

**Report of the  
Mental Health data  
collected by  
Healthwatch Tameside  
2014 to 2016**

**Published in March 2017**

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## Executive Summary

Healthwatch Tameside is the independent consumer champion for health and social care in Tameside.

We listen to local people, and gather information about their experiences of using health and social care services.

We use this information to talk to the people who arrange (commission) the services and the people who provide the services. We can influence changes which will make these services better for everyone. If we hear about good practice, we encourage this to be shared. If you tell us about something that could be improved, we will talk to the people in charge about this too.

Any information we are given will remain anonymous. We are careful to share ideas in a way which will not identify any individuals.

Healthwatch Tameside regularly hold Healthwatch Champions sessions in various public buildings around the borough. We also visit groups, attend events, have market stalls and are always looking for new ways to engage with the residents of Tameside.

However, the information collected about experiences of mental health care was quite limited. People are generally happier, we find, to talk about what they think about care they have received for their physical health.

During 2016, we noted an increase in the number of people contacting Healthwatch Tameside for guidance through the NHS complaints process, in connection with their mental health care.

A decision was made to actively visit places where people might go to get support for their mental health.

This report is the result of the recent work of Healthwatch Tameside. It includes a summary of all information collated during 2014, 2015 and 2016, with a more detailed focus on information from 2016. We have maintained anonymity, therefore only an overview of stories has been included. A few people have given permission for more detail to be included, and some stories are already in the public domain - on Patient Opinion or NHS Choices.

The information contained in this report is the starting point for a mental health project to be carried out by Healthwatch Tameside during 2017.

### Key messages

From the information contained in this report, Healthwatch Tameside have identified some key messages.

1. Any person receiving mental health care is to be respected as a human being, who has feelings.

2. Getting the access to services right is critical, including:
  - a. The length of waiting times to start treatment, or for follow-up appointments.
  - b. Appropriate support at a time of crisis.
  - c. Each patient being treated in a personalised way - if they have tried one form of treatment, and it did not work for them, do not expect them to try that again at a later date, before alternatives are considered.
  - d. The location of the service being provided, and whether people can get there (physical, emotional and financial considerations).
  - e. Where self-referral is available, remembering that not everyone can use a computer.
3. Effective communication can make the difference between a positive and negative experience.
4. When a person is a multi-service user, all the agencies involved need to work together, whilst respecting confidentiality.
5. The health of vulnerable people needs to be given extra consideration.
6. The way a member of staff interacts with service users is remembered. For example, do they always smile, even when they are busy?

This report includes many comments and quotations about mental health services which have been used by people in Tameside. However, Healthwatch Tameside are aware they have only spoken to, or heard from, a small minority of the people who use the services. The information may therefore not be representative of all users.

The comments made by Healthwatch Tameside will be based on what we have been told so far.

Mental health services, at Tameside Hospital and Stepping Hill Hospital, are provided by Pennine Care Foundation Trust. Visits to A & E at either hospital will initially be triaged by A & E staff of the relevant hospital, before arranging for the mental health service to treat the patient.

From our experience, people will write to complain about a service, but not to praise a service they have used. Out of the 206 stories, 54 people made a comment that was positive (although they may also have included negative comments). This is worth noting. Healthwatch Tameside would like the contributions of all staff who helped people to have a positive experience to be recognised.

There are several areas where the patient or service user feels that the service they received was not satisfactory. Healthwatch are aware of the financial pressures faced by all commissioners and providers. However, as the voice of the

residents of Tameside, and as an independent organisation, we will be taking these issues further (see Next Steps below). Everyone has a right to have care provided in a way which provides them with a positive experience. A simple change in an area, such as communication, can make a big difference to how an individual feels they were treated.

Tameside is leading the way nationally, in making changes to the way health and social care is provided, through Care Together. Mental health care, in the opinion of Healthwatch Tameside, deserves the same level of review. The information collected by Healthwatch Tameside (as an independent organisation) will be used in discussions with Pennine Care NHS Foundation Trust and their commissioners, to influence the way forward for the provision of mental health care in Tameside.

## Next Steps

The information contained in this report is a starting point for a mental health project to be carried out by Healthwatch Tameside.

1. We will share our findings, so far, with providers and commissioners of mental health services.
2. Healthwatch Tameside want to capture the experiences of mental health care from as many people as they can. We are aware many people do not attend support groups, and will be investigating ways to connect with people in different ways.

We want to hear from people of all ages, and all areas of Tameside.

We know people do not always want to talk about how they are feeling in a public meeting. During the spring of 2017, opportunities will be provided for people to tell us about their experiences, in a way that is comfortable for them. This will include a public meeting.

If someone has information about mental health care, they are welcome to contact the Healthwatch team, and we will arrange for them to tell us.

3. Once we have more information, we will be looking to see how this compares to the stories contained in this report.
4. The recommendations shown on the next page will be reviewed, and amended if necessary.
5. Healthwatch Tameside will be working with the commissioners and providers of mental health services, to influence changes to services provided, based on our recommendations.

## Recommendations

Based on the information available in this report, the following are areas where people would like to see improvements made.

### 1. Guarantee the care of patients will not be affected if they speak out.

Many people Healthwatch speak to, have concerns that if they make any comment about the care they are receiving, then this will be held against them during future care.

### 2. Ensure people who receive care feel it was a good experience.

Small changes can have a big impact, and do not necessarily cost anything financially. For example:

- a. People need to feel that they are being taken seriously.
- b. Staff attitude is important - a smile and showing compassion make a big difference.

### 3. Provide support when it is needed.

- a. People said the waiting time for appointments was too long. This was for first appointments after referral, follow-ups, review after a medication change and times of crisis.
- b. Families were surprised how difficult it was to get help when it was needed.
- c. Meetings with a CPN did not always go ahead as planned, and phone calls were not always returned.

### 4. Improve communication.

- a. Treatment or medication prescribed by a hospital consultant is sometimes changed by a GP later - this suggests a lack of communication between services about a course of treatment and the proposed outcomes.
- b. Patients say they want to talk to the same practitioner each time they have an appointment. They want to be given time to talk, they want to talk about mental health care face-to-face, and they want to be listened to.
- c. Phone calls should be returned within a reasonable time.

### 5. Improve access.

- a. Not everyone has a computer - library computers are not private when describing sensitive issues, and have limited usage times - consider the provision of a phone number as an alternative.



- b. When choosing the location of a service, for example, the Health and Wellbeing College, consider the location in relation to public transport, and the cost involved in getting there. Also consider the ability of people to travel out of area, especially if they have deteriorating mental health.
- c. Bear in mind access needs - for example, Deaf patients - a group therapy session is not suitable for everyone.

**6. Improve the way services work together.**

- a. When a patient has both physical and mental conditions, different organisations provide the care. One condition can affect another - the organisations need to co-ordinate care effectively.
- b. When someone has a diagnosed mental health condition in addition to drug or alcohol dependency, the two care teams need to work side-by-side to provide care.

**7. Be aware of vulnerable people.**

- a. Certain conditions are more likely to see a person developing mental health issues. These include people with brain conditions (eg. dementia, learning difficulties, cerebral palsy, autistic spectrum).
- b. Social isolation also affects people, whether caused by an illness making them housebound, or because they have no friends or relatives.
- c. Health and care professionals should consider whether a person is vulnerable, whenever they have contact with patients or service users - early diagnosis of mental health issues is essential.

**8. Review experience of patients where the police have been involved.**

From the information contained in this report, the experiences of this group of patients are the most complicated, often involving other agencies, such as housing associations. They have often been through a period of crisis.

- a. Are there any common factors?
- b. What was the trigger for police involvement?
- c. What learning can there be, to avoid situations escalating in future?

## **Statement in response to Mental Health Report by Healthwatch Tameside - February 2017 - Pennine Care NHS Foundation Trust**

We would like to thank Healthwatch Tameside for producing this report and extend that gratitude to all the service users and carers who gave their feedback.

Along with mental health providers across the country, Pennine Care faces significant financial challenges but the Trust does all it can to minimise the impact this has on patient care. Providing safe and high quality services to those who need our support is the Trust's top priority - we want to ensure every patient has the best possible experience. Therefore, we welcome the opportunity to listen to honest feedback and identify areas for further development.

We agree with the recommendations in this report and fully support the next steps. At the same time, Pennine Care is currently developing a new strategy for mental health, spanning the breadth of the system including access, children's, adults and older people and specialist services. As part of developing the strategy we held a series of engagement sessions with staff, service users and carers to learn from their personal experiences. We would very much like to work with Healthwatch to further inform this work and the future design of services.

Pennine Care is a member of the Greater Manchester Mental Health Implementation Executive, which is overseeing implementation of the city region's mental health strategy. This will assist development of the Trust's own strategy and influence plans moving forward.

We look forward to working in collaboration with Healthwatch Tameside, our commissioners and other local partners, to ensure improvements are made to the whole health and social care system to better support those with mental health needs.

**Dr Henry Ticehurst, Medical Director, Pennine Care NHS Foundation Trust**

# Introduction

## Background and purpose

Healthwatch Tameside has a statutory duty to listen to local people and find out what their experiences of health and social care services are. This information is collated anonymously, and Healthwatch Tameside talk to the providers and commissioners of these services on a regular basis. Using the anonymous stories from members of the public, we can help to influence improvements in the services provided.

As the information is collated, we become aware of trends and themes, which help to inform the future work of Healthwatch Tameside. Sometimes it is the lack of information about an area or service that creates a focused project.

As a staff team, we are aware that mental health is an ongoing problem for many people. However, we were not receiving much information about this service, to be able to evidence where there were good aspects of the service provided, or where there might be areas where improvements could be made.

During 2016, Healthwatch Tameside started looking at ways to gather additional information about mental health and the care people were receiving. Several opportunities all came together, giving us the chance to look more deeply into this service:

- A regular monthly session was arranged for a Healthwatch Champion to attend an Opt-in Group meeting.
- Healthwatch Tameside were invited to talk to people who attended the drop-in session at The Anthony Seddon Trust (this followed discussions at the Healthwatch Big Health and Care Debate in July 2016). A monthly visit has been agreed.
- Healthwatch Tameside were invited to talk to a Women's Group based in Cavendish Mill.
- Healthwatch Tameside were invited to set up Healthwatch Champion sessions at Loxley House in Dukinfield. There are a number of groups who meet at this location, and all have welcomed the Champions.
- Several families asked Healthwatch Tameside to assist them with complex complaints about the mental health care received by family members.
- Several complex signposting requests were received, from people looking for support for mental health issues.

Healthwatch Tameside have been told by a number of people that they do not like to talk about their mental health with strangers. The Champions will attend a session to build up relationships, and to become a face people recognise. Once a

level of trust and familiarity has been established, people find it easier to talk about their mental health care, and how they are feeling.

Healthwatch Tameside shares collated information with providers, in a way which does not identify individuals, unless the patient or service user has given consent to be more specific.

Within our report, we are also including stories relating to mental health issues where the patient or service user has dementia, a brain injury or disease, has a diagnosis on the autistic spectrum or has a learning disability.

## **Methodology**

The information collected about mental health care comes from different sources. In addition to the face-to-face contacts mentioned above, we have collated stories and comments from the following:

- Brief comments on the Healthwatch Tameside short survey form.
- Stories collected by Healthwatch Champions in the community.
- Stories posted on Patient Opinion.
- Reviews about care received at GP practices posted on NHS Choices.
- NHS Complaints where Healthwatch Tameside are providing guidance through the process.
- Signposting requests received by Healthwatch Tameside.

We have included all information collected from these sources between January 2014 and November 2016.

The comments and quotations are from 2016.

Mental health services located at Tameside Hospital and Stepping Hill Hospital are provided by Pennine Care Foundation Trust, with the exception of A & E visits.

## **Sources of information**

Here are brief descriptions of each source of information.

**Short survey form** - Healthwatch Tameside have a survey form which asks questions about which services people have used in the past 12 months. It also asks which gave the best service and which the worst service (this could still be good), along with what was particularly good and how they think the services can be improved. There are two ways to complete the survey:

- Online via the Healthwatch Tameside website - <http://www.healthwatchtameside.co.uk/our-survey> .
- On a paper questionnaire. The details from the paper copies are then manually added to the online data.

We also have a young people's survey which is available on paper or online at <http://www.healthwatchtameside.co.uk/young-peoples-survey> .

There is also an easy-read version available on paper.

The Healthwatch Champions and staff members have copies of the paper forms, and they are available at events which are attended by Healthwatch Tameside. The online forms are advertised regularly in the Healthwatch Tameside ebulletins.

**Healthwatch Champions** - these are volunteers who talk to people at various community venues around Tameside. Many of the stories we have are collected by the Champions. Sometimes the Champions record what they have themselves seen and heard, whilst out in the community.

**Patient Opinion** - there are different ways for people to tell their story (or report their experience) using Patient Opinion:

- They can type it themselves via the Healthwatch Tameside website or directly onto the Patient Opinion/Care Opinion (referred to as Patient Opinion for the rest of this report) websites.
- They can record comments on the NHS Choices website. Comments about some providers will also show on Patient Opinion, but without a criticality rating (see explanation below), because they have not been moderated.
- They can complete a paper form and send it to the Healthwatch Office.
- They can speak to a member of staff or Healthwatch Champion, who will record the details. This could be face-to-face in the community, by appointment in the office, or by phone. The story is then recorded on Patient Opinion on their behalf.

When information is sent to the Healthwatch office, it is recorded on Patient Opinion using a staff login, so maintaining anonymity, if requested.

When Patient Opinion receive a story, it is looked at by a member of their team and moderated. The story is not usually changed, although anything which could be seen to be defamatory may be reworded. They also allocate a level of criticality to the story. This is not a level of criticism, but is based on the impact on an individual of something going wrong. This ranges from 0 (not critical) through to 5 (severely critical). It will then be published. A level 5 will result in the provider being contacted directly by Patient Opinion, instead of waiting for them to see the story online.

**NHS Choices** - reviews posted on the NHS Choices website about GP practices do not appear on Patient Opinion. The information is available for the public to see. NHS Choices forwarded a spreadsheet containing all the reviews for GP practices in

Tameside and Glossop, to Healthwatch Tameside, for the period from January 2014 to June 2016.

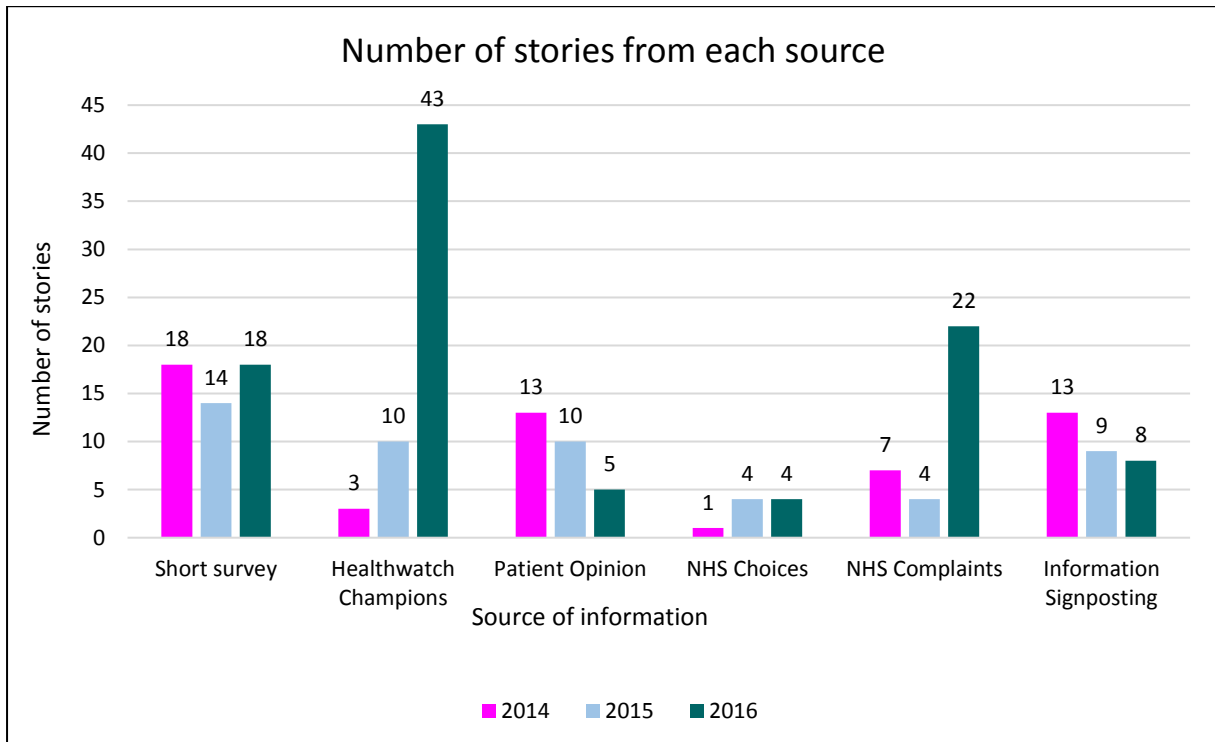
**NHS Complaints** - Healthwatch Tameside assists people to access the complaints system of any publicly funded health or social care service.

**Information signposting** - One of the functions of Healthwatch Tameside is to provide an information signposting service. We can help people get information that will help them to make an informed choice about what health or care service they (or a family member) might access for treatment, care or support.

# Information

## Total number of stories

We have 206 stories in total from the sources outlined above, which mention mental health care. These are split:



## Themes

We have analysed all the information, and many different themes have emerged. Many of the stories are multi-themed.

We will start by looking at a summary of all the different themes. The remainder of the report will consider each theme independently, and will include quotes from patients and service users. Where there are only a few comments about a theme, these will be included in sections with other similar themes.

The numbers in respect of most themes are higher in 2016, due to the targeted efforts to speak to people experiencing mental health issues, in an environment where they feel comfortable. In respect of some of the complaints assistance provided, this was in their own home, because, for example, they are agoraphobic.

