

**Report of the
Heart and Lung data
collected by
Healthwatch Tameside
March and April 2019**

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Executive Summary

Who are Healthwatch Tameside?

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.

NHS Long-term plan

The Government has announced that the NHS budget will be increased by £20bn a year. In January 2019, the NHS in England published a ten-year plan showing how this extra money will be spent.

The plan sets out the areas the NHS wants to make better, including:

- **Improving how the NHS works** so that people can get help more easily and closer to home.
- **Helping more people to stay well.**
- **Making care better.** The NHS wants to get even better at looking after people with cancer, mental health, dementia, lung and heart diseases and learning disabilities, and autism.
- **More money invested in technology** so that everyone is able to access services using their phone or computer, and so that health professionals can make better, faster decisions.

The NHS hopes that by spending more money on services in the community, and by making sure that care works as well as possible, it can save money overall and ensure people have all the support they need.

NHS organisations have been asked to come up with a local plan explaining how these priorities will be delivered in your area. Healthwatch England planned a project to make sure all local Healthwatch asked the same questions. Healthwatch Tameside has been working together with the other local Healthwatch in Greater Manchester to find out what local people think. What people tell each Healthwatch will be shared with the NHS locally and will also be used to help develop the plan for Greater Manchester. The overall findings will be sent to Healthwatch England to be added to data from across the country, to create a national picture of what people would like to see.

What is this report about?

In addition to publicising the general survey to people who live and work in Tameside (to be reported on separately), Healthwatch Tameside chose as our focus the Heart and Lung specific survey. This is an area we have not looked at closely before, and heart and lung diseases affect a high number of people in Tameside.

We asked people to fill out the survey, if they (or a family member or friend) had used heart and/or lung services. This was available online or on paper, and was publicised widely, including:

- Healthwatch Tameside website
- Healthwatch Tameside ebulletins
- Healthwatch Tameside Twitter
- Healthwatch Tameside paper newsletter which included a paper survey
- Healthwatch Tameside regular outreach sessions
- Healthwatch Tameside additional visits to community groups
- Action Together staff e-news
- Tameside Council website
- Tameside Council Twitter
- Care Together Twitter
- Tameside & Glossop Clinical Commissioning Group (T & G CCG) website
- Tameside & Glossop CCG Twitter
- Tameside & Glossop Integrated Care NHS Foundation Trust website
- Tameside Hospital inpatient wards and health information centre
- Partnership Engagement Network (PEN) ebulletin
- Visits to community groups to talk to members
- Direct emails to local organisations and community groups for sharing with their members and service users

We also held two focus groups, on 17 and 26 April 2019, at The Volunteer Centre, Penny Meadow, Ashton-under-Lyne, OL6 6EP.

All the comments in this report have come from the people who completed the survey or attended the focus groups, either summarised by Healthwatch or as quoted (*in italics*).

Key Messages

Communication is at the centre of all the themes covered by this survey. It was stated that “*Communication gets in the way of service all the time,*” during one focus group.

Good communication is the basis of a good service and a good patient experience, Healthwatch Tameside were told repeatedly in both the survey responses and the focus group discussions.

Good communication includes providing information, listening, explaining and talking to all relevant people.

Diagnosis, treatment and support

Currently, for both heart and lung conditions, some people have a positive experience, whilst others wait a long time for diagnosis and/or treatment and support and describe their experience in a negative way.

People want to know what is wrong with them as soon as possible, what their options are, and to have suitable care provided quickly. Other existing conditions need to be taken into account.

Long-term support should be available to all who need it. This should include all the health conditions a person is receiving care for.

Families and carers want to be involved more, and to also be provided with support.

Support and care in the community has received mixed reviews. Some people are happy with what is available, whilst others are not.

Technology

Anything which will improve care for patients is welcomed, whilst remembering that not everyone can access technology.

Recommendations

Based on the contents of this report, and what the people who completed the survey and/or attended the focus groups said, the following are recommended as areas for all commissioners and providers of services to review.

