeping them, leaving the patient vulnerable" (carer)

"A quicker response to rearranging meeting with my CPN/ Care Coordinator when they have postponed an appointment due to being called away to deal with an emergency" (service user)

"High risk, is self-harming and has had 4 appointments cancelled by Dr XXX with no alternative appointments provided over a period of 8 months" (carer)

Finally, a number of people raised concerns about staffing levels and the impact of current levels on service quality and on staff welfare:

"Not enough staff to ensure regular appointments and continuity of care." (carer)

"The difficulty appeared to be on the part of the hard-pressed councillor, who simply did not have the time." (service user)

"There are too few people with massive caseloads and the situation is going to get worse." (service user)

Physical health

The need to improve the physical health of people who have mental health problems has been identified as a key objective of the strategy 'No Health without Mental Health'.

17% of comments in this area relate to service users who feel that their physical health needs are being met.

However, 24% of comments about physical health describe situations where physical health problems have been wrongly attributed to psychiatric issues. In some cases this has led to long term problems:

"This person had chronic back pain but was told it was in his mind" (service user)

"What I faced was the doctors blaming the condition on my mental state as thought its all in my head. Sure my anxiety can make me panic more about the experience but I know the difference between something physical rather than just a medical issue" (service user)

"ALL physical problems are automatically linked to her mental health, it's often only after A&E hospitalisation that her physical needs are believed" (carer)

Some people went on to explain that their physical health issues can compound their mental health problems and others report that long term use of their medication treatment for their mental health needs is having an impact on their physical health:

"Meds have led to lethargy, weight gain and goodness knows what internally." (service user)

These findings support the North Tyneside Mental Health Needs Assessment which recommends that services "strengthen support for people with serious mental illness who are at risk of developing, or who already have, long term physical health conditions or unhealthy lifestyles."

Actions need to be identified and put in place to address this issue.

Family and carers needs

'No Health without Mental Health' sets out a key action to improve to "work with the whole family using whole family assessment and support plans where appropriate".

People highlighted the importance of the role that their family and carers play in their support:

"The family can stand by you as rods and I believe you need this" (service user)

More than 70% of comments about the needs of family and carers were in relation to the involvement of carers in the care of the person who uses mental health services. Family members and carers report that they feel uninformed and unsupported in their caring role:

"Family are not aware if there is a care plan in place following the completion of rehabilitation." (carer)

"It would have been helpful to have had more input on how to support him at home." (carer)

"They didn't recognise the on-going support given by family or try to inform us how we could support our daughter's progress." (carer)

One person called for **"education for families so that they can support and help family members suffering."**

Some carers told us they were excluded from discussions for reasons of confidentiality:

> **"We were excluded from our son's care for reasons of confidentiality, even though we were living with his illness and had no knowledge of how to deal with it……You cannot divorce the child from the family in these situations." (carer)**

> **"Don't send correspondence to someone who lacks capacity. Send to both or copy in carer." (carer)**

People felt that the lack of involvement of family members and carers in the delivery of services means that the quality of care and appropriateness of treatment is less effective:

> **"Without information from caregivers they are totally reliant on what the patient can remember or discloses and relevant."(carer)**

> **"Maybe if we had been allowed some input and given advice/ strategies, it would have benefited us and our son." (carer)**

Some carers reported that they found it difficult to access support for the mental health service user during crisis:

> **"Surely when a person has repeated bouts of mental ill health and is known to the mental health team, they and their family deserve to have a named person to turn to."(carer)**

> **"Make it possible for us to get help for our loved ones, who through no fault of their own do not realise they are ill." (carer)**

The North Tyneside Mental Health Needs Assessment identifies support for carers as priority: "Families and carers can play an important part in supporting someone with a mental health problem and are often a vital part of recovery. North Tyneside should strengthen support through carer assessments, support groups and better sharing of information with carers/parents".

The Crisis Care Concordat for North Tyneside sets out the ambition to: "improve support and involvement for carers (including young carers) by working with them to better understand their needs and to enable them to be more involved and supported in their caring role" (2.9). This action is felt by this steering group to have been met by the North Tyneside Commitment to Carers being launched.

Based on what Healthwatch have been told, more work is required to ensure that this action is completed.

Financial factors

Comments about financial factors overwhelmingly identified mental health services need more funding and that cuts to funding are reducing the quality and accessibility of services.

> **"Lack of finances in mental health is atrocious" (service user)**

> **"More funds and services are required" (service user)**

Some people expressed the view that mental health services had been disproportionately affected by austerity measures:

> **"It feels as if Mental Health is reducing as a priority, I understand there are huge cuts to Local Government funding, but I do feel that mental health may be suffering disproportionately in North Tyneside." (service user)**

Some people thought that cuts had led to the closure of services and that this was having a detrimental effect on service users:

> **"GAP was closed a few years ago and it was such a big loss to the local people. I ended up with depression because of it." (service user)**

> **"The closure of many services have shocked me and I am left with the ideas and thoughts running through my mind that I have been left out and I have no one to turn to." (service user)**

Not surprisingly people said more funding was needed:

> **"More resources focused on those most in need." (professional)**

> **"With more resources would come more capacity, better service models. I think it's a hard time for services generally with the lack of resources around." (professional)**

> **"Investment in community mental health services needs to be consolidated so that there is some stability in funding arrangements. Any future movement in provision from in-patient mental health beds needs to be supported by a transfer of funds into community based services." (professional)**

> **"There needs to be more funding to get enough specialists back into the community to meet these unmet needs." (carer)**

Recommendations

Based on what we have been told by people in North Tyneside we make the following recommendations:

For North Tyneside Health and Wellbeing Board

1. Strengthen the Mental Health Integration Board as a mechanism for the monitoring of a North Tyneside Integrated Mental Health offer and strategy. This should include engaging service users in the monitoring of services.

For commissioners of services

1. Review local performance indicators and quality standards for mental health services in North Tyneside in consultation with local service users to ensure compliance with national standards.

2. In partnership with the voluntary sector, develop a plan to increase the voluntary and community sector provision of mental health services in North Tyneside and enable them to bring more money in to the local health and care economy by supporting fundraising efforts.

For all providers of mental health services

1. Create a single point of access for all community based services (including those which are not commissioned by the statutory sector) which complies with NICE Standards.

2. Reduce waiting times to bring them into line with NICE standards by:
    - Setting standards for waiting times across commissioned services and publishing information about compliance.
    - Develop a network of support for people on any waiting list such as a support group or online forum.

3. Fully implement the North Tyneside Carers' Commitment to families and carers of people who access mental health services. Develop an action plan for carers and families of people with mental health needs that will deliver.
    - Earlier identification of carers and provide quality information (for example, carers wellbeing assessments and better information about support and services)
    - Improved communication recognising the importance of carers and listening to their input
    - Improved carer health, wellbeing and support

4. Develop and implement a clear support pathway, including out of hours, for people who feel that they want to end their lives, harm themselves or who are experiencing a crisis. This should include support pathways for people who already access services and those who do not.

5. Support staff in a variety of settings to better meet the needs of people with mental health problems:
    - Provide mental health awareness training for non- specialist staff, for example in A&E, GPs, receptionists.
    - Provide training for mental health professionals in relation to handling crisis, tackling stigma, listening skills, service availability and managing stress.