The themes are ordered with the largest number of comments first, down to the smallest.

| Theme   | 2014 | 2015 | 2016 | Total |
|---|------|------|------|-------|
| Attitude of staff   | 18   | 23   | 30   | 71    |
| Outpatient and community care (mental health)   | 16   | 17   | 29   | 62    |
| Communication, information, talking, listening, advice  | 13   | 14   | 33   | 60    |
| Positive comments   | 17   | 19   | 18   | 54    |
| ADHD, agoraphobia, anger, anxiety, bipolar, eating disorder, hallucinations, OCD, panic attacks, personality disorder, psychosis, PTSD, schizophrenia | 10   | 10   | 28   | 48    |
| Appointment   | 10   | 15   | 22   | 47    |
| Medication  | 12   | 8    | 23   | 43    |
| Contact with charities and support groups   | 10   | 9    | 21   | 40    |
| Inpatient (mental health care)  | 11   | 11   | 15   | 37    |
| Depression  | 7    | 6    | 12   | 25    |
| Physical issues (in a mental health patient)  | 6    | 5    | 13   | 24    |
| Dementia, brain injury or disease, cerebral palsy   | 10   | 3    | 9    | 22    |
| Benefits, social care   | 3    | 5    | 12   | 20    |
| Not being taken seriously, being made to feel bad   | 5    | 5    | 10   | 20    |
| Unspecified therapy, CBT, bereavement counselling   | 3    | 2    | 13   | 18    |
| Suicidal  | 4    | 4    | 8    | 16    |
| Referral or signposting to Cloverleaf   | 6    | 3    | 5    | 14    |
| Autistic spectrum, learning disability  | 4    | 3    | 7    | 14    |
| 999 ambulance, patient transport, 111   | 4    | 0    | 8    | 12    |
| Crisis  | 2    | 0    | 10   | 12    |
| Care - home, residential, respite, carers   | 1    | 3    | 8    | 12    |
| Healthy Minds (including College)   | 0    | 2    | 9    | 11    |
| Social isolation  | 3    | 3    | 5    | 11    |

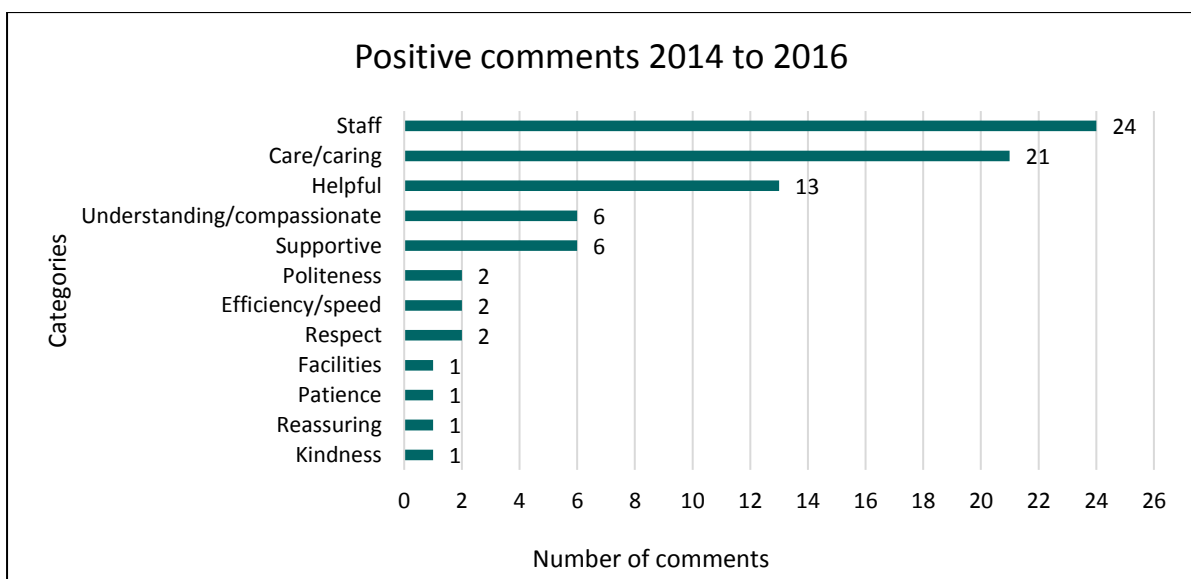


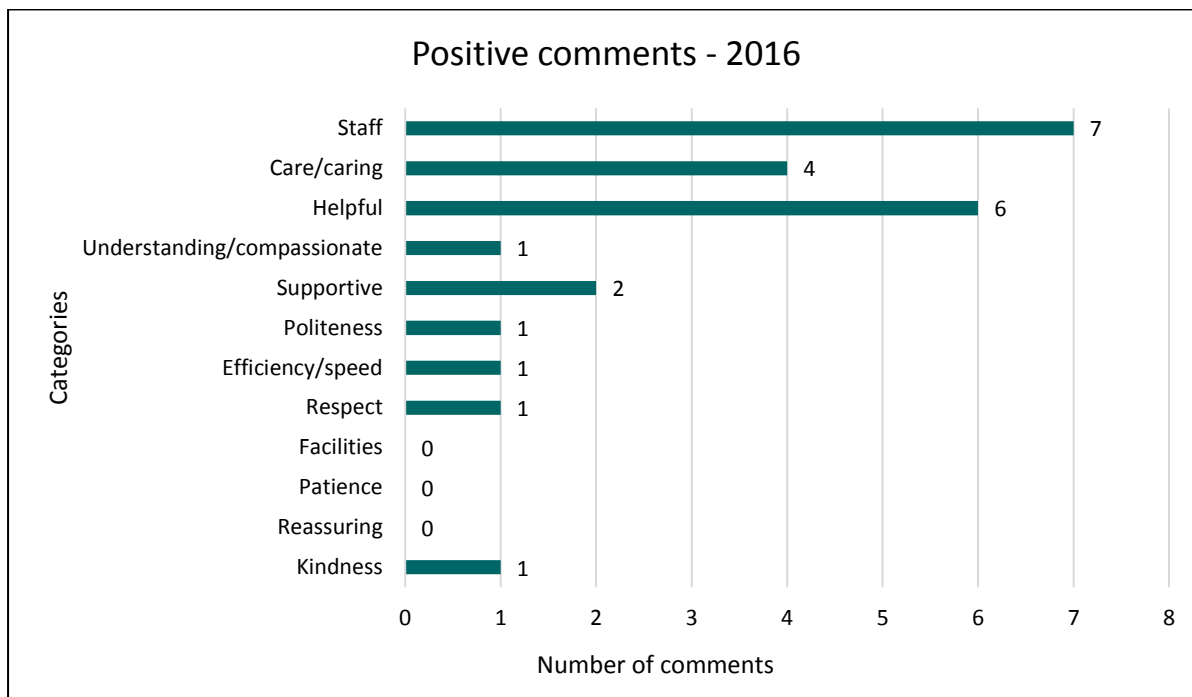
|  |   |   |   |    |
|--|---|---|---|----|
| Inpatient (for physical care in a mental health patient) | 3 | 2 | 6 | 11 |
| Young Healthy Minds (CAMHS)                              | 1 | 2 | 7 | 10 |
| Fear for the consequences                                | 2 | 1 | 6 | 9  |
| Alcohol, drugs   | 3 | 0 | 5 | 8  |
| Want to change medical practitioner                      | 3 | 3 | 2 | 8  |
| Housing Association, rented social housing               | 1 | 0 | 6 | 7  |
| Miscellaneous  | 1 | 2 | 4 | 7  |
| Safeguarding   | 2 | 0 | 3 | 5  |
| Police involvement                                       | 0 | 0 | 5 | 5  |
| Breach of confidentiality                                | 0 | 0 | 4 | 4  |
| Training   | 2 | 1 | 1 | 4  |
| Diagnosis  | 1 | 1 | 2 | 4  |
| Disengaged from care                                     | 1 | 1 | 0 | 2  |

Within each of the themes in the table above, there could be positive and/or negative comments.

### Positive comments (all themes)

It is important to look at all aspects of care, and not just areas where people feel improvements could be made. Healthwatch Tameside encourage sharing of good practice. 54 people included positive comments (sometimes alongside negative comments), and here is a breakdown.





The shape of the graph for 2016 comments is different to that for three years. 'Staff' has remained in proportion with 30% of the comments on each graph. 'Care/caring' has reduced from 26 % of comments over 3 years, to 17% of comments in 2016. 'Helpful' has increased from 16% to 25% in 2016, and makes up almost half of the 'Helpful' comments over the three years. However, different people use different words to describe how they are feeling, and positive feelings around 'care/caring' and 'being helpful' could be seen to be interchangeable.

Overall, the level of positivity seems to be staying the same over the three years.

Here is a selection of comments:

'Staff' -

- *I have been able to speak to the manager who has helped me and treated me like a person. I would recommend this practice as over the past week they have dealt with the issues nicely and politely thank you.*
- *I have been a patient at this practice for 26 years and I have always experienced 5 star service from both staff and medical staff alike. The last 10 years of my life have been very difficult indeed and without the help of ..... Practice, I don't know what I would have done.*
- *When I go to the surgery the receptionists are great, they know I have a mental health issue so they always ask if I want a 20 minute appointment and do I want to see Dr.....*
- One person was very happy with staff on Saxon ward at weekends. This contrasts with other comments from a group discussion where people reported Saxon ward staff as not treating people well, they are rude, look

down on the patients, don't take time to talk to them and are not interested. They said staff tend to be nice to new patients. Not sure if the staff concerned are permanent or agency staff.

- *Lifeline - Helped with alcohol abuse. Very compassionate and supportive staff.*
- *Consultant. Very good relationship and helps me a lot.*

'Care/caring' and 'helpful' -

- Husband in and out of mental health ward over 18 months after attempted suicide. Great care for husband and support for wife. Psychologist visiting husband at home and supporting wife.
- Husband goes to Wilshaw House for respite care - he has Parkinson's and dementia. Wife finds it too difficult to look after him all the time at home. He gets good care and is treated with respect and kindness.
- *I didn't have a long waiting time for the service.*
- *Anthony Seddon - helps me with my mental health. Gets me out meeting others.*
- *CAMHS -it helped me a lot.*

## Individual themes

The next section of the report shows more detailed information about the individual themes. Healthwatch Tameside always tell members of the public that their anonymity will be protected, unless specific consent is provided otherwise. This helps to overcome the reluctance people have in talking about their experiences.

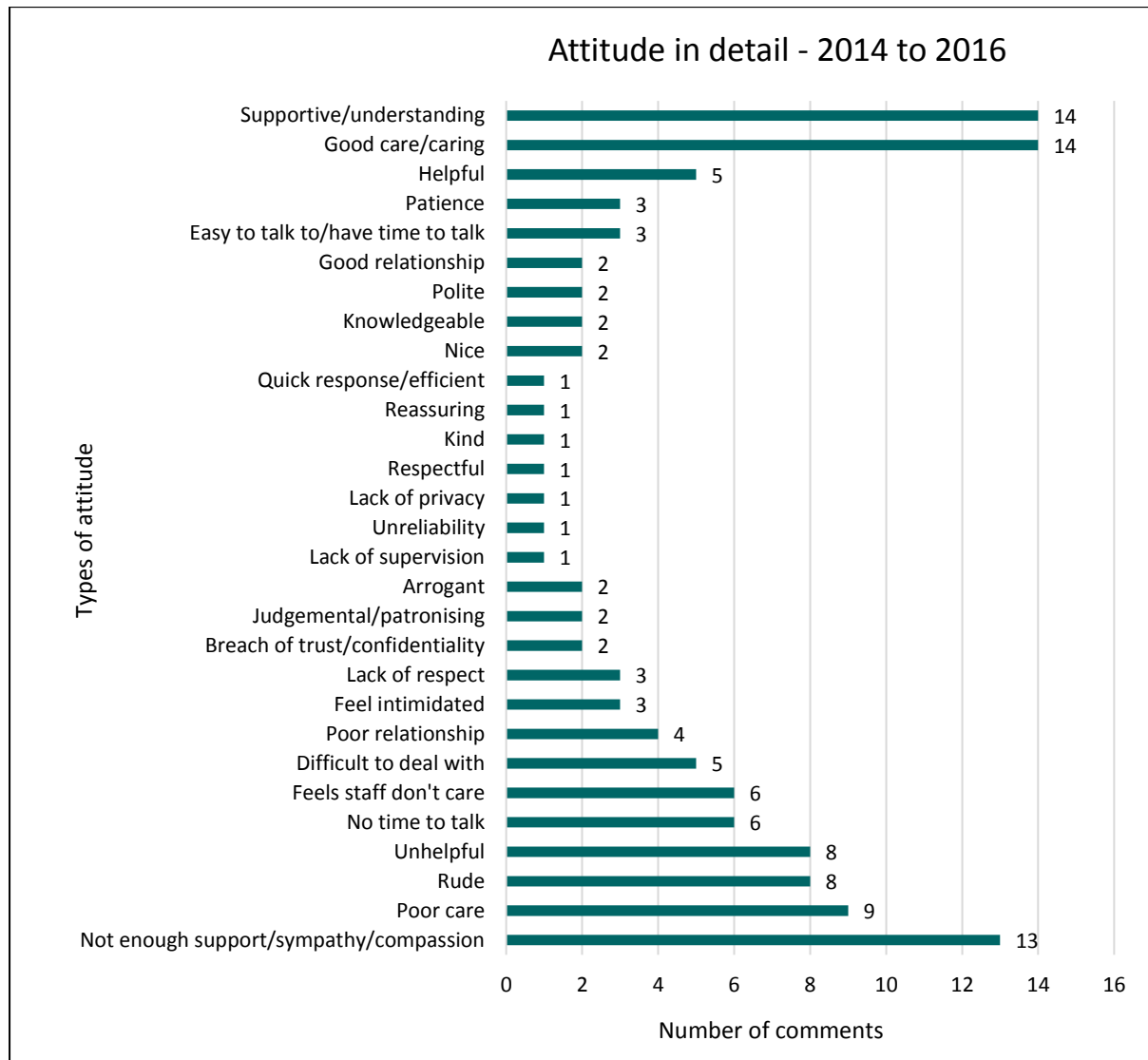
Many people tell us they are worried about how their care will be affected if the service they use finds out that they have talked about their experiences (even when they are positive).

The report has been written to maintain confidentiality. We have been able to include more detail when the story is in the public domain already, for example, on the Patient Opinion or NHS Choices websites.

All the specific comments and quotations (in italics) have been provided during 2016.

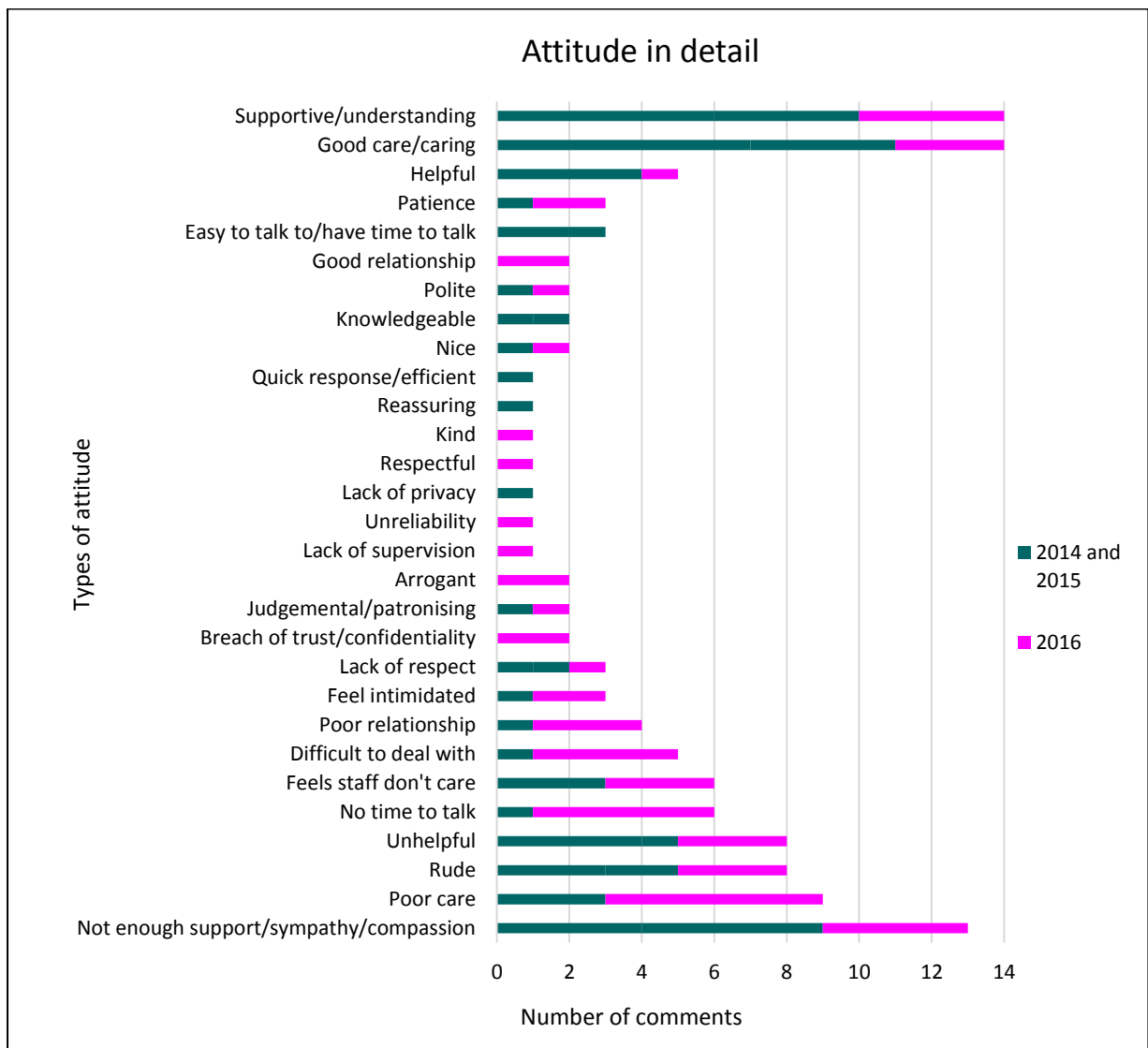
## Attitude of staff

This is the theme with the highest number of comments at 71. Some comments are positive and some are negative. We will look at the different areas which were commented upon throughout this report. Many of the stories included more than one of the areas.



We have grouped together positive comments at the top of the graph and negative comments at the bottom, with the highest numbers at the top and bottom. It is interesting to note that the areas with the highest number of comments are 'support/understanding' and 'care/caring'. This is the same for both positive and negative comments.

The next graph shows the same information as above. We have added a pink bar to each of the groups of comments. This shows how many comments were collected during 2016 (pink bar) out of the total for that theme.