1) Communication

- a) Information to be provided:
 - i) At the right time.
 - ii) In a way that is easy to understand, but still includes the right amount of detail. The use of jargon is to be avoided. Check that the information

provided has been understood, and offer to signpost to additional information and/or support if required.

iii) With an opportunity for people to ask questions.

iv) In a way that includes carers and family members, when the patient agrees.

b) Clinical staff to listen to:

i) The patient, who knows their own body and health.

ii) Any family or carers who often have additional information.

c) Clinical staff to communicate effectively with others including:

i) Their colleagues.

ii) Other care providers involved with the patient.

iii) The patient and any family or carers.

2) Diagnosis, treatment and support

a) Both diagnosis and treatment are to be provided at the right time, without unnecessary delay. Any unavoidable delays should be explained.

b) Follow-up care and support, including rehabilitation, to be available to all who need it. This support is to include carers and family members too.

c) Care to be more joined up between different departments and providers, especially where a person is living with multiple conditions.

3) Technology

a) Provide options for people when introducing new technology, to make sure that anyone who cannot use it still receives the same level of care as the technology offers.

b) Reduce the amount of paper correspondence, where people have access to email, for example.

c) Training to be provided for staff and patients, to get the most out of the technology available.

4) Travel

When sending out appointments, consider:

a) How far is the patient travelling?

b) What method of transport will they be using?

c) How will the medical condition of the patient affect their ability to travel?

d) How much do patients know about all the options available to help with travel and is additional information required?

Conclusion

Whilst this project has only provided a snapshot of the opinions of people using heart and lung services, there are some common themes. These are the same themes as have been seen in other projects carried out by Healthwatch Tameside.

Communication is very important. If communication is not good, it is seen as a major barrier to receiving good care.

In addition to providing good care and support for the patient, the carers and family also need to be included.

Thinking about the care and support to be provided for the patient from their point of view is really important. Taking time to think about their other conditions and medications, how far they need to travel and how they will get to places, and making sure they know what to expect, will make a big difference to the overall experience of care.

‘Care needs to be joined up’ was a message we heard in both the surveys and the focus groups.

Next steps

This report will be:

- Shared with commissioners of heart and lung services in Tameside
- Shared with providers of heart and lung services in Tameside
- Shared with other local Healthwatch in Greater Manchester
- Shared with Healthwatch England
- Shared with Greater Manchester Health and Social Care Partnership
- Published on Healthwatch Tameside website
- Publicised in Healthwatch Tameside news bulletins and on Twitter

Healthwatch Tameside have already been notified by both Tameside & Glossop Clinical Commissioning Group and the Public Health Team in Tameside that the contents of the report will be considered in work that is happening shortly.

Response from Tameside and Glossop Integrated Care NHS Foundation Trust

We would like to offer our thanks to Healthwatch Tameside for producing and sharing this report and also to send our appreciation to those who have taken the time to share their experiences. The information that people have provided in the survey and focus groups will be used to help improve services and the overall experience of care.

We recognise the importance of providing a holistic, joined up heart and lung service and we have established a specific cardio-respiratory programme board which is focused on improving the overall care provided to the patients who use these services. As part of this board, we invite patients to share their views so we can understand their specific needs for the delivery of their healthcare. As well as patient representatives, the board includes a range of healthcare professionals including people from hospital, community, primary care, ambulance and voluntary organisations to ensure we operate as part of a truly integrated system that meets the needs of the people it serves.

We welcome the recommendations made in the report and will discuss these at future forthcoming cardio-respiratory programme boards, as well as using them to inform our trust-wide patient and service user strategy and to drive our improvement plan. Some areas we are currently progressing which speak to the recommendations in the report include:

- Earlier identification of people with lung and cardiac conditions in primary care
- Providing supported discharge for people with Chronic obstructive pulmonary disease (COPD) and use of the patient activation measure to enable patients to manage their own conditions more effectively
- Ensuring people are treated in the right setting to reduce waiting times for clinic appointments
- Developing mobile applications (e.g. myCOPD app) to help patients manage their condition in their own homes
- Ensuring efficient referral of patients to both heart and lung rehabilitation
- Working together with the local Heart Link support group, with a member attending divisional meetings to help share their experiences of our cardiology services

As highlighted in the report, we agree that care needs to be joined up and that effective communication is essential to the overall delivery of high-quality patient care. We continue to work on making information accessible for all, and to do this we are creating more opportunities to work in partnership with patients and the public to design information and services together, as well as identifying areas for further development. Healthwatch Tameside remain a key and active partner in our patient and service user engagement work, and improving patient information and communication remains a focus for this group.