6. Develop action plans that will address the specific needs of people who face particular barriers in accessing mainstream services. These include:
    - People diagnosed with a personality or borderline personality disorder
    - People with a learning disabilities and Autistic Spectrum Disorders
    - Survivors of sexual violence and abuse

7. Ensure that people's physical health needs are properly addressed in care planning, including the identification and management of medication.

8. Examine the evidence to ascertain if best practice is being implemented by providers in North Tyneside in relation to multi-disciplinary team working and take remedial action where required. Specifically this should focus on:

    - Care planning - Are care plans developed jointly with service users and other professionals?
    - Are providers working to promote active participation in treatment decisions including the management of medications?
    - Are service users being supported by a multi-disciplinary team with whom they have a continuous relationship?
    - Is discharge discussed and planned carefully with service users and a multi-disciplinary team beforehand, structured and phased and organised to include contingency plans in case of problems arising?

9. Agree a set of local standards and monitor their implementation in relation to:
    - Individual choice (in care and treatment) and enabling shared decision making,
    - Second opinion
    - Identifying and tackling stigma where it exists within services
    - Ensuring empathy, dignity and respect

10. Develop a strategy for providing support to people with mild to moderate mental health needs. This should include services available in primary care and in the community through the voluntary and community sector.

What happened next?

We wrote to commissioners and providers to ask for a formal response to the recommendations above and received their responses (see Appendix 6).

We shared all service specific data with providers and commissioners and presented our findings to provider teams.

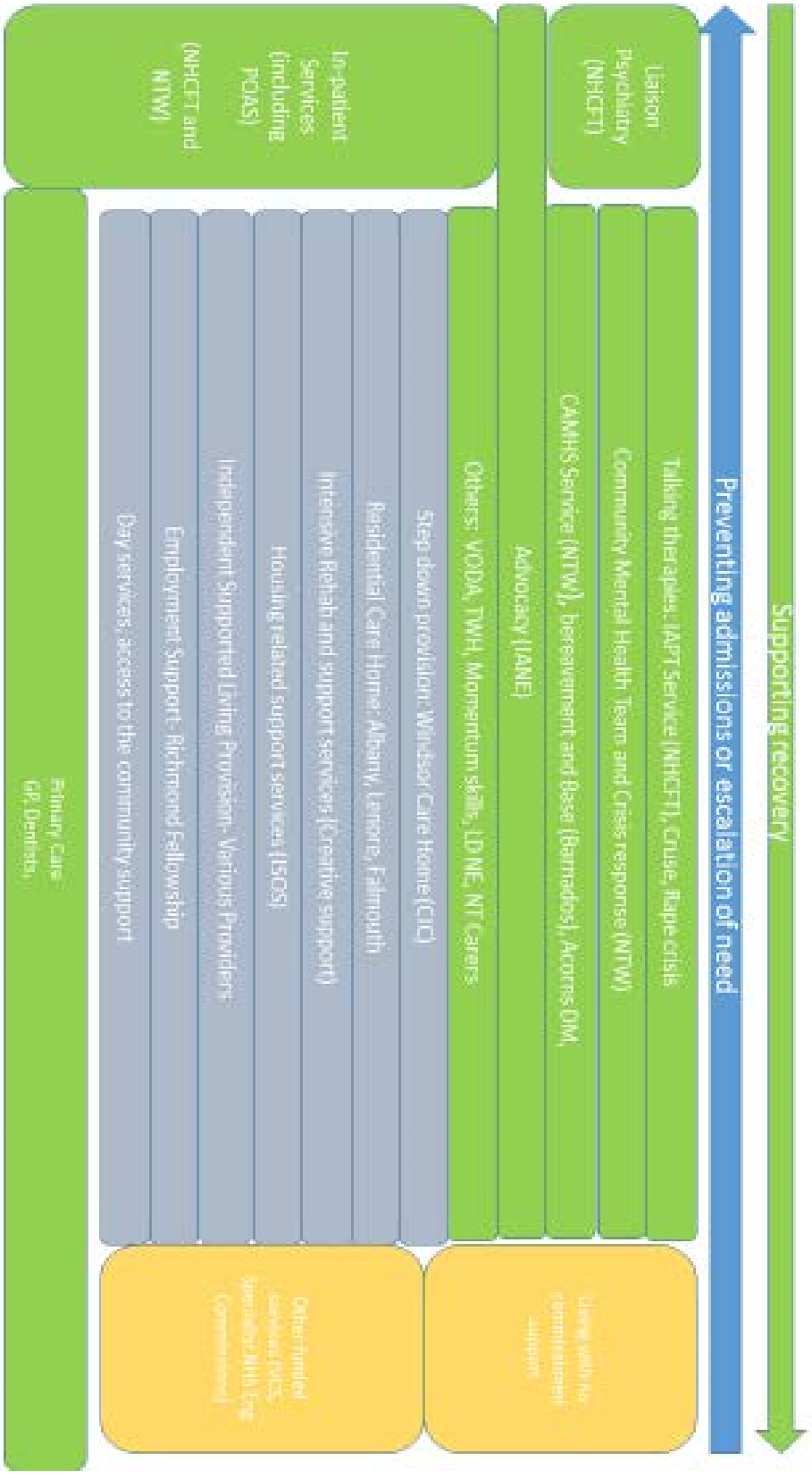
We held the commissioners and providers to account for implementing their commitments.

The views expressed were used to develop the Mental Health Strategy in North Tyneside and we will continue to monitor its implementation, in relation to what you have told us.

Following this, we are now working with Tyne and Wear Museums to develop a video to highlight mental health services user's experiences.

Whilst carrying out this research we identified mental health crisis services as an area in need of further investigation. Our next project will therefore focus on people's experiences of crisis care services within North Tyneside.

Appendix 1- Local mental health service map



Appendix 2: Demographic data about participants

Based on the assertion that:

"About a quarter of the population will experience some kind of mental health problem in the course of a year"[8]

Around 50,200 of North Tyneside's 200,800 population could be assumed to be the population size impacted by this data gathering.

With 95% confidence margin and 5% margin for error we should be aiming for a sample size of 347- 382. Therefore there is around a 6-7% margin for error in the reported findings.

Where were people from in North Tyneside?

52 people to the survey indicated which part of the borough they or the person they care for live. The majority of people come from Wallsend ward (17%), Monkseaton North (11%) and Chirton (9%), Whitley Bay (8%) and Riverside (8%). This appears to relate closely to local maps of need[9] and would indicate that our data gathering has reasonable reach across the borough.