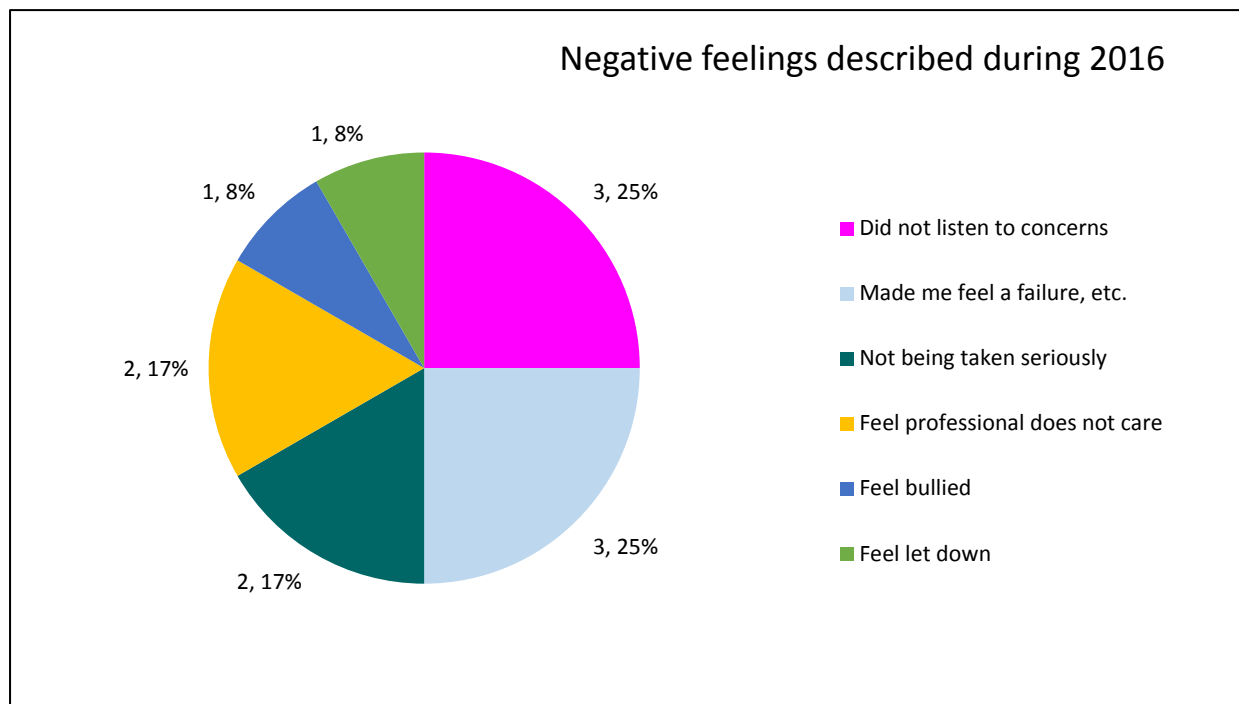
As a proportion of the total, 31.4% (16 out of 51) of the positive comments, and 55.4% (41 out of 74) of the negative comments were collected during 2016.

‘Lack of supervision’ refers to one story, however there has been more than one occasion during different periods of inpatient admission, in 2016, where this patient was left unattended (ignoring the request of the patient’s partner that constant supervision was provided). The result each time led to the patient attempting suicide.

‘Poor care’, ‘Rude’ and ‘Feels staff don’t care’ include comments from group discussions in 2016. These have been recorded as one comment within each category, as it is not clear how many people in the group had the same opinion (although the notes from the meeting suggest there were a few people in agreement).

## Negative feelings

People described various types of negative feelings they experienced, as shown in the graph below.



The sector on the graph for ‘Made me feel a failure, etc.’ includes various descriptions about how people felt. For example:

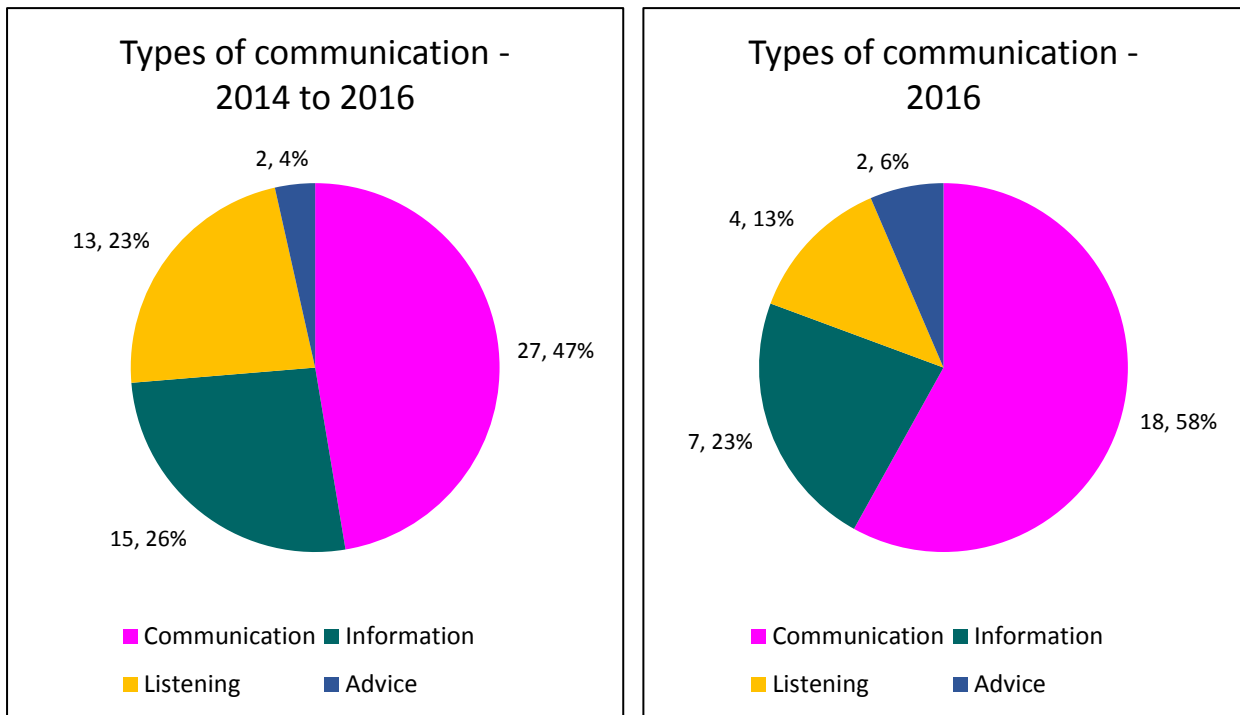
- *There are numerous incidents that have made me personally feel a) uncomfortable and b) like a piece of dirt.* (From an inpatient)
- *They made me feel useless, worthless, and a burden.* (From an outpatient)

Other comments people made, which fall under this theme, include:

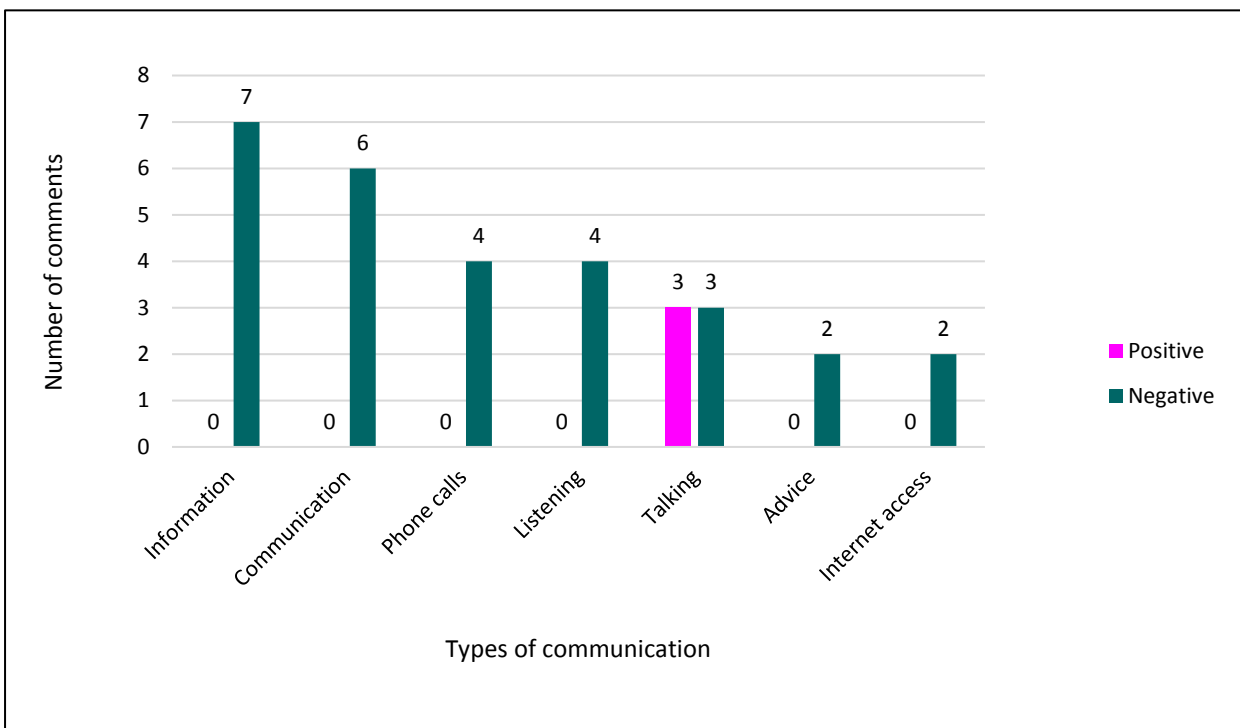
- One person has had a medical condition for a number of years, during childhood, but now falls under adult care, and feels that they are not being taken seriously.
- *I struggled tremendously to access the service they made available to me, and felt bullied out of the service, because I was told I was not meeting their expectations.*
- *I think that because I have mental health problems I am invisible to the Council. I do not exist.*
- *I feel extremely let down and still in a very bad place.*

## Communication

This theme includes information, talking, listening, advice, and phone calls. 57 people mentioned at least one topic. These are shown in the graph below. In the graphs, 'communication' includes talking and phone calls.



Here is a more detailed breakdown of the types of communication comments collected in 2016.



Only three of the comments were positive, including:

- *I overdosed and was taken to the hospital where I got time to talk and the help I needed.*
- *Had a great experience with The Sanctuary and mental health. I needed somebody to talk to as I was very distressed. They were great. I could talk as long as I wanted.*

‘Information’ was mentioned the most often, including, we were told:

- Incorrect information was passed to the DWP, without the patient’s permission, resulting in a PIP application being declined.
- A patient was transferred from Saxon Ward (Tameside) to Cobden Ward (Stepping Hill). Cobden Ward staff queried whether they had the right paperwork, because the information about the patient’s condition did not match the behaviour of the patient who arrived. They had not expected someone who was calm.
- *Helpful if GP had more information about where to refer people, ie. Anthony Seddon Trust, or mental health services.*

‘Communication’ - On the Healthwatch survey we ask ‘What could be improved?’ One response was:

- *Communication between services.*

‘Phone calls’ - here are some comments:

- *Can't get information from ..... (inpatient hospital out of area). Keep ringing but calls not returned.*
- *MIND - Used to be really good but gone downhill now, don't respond to telephone calls and can't get through the receptionist.*
- *I'm not keen on The Sanctuary idea. I don't want to talk to a stranger on a phone when I'm not well. I prefer to go somewhere local where there are people I know.*

‘Listening’ - here are some examples where Healthwatch has been involved:

- Healthwatch was approached for assistance - the person needed an advocate to attend a meeting about their mental health. They said the hospital wasn’t listening, and wanted to reduce the level of medication that they were taking, which they were not happy about. They were referred to Cloverleaf.
- Another person got in touch with Healthwatch. Their partner was a patient on Taylor Ward. This was not the first time the mental health of their partner had become critical, and they knew what was needed to help them. The doctors would not listen, and started the process of finding the right



medication again. This delayed the provision of the most suitable medication, resulting in a worsening condition.

‘Advice’ - this comment was from a person completing the young people’s survey:

- *Wasn't much advice given just to carry on. There should be more support for mental health and eating disorders.*

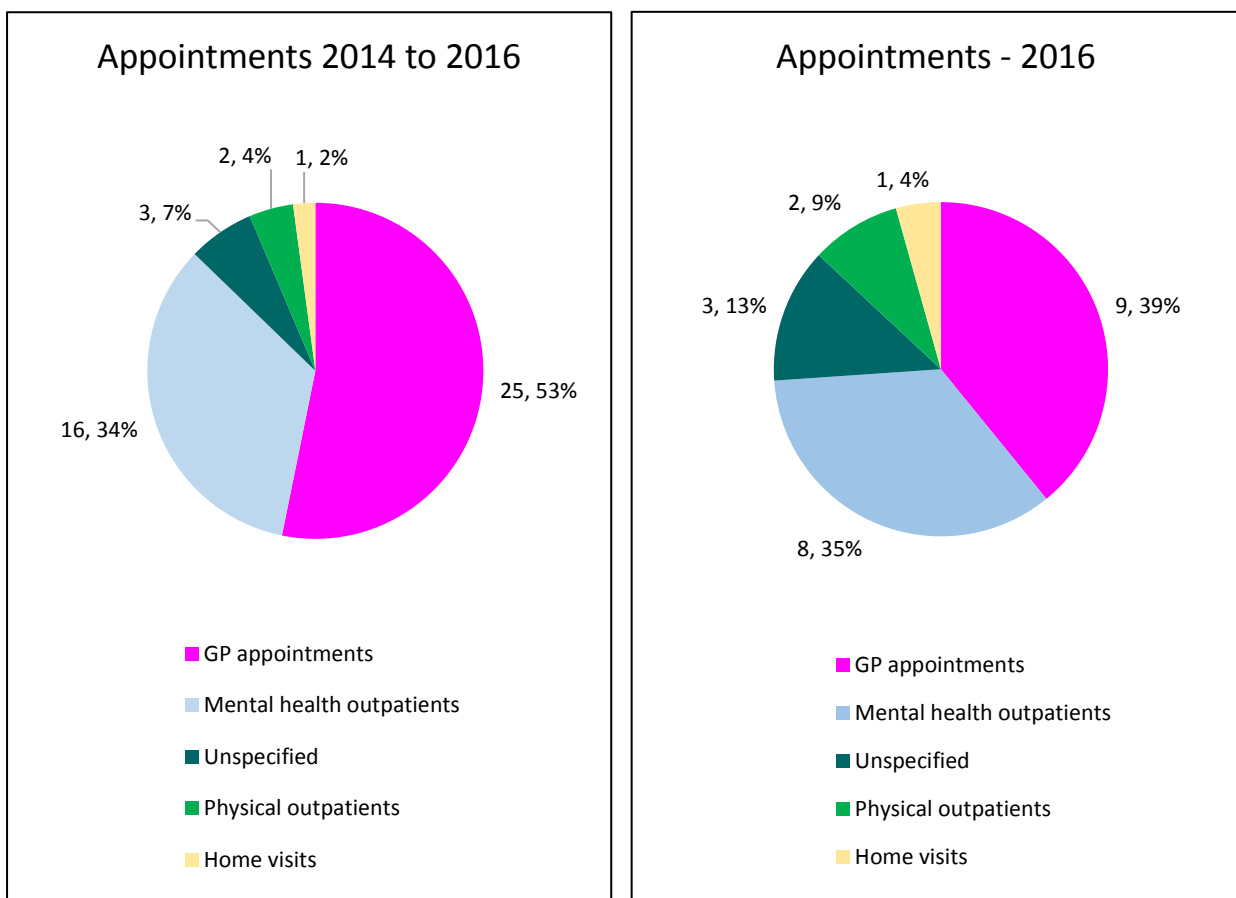
‘Internet access’-

- People have told Healthwatch that they find it difficult to access services, if they have to use the internet. Some people use library computers, which are not private, and have limited time allowed per session.

### Appointments

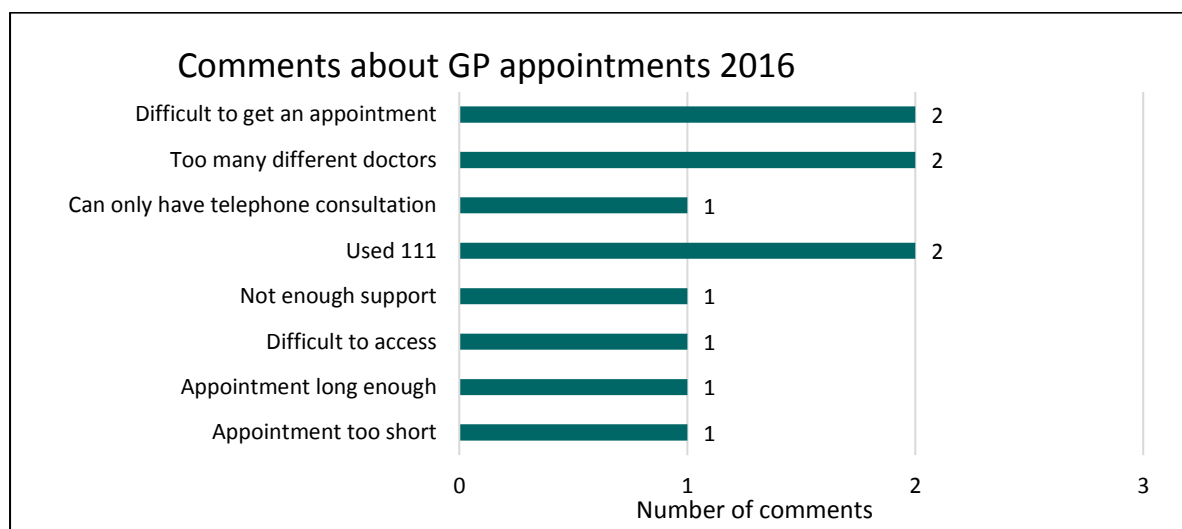
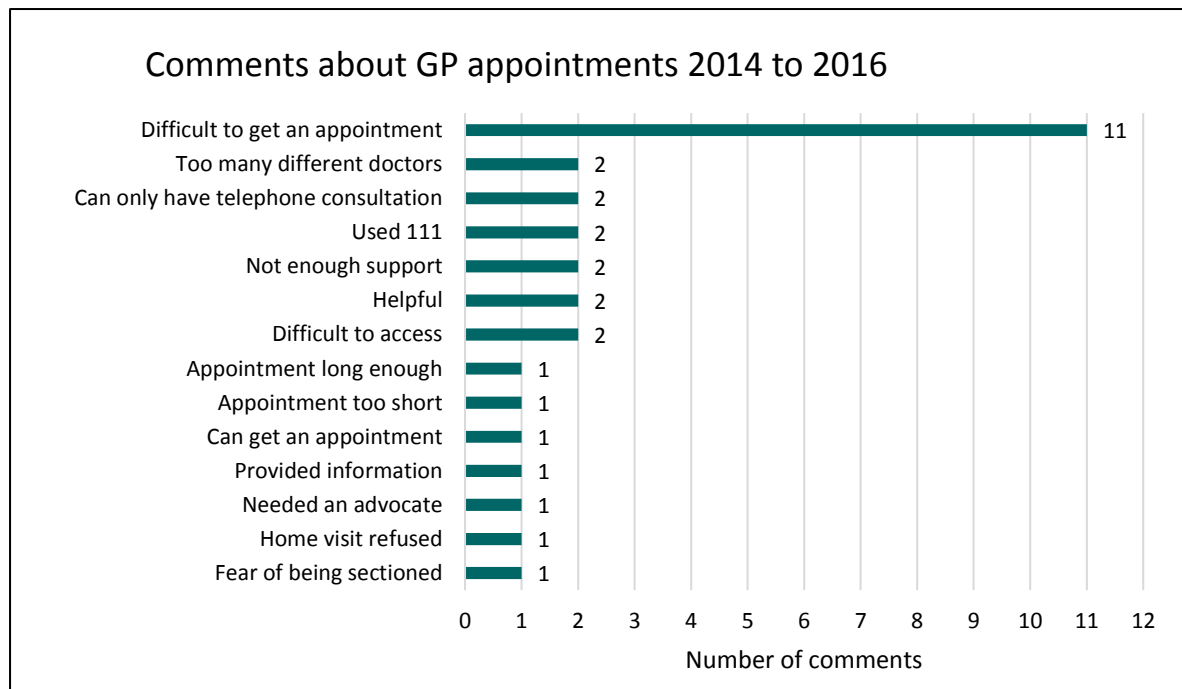
This section of the report includes all the types of appointment someone with a mental health condition may need, as used by the people who told their stories.