We look forward to working together with Healthwatch to improve services and will continue to work in collaboration with our commissioners and other local partners, to ensure improvements are made across the whole health and social care system.

Introduction

The analysis for this report is based on 64 completed surveys (there were 80 completed in total across Greater Manchester Healthwatch). Of these, 52 (81%) were completed on paper and 12 online. Not everyone answered every question.

The questions were compiled by Healthwatch England, so that all local Healthwatch across England were asking for the same information. When all the data is combined, a national picture will be produced, which will influence national policy set by NHS England.

The number of surveys is small compared to the total number of residents using these services and is therefore not statistically significant. However, the trends in the comments can be clearly seen. They will provide an overview of experiences of care and offer recommendations for areas to look at in more detail.

It is noted that there is wide variation in the timeframe of experiences, with a few people being diagnosed as a child (e.g. asthma), and others much more recently. Some people are still going through the process of diagnosis and treatment. Survey comments about diagnosis may therefore not be about current service provision.

The focus groups were attended by 15 people, with experience of NHS heart and lung services. All these people had current experience of service provision.

We will show the responses to the survey questions with multiple choice answers first. This will be followed by a themed breakdown of the written survey responses and the focus group discussions together.

Details from the heart and lung survey questions

How long did it take from first seeking help to being diagnosed?

	Number of responses
Less than a month	11
Between 1 and 3 months	18
Between 3 and 6 months	11
Between 6 and 12 months	3
Longer than 12 months	13
No answer	8

Looking at the people who received treatment in less than a month, there is a mix of heart and lung patients, including people living with both conditions.

People who waited over 12 months for a diagnosis were again a mix of heart and lung patients. One patient went to see a private doctor after waiting this long, and was diagnosed with heart failure.

How would you describe your or your loved one's overall experience from when you first sought help to the point of getting a diagnosis?

	Number of responses
Very positive	7
Positive	19
Neutral	14
Negative	2
Very negative	1
Mixed	14
No answer	7

The mixed responses were mainly from people who waited a longer time for diagnosis and were not happy about the delay. There were some people who would have liked more information and support.

The negative and very negative responses were all in relation to either a late or incorrect diagnosis, which then delayed receiving the right treatment.

How long did it take from first getting a diagnosis to getting treatment or support?

	Number of responses
Less than a month	20
Between 1 and 3 months	14
Between 3 and 6 months	10
Between 6 and 12 months	3
Longer than 12 months	7
No answer	10

Whilst waiting:

11 people said they would have liked more information about what was happening.

6 people would have appreciated more support (such as someone to talk to and ask questions of).

How would you describe the overall experience of your treatment or support?

	Number of responses
Very positive	12
Positive	20
Neutral	10
Negative	4
Very negative	1
Mixed	12
No answer	5

Have you or your loved one had, or would you like to have, any post treatment support? (please tick all that apply)

Type of support	Have had	Would like to have
No post treatment support	20	15
On-going specialist treatment with consultant	33	13
Post treatment support in the community from a specialist community health team (e.g. specialist nursing team)	22	22
Post treatment support from my GP practice (GP or other practice-based practitioner)	34	15
Post treatment support from a community group or peer support group	20	15
Remote support using technology (e.g. tele monitoring of my condition, video consultations with specialist, etc.)	5	22
Online peer support	4	17

Whilst 20 people said they had received no post-treatment support, this may be inaccurate and due to misunderstanding the question. When you read across their other answers, all have received support from somewhere, e.g. consultant, GP or community care.

Of the 15 people who would like to have post treatment support, 6 people received support from their GP, but the rest answered all the support questions negatively.

How would you describe your or your loved one's overall experience of post treatment support?

	Number of responses
Very positive	7
Positive	23
Neutral	10
Negative	4
Very negative	3
Mixed	12
No answer	5

Three of the people who answered 'Mixed' had not completed treatment, and two said their support was from community groups or the local hospice rather than the NHS. Some people said they would like more support, and some people did not explain their reason.

Have you or your loved one used, or would you like to be able to use, any of these technologies to help manage your/their health and wellbeing?