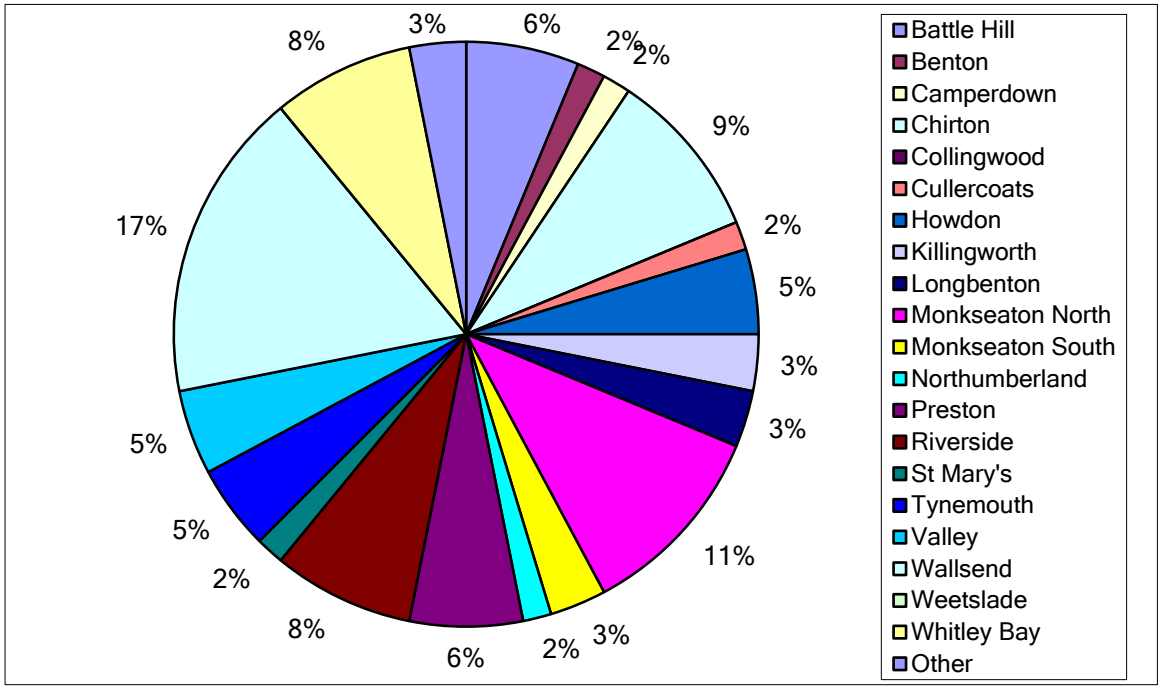


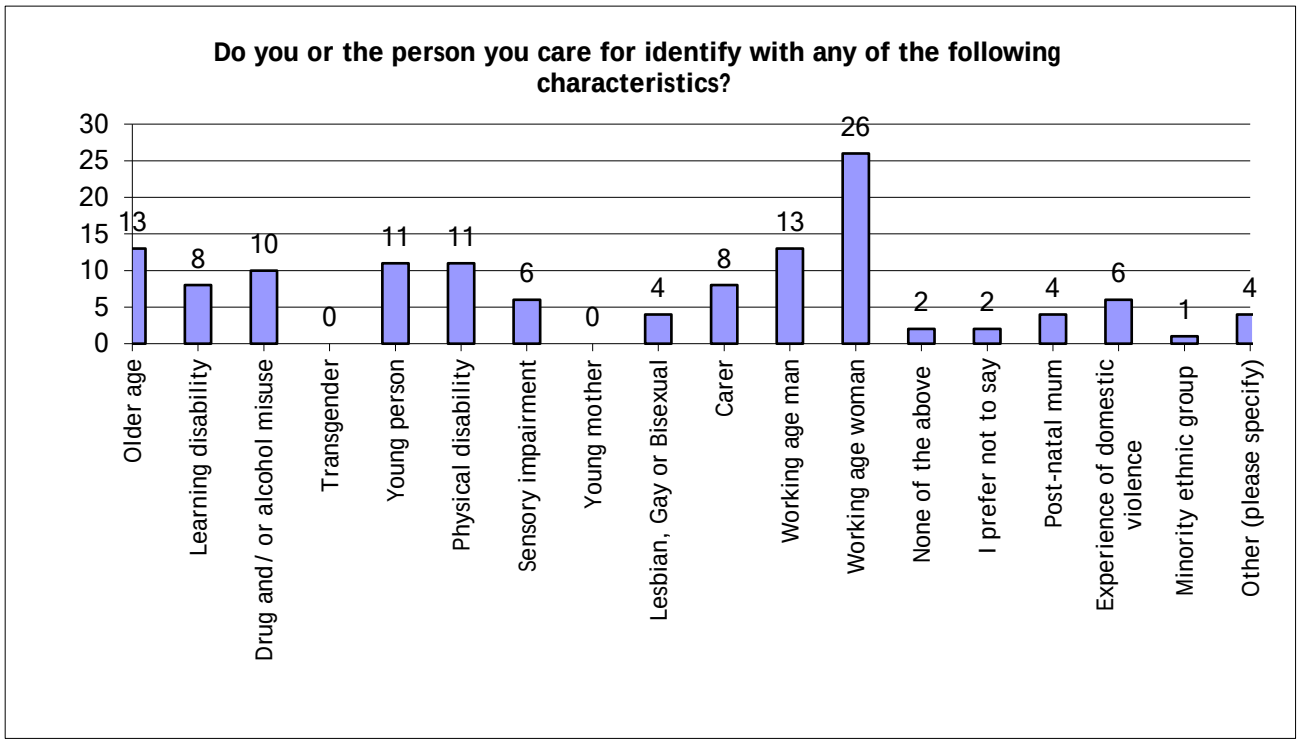
Figure 1- People by council ward

[8] Mental Health Foundation (http://www.mentalhealth.org.uk/help-information/mental-health-statistics/) Accessed on 10th December 2015

[9] Map of employment support allowance and incapacity benefit claimants for mental health category in North Tyneside by LSOA 2014, Policy, Performance and Research Team North Tyneside Council, March 2015.

Service user characteristics (survey data)

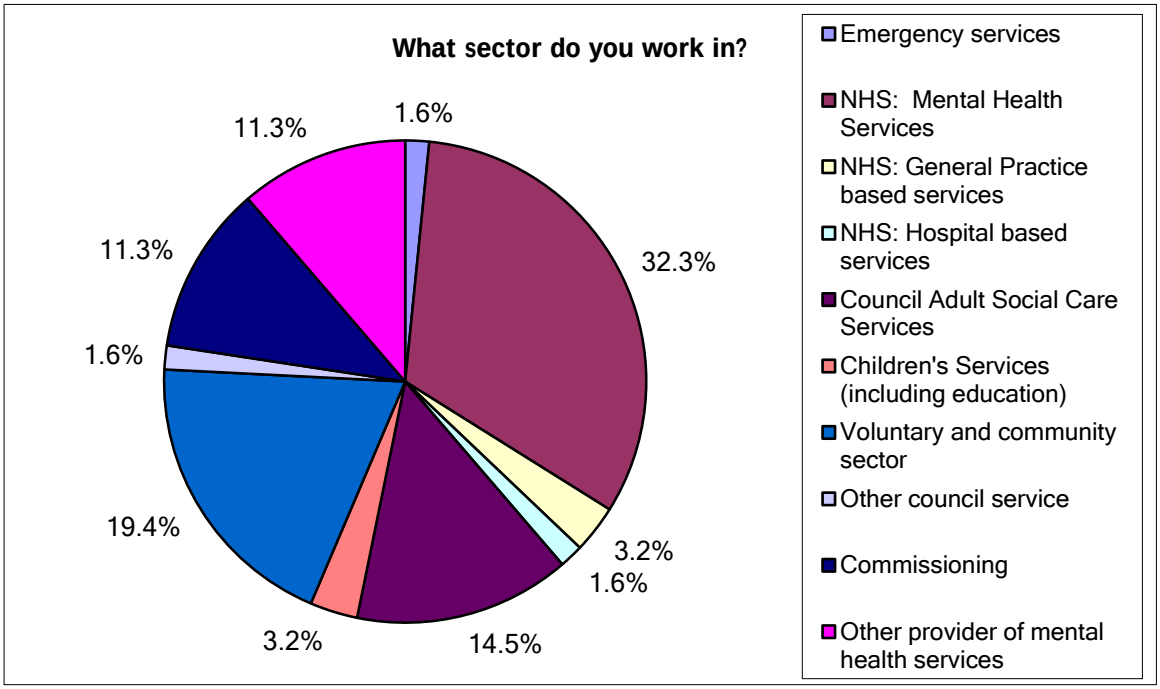
70 people responding to the survey categorised themselves or those they care for against a set of characteristics. People were able to categorise in more than one area. The majority of service users were working age women, working age men or older people (see below in figure 3).