Within ‘GP appointments’ in the graph, we have included telephone consultations, referral by 111 and the walk-in centre. ‘Physical outpatients’ refers to appointments for treatment other than mental health.



## Comments about GP appointments for mental health

GP appointments have the highest number of comments, which is to be expected when your GP is the first place people go when they feel unwell. Here is a summary of what the comments included.



From comments collected during 2014 and 2015, difficulties in getting a GP appointment were highlighted most frequently. However, during 2016, only two people mentioned this as being a problem. One person said:

- This person has a lot of medical problems and is very depressed, on anti-depressants. They cannot get appointments - if they do get through ringing

from 8.00am, all the appointments are gone by 8.45 - and anyway they have to work. At other times only telephone consultations are offered, usually at times when they have to be at work. They never speak to the same doctor twice. They feel doctors don't care.

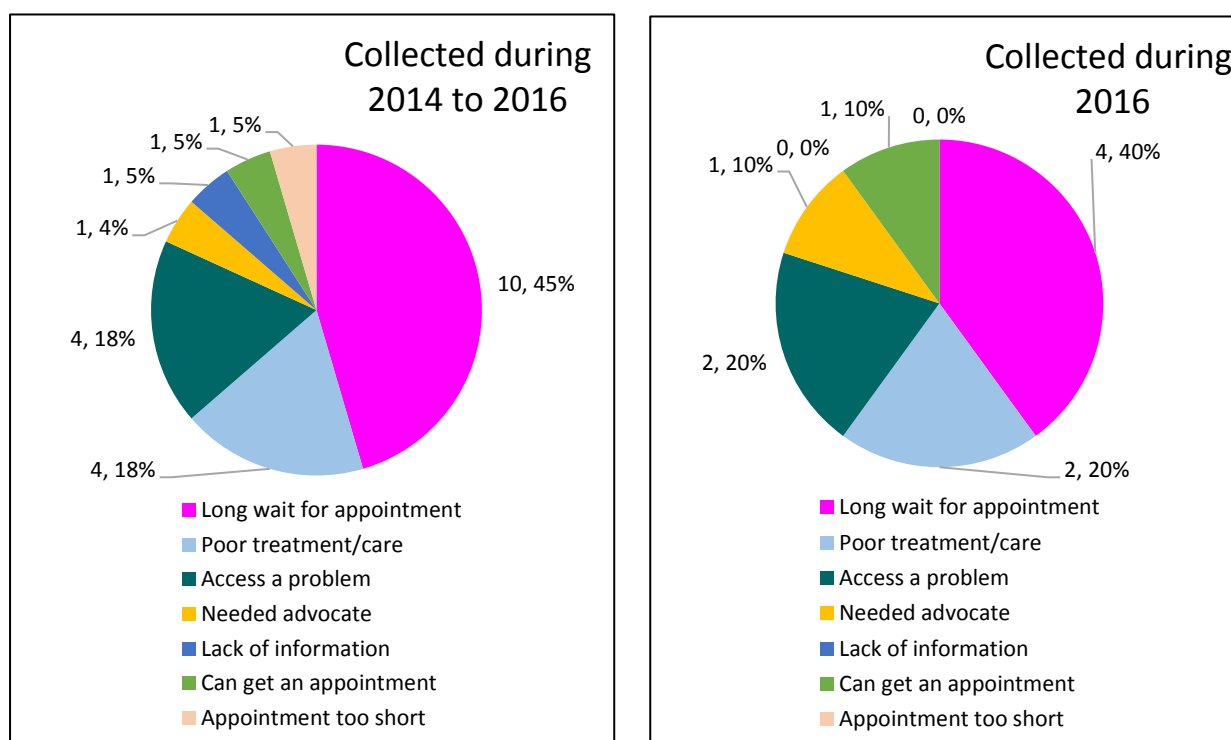
Other comments included:

- *GP doesn't have time to talk when you are asking for help with a mental health issue as you only get a 10-minute slot.*
- *It isn't too bad when you get the same doctor you build up a relationship with them but sometimes you can't get in to see a specific Doctor, either they are not in or there are no appointments to see them.*
- *Rang the GP surgery The surgery was closed but the recorded message said ring 111. I rang 111 - they took all the details and made me an appointment at the walk-in centre in Ashton. I attended and was told that they do not see people about mental health problems, but they did take my blood pressure and sent the details to the GP.*

'Difficult to access' refers to people with agoraphobia, who find it difficult to leave the house.

'Fear of being sectioned' refers to a patient who did not want to make a GP appointment, even though their mental health was deteriorating, because they were worried about what would happen. They did not want to go into hospital.

### Comments about mental health appointments (in the community and outpatients)



As with GP appointments, the length of time to wait for a mental health outpatient appointment was the type of comment mentioned most often.

- *I had a 20-minute appointment with a psychiatrist, only spent 10 minutes talking to me and then prescribed a new medication. I then had a 3 month wait for my next appointment which I think isn't right when on new medication, it's too long.*

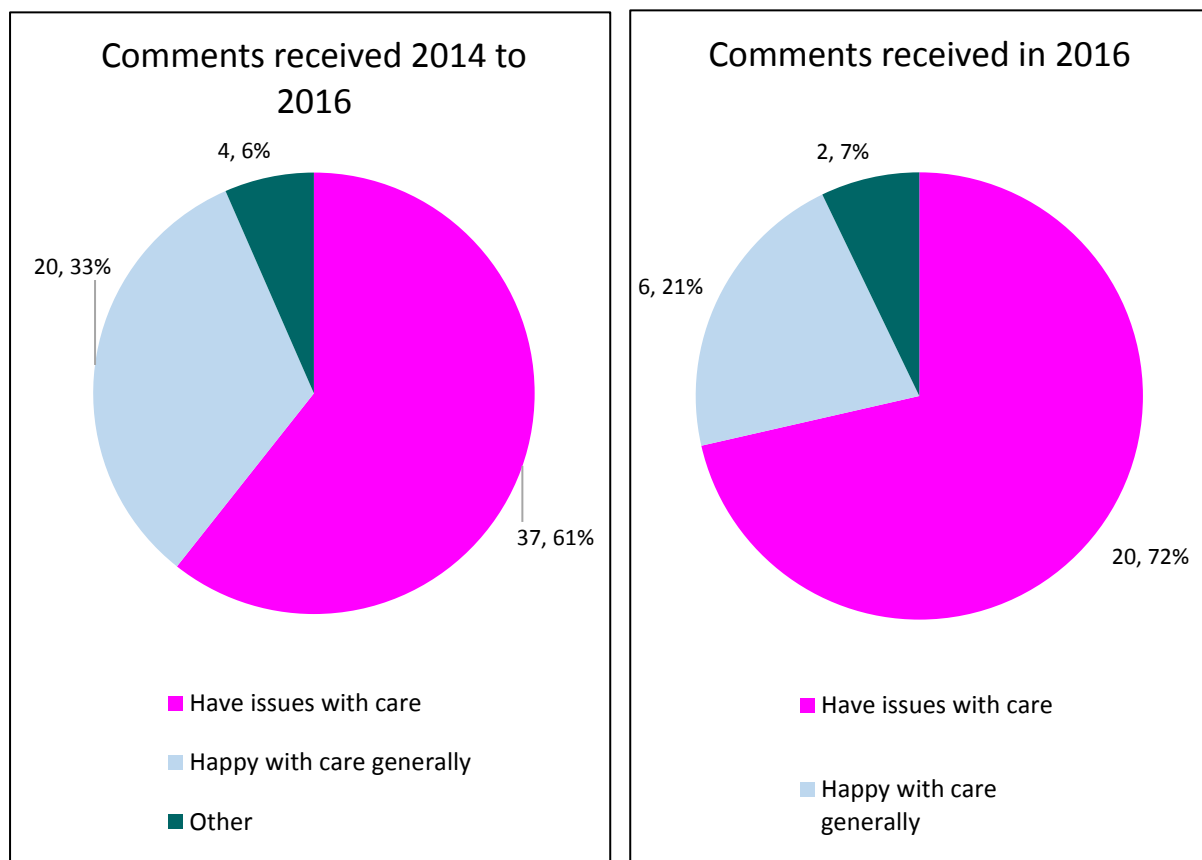
### Outpatient and community care (mental health)

There were 61 stories which included comments about mental health care in an outpatient or community care setting.

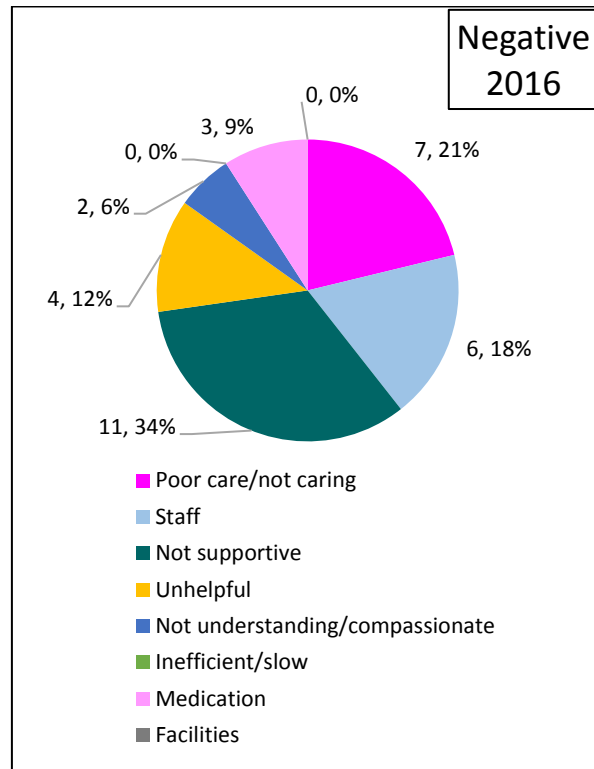
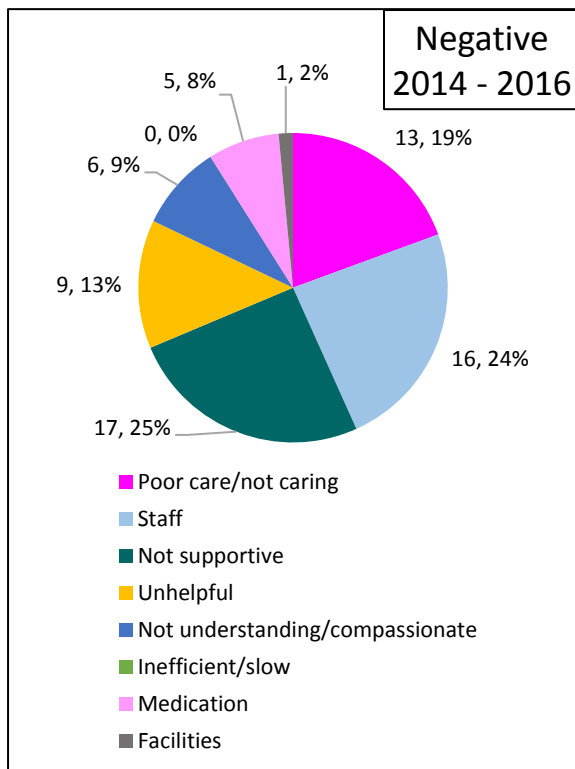
Of these comments 61% (37) are from people who had difficulties with their care.

33% (20) people were generally happy with the care they received, although many felt improvements could still be made.

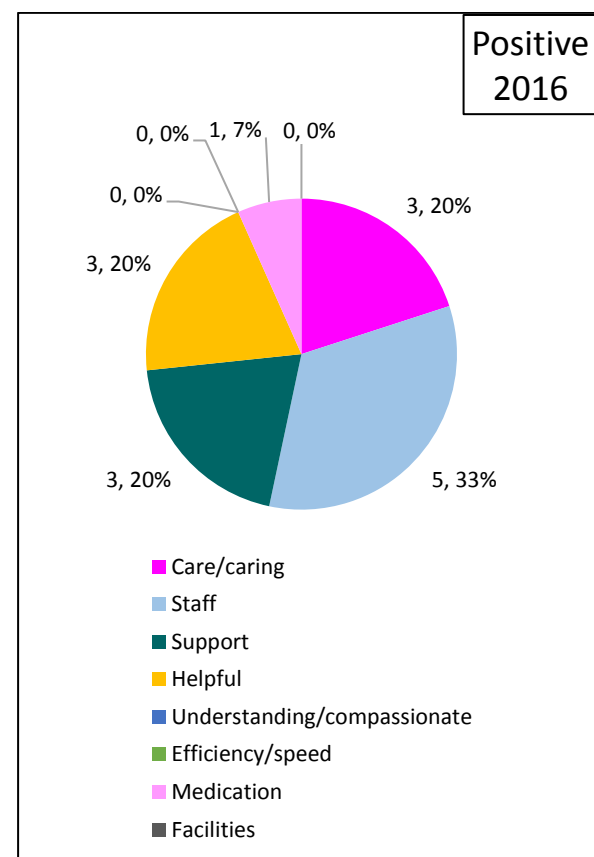
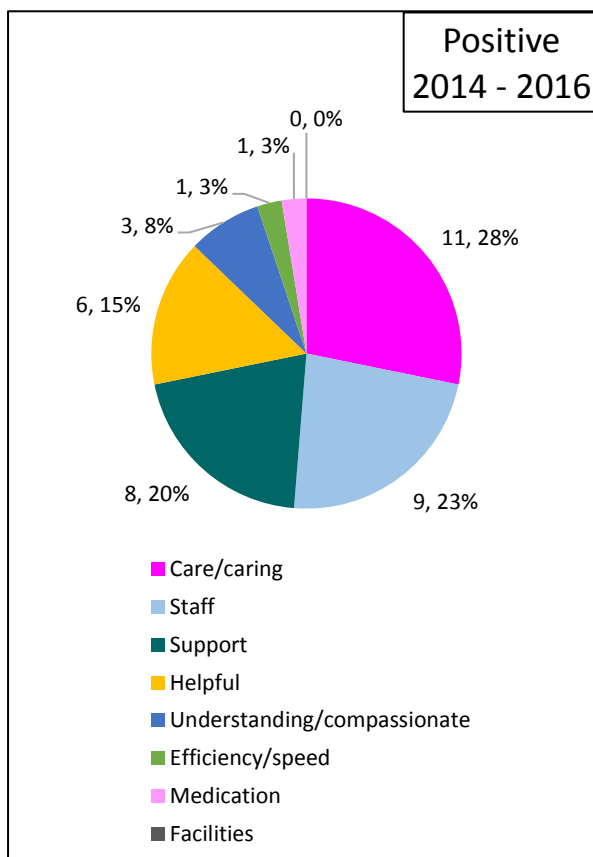
The following graphs show more detail about the areas where people had issues or where they were more satisfied. Some people mentioned more than one area.



Looking at where people had issues with their care in mental health outpatients and the community, here are two graphs - the first showing all data from 2014 to 2016, and the second showing only data from 2016.



The next two graphs show the areas where people were more satisfied.

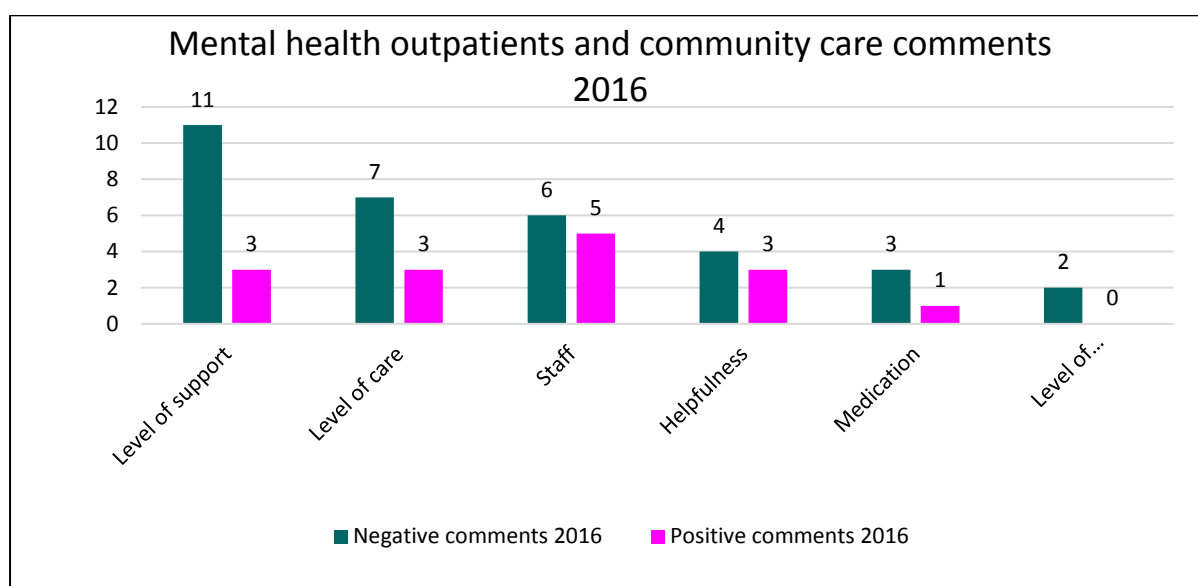


Comparing the three-year graphs with 2016, we note:

On the graphs about negative comments, the largest difference was ‘Not supportive’, with 25% referring to this theme across three years, but increasing to 34% in 2016.

On the graphs about positive comments, ‘Care/caring’ reduces from 28% across three years to 20% in 2016, but positive general comments about ‘Staff’ have increased from 23% across three years to 33% in 2016. These two categories together make up 51% (over three years) and 53% (2016) of the total positive comments.