Technology	Have used	Would like to use	Don't know	No answer
Video consultations with healthcare professionals	2	20	19	23
Online peer support group	6	15	13	30
Remote health monitoring device	4	18	16	26
Smart phone app about my specific condition	3	18	17	26
General health and wellbeing smart phone app	4	16	17	27
Technology devices to help me manage better at home	3	16	16	29
Online information about my condition	15	19	9	21
Online information about general health and wellbeing issues	16	19	7	22

There are mixed messages about the use of technology (see page 25 for more details), and the accessibility of the internet. 14 people said they did not have access to a computer and/or smartphone.

We have looked at whether the picture changes based on the age of the patient.

The two video consultations were with people aged between 45 and 64.

Here is the breakdown of which age groups (from the surveys) have looked online for either condition specific and/or general health information:

Age	Number of people who have searched online
18 -24	1 (of 1)
25 - 34	1 (of 2)
35 - 44	0 (of 1)
45 - 54	5 (of 6)
55 - 64	4 (of 11)
65+	7 (of 37)

Do you / your loved one have any other physical or mental health conditions?

	Number of responses
Other physical health condition	16
Mental health condition	3
Learning disability	0
Other (please specify)	29
No answer	16

Under ‘other physical health conditions’ and ‘other (please specify)’, 34 types of condition were mentioned. Those that recurred the most were diabetes and different forms of arthritis.

Have your other conditions been taken into account during your treatment and support?

	Number of responses
Yes, always	14
Sometimes	18
Not always	11
Not at all	4
Not sure	7
No answer	10

Themes

In this section the comments from the written survey questions and the focus group discussions are brought together. We will look at them under themed headings. Often, the comments will fall under more than theme, but they will only be included once in the report.

For information, the types of heart and lung conditions identified in people's comments are:

Heart conditions	Number	Lung conditions	Number
Angina	1	Asthma	4
Atrial Fibrillation (AF)	2	COPD	2
Cardiac arrest	2	Emphysema	2
Heart blockage	2	Idiopathic Lung Fibrosis (IPF)	2
Heart by-pass	4	Lung cancer	1
Heart failure	2	Lung removal	2
Pacemaker	4	Pulmonary Fibrosis (PF)	3
Unspecified cardiac	4	Pulmonary unspecified	7

Within these numbers, 4 people have both heart and lung conditions.

Communication



This section includes providing information, medical staff listening to what patients say, and talking to others. Some people said communication training is required for staff. Poor communication was talked about at both focus groups, and everyone had something to say. Good communication is said to be extremely important for good patient experiences.

- **Providing information**

Many of the people who completed the survey said that they would like to have more information, especially around the time of diagnosis and initial treatment. When a doctor or nurse does explain, the information is not always understood - medical words (jargon) are used or there is not enough detail. People feel there is not enough time to ask questions and leave appointments confused. The comments are often in answer to questions about how improvements could be made. Here are some examples:

- Two people complained they received a diagnosis by letter and not in person. One of these said they had to look up what the words meant.
- Several people wanted updates on what was happening, and how much longer they would have to wait for their next appointment. They said they should not have to keep ringing up to ask. Also, they would like to know what they should expect in the future from their condition.

Here is a positive comment:

I was treated really well. But I asked questions and not everyone is as forward as me at getting answers.

Where people feel improvements could be made, they made suggestions they would like to see, including:

- *Balanced and up to date information so that not too much out of date information is taken in from Google etc.*
- *British Heart Foundation have good free information available at Wythenshawe and Manchester Royal, but it is not available at Tameside Hospital.*

- *Had an MRI test for heart. Heart was OK but was told I'd pulmonary fibrosis instead. My mum had died from it, so I knew about it. When the consultant realised what I knew, he just walked out of the room, leaving me in tears. There was no compassion.*
- *More information between waiting times for appointments.*
- *Went to A & E with pneumonia. Was told I could have lung disease. Why did they tell me then? I just went home, looked on Google and panicked. There was a lack of consideration - there needs to be a better process and support.*
- *When diagnosed with anything, but especially a life-limiting disease, information should be at the forefront of any treatment.*

- **Listening**

People want doctors to listen to what they have to say.