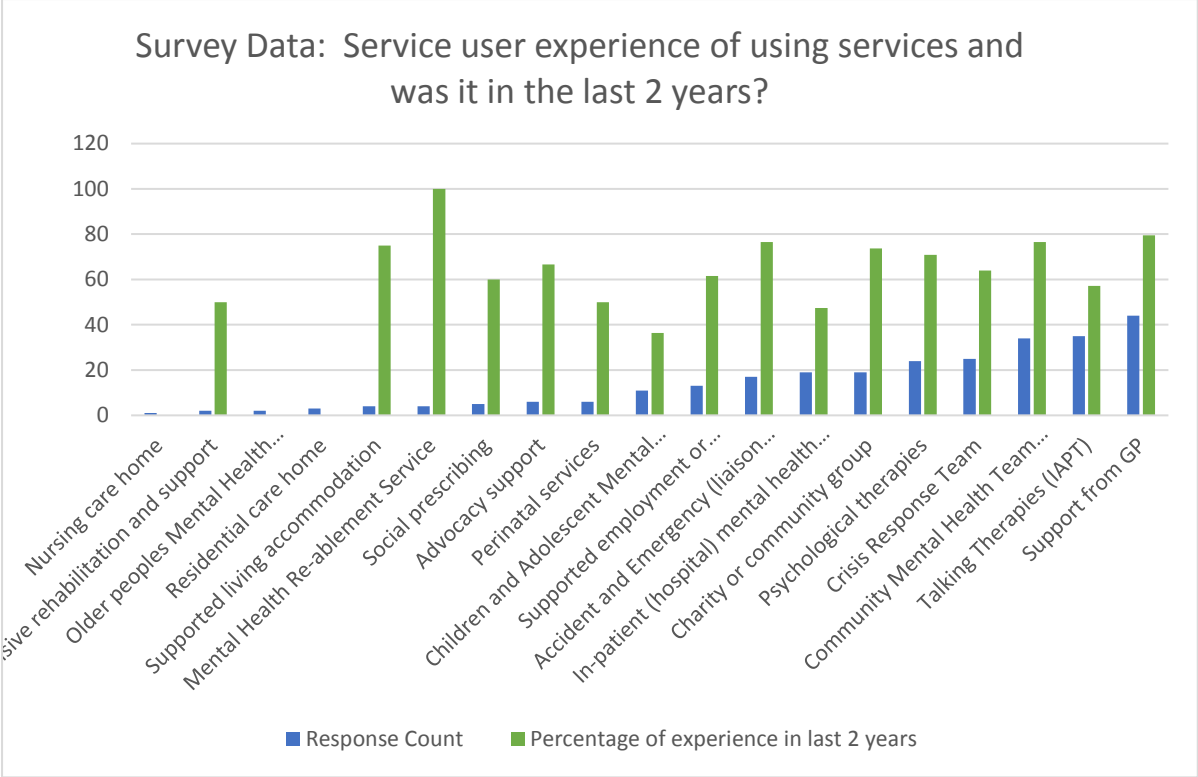


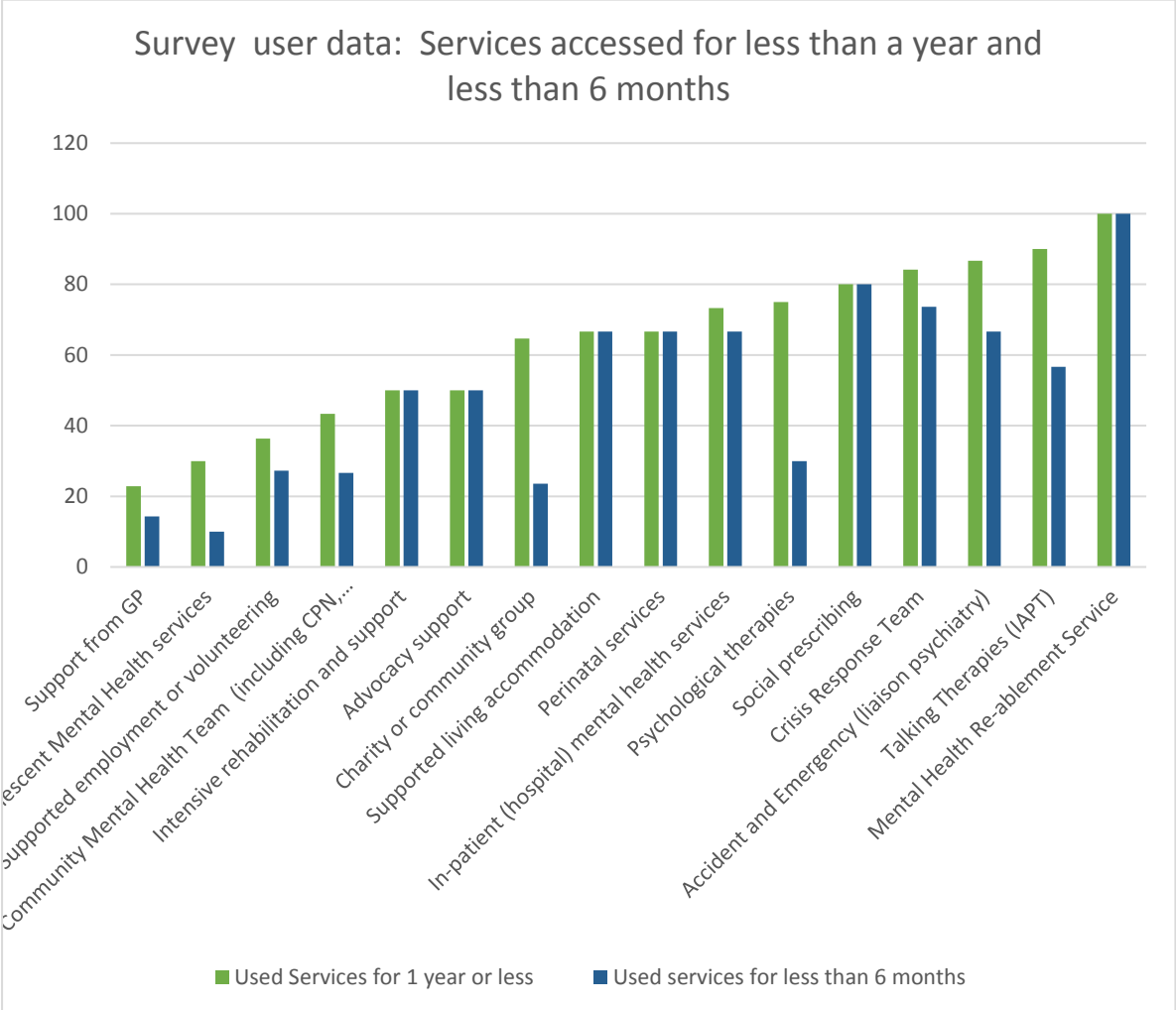
Appendix 3: Breakdown of professionals and service users by service

What sectors were professional participants from?