For easier comparison, we have combined the 2016 comments into one graph.



The largest difference between the positive and negative comments in 2016 is about ‘Support’.

Here is a selection of the comments:

### Support

- Great care for husband and support for wife. Psychologist visiting husband at home and supporting wife.
- Husband refused to become official carer for his wife because he didn't feel there would be adequate support or proper training.
- *If all you need is CBT, and very short term care, and you can manage to do it with little support, then their service may be for you. If however you have more acute needs and need more complex help and support, I seriously would not recommend them at all.*
- *I had an intense 6 months of being unwell and had home treatment for 4 months, constant support from my care co-ordinator and my psychiatrist. Consistent support.*

## Level of care

- *Have a number of medical issues, not being looked after properly.*
- *There were ongoing mental and physical health concerns over a period of years - Healthwatch were told that there were particular issues with care over a few months. Son (young adult) passed away before care was provided.*

## Staff

- *Wants to complain about GP who suggested it was all in her head.*
- *Problems with CPN. Calls made by mother not returned. Eventually home visit made by CPN who rang GP.*
- *Came to surgery saw doc who contradicted everything he had been told at the hospital. They said arrogantly I'm your doctor now.*
- *The nurse was extremely rude made me feel very upset.*
- *The receptionists are great, they know I have a mental health issue so they always ask if I want a 20 minute appointment.*

## Helpfulness

- *Consultant - very good relationship and helps me a lot.*
- *I'm shocked at how little help there is to try and get care for family when they need it.*
- *I have been able to speak to the manager who has helped me and treated me like a person.*
- *I find it disturbing at the lack of help and the attitudes of staff.*

## Medication

- *Problems getting medication from GP for mental health. Only give a week at a time, but prescription keeps being late. Boots chemist helping out, and Haughton House brilliant.*
- *They were treated at a private hospital and made good progress, however back at home their GP changed the medication they had been prescribed and now they are not well again.*
- *Medication helps but drop-in is the most effective.*

## Level of understanding/compassion

- *They clearly have very little understanding of the difficulties involved with someone who has my conditions.*

Within the theme of 'Outpatient and community care (mental health)', we have comments about specific areas. These are:

### Healthy Minds

Access appears to be an issue for some people.

- This person has had some sessions with the Healthy Minds service. They feel that these have been helpful, but that they need to have further contact with Healthy Minds. They have tried to re-refer but have had problems using the website.
- Healthwatch have been told that members of the Deaf community need to use BSL Healthy Minds when accessing mental health counselling, rather than normal counselling with an interpreter.
- A person contacted Healthwatch after trying to attend Healthy Minds. They were not aware of the referral process and had tried to just turn up.
- *Very difficult to get counselling, even when I have been put referred as 'high priority', I have been told there is a 12 week wait for counselling. When I am not feeling well I don't want to push, and so I end up getting into a cycle of going further down.*
- *You need a phone number for Healthy Minds. You have to go through the website and that isn't easy when you don't feel well.*
- Two people told us about not having internet access and so getting onto the Healthy Minds website is difficult. Both of them said they go to the library to use the computers. One person said that it was really embarrassing because you are sitting very close to other people when having to type in very personal and confidential information. The other person said that their computer skills aren't very good and you are on a timer at the library and they have had their session timed out before they could complete the referral.
- *What they offer is too set, it doesn't take account of people's needs.*

### Health and Wellbeing College

Again, access can be a problem for some people.

- *Starts at 10am and my bus pass can't be used until 9.30am and couldn't get from Ashton to Oldham in 30 minutes.*
- *It is too far for me particularly when I am not well. I panic if I have to go too far on my own. If it was closer I would do one of the courses now.*
- *Would like to do some courses but I have been told that they are full until January 2017. (Comment made to Healthwatch in October 2016)*



- *I was looking at doing some courses at the Health and Wellbeing College but when I looked into getting to the college, I found that it was in an industrial estate and would take 2-3 buses to get there. With my conditions I find it next to impossible to catch one bus with help from my carer/wife so could not make the journey for the courses.*

Other comments about the college included:

- *Too far away.*
- *Need to ensure benefits are not at risk.*
- *It is good for me. There are around 15 people in the classes with a tutor but there is no pressure. I like that you can learn from other people in the group who have similar experiences. I live in Ashton so just get the one bus into Oldham and then walk but it is a 15-minute walk from there.*
- *My GP didn't know about the college; I took some information in for them.*

### **Young Healthy Minds (CAMHS)**

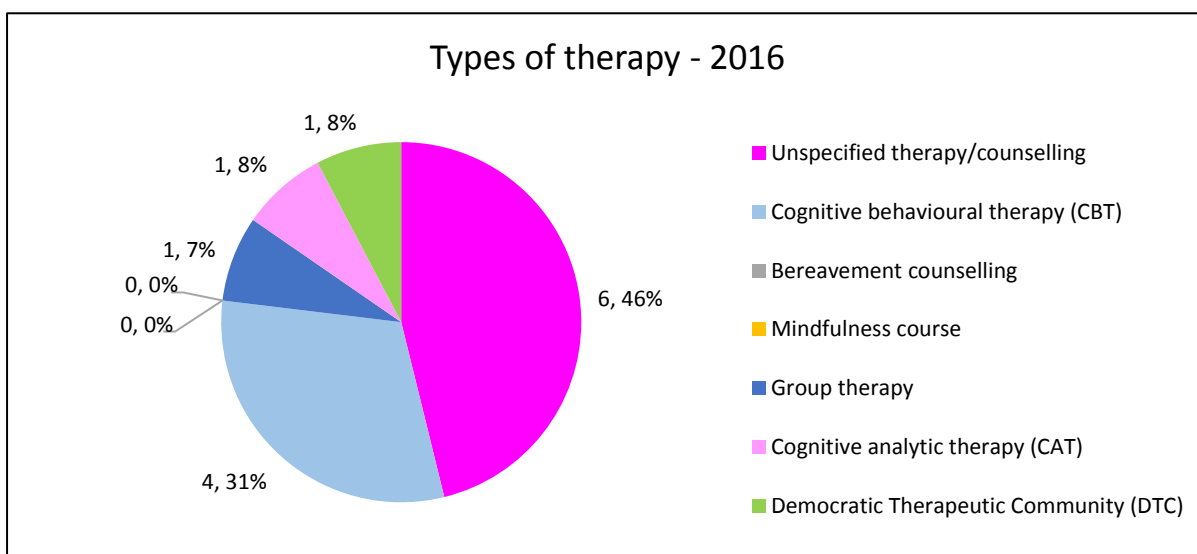
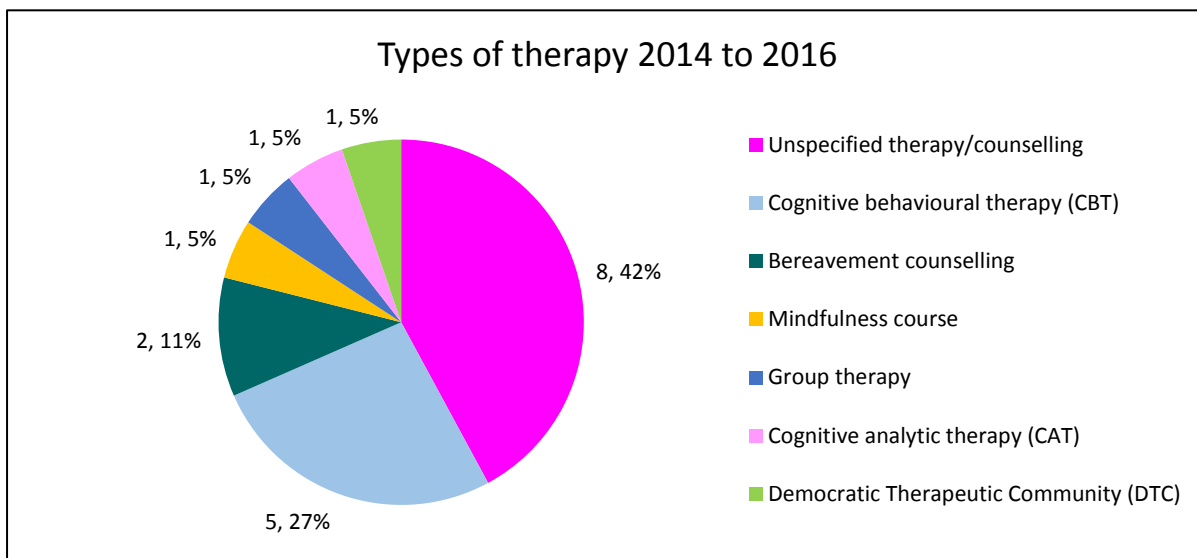
The comments about this service have mainly been taken from a Healthwatch survey, so are brief. Here is a selection:

- *Very patronising, wasn't helpful, awkward, didn't feel I could tell them anything.*
- *I didn't have a long waiting time for the service.*
- *It helped me a lot.*
- *No one bothered to catch up with me after I missed an appointment even though I was classed as high risk.*
- *The waiting time to access CAMHS is pretty long which can be a problem if people have serious mental health issues!*

### **Therapy, CBT, bereavement counselling**

There are different types of help available for people experiencing deteriorating mental health.

Here are the courses mentioned in the comments collated by Healthwatch Tameside.



CBT (Cognitive Behavioural Therapy) is offered as a form of therapy. The people we spoke to had mixed feelings about the effectiveness of this form of therapy. The comments from 2016 were all negative.

Here are some of the comments:

- *CAMHS want her to have CBT, but she doesn't like the venue - 'all locked doors' which make her anxious. Also, her mother tried CBT and it didn't work.*
- *CBT for 6 weeks at a time and then has to be referred again by GP. No feedback from sessions, so no evidence when completing PIP application.*
- *They said I was on a list for CBT (which has not worked for me). On explaining this, and asking for a different therapy, I was told I would need to do the CBT again before anything else was offered.*

Here are some comments about other types of therapy:

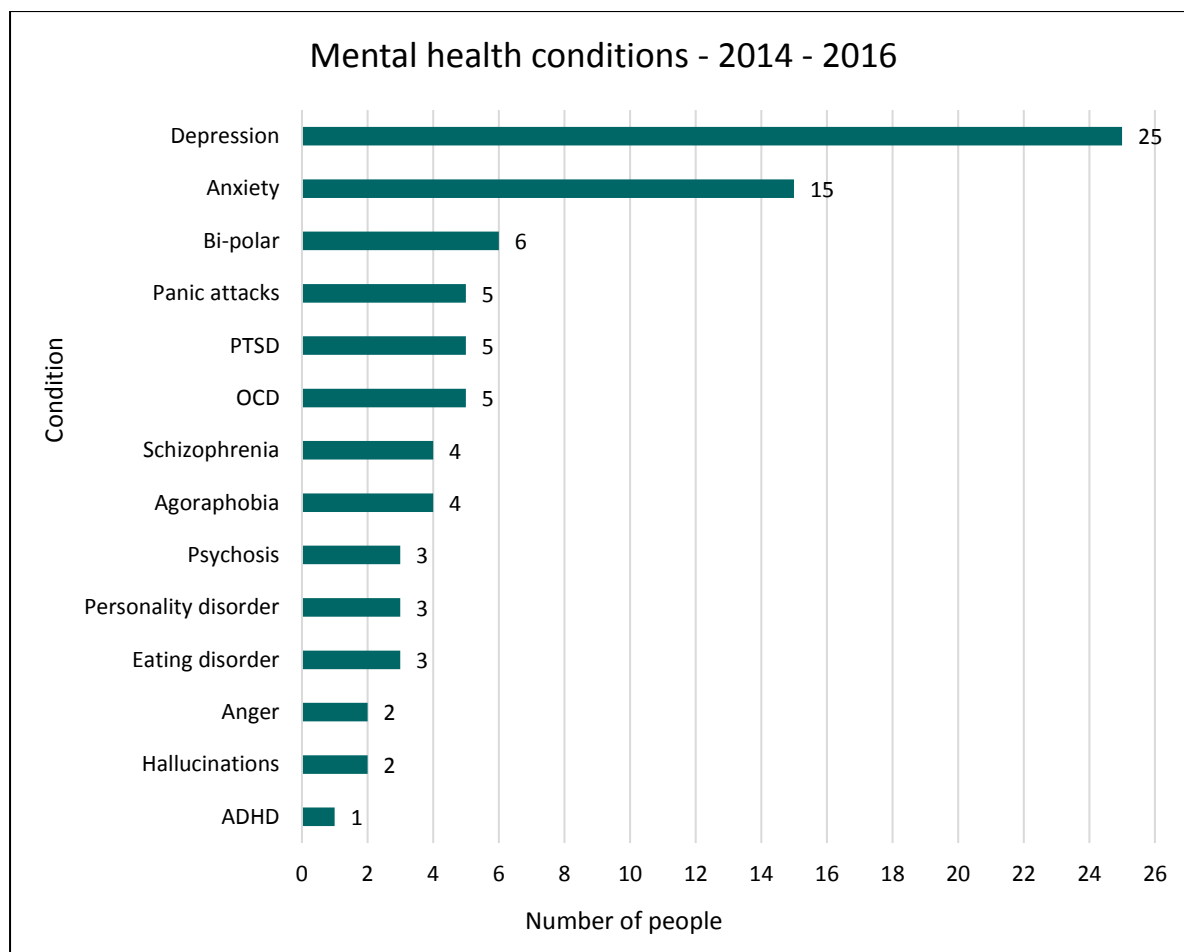
- *My daughter was sectioned in Tameside and then sent to a hospital much further away. Why was therapy not available in Tameside?*
- *Like CAT therapy. Don't want it to end.*
- *DTC Group is really good.*

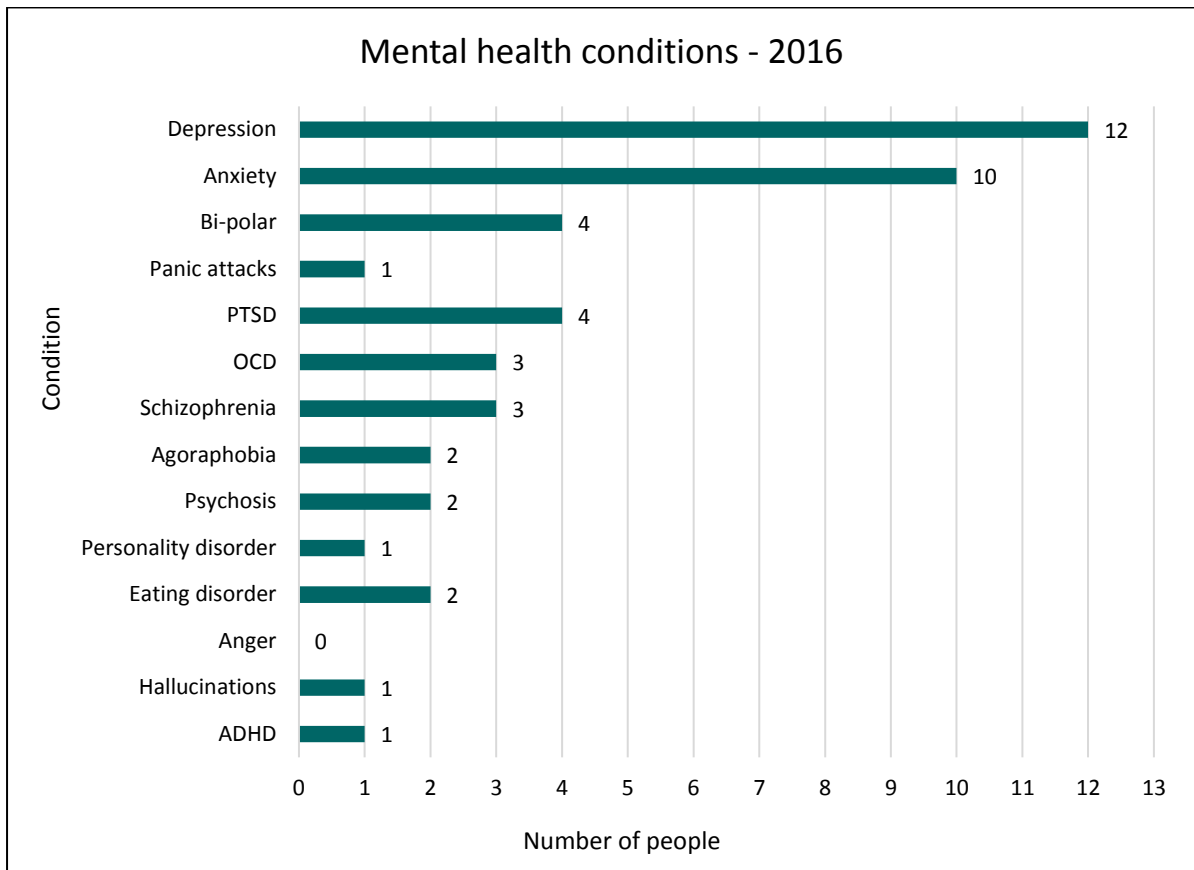
### Mental health conditions

**ADHD, agoraphobia, anger, anxiety, bi-polar, depression, eating disorder, hallucinations, OCD, panic attacks, personality disorder, psychosis, PTSD, schizophrenia**

Mental health can be affected in many ways, and symptoms vary widely between people. The list above includes all the issues mentioned in the stories we collated.

People can be diagnosed with more than one mental health condition. 8 people said they had more than one mental health condition affecting them.





Depression and anxiety are the most common mental health conditions experienced, in the stories collated by Healthwatch Tameside.