- *If my GP had listened to me - I told them my mother had angina, my grandma a heart attack. Women don't have heart attacks, he said, it was indigestion and gave me Gaviscon. Lots of tests at hospital but no ECG. A stent was put in due to a blood clot.*
- *The GP could have listened to me instead of telling me it was nothing. All the time for 9 months it was serious.*
- *They don't listen. They only want to treat the condition you are there for, regardless of what else is wrong with you, and what it says in your records about what you can/can't have or do, e.g. given general anaesthetic with a severe lung condition, which shouldn't happen.*

- **Talking to others**

Many people said that they would like to see more communication between staff within one building, between staff at different care providers, and between staff and patients and their families/carers. Here are some comments about what people would like to improve:

- *Better communication and follow up between GP/Hospital etc.*
- *Bit more consultation between services.*
- *More messages between doctors and nurses.*
- *Services talk to each other.*



Diagnosis

Many of the comments included wanting improved communication (see above). When people received a diagnosis within a short period of time, they often did not make additional comments on the survey. Where the diagnosis took longer, there are more concerns raised, and suggestions for improvements. These included:

- **Quicker referrals:**
 - *Doctors should have referred me sooner, I was bringing up green sputum, nothing cleared it. I went to see a specialist and I was diagnosed quickly and given the correct meds.*
 - *GP makes a referral to a consultant for diagnosis who sends it back to the GP for action. You wait weeks going round in circles.*
 - *Needed to access private services to expedite diagnoses and treatment. (Heart failure)*
 - *Oxygen testing for ambulatory use should have been investigated sooner. Delayed confirmation of a referral to Wythenshawe.*
 - *Passed around from Christies to Tameside but they couldn't open scan results. Then passed onto Wythenshawe.*
- **Waiting for diagnosis:**

Here are some examples of people who are still waiting for their diagnosis:

- *I am still waiting for a definitive diagnosis for type of pulmonary fibrosis, to see if there is any treatment available.*
- *Since being admitted to Tameside Hospital with breathing difficulties in January 2018, I still don't know why both consultants have been unable to give me a diagnosis - its ongoing!*



These comments are from people who did receive a diagnosis, but it took a long time:

- *Asthma sprays from GP and x-rays for 30 years. Eventually went to Salford with something else. Appointment with respiratory consultant day after.*
- *I felt ill several times (several years ago) and had a check-up with GP. No doctor gave me an ECG. I felt ill, the paramedics diagnosed A/F and took me to hospital. Since then had heart attacks and was fitted with a stent followed by a triple by-pass. More thorough examinations could have saved time and money.*

- *Sent to A&E by family doctor as an emergency to be discharged by A&E doctor -said that there was nothing wrong when in fact I had a blockage in my heart. Referred to cardiology by my GP had to wait weeks for an angiogram.*
- *Went to GP for 3 years, and all they said was stop smoking - no other help. Found out I had COPD by accident when I got a sicknote for work and it was on there.*

Treatment

As with 'diagnosis' above, there is a request for more information and better communication. Also, some people received treatment quickly, whilst others had a long wait. Here are some of the comments:



- **Waiting for treatment:**

- *Was recorded that I failed to keep appointment for monitor to be fitted, but they didn't send me one.*
- *Told I had a blockage but no further treatment. (Heart)*
- *Good diagnosis and care but long wait and pestering to get an appointment just to see the specialist I need. Previously fitted stents completely blocked.*
- *Received treatment for a problem I didn't know I had but I can't get anything to help me breathe easier.*
- *(Would like to see) - More support for cardiac specialists, reducing wait times. Living on multi medications for extended periods is not a good lifestyle, and fitness is quickly lost.*

- **Treatment:**

Here are some comments about treatment received:

- *(3 to 6 months wait) - triple heart bypass. No symptoms - elevated blood pressure.*
- *I have received all cardiac and pulmonary treatments required without having to wait too long. Initially getting the right dosage of drugs correct was troublesome.*
- *NHS care within a private hospital is quicker, they are polite, and you can choose your appointment date.*
- *Shortness of breath - resulted in fitting a pacemaker.*

Once I went to see the specialist, I recovered in about 3 months.