The majority of professional participants were from the NHS mental health services (32%) followed by the Voluntary and Community Sector (19%) and NTC Adult Social Care (14.5%). There was limited engagement from GPs and emergency services despite publication of this through organisational newsletters. It is possible that these views would have further enriched the experiences reported and thus further engagement with these groups by commissioners is advised.

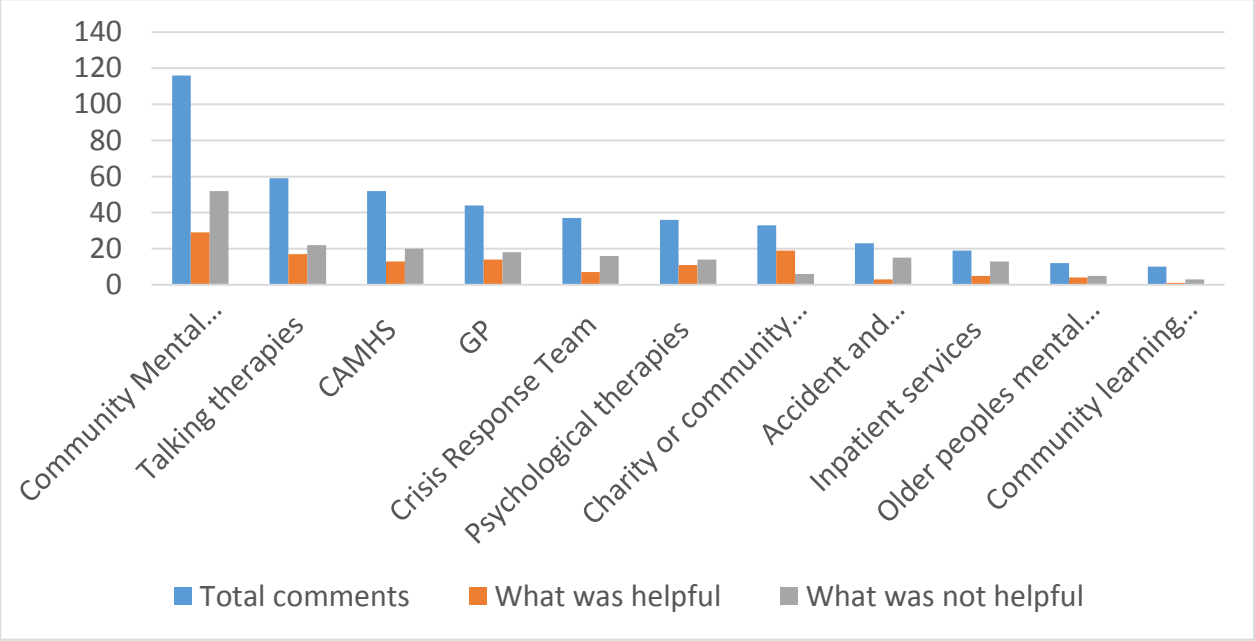



Survey Data: Service user experience of using services and was it in the last 2 years?
120
100
80
60
40
20
0
Nursing care home
sive rehabilitation and support
Older peoples Mental Health...
Residential care home
Supported living accommodation
Mental Health Re-ablement Service
Social prescribing
Advocacy support
Perinatal services
Children and Adolescent Mental...
Supported employment or...
Accident and Emergency (liaison...
In-patient (hospital) mental health...
Charity or community group
Psychological therapies
Crisis Response Team
Community Mental Health Team...
Talking Therapies (IAPT)
Support from GP
Response Count
Percentage of experience in last 2 years

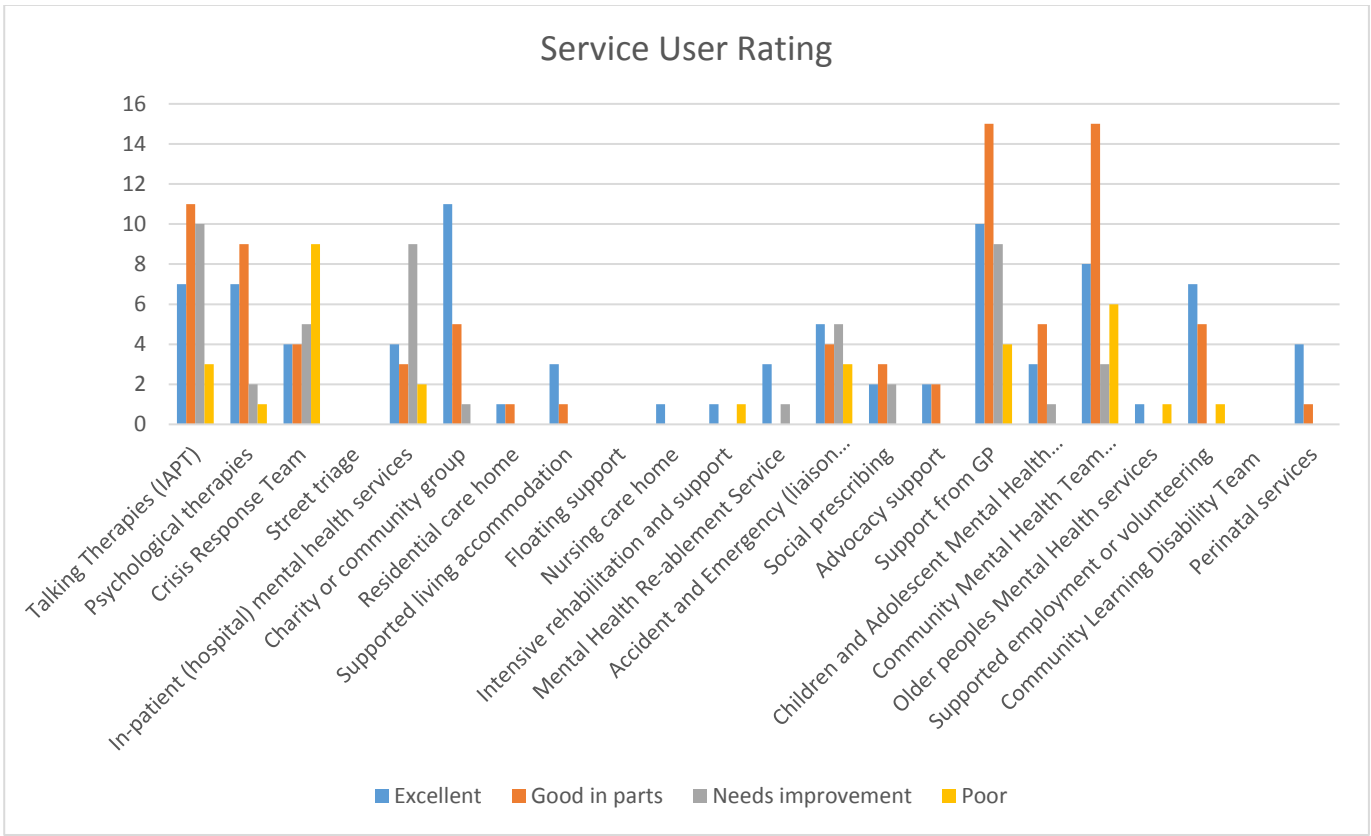

Survey user data: Services accessed for less than a year and less than 6 months
120
100
80
60
40
20
0
Support from GP
escent Mental Health services
upported employment or volunteering
Community Mental Health Team (including CPN,...
Intensive rehabilitation and support
Advocacy support
Charity or community group
Supported living accommodation
Perinatal services
In-patient (hospital) mental health services
Psychological therapies
Social prescribing
Crisis Response Team
Accident and Emergency (liaison psychiatry)
Talking Therapies (IAPT)
Mental Health Re-ablement Service
Used Services for 1 year or less
Used services for less than 6 months

Appendix 4: Service level analysis

Sentiment for services



Service user ratings from survey:



healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

Welcome to the North Tyneside Mental Healthwatch Survey

Who are Healthwatch North Tyneside?