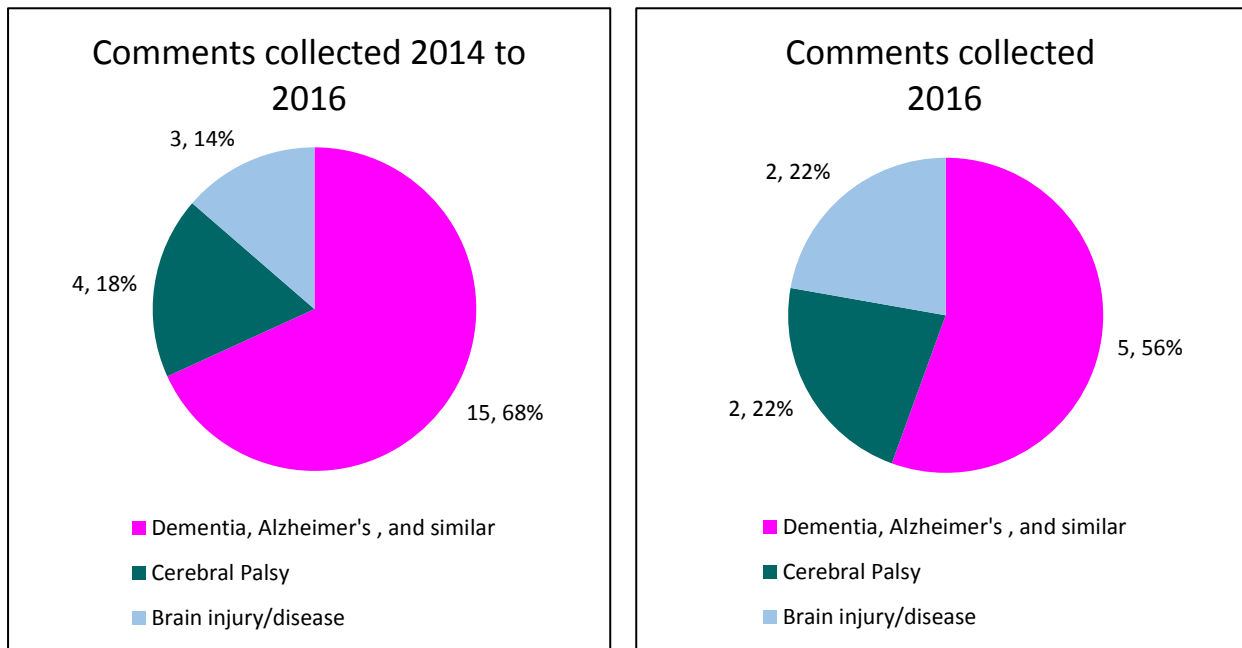
Healthwatch Tameside has noticed that whole families are sometimes diagnosed with mental health conditions. Examples include:

- A mother who is agoraphobic has children who are being treated by CAMHS, and are home-schooled.
- Siblings can be diagnosed with mental health conditions. If one of them passes away, the mental health of the remaining sibling deteriorates. This affects all generations, with grandparents having to look after grandchildren.

### Brain conditions

We have included stories/comments from people with conditions affecting the brain in some way. It appears these people could be more likely to experience mental health issues than people without brain conditions.

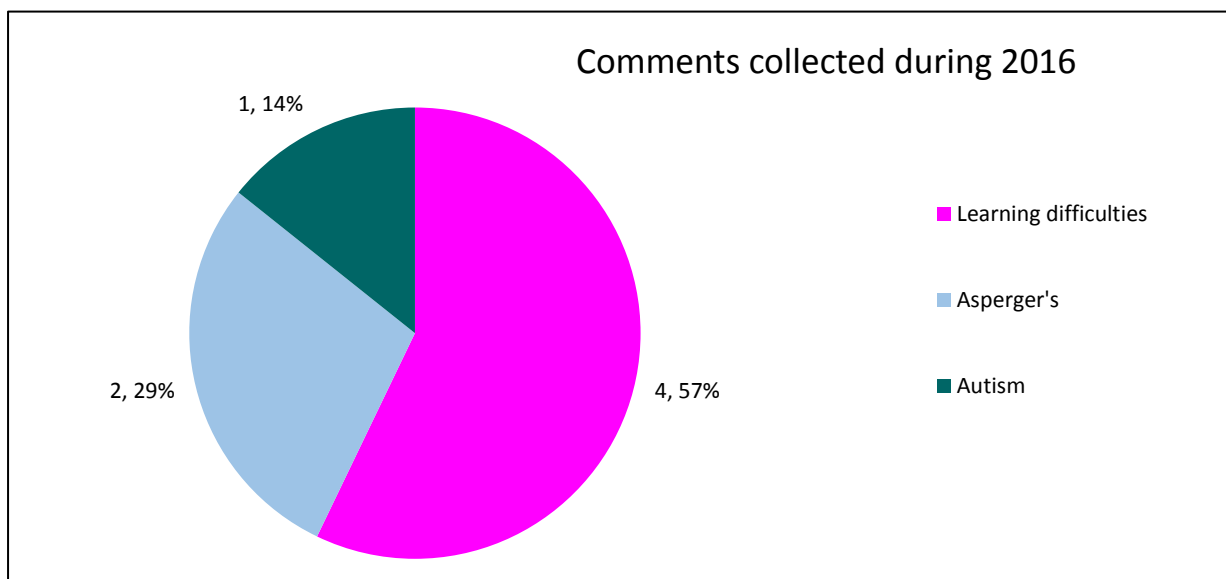
## Dementia, brain injury or disease, cerebral palsy



Some people have brain conditions and are also diagnosed with mental health issues. For example:

- One of the people with a brain injury is also bi-polar.
- One person with cerebral palsy has depression.

## Autistic spectrum, learning disability



Again, some of the people in these graphs also have diagnosed mental health conditions, including:

- One person with learning difficulties had depression.
- Another suffered with anxiety.
- One was seriously ill in hospital with a physical condition which was affecting their mental health.
- A person with Asperger's also has depression and social anxiety.

Here are some examples of difficulties people have faced:

- Healthwatch Tameside were contacted for signposting assistance from a relative of a vulnerable adult with learning difficulties - if their relative was asked questions they would give the answer they think is expected, rather than the actual answer relevant to themselves.

They also had mental health issues, and would spend all day pacing up and down. They had a benefits assessment, and answered the questions incorrectly, resulting in all benefits being stopped. They risked being made homeless as the rent could not be paid. (Agreement was reached to remain in the housing, while relatives tried to resolve matters.) They had no food and were losing weight.

The relative was left trying to help with an appeal. They needed information from the medical records, for which there was a charge, but the patient had no money.

Questions Healthwatch asked included 'Was a Mental Capacity Act assessment carried out? Are they entitled to an IMCA advocate? Do they have a social worker? Should the relative have had an assessment without support?'

Healthwatch have not heard the outcome.

- Another person said they had a 17-year old child who had been diagnosed with autism, but was not receiving services - they were falling between children's and adult's services.

Their 8-year old was getting support at school but it had been withdrawn. Feels this child is also on the spectrum and would like an assessment. They are going to speak to the Head at school.

## Alcohol, drugs

Several of the stories/comments about mental health issues also included mention of using drugs or alcohol, often leading to addiction. It would appear the mental health issue and the help required for the addiction are treated separately, by different providers. One person said:

- *When you go to A & E you need to have reps from the alcohol team and mental health working together with you.*

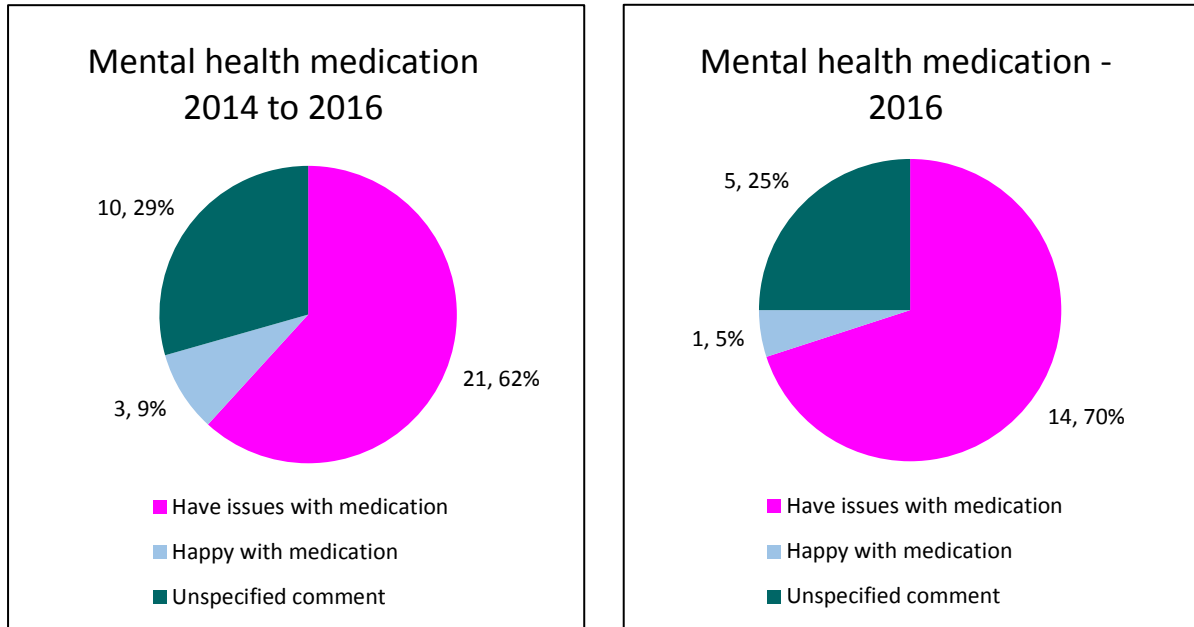
Here are some other comments:

- A service user has needed help with addiction for a long time. The contract changed to Lifeline - problems started with meetings being cancelled, medication being changed, support workers not being available.
- Daughter in a hospital out of area - sent by Tameside for therapy. Bi-polar and sectioned in Tameside. Didn't like - staff have no time to talk, used bank staff. Why is there no therapy in Tameside? Not receiving any therapy now, but still in the same place. Used to attend Lifeline (drugs/alcohol) but not good for those with mental health issues. Had CPN didn't turn up when meant to - ringing with excuse. Father can't get information. Keeps ringing but calls not returned.
- *Problem with alcohol. Attend groups - prefer groups and do 1:1 (if get right person/home visits). Lots of agency workers, moving from pillar to post. More settled now. Come for 1:1 - get there it's cancelled - same with groups - sit in reception - person running group not there. Much better to listen to people.*
- *What was good? Lifeline - Helped with alcohol abuse. Very compassionate and supportive staff.*
- *Tameside Hospital A & E - Waiting for 5 hours to be seen. Left then for 2 hours - not checked - no blood taken, sent home. Not doing anything - told to go home. Have another drink - can have fits with - there they don't alcoholism. Don't deal with it very well - told us have unit in Preston. Have alcohol team - have another drink - no immediate medical help - just get librium*
- *Really bad mental health/alcohol issues. GP me sent to hospital to see mental health doctor. (Refer to page 49 for full experience)*

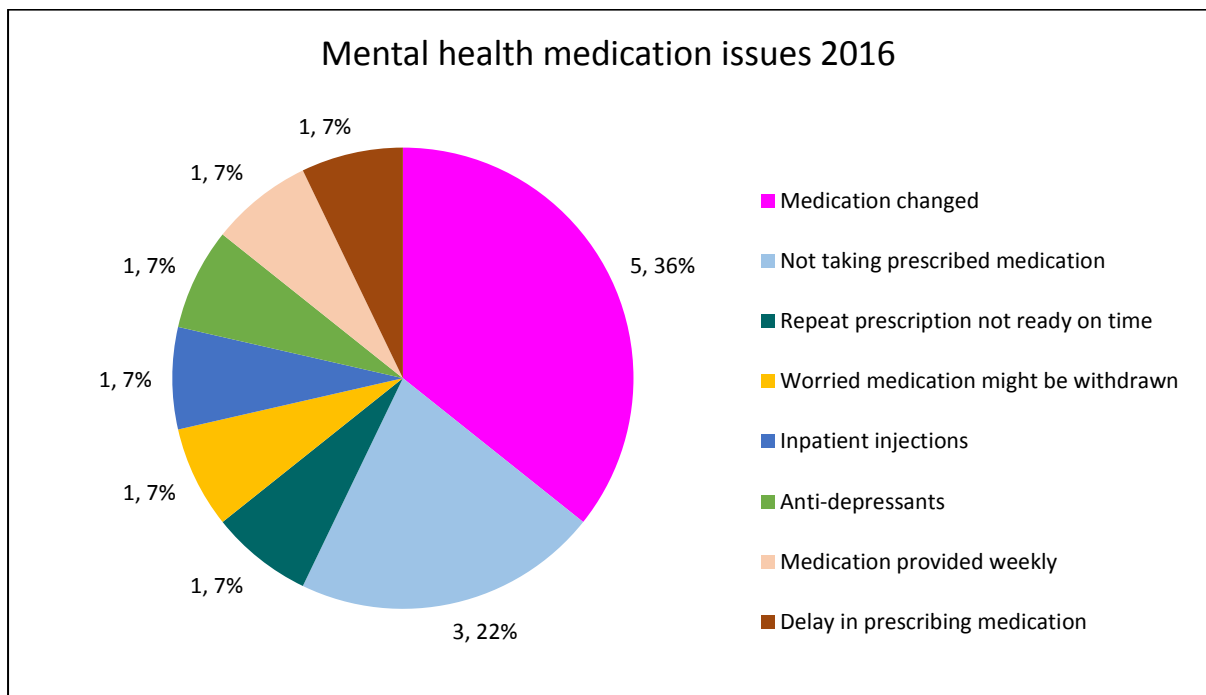
## Medication

Of the 43 comments about medication, the majority are about medication for a mental health condition. The other comments either do not specify what the medication is for, or it is treatment for a physical condition.

Looking at the mental health medication in more detail, many people have issues. Others have not been specific with their comments.



Here is a breakdown of the issues from 2016.





'Medication changed' gave the highest number of comments, including:

- *Have OCD. Changed medication. Had diazapam - taking ages to work. Rang 111 feeling manic and with chest pain. They said someone would ring with an appointment.*

*Rang back - said put on different pathway. Sanctuary rang to talk but I needed meds - was manic. Rang 111 - doc rang back but don't have meds. So had to go to doctors in the morning.*

- Summary - Young adult was prescribed medication by the hospital. Visited GP (with their parent) who tried to change the medication and accused the patient of trying to get drugs. Patient very confused and upset and their parent asked to see a different doctor, who provided the prescription.

The patient received a letter a few days later (security warning) about abusive behaviour. The parent says there was no such behaviour, and the severely depressed patient has been put off seeing doctors.

Healthwatch were told that not everyone is taking their prescribed medication, for different reasons, including:

- *The hospital should prescribe medication for mental health issues, rather than writing to GP's to do it.*

2 people reported that they have been prescribed medication by the hospital and not been to the GP to collect it for fear they will be judged.

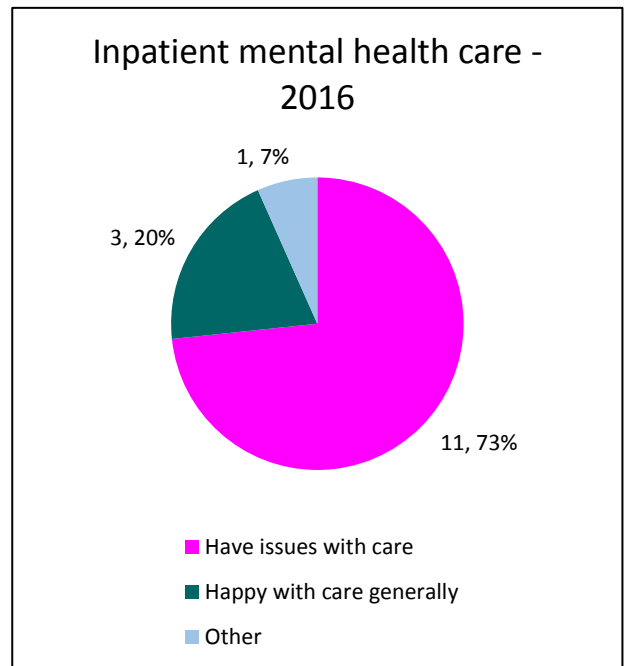
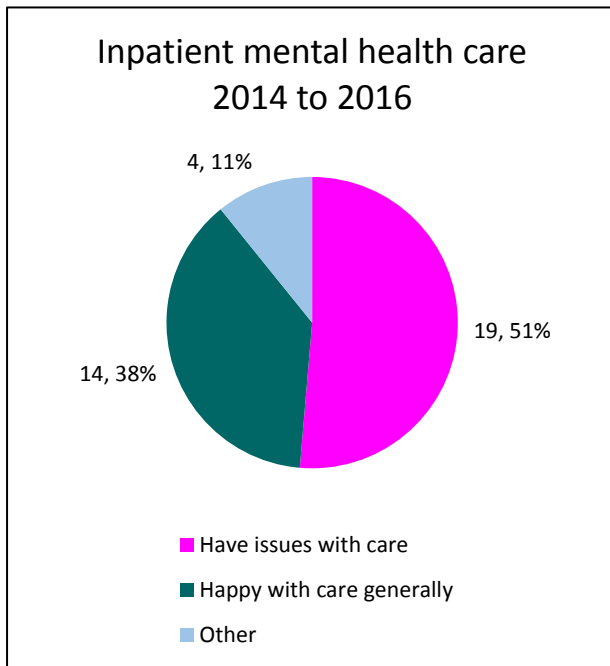
- This person has problems accessing medical services, so is not currently in the mental health system. GP prescribes medication which they can't take due to a heart problem. They have not left the house for 3 years.

One person received injections of medication as an inpatient. This is what Healthwatch was told:

- Medication was injected several times against the patient's will in one day. They had to be weaned off the medication given by the mental health ward at Tameside Hospital (Pennine Care), and be given other medication to counteract the effects at Stepping Hill Hospital when they were transferred there.

### **Inpatient (mental health care)**

People experiencing a more advanced deterioration of mental health, or a crisis period, may spend time in a hospital, to help their recovery. Here is a summary of whether people had positive or negative comments to make about their care.