Here are some comments referring to inpatient hospital stays:

- *Discharge - up to 6 hours waiting for medication to come from pharmacy, which leads to bed blocking. They know you are leaving the day before, so why not arrange then? These delays lead to long waits in A & E. Waited 10 hours for a bed.*
- *If you have an unplanned stay in hospital, then have a pre-arranged outpatient appointment shortly afterwards, the notes from your stay on a ward are not available to the clinic.*
- *They tried to send husband home, saying it cost £500 per bed per night. He was not well enough. You need to be firm, but polite. (Wife stood up to them and he was admitted.)*



Here are some suggestions about changes people would like to see:

- *Having a 'one stop' heart failure service which was available in the past. Investigations and scans etc. not being limited to a certain number per clinic.*
 - *I was asked to sign a form before husband had surgery. I asked what it was, and it was DNR. I had to ask for the information though. Altogether seven different people asked about the same form. Only one person needed to have asked. No-one believed he would survive the operation.*
 - *People are scared to speak up. They are pressured down a route they are not happy with for their care.*
 - *There is misdiagnosis of lung conditions - COPD or pulmonary fibrosis. They just give inhalers without testing which disease it is, and inhalers do not work for P.F.*
- **Follow-up to treatment:**

Some people were happy with the follow-up care they received or are receiving. These include:

- *COPD's clinics, long term conditions team excellent.*
- *I was taken by ambulance from home to hospital. I was admitted and had a pacemaker fitted 5 days later. I am now having follow up checks and further treatment for heart failure.*
- *Still at Wythenshawe Hospital and still receiving excellent treatment.*

I always have a backup supply of antibiotics in case I have a chest infection.

Other people were less happy:

- *Between hospital visit and physio time lapse was very long in waiting.*
- *Careful monitoring absent.*
- *My consultant did not forward me to cardiac after my pacemaker and ablation op. They won't accept me without it.*
- *No after care from surgery after discharge from hospital.*
- *Problems getting O2 to take away on holiday.*
- *Should have seen to me quicker. Had to wait months for follow up appointment and then had to go back to Doctor.*
- *Staff in the Hospital on the GP unit and assessment wards were great but let down by the lack of follow up or support following discharge. (heart)*
- *The oxygen was an issue - should not have been discharged without it and we had to escalate our pulmonary appointment to get it, very stressful.*



Here are some suggestions people say would improve their experience:

- *Dedicated medical personnel - avoid being passed from pillar to post.*
- *GP to give 6-month review instead of us contacting GP if problem. Consultant states this but it doesn't happen.*
- *Need to see the same GP each time, who knows about your health.*
- *You wait too long for an appointment, or you get two in a week, e.g. cardiology at Wythenshawe then the following week an appointment locally. You get duplication then big gaps between being seen. It's disjointed and they are not talking to each other.*

Care in the community

Comments often referred to both care and support in the community. Some have been included under each section, rather than repeating them.

These comments are from satisfied people:

- *The support I now receive from international lung disease centre at Wythenshawe hospital is good.*
- *The treatment I received at the heart and lung nurses on Crickets Lane were very understanding.*

Some people were not very happy:

- *GP refused to see me. Sent to GTD in a taxi before I could get access to nebuliser. They shouted at my husband for taking so long.*
- *Two people required removal of stitches after surgery. District nurses unable to attend and told them to go to the surgery. One person refused as they don't drive and did eventually receive a home visit. The other tried the walk-in centre, who sent them on to A & E. Both patients said this should happen in the community, without these difficulties.*

Here are some suggestions people would like to see happen:

- *Access to appointments with heart nurse. I have used this but it seems to have stopped.*
- *Emergency packs at home - need to make sure that if one person can have them, they should be available to all e.g. nebulisers, etc.*
- *Follow up to discharge does not take into account how tiring major surgery can be. Priority in appointments should be the patient's choice, not hospital protocol. If it is more convenient to go to a GP INR clinic, rather than a remote hospital, it should be patient choice.*
- *I think people need more access to clinics and leaflets to explain what is going on.*
- *Tameside Hospital sends aids home, but they don't accept them back. They need to do an assessment to make sure they are the correct items.*
- *Understanding at the doctor's surgery that when I asked for Doctor to attend at home it was done because of necessity.*

Support

- *A few people praised the support received.*
 - *A group meets weekly on heart matters. A nurse tries to answer questions.*
 - *Can't fault support from Willow Wood.*
 - *Got more information from the Breathe Easy Group than from the doctors and consultants.*
 - *I have had all the support I needed from my surgery and Tameside hospital.*
 - *The support I receive is not from the NHS but local hospice drop-in centre and voluntary support group. Both very good.*
 - *Willow Wood taught breathing exercises and said to ring them if I had a problem.*