We gather views from residents and use our statutory powers to improve in local Health and Social Care services (website).

Why are we asking these questions?

We hear a lot about mental health services in North Tyneside but we need to ask more people what they think of these services to understand what needs to improve.

What will we do with the information?

1) We will publish a report and write a statutory letter to hold services to account for responding to recommendations.
2) We will feed this into the development of local strategy.
3) We will carry on the project to focus on more specific areas that require more attention later in the year.

If you would prefer to speak to someone who can complete this survey for you call us: 0191 263 5321

healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

Questions for people who have experience of using mental health services in North Tyneside

We want to know which services you have accessed and what you think about them.

Your responses will be reported in a way which will ensure that you are not identified.

If you would prefer to fill this in over the phone you are welcome to contact Healthwatch North Tyneside on: info@healthwatchnorthtyneside.co.uk or telephone 0191 263 5321

Do you consider yourself to have a mental health issue?

Please rate your experience of using mental health services in North Tyneside by choosing an options from the drop down boxes. If you service is not listed please add below.

	Have you used this service?	When did you use this service?	For how long did you use this service?	How would you rate this service?
Talking Therapies (IAPT)				
Psychological therapies				
Crisis Response Team				
Street triage				
In-patient (hospital) mental health services				
Charity or community group				
Residential care home				
Supported living accommodation				
Floating support				

	Have you used this service?	When did you use this service?	For how long did you use this service?	How would you rate this service?
Nursing care home				
Intensive rehabilitation and support				
Mental Health Re-ablement Service				
Accident and Emergency (liaison psychiatry)				
Social prescribing				
Advocacy support				
Support from GP				
Children and Adolescent Mental Health services				
Community Mental Health Team (including CPN, social worker, psychiatrist)				
Older peoples Mental Health services				
Supported employment or volunteering				
Community Learning Disability Team				
Perinatal services				

Other service not mentioned above

healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

Questions for people who have experience of using mental health services in North Tyneside

This is a chance to share your story. Please tell us more about your experience of using services to support your mental health.

Please name the services where possible.

What was helpful about these services?

What do you think was difficult about these services?

What could be improved about these services?

Do you feel you have been supported to move on from services when you are ready?

healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

Questions for people who have experience of using mental health services in North Tyneside

What mental health needs do you have that you don't feel are being met?

What physical health needs do you have which aren't being met and why?

What change in services are needed to address these unmet needs?

If you have ever felt that you wanted your life to end or to harm yourself, what support was helpful and what else should be in place?

Is there anything else you would like to tell us about mental health services?

healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

Questions for people who have experience of using mental health services in North Tyneside

We are interested in understanding how people's views of services differ depending on a number of characteristics.
Feel free to skip this question if you prefer.

Do you identify with any of the following characteristics? (select as many as apply)

- [ ] Older age
- [ ] Learning disability
- [ ] Drug and/ or alcohol misuse
- [ ] Transgender
- [ ] Young person
- [ ] Physical disability
- [ ] Sensory impairment
- [ ] Young mother
- [ ] Lesbian, Gay or Bisexual
- [ ] Carer
- [ ] Working age man
- [ ] Working age woman
- [ ] None of the above
- [ ] I prefer not to say
- [ ] Post-natal mum
- [ ] Experience of domestic violence
- [ ] Minority ethnic group

Other (please specify)

Please tell us which council ward in North Tyneside you live in. If you do not know the name of your council ward please give the first half of your post code in the 'other' box below.

Other (please specify)

healthwatch North Tyneside

Mental Healthwatch - Local people's views of mental health services

You have reached the end of the survey

Thank you for taking time out to respond to our survey.

Please don't hesitate to contact us on with any concerns or questions on info@healthwatchnorthtyneside.co.uk or telephone: 0191 263 5321

If you would like us to keep you informed about the outcome of this survey and the work of Healthwatch North Tyneside please leave your contact details below.

Name	
Address	
Address 2	
Town	
Post code	
Email address	

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NHS Foundation Trust

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JL/ka

6 June 2017

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Dear Jenny,

Thank you for the opportunity to respond to the recommendations contained in your report 'People's experience of mental health services in North Tyneside (September 2016)'

We have received and considered the report in the Trust, particularly focussing on our local services in the borough. I am sorry that there was some delay in responding to your report which we received at the end of March 2017. I have asked managers to share it with local teams so that they can also understand the insights you have gained from our service users.

I have included our formal response to your recommendations below but am keen that we continue to engage positively in ongoing discussions. The Trust is putting arrangements in place to ensure more of a locality focus for our services, and I hope this will support our future working arrangements.

Recommendation 1. Create a single point of access for all community based services (including those which are not commissioned by the statutory sector) which complies with NICE Standards.

NTW has been working closely with health commissioners to consider the best ways to provide easy access to our services. Unfortunately, it has not been possible for us to provide a single point of access to NTW services at the present time. We are in the process of providing up to date information with contact details of all of the NTW services for people in North Tyneside. We will continue to work closely with the council and commissioners to consider ways to improve access to mantel health services.

Recommendation 2. Reduce waiting times to bring them into line with NICE standards by setting standards for waiting times across commissioned services and publishing information about compliance; develop a network of support for people on any waiting list such as a support group or online forum.

Waiting times for adult community teams have continued to improve. The Crisis Service ensures that those with the most urgent needs are supported straight away. Community Treatment Teams offer urgent mental health assessment slots within 72 hours if the service user need this.

Community Treatment Teams aim to ensure assessments for non-urgent, planned interventions are completed within 6 weeks from receipt of referral and aim to offer treatment within 18 weeks from initial referral. The team in North Tyneside work within the targets with a number of appointments being offered in less than the 6 week and 18 weeks. Standards for waiting times are monitored by our commissioners and our waiting times are also published on our website.

A waiting list management process is in place, this includes standards for contacting service users on waiting lists to in order to provide support, update them on progress and monitor their well-being.

Recommendation 3. Fully implement the North Tyneside Carers' Commitment to families and carers of people who access mental health services. Develop an action plan for carers and families of people with mental health needs that will deliver.

- **Earlier identification of carers and provide quality information (for example, carers wellbeing assessments and better information about support and services)**
- **Improved communication recognising the importance of carers and listening to their input**
- **Improved carer health, wellbeing and support**

The Trust has worked with local carers and carer's centres over many years to develop effective support for carers. This includes developing the Carers Charter which has been implemented across all of our services and we are a pioneer for the use of a Common Sense Confidentiality approach to information sharing.