‘Other’ is about the shortage of beds:

- *Not for the first time have I been to visit a person on the mental health unit at Stepping Hill hospital to find they had been admitted and due to no beds available were left to sleep on 2 chairs pushed together this seem to be a continuing issue when a patient is moved from a general ward due to self-harm on to this mental health unit, it used to be a good mental health unit now it's a nightmare.*

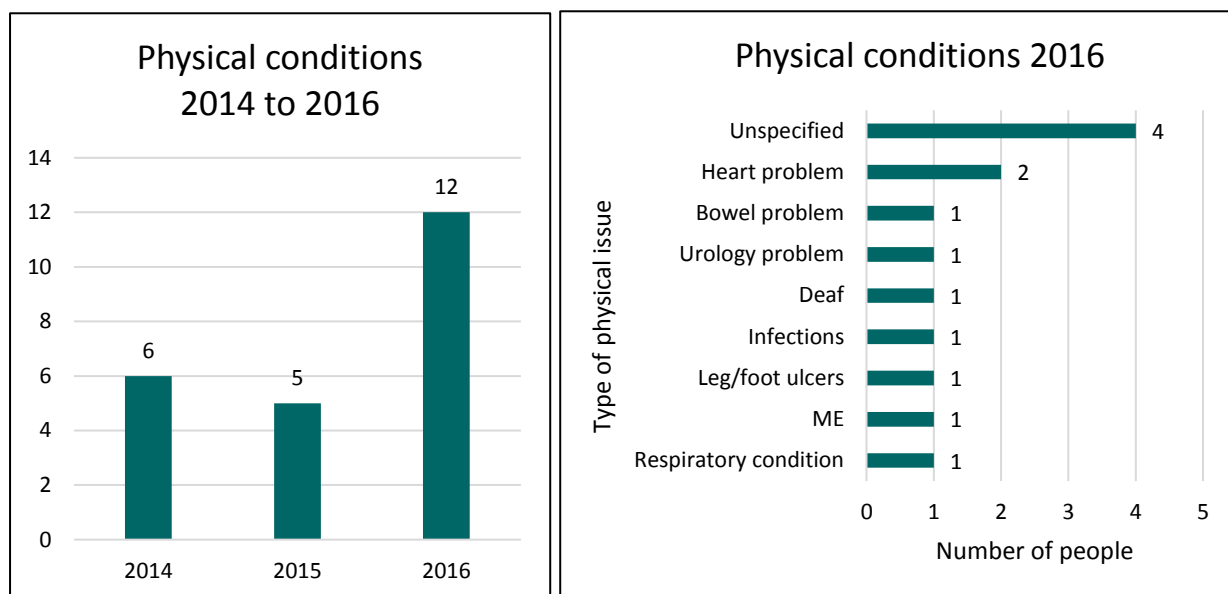
Here is a list of the areas where people said they had issues with inpatient care in 2016.

| Issues   | 2016 |
|--|------|
| Poor supervision for suicidal patient              | 2    |
| Delay in providing treatment making symptoms worse | 2    |
| Staff not treating patient well                    | 2    |
| Prescribed medication not available when needed    | 1    |
| Over-medication by staff                           | 1    |
| Unspecified issue                                  | 1    |
| Not enough time to talk                            | 1    |
| Too many bank staff                                | 1    |

Out of the 11 people with issues during 2016, seven of these came to Healthwatch for assistance with making a complaint about the care received whilst an inpatient. These complaints are complex (please refer to details later in the report).

### Physical issues (in a mental health patient)

Some of the people who told their stories about their mental health experiences, also had physical conditions they needed treatment for.



### Inpatient (for physical care)

The comments about inpatient care for physical conditions were not relevant to this report about mental health care experiences, so have not been included.

The following comment is relevant and is from a person who was admitted for planned surgery as a day patient at Stepping Hill Hospital.

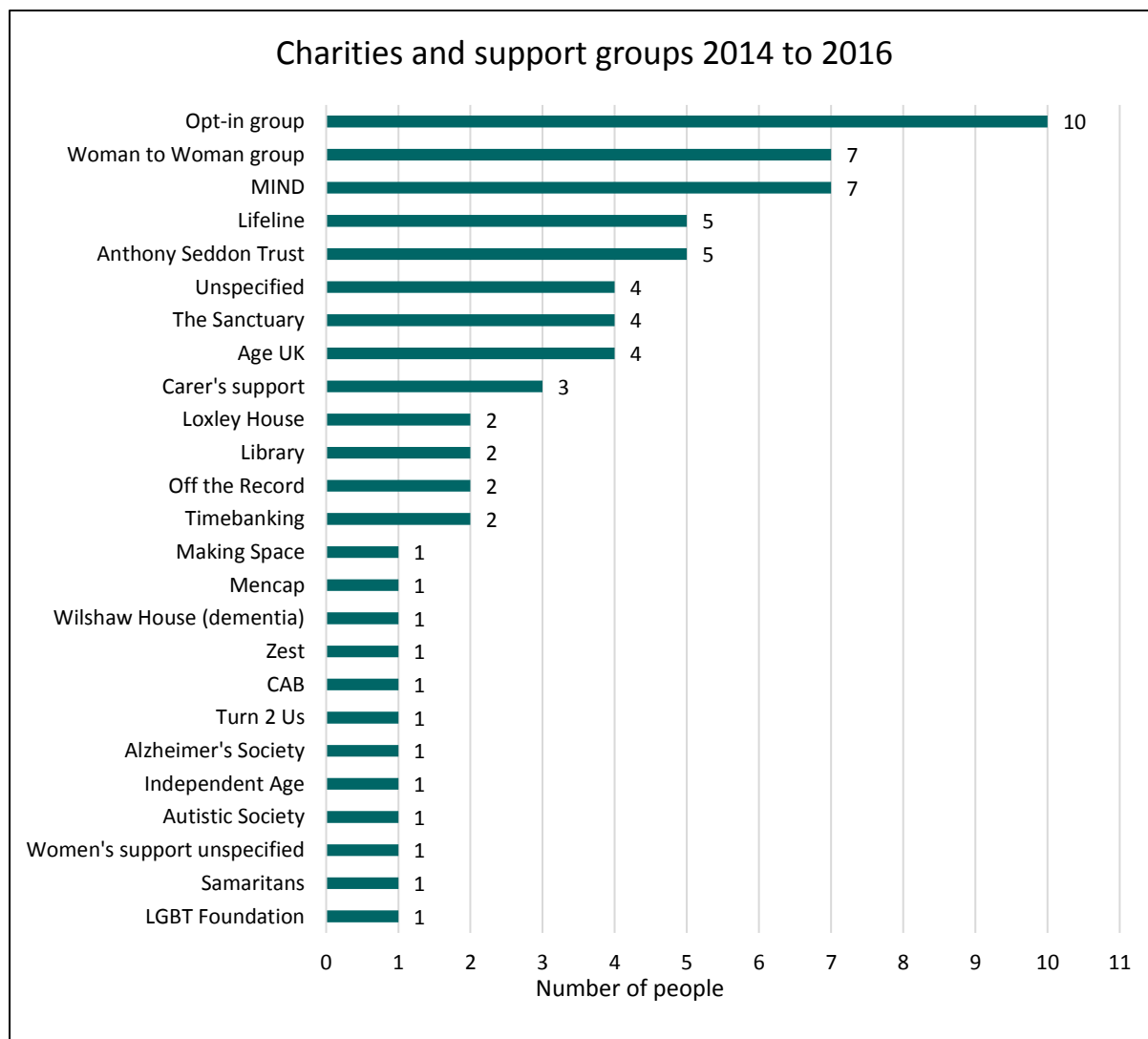
- *The whole experience was traumatic. Had the experience of health professionals treating those with mental health issues like they have a learning disability.*

*I feel like my mental health condition is not taken into account. Physical illnesses are frequently blamed on mental health condition.*

## Contact with charities and support groups

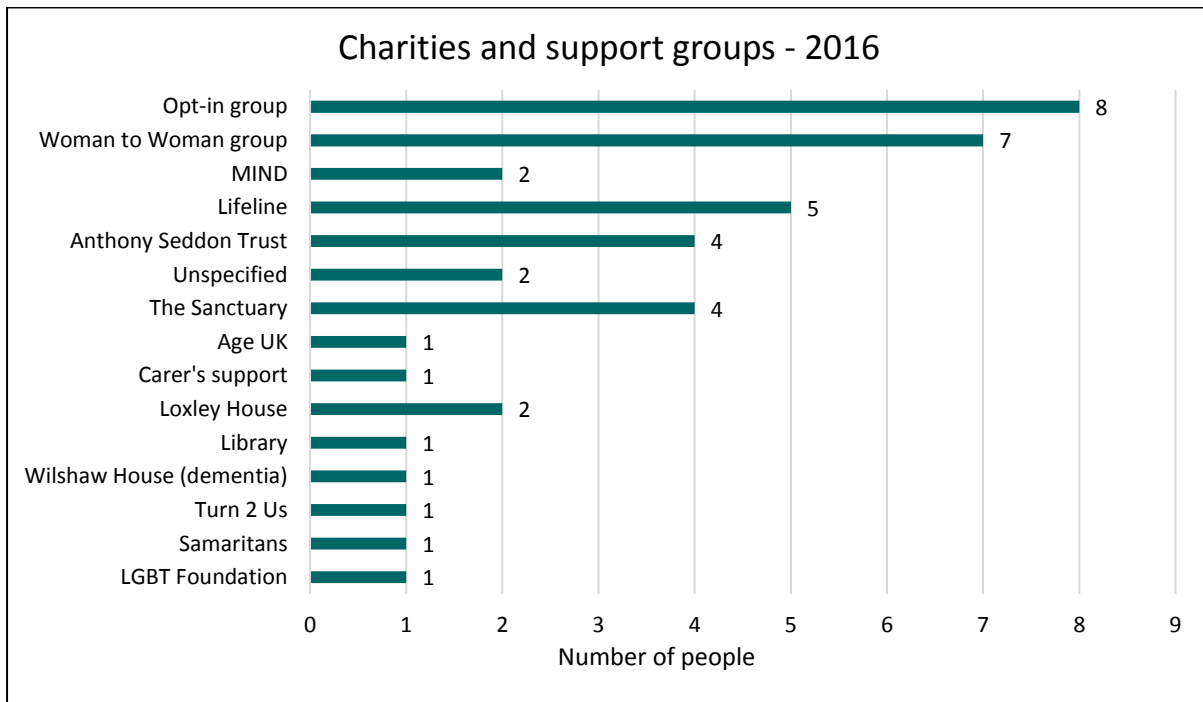
Looking at the years 2014 to 2016, there is a long list of different charities and support groups mentioned. Some of these are NHS funded, and others rely on voluntary support.

13 of these were groups where Healthwatch signposted people. Six people were signposted to more than one group.



The groups mentioned in 2016 are mainly where people have said they are already using these services, with only a few from Healthwatch signposting. (Most of the signposting this year has been from people wanting assistance or knowledge about accessing a service, rather than a support group.)

For Loxley House the number is low. This is because we have only included the location if it is mentioned in a comment. Quite a few of the people we spoke to were attending a group there.



Here is a selection of comments:

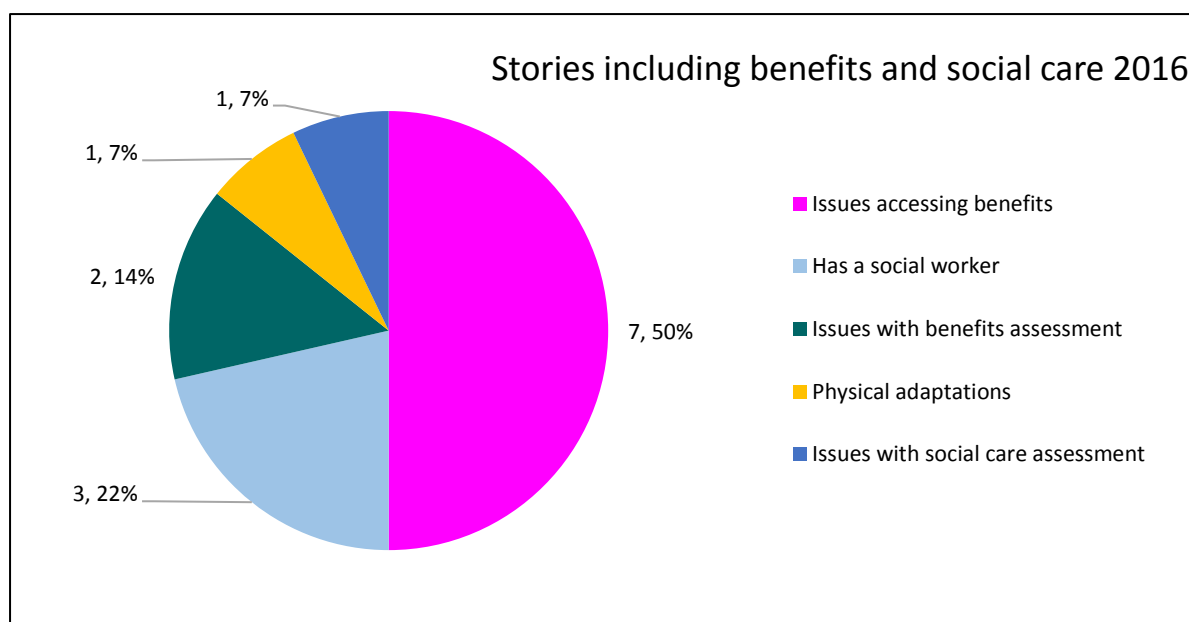
- This person has severe OCD with a terror of anything hot. They only eat cold food, and can't have a hot shower. They also have anxiety about other aspects of daily living but cope outwardly so appear to be functioning well, but are not. They have been in hospital in London and group therapy helped. They feel there is no group in Tameside for OCD sufferers.
- *MIND - rang them with anxiety and depression and also had been bereaved, was told had to wait 6 months for counselling, other than that I would have to pay.*
- *Mental health support - if I can't cope and feel overwhelmed, groups like this Woman to Woman and the depression and anxiety group help me. I don't know what I would do without them I wouldn't know where to go.*
- This person was referred to Healthwatch by one of the groups in the table. Had a lengthy conversation about the issues faced and what support they were looking for. Gave the person phone numbers for LGBT Foundation to get support, and The Sanctuary and The Samaritans who have 24 hour helplines, if they needed to chat to someone urgently.
- From the Healthwatch survey - What was good? *Lifeline - Helped with alcohol abuse. Very compassionate and supportive staff.*
- From the Healthwatch survey - What was good? - *Lifeline - Stabilisation medication corrected*
- From the Healthwatch survey - What was good? - *Adult Mental health services and Anthony Seddon Trust. Medication helps but drop-in is the most effective and GP good.*

Comments from a group discussion about the Sanctuary:

- *Had a great experience with The Sanctuary and mental health. I needed somebody to talk to as I was very distressed. They were great. I could talk as long as I wanted. They made three follow-up calls and they faxed notes through to my GP. I thought it was good that if I wanted they would have sent a taxi for me.*
- *It was great. They sent a taxi for me. I could sit and chat and drink coffee for as long as I wanted, then they got me a taxi home.*
- *I'm not keen on The Sanctuary idea. I don't want to talk to a stranger on a phone when I'm not well. I prefer to go somewhere local where there are people I know.*

### Social care and benefits

Sometimes people receiving mental health care need assistance from social services, and/or may be in receipt of benefits.



Here are some examples where people had issues.

- This person was discharged from a secure unit into supported housing in Tameside, with support workers and a social worker. Due to breach of confidentiality on the ward, and disclosure of incorrect information, their application for PIP was declined.
- Two people who use Loxley House said there had been issues in the past with the number of days they are entitled to attend being reduced. One has

cerebral palsy with manic depression, and the other a learning disability. Staff and social workers helped have the days re-instated. They said that attending Loxley helps with depression and reduces loneliness.

- A husband was asked to become the carer for his wife, who had a long-term mental health condition. If he had agreed to become her carer, his wife would have lost some of her benefits, which would be passed to him as carer. They lived apart, and his wife needed the benefits.
- This person had his PIP stopped - he should have attended a medical but was in a police cell and couldn't go.
- *Benefits assessment this morning - don't they know how stressful it is, especially for people with mental health problems? All the questions are about what you can physically do, but not about state of your mental health. Brother came with me but now feel really depressed.*

### **Complex multi-themed stories/comments**

Many of the multi-themed stories/comments that Healthwatch Tameside have, are the subject of complaints to the providers involved, where Healthwatch have been asked to provide guidance through the complaints process.

The themes these include are:

**Mental health care (inpatient and outpatient/community)**

**Housing provided by a registered social landlord** (Healthwatch Tameside will use the phrase 'housing association' for the remainder of this report)

**Police involvement**

**Fear for the consequences**

**Suicidal/crisis**

Here are some of the stories/comments from people who experienced episodes of crisis:

- One person has requested assistance from Healthwatch five times over the past 18 months. They care for their partner, who has episodes of crisis, and has been sectioned several times. The partner has attempted suicide at least three times to our knowledge, twice whilst an inpatient. 24 hour supervision was not maintained, even though requested by the carer. The patient has been referred to Cloverleaf for support. The carer is exhausted, and their own mental health is being affected, with the strain of what has been happening.

- *I recently had a severe relapse, and felt suicidal. My GP referred me urgently to the Mental Health team, who proceeded to take weeks to send me a list of helpline numbers, and absolutely nothing else.*
- *I phoned the surgery as I felt I was in a very dark place. I was told that the doctor would phone me back and they did. I have had suicidal tendencies in the past so was aware where this state of mind was possibly leading. When the doctor phoned back I was told that it was only me that could do anything about it..... Not told to come in and speak to someone. Then the Dr phoned me back a week or so later when I was in work and asked if I felt any better and did I feel as though I would harm myself ..... I was in work with people with me ..... What was I supposed to say... " yes I plan on hanging myself and have been googling how to tie a proper noose ".... No I said I was fine and clearly I'm not as a normal person wouldn't be looking on the Internet on how to die. (NHS Choices story)*
- *I overdosed and was taken to the hospital where I got time to talk and the help I needed.*
- *My son is in crisis. He is acting out of character. Been telling his GP for months he is not well, but nothing has been done. I had to keep phoning the police to get into his house, as he's not communicating with anyone. The police have been good but can't do anything without the doctor. I rang the RAID team, but they are not taking me seriously. They didn't return the call and haven't done anything. No help has been offered. I'm shocked at how little help there is to try and get care for family when they need it. (Pennine Care responded to the Patient Opinion post and provided a phone number to make direct contact with the Access team.)*
- *On several occasions this person has turned up at A&E in crisis, a room has been found for them to wait for staff to see them. Sometimes it is quite a long wait, on one occasion from early evening until 4am but someone will always see them. On another crisis occasion, this person couldn't face A&E so phoned the ward and a member of staff came out to the car. The only criticism is that when having to wait in A&E the person was not asked who they wanted to wait with them and so family were allowed to stay. This person would have preferred them not to be there.*
- *Another person who had periods of crisis, and at times felt suicidal, had become addicted to drugs. They had been waiting for a diagnosis of a mental health condition for 14 months. This has finally been given, after Healthwatch were contacted for assistance, and medication has been provided. The patient had become homeless after breaking up with their partner and being persuaded by the housing association to release the flat back to them. They have restricted rights to see their children. The family are left wondering how different their lives might have been if the diagnosis had been provided during childhood. All generations of the family have been affected.*



The next few stories are summaries of complicated multi-agency experiences. Some are the subject of ongoing complaints, therefore only brief details are provided. The information has been provided by either the patient or their families, with their permission.