We are also committed to the 'Triangle of Care' – a national approach to support carers as equal partners. Currently the locality's carer's pathway is being reviewed in partnership with Local NTW teams, North Tyneside Carers Centre and North Tyneside Council. There is also a plan to develop bespoke training for NTW staff. A specific carers group for those who support people with Emotionally Unstable Personality Disorder who are receiving services from our locality Community Treatment Teams is a further development about to get underway in the next few weeks.

Recommendation 4. Develop and implement a clear support pathway, including out of hours, for people who feel that they want to end their lives, harm themselves or who are experiencing a crisis. This should include support pathways for people who already access services and those who do not.

NTW provides the local crisis services which are available 24 hours a day for people who are experiencing a mental health crisis and would otherwise require an admission to hospital. Anyone can call the crisis team, whether or not they have previously accessed NTW services. NTW also provide liaison psychiatry, street triage and custody diversion services who will offer an early assessment in mental health crisis situations.

Where appropriate, people who are already accessing NTW services may also have support to collaboratively develop a robust crisis and contingency plan which will set out what they should do if they experience a relapse of their mental health symptoms.

Increasingly, people are supported to develop a WRAP (wellness recovery action plan) to support them in such situations and as part of their recovery pathway.

Recommendation 5. Support staff in a variety of settings to better meet the needs of people with mental health problems:

- **Provide mental health awareness training for non- specialist staff, for example in A&E, GPs, receptionists.**
- **Provide training for mental health professionals in relation to handling crisis, tackling stigma, listening skills, service availability and managing stress.**

The Trust is keen to challenge the stigma associated with mental health and other disabilities and we see ourselves as having an important role to play. Individual teams do provide support such as this on an ad hoc basis, however we are not able to provide training on a routine and regular basis to other organisations.

A wide range of training opportunities are available to staff working in NTW in relation to stigma and meeting the needs of service users. NTW took part in a pilot programme with the Time to Change campaign in relation to stigma from mental health services. Alongside that, we have introduced peer support workers to ensure that the views and the voice of people who use our services is embedded into each team.

Recommendation 6. Develop action plans that will address the specific needs of people who face particular barriers in accessing mainstream services. These include:

- **People diagnosed with a personality or borderline personality disorder**
- **People with a learning disabilities and Autistic Spectrum Disorders**
- **Survivors of sexual violence and abuse**

North Tyneside community teams offer a Dialectical Behavioural Therapy service to meet the needs of those diagnosed with emotionally unstable or borderline personality disorder, this includes individual treatment, group therapy and carer

support. We also offer a structured clinical management approach and access to a peer support worker to improve engagement.

NTW provides a trust wide specialist service, the PD Hub, which provides specialist clinical advice and consultation to the community teams and can offer care co-ordination with treatment to individuals with complex needs and significant risks.

The majority of the specialist learning disability services in North Tyneside are provided by Northumbria Healthcare with NTW only providing psychiatry and inpatient care. We do, however, support people with a learning disability who also have a mental health condition. This has been developed and strengthened through the 'Green light toolkit' a national approach for improving access to mainstream mental health service for people with a learning disability.

NTW offers services to those who are survivors of sexual violence and abuse if they have a co-existing mental illness. NTW will signpost and work closely in collaboration with partner agencies with a speciality in this area to ensure the assessed needs of the service user are met.

Recommendation 7. Ensure that people's physical health needs are properly addressed in care planning, including the identification and management of medication.

The Trust continues to work to improve physical health outcomes and reduce premature death for people who use our services. This is to support 'parity of esteem', where mental and physical health is given equal priority. There are a number of initiatives across the Trust to support this including a Physical Health CQUIN for 2017-2018. This builds on the sustainable and high quality training programme we have in place for all relevant clinical staff caring for people with Serious Mental Illness (SMI) who have an increased risk of stroke, heart attacks and metabolic syndrome.

Community Treatment Teams in North Tyneside have dedicated physical health clinics and work within the CQUIN targets using the Lester Tool.
All service users supported by the team are offered a physical health check on a yearly basis, particularly targeting those who are prescribed antipsychotic medication.

All service users are given information on the medication they are prescribed, which includes any side effects they may experience to enable them to make an informed choice. Medication prescribing and concordance is recorded as part of the service users care plan and is reviewed in care coordination reviews and at outpatient appointments. The Trust has recently provided access to the 'Choice and medication' website, an independent information resource about medicines for mental health problems which is available to all service users and carers at http://www.choiceandmedication.org/ntw/

Recommendation 8. Examine the evidence to ascertain if best practice is being implemented by providers in North Tyneside in relation to multi-disciplinary team working and take remedial action where required. Specifically this should focus on:

- **Care planning - Are care plans developed jointly with service users and other professionals?**
- **Are providers working to promote active participation in treatment decisions including the management of medications?**
- **Are service users being supported by a multi-disciplinary team with whom they have a continuous relationship?**
- **Is discharge discussed and planned carefully with service users and a multi-disciplinary team beforehand, structured and phased and organised to include contingency plans in case of problems arising?**

North Tyneside Community Treatment Teams provide a multidisciplinary approach to treatment working in collaboration with service users and their family, friends and carers as part of the Care Program Approach (CPA).

Service Users have an identified care co-ordinator or lead professional who regularly reviews their care and treatment options alongside other care providers and supporting services, including carers.

Service users are supported in making an informed choice around treatment which includes medication management and access to psychological therapies.

Discharge from services is planned and structured in collaboration with the service user and carers with a WRAP plan to enable them to manage their own mental wellbeing and a robust contingency plan should relapse occur. An individual plan around how to re-access services, if required, is also provided.

Compliance to the standards in place is monitored regularly through audit and through NTW dashboards. Points of View and the Picker Survey also enable service users/carers to feedback to NTW. The trusts Community Treatment Teams were assessed by the CQC in the summer of 2016 as part of their comprehensive assessment of NTW. The findings of the CQC were that these teams were judged to be 'Outstanding'. While we acknowledge that there is always more we can do, it does provide external, independent assurance that teams are operating effectively.

Learning through incidents and complaints that highlights unsatisfactory practice is addressed robustly and is monitored through action plans which are developed to ensure learning is disseminated and embedded in practice.

Recommendation 9. Agree a set of local standards and monitor their implementation in relation to:

- **Individual choice (in care and treatment) and enabling shared decision making,**
- **Second opinion**
- **Identifying and tackling stigma where it exists within services**
- **Ensuring empathy, dignity and respect**

NTW have a wide range of policies and practices which guide our standards of practice and all NTW Policies have an Equality & Diversity impact assessment.

These include:

- NTW CPA Policy
- NTW Equality & Diversity Policy and training for staff
- NTW Second Opinion Policy and Change of consultant policy

We work within national legislative frameworks including the Mental Capacity Act and Mental Health Act and local policies include guiding principles from the codes of practice such as least restrictive option, maximising independence and respecting dignity.

NTW have developed a core set of Values (Caring & Compassionate, Respectful, and Honest & Transparent) which are incorporated into all staff appraisals and are central to our recruitment process which is values based.

Recommendation 10. Develop a strategy for providing support to people with mild to moderate mental health needs. This should include services available in primary care and in the community through the voluntary and community sector.

Community Treatment Teams provide support to those with the most complex mental health needs we would welcome the opportunity to work alongside commissioners to develop a strategy.