- An adult had been sectioned at Tameside Hospital, where there had been issues. The ward manager told this person to leave. This person believed that the hospital had discharged them. The ward staff informed the police that this person had left the ward and the police were sent to arrest and return to the hospital. The patient was extremely frightened when this took place. The housing association responsible for the flat where the patient had lived for many years wanted to evict them. The full experience covers a period of weeks, is lengthy, complicated and is ongoing.
- A young adult attended the mental health ward at Tameside voluntarily. They were offered medication, which they refused. They were sectioned and forced to take medication by injection several times during one day. The affect caused by the medication was a change of character. They were very frightened when the police were called to the ward. The patient was tasered 5 times, leaving barbs in the skin and burns. They were also beaten with a baton, breaking a bone in their hand. They were taken into custody, without the correct supervision or medication. They were later transferred to Stepping Hill. The patient was suffering from withdrawal symptoms from the medication previously administered. A different medication was provided to counter this. No treatment had been provided for the broken bone. The patient is worried they will have a police record for being ill.
- *This is a case study of a young adult male who has suffered with mental health issues over a period of many years. The family of this patient had no previous issues or concerns around his care which was provided by the community mental health team. However, the level of care and input previously received was found to be seriously lacking at a time when it was most required both physically and mentally. The decline in care and support became apparent when the patient was allocated a new CPN. The patient had a diagnosis of paranoid schizophrenia with psychosis. The patients mother made repeated calls to the mental health team to discuss her concerns regarding the steep decline in both the mental and physical wellbeing of the patient. It was noted the response to these calls were seldom returned or acted upon despite numerous attempts from his mother. Such was the decline of the patient, the mother repeatedly requested that the patient be sectioned under the mental health act for their safety. This request was never actioned. The patient became seriously malnourished and withdrew from society. At this point the patient began to self-medicate due to the exacerbation of pain and lack of input or support from professionals who had a duty of care.*

*The patient was severely let down when medical intervention and support was paramount.*

*This lack of care both medically and emotionally subsequently led to his death.*

- This person was sectioned in Tameside hospital after her ex-husband, who was living separately, called the police. Over a period of months, her mental health had deteriorated, resulting in losing her job, so debts had spiralled. The rent was in arrears and the housing association gave notice to leave whilst they were in hospital. A social worker collected one box from the property, but everything else was lost and the patient was sent a bill for house clearance and removal of laminate flooring. They left hospital with nothing but a few clothes, and debts. They were housed in temporary accommodation, in an area where transport links were very difficult and no aftercare was provided from community services.
- *Had really bad mental health/alcohol issues. GP sent me to hospital to see mental health doctor. I was no threat to the doctor or any other person. The doctor rang his manager and he got me arrested and sent to prison for 5 days -the magistrate threw the case out. I came out on tag. Not allowed to live at my home, but I was still charged rent. Lifeline worker got me new home to help recovery. Have had my PIP stopped - should have had a medical but was in a cell and couldn't go. Lifeline saved my life.*

*I am still suffering from the after effects of what happened. Feel I got left in limbo - alcohol and mental health go hand in hand. When you go to A & E you need to have reps from the alcohol team and mental health working together with you.*

*People will stop talking to mental health workers if they think the police will be called.*

## **Care - home, residential, respite, carers Safeguarding**

The care provided in these locations may be required due to a physical condition. However, there can also be mental health conditions alongside. Examples are shown below, including any concerns or positive comments.

- Lady is the registered carer for her elderly husband (who has memory issues) but is not getting a break. He wants them to go out together and won't have strangers in the house although now sometimes he doesn't recognise his wife. The house has all the necessary physical adaptations - it's social help that is needed. She doesn't know where to go or what to do. Healthwatch signposted to Age UK.

- Person bed-bound and requiring oxygen, received care at home from a palliative care nurse. Person rang Healthwatch for help - their partner had had them sectioned the previous week. There were a number of things the patient was unhappy about. The nurse was there and also spoke to Healthwatch. The result of the conversation was the reporting of a safeguarding issue (caused by the partner) by the nurse to her manager. The patient was not previously known to the mental health team, although the partner was. Cloverleaf became involved at a later date.
- A person who had dementia, lived in a care home. An ambulance was called at the request of the family during one visit. The resident was severely dehydrated, and had tablets for a chest infection still in their mouth and on the floor. They had two pressure ulcers, only one of which was being dressed. The paramedics reported a safeguarding issue. A water infection was not being treated. The person developed sepsis and passed away.
- Husband in and out of mental health ward over 18 months after attempted suicide. Great care for husband and support for wife. Psychologist visiting husband at home and supporting wife. Trying to get support as a carer.
- One person described problems they had experienced when they married someone with a mental health condition. This person was asked to become the official carer, although they lived apart for personal reasons. Professionals wanted to reduce the support provided. The carer would become the first point of call. One time the police needed to be called, but the person was told they would have to go in first as carer, even though not trained or receiving support. They had to enter a potentially dangerous situation which did need police and ambulance presence. They refused to become the official carer because they didn't feel there would be adequate support or proper training.
- Husband goes to Wilshaw House for respite care - he has Parkinson's and dementia. His wife finds it too difficult to look after him all the time at home. He gets good care and is treated with respect and kindness.
- Neighbour's daughter has cerebral palsy (in her 40's). The district nurse attends to change her bag, but no specific time is given. One day they didn't come at all. One nurse was very rude to her.
- *I was crying, I begged and pleaded with them to do something, but all they kept saying was that it was life style choices. Those choices were made because he was ill and NOBODY chooses to have mental illness.*

### **Referral or signposting to an advocate**

Sometimes people need assistance to get the care they need. If an advocate is required, Cloverleaf, for example, can take referrals in Tameside. Here are some examples of people helped by Cloverleaf, where Healthwatch have also been involved:

- Referral by Healthwatch to assist inpatient in a mental health ward, who was not in a position to say what was needed for themselves.
- Referral by Healthwatch to assist the family with a court case about eviction of the patient from a housing association property. The patient has an acquired brain injury, as well as a mental health condition.

The following people were signposted to Cloverleaf by Healthwatch. We do not know whether a self-referral was made, and if it was, whether it was accepted.

- Person needed assistance with a mental health hospital appointment.
- Family had a son in crisis, and were finding it difficult to get the assistance he needed.
- Person wanted help for sister who was having a mental health crisis.

### **Social isolation**

Being alone at home does not help people with mental health issues, Healthwatch were told.

Two of the people we spoke to attended Loxley House on a regular basis. Here is what they say happened when the number of days they were allowed to attend was reduced:

- *I have manic depression. My GP and social worker suggested I socialise more. I have cerebral palsy. I started attending here in the 70's with 3 days. Then I lost a day. I went through a bad patch. I had to appeal to get the day back. Only Loxley can deal with my disabilities.*
- *I have a learning disability. At Loxley House the criteria changed, and I lost 1 day a week. I became quite ill - I lost weight and became depressed. My social worker and staff fought to get my day back. I have friends here, and do activities. I am lonely at home.*

Healthwatch attend a session at Opt-in once a month. One of the questions we asked the group was 'What difference would it make to you if Opt-in closes?' This was at the time the future of the group was being considered by Tameside Council. Here are the comments:

- *I think it would be disastrous for everyone. There would be nowhere for anyone to go. Probably have more people going to A & E with mental health problems rather than the problem being picked up in Opt-in. Probably get an increase in people overdosing.*

- *It would make a big difference if Opt-in closed. I have got used to the people here and they are nice and usually happy. I would just have to stay at home.*
- *I would probably be alright. I would just stay at home but I think many people would end up committing suicide.*
- *I enjoy coming. It gets me out of the house and gives me a break. If Opt-in stopped I would stay at home and read a book.*
- *It would cause social isolation and a deterioration in mental health.*
- *If Opt-in did not continue it would make a big difference to my life. I would go insane without anyone to talk to. I would have nowhere to go except sit alone in my flat or go shopping and buy things I can't afford.*
- *I think that because I have mental health problems I am invisible to the Council. I do not exist.*
- *I'd have nowhere else to go. I would be sat in four walls all day. Other than the Opt-in groups there are no other groups available to people with mental health problems.*

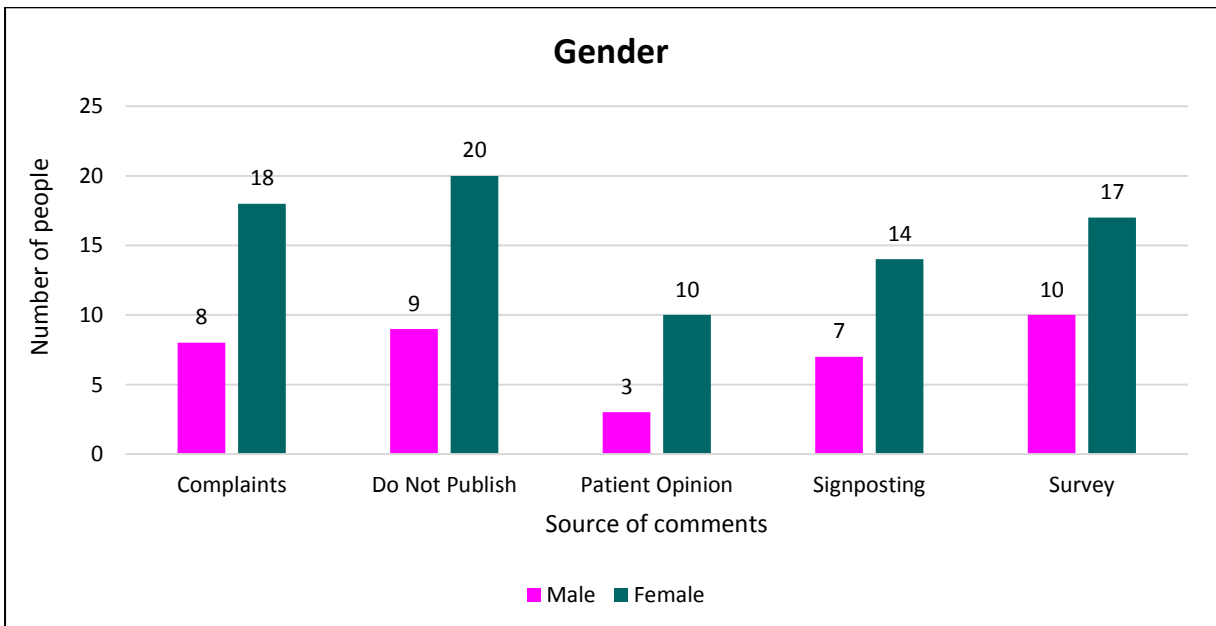
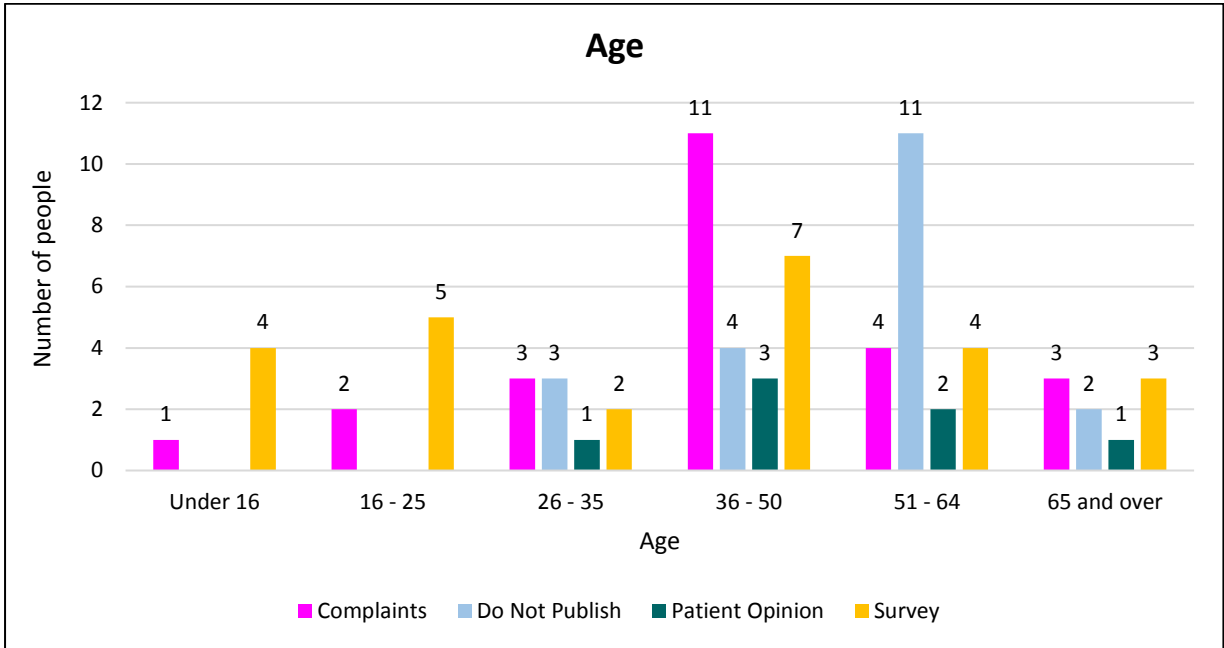
One of our signposting requests, featured isolation:

- Healthwatch Tameside were contacted by a person who was transgender. They suffered from a number of mental health issues. When feeling particularly anxious, they didn't want to leave the house, and the fridge would become empty. They had no support network. Some benefits were received, but not enough to cover the cost of the medication being taken. GP has referred them back into the mental health system, but still waiting for an appointment. Healthwatch referred to the LGBT Foundation for support.

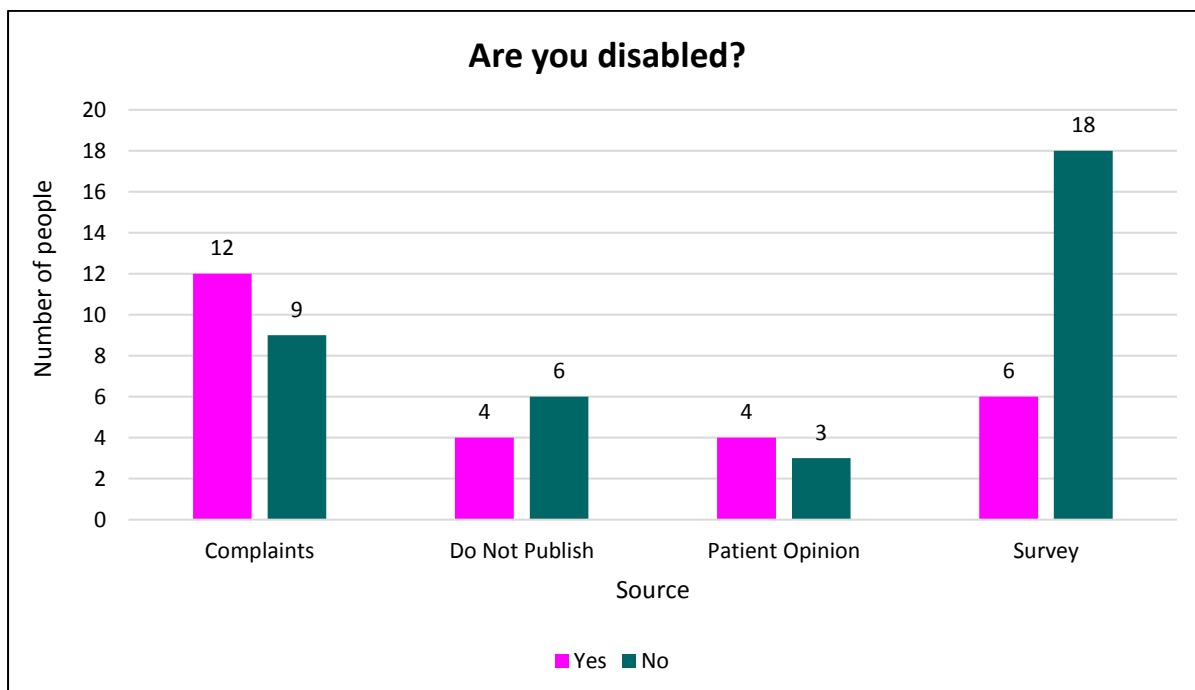
## Demographics

Here is a summary of the people who provided information, where known. Healthwatch Tameside have no information about people who told their story on NHS Choices or Patient Opinion directly.

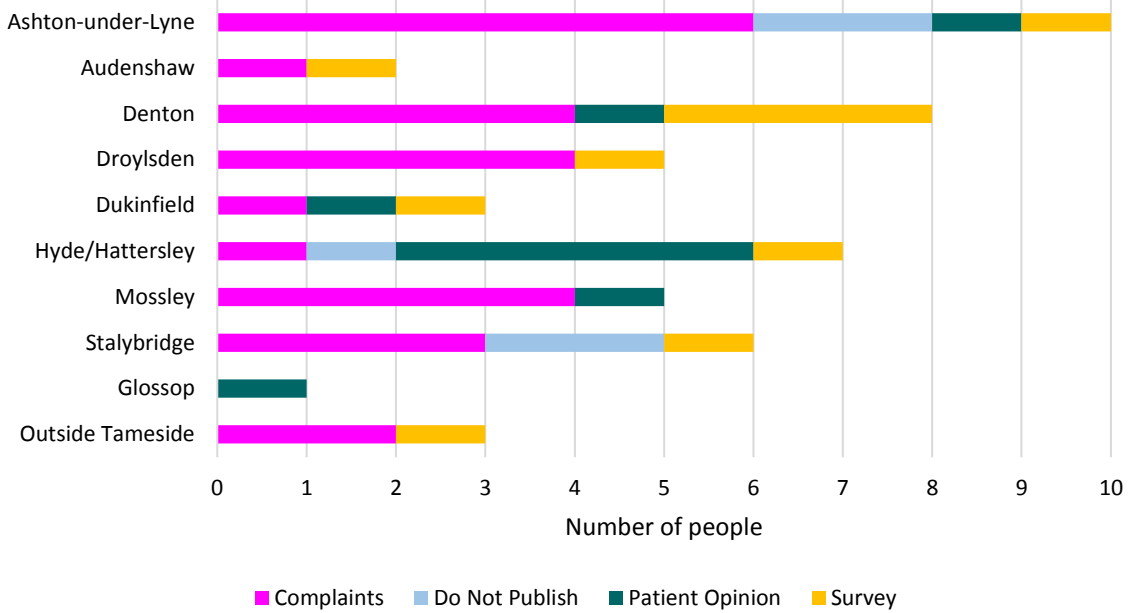
We will consider this information when planning the next stage of the project. Healthwatch Tameside is committed to speaking to all people, including people with protected characteristics.



| Nationality      | Source of information |                |                 |        |
|------------------|-----------------------|----------------|-----------------|--------|
|                  | Complaints            | Do Not Publish | Patient Opinion | Survey |
| White British    | 17                    | 19             | 6               | 21     |
| White Irish      |                       |                | 1               |        |
| Eastern European | 1                     |                |                 |        |
| Asian British    | 1                     |                |                 |        |
| Asian Indian     |                       | 1              |                 |        |
| Asian Pakistani  |                       | 1              |                 |        |
| Other Black      |                       |                |                 | 1      |
| Dual heritage    |                       |                |                 | 1      |



### Which town do you live in?





## **Acknowledgements**

Healthwatch Tameside would like to take this opportunity to thank all the people who have helped with this report in any way. This includes:

Patients and service users

Patient Opinion

NHS Choices

Healthwatch Champions

Loxley House and the groups meeting there

Opt-in support group

Woman to Woman support group

Anthony Seddon Trust

Healthwatch Tameside staff