NTW Community Treatment Teams currently work closely with the Improving Access to Psychological Therapies (IAPT) service and hold regular interface meetings occur.

The Community Treatment Teams also work collaboratively with other health and social care providers within the locality to maximise opportunities for service users' recovery and well-being. A vocational pathway to support services users back into meaningful employment is also being progressed.

I trust that this comprehensive reply to your very useful report is helpful and provides you with confidence that we strive to continuously improve our services across North Tyneside.

Yours sincerely

John Lawlor
Chief Executive

NHS
North Tyneside
Clinical Commissioning Group

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19 October 2016

Our Ref: RE/de

Code	
Date Received	21 OCT 2016
Signature	
Print Name	

Mr P Kenrick
Chair
Healthwatch North Tyneside
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Elton Street East
Wallsend
Tyne and Wear
NE28 8QU

Dear Mr Kenrick

We appreciate the opportunity to preview the Heathwatch Mental Health (HW MH) report, which will be really helpful to North Tyneside Clinical Commissioning Group (NTCCG) in our task as commissioners of NHS mental health services. We received a copy of your letter to Jacqui Old requesting comments.

I thought it would be helpful initially to clarify a general issue about NHS mental health services. NTCCG has a budget to buy NHS care for the population of North Tyneside. For mental health issues, the NHS provides assessment, advice, and interventions. We appreciate that there is often a need for ongoing low level support of people with mental health needs. There is a debate to be had about who and how this 'support' should be provided for people, when there are ongoing physical and/or mental health issues as it is not possible for the NHS to provide all of this.

Specifically, the HW MH report, undertaken by Public Health, references the Mental Health needs assessment (p8), which, as the report correctly states, is not publicly available. NTCCG has seen one version of the MH NA dated September 2014. Unfortunately, there were a large number of unhelpful errors; in particular the inaccurate application of national information, to the local setting eg lack of perinatal MH services nationally, whereas we have an excellent local perinatal MH service.

There are a few points that the CCG has noted in the report:

1. The report is based on 272 views in a six week period in October/November 2015. North Tyneside MH services (including drug and alcohol) will have more than 6000 patient

contacts in a six week period, so this represents a very small sample. Appendix 2, p36, notes a '6-7% margin for error in reported findings' and bearing in mind the small sample size, this perhaps needs to be highlighted in the report.

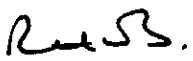
2. Since the survey was undertaken, commissioning of mental health services has developed considerably since October/November 2015:
   - Liaison psychiatry is well established (and evaluating well) in NSECH A&E department and in the older peoples mental health services;
   - The North Tyneside Mental Health Crisis Concordat work is addressing many of the concerns about accessing care in crisis. We appreciate further work is to be done but we are addressing these issues via the Concordat;
   - NTW has begun the implementation of the 'transformation' of mental health pathways, which was co-produced by service users in workshops back in 2014. These changes are addressing issues around accessing specialist interventions, such as for Personality Disorder, and the quality of initial assessment and amount of clinical contact time available;
   - IAPT (Improving Access to Psychological Therapies) and NTRP (North Tyneside Recovery Partnership) - drug and alcohol services - are both now open to self-referrals as well as professional referrals, which is a very positive move forward;
   - IAPT recovery rate has improved considerably, while its access rate is one of the best in the country.

3. A new MH strategy has been signed off by the Health & Well-Being Board (H&WB Board). The action plan is being implemented by the MH Integration Board (which reports to the H&WB Board) and is being closely monitored.

There are points raised in the report which we, as commissioners, will take note of, including the service user comments. We will use these to consider carefully how to work with providers to deliver the best possible care. Of course, as we are all aware, there are limited resources to do this and some of the wishes of service users will be a huge challenge or may not be achievable, such as more appointments even when people miss appointments (see p24/ 25). This makes it imperative that the task of supporting people towards robust mental health requires broader engagement from society as a whole, not just the NHS.

NTCCG looks forward to working with Healthwatch and others, to make best use of service user/carer experiences to maintain and improve Mental Health services within the resources available.

Yours sincerely



Dr Ruth L Evans
GMC3273379
Chair of the MH Integration Board

North Tyneside Council

Director for Children's & Adult's Services
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20 October 2016

Mr P Kenrick
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Dear Peter

Healthwatch Report - Mental Health Services in North Tyneside

Thank you for your letter dated 22 September enclosing a copy of the above report for my comment and response. I have now had a chance to discuss this with various colleagues across the Local Authority and set out my response as follows.

In terms of overall accuracy and general comments the report is helpful in setting out some key priorities though the appendices were slightly difficult to read and it would be useful if we could get a copy of the graphs separately in a larger format and to have a look at some of the data in some more detail.

The report seemed to concentrate more on adult mental health services (inferred from the way feedback was presented e.g. references to specific adult mental health services) which may be a result of who completed the survey but it made it difficult to extract children and young people's experiences and understand what their priorities are. This is especially important if their responses and priorities are different to adult respondents. It may be that, for example, references to IAPT services were relevant also to CYP IAPT but this was not clear so could not be inferred from the report.

However, overall the messages were most likely to be relevant across the age groups and the specific section on transition was particularly helpful.

For suicide data the report should identify the dates being referred to, while the report makes reference to the Needs Assessment which was conducted some time ago there is more up to date data on suicide which reveals that for the last 5 years the suicide rate in the North East of England has been consistently higher than for England as a whole. However the most recent 2012-14 data, shows that North Tyneside's rate has reduced to a rate that is similar to England.

The Healthwatch report highlights some issues around support for people in high risk groups of suicide, particularly around follow up support. The local Suicide Prevention task and finish group will take on board the issues raised in the report and will add them into their action plan.

In terms of how we can take forward the recommendations, this can be done in two ways, one for adults and one for children.

For adults you will be aware we now have the Adult Mental Health and Wellbeing Strategy that was agreed by the Health and Wellbeing Board in June 2016. Below the Health and Wellbeing Board we have a Mental Health Integration Board and it is this Board that has ownership of the strategy and the action plan that has been compiled. This is a holistic action plan and sets out changes required in the current year as well as longer term. Healthwatch are members of the Board and play a key role in the work of the Board. The Board receives updates and reports this back in to the Health and Wellbeing Board quarterly. The recommendations outlined in your final published report can be tabled and discussed at a future meeting of the Mental Health Integration Board and the action plan updated as appropriate..

For children, we have recently taken the Children and Young People's Mental Health and Emotional Wellbeing Strategy to the Health and Wellbeing Board. This was signed off in September 2016 and we are currently finalising our action plan which wraps around the Local Transformation Plan (which is referenced in your report). This work is overseen by the Children and Young People's Mental Health and Emotional Wellbeing Strategic Group (members include statutory partners as well as Healthwatch and the voluntary sector and youth engagement) and this links in to the Mental Health Integration Board and the Children and Young People's Partnership Board.

Many of the issues in the Healthwatch report were also brought out in the needs assessment and development of our strategy e.g. transition arrangements. Therefore the recommendations can be considered within the development of our action plan. The strategy covers the whole of the mental health and emotional wellbeing pathway with a keen focus on early intervention and prevention and harnessing universal services to promote children and young people's mental health.

I do hope this helps you finalise the report for publication.

Yours sincerely

J A Old

Jacqui Old
Director of Children's & Adult Services

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