- More support in the community was requested by several people.
 - *Did have LT condition team coming but that just stopped after 6 weeks then I was dropped - not enough support.*
 - *I think a lot of the older population feel they have to get on with it and informal chats with professional nurses would be nice to be able to set any fears to bed sometimes prevention is better than cure.*
 - *Still awaiting community support as it is not available. (heart)*
 - *There was Heartlink - is it still going?*

Here are some ideas of areas to change to improve support:

- *Heart - don't feel support any better than lung, even though a higher profile. You look OK so people assume you are OK - they can't see heart failure in a person.*
- *Improved emotional support. Support is available but you have to 'fight' for it. No single group can answer questions.*
- *Initially not good at all - thankfully I use social media and found support through PF UK/British Lung Foundation. Once seen by ILP very good. (Would like) earlier support and care. Someone to talk to me.*
- *Lung support should be on a par with cancer.*
- *Prior to my current heart problem, I have had fantastic support (Would like) an outreach support telephone number.*
- *Someone to talk to about day to day coping with the condition.*

Rehabilitation

Only a few people talked about rehabilitation in their replies on the survey. It was also included in the focus group discussions.

These comments are from people who were pleased with the care they received:

- *Cardiac rehab very good, GP support very good. There appears to be a charity that raises funds, but they do not seem to have any group activities.*
- *Heart rehab at primary care centre really good.*
- *I have remained under Tameside, doing cardiac rehab programme and physio and still attend cardiac clinic now. I am not sure if this is how cardiac patients still receive their treatment. I would like to strongly advocate that this is crucial to my recovery and ongoing support.*
- *Rehab programme (very informative) yearly respiratory appointment.*

Some people were less happy:

- *Communication between physio at the gym and medics appalling. The physio doesn't know much about cardiac conditions and the medic doesn't know about what is happening at the gym. The physio will take blood pressure, but it isn't fed back to the medics - why not?*
- *Diabetic nurse sent me to pulmonary rehab. (Said they should have been referred during pulmonary care.)*
- *Long waiting time for pulmonary rehab*
- *Nebuliser, inhalers, tablets, 4 years later on pulmonary rehabilitation. Pulmonary rehabilitation should have been available earlier.*
- *Pulmonary exercises - treadmill does more harm than good, due to my balance problems. Tried exercises but it made me worse. They did send the physio round to the house to do aids assessment.*
- *Pulmonary rehab delayed when on oxygen*

Here are some suggestions people say would improve their experience:

- *Given an offer of cardiac rehab sooner and available nearer to my home.*
- *Pulmonary rehab only available in Ashton. Should be in different localities.*
- *The CCG rely on the doctor to tell you. There is not enough publicity about pulmonary rehab.*
- *There is no Pulmonary Rehabilitation designed specifically for Pulmonary Fibrosis patients, and this would be very beneficial. At the moment it's designed for COPD Patients.*

Technology

There is mixed feedback about the use of technology. The number of people who completed the survey in Tameside was much higher on paper (81%), even though the online link was publicised widely. Fourteen people (22%) said they did not have access to computers and/or smart phones. Of these, two people said they would like to learn. Two of the people said they had sight problems so couldn't see screens.



Other comments included:

- *I have no interest in the above (technology). I want person to person which I had and been very happy with.*

- People told us about apps which are available, e.g. COPD. They said you need to make sure they are calibrated properly to get the right results. You can become obsessed with looking at them, which for some people is not good.
- Person uses Patient Doctor now. *GPs are too busy to get an appointment. They used to be really good, but something is going wrong now.*
- Talked about technology such as Skype - the group felt it was OK for some appointments, but a doctor can't listen to your chest online.
- *Technology saved time.*
- *Telehealth - was really good. Dedicated nurses looked at it. If it is red you got a phone call and a visit if needed from a nurse who can prescribe. It kept you out of hospital. That was 12 months ago - it's changed now. Nurses can't do it now. You have to go to your GP. Nurses were specialised and it was great. It was working well, and it was changed. Now it is not working as well.*
- There are wristbands for people with COPD which show what your normal oxygen levels are. This information is useful to paramedics and emergency staff.

The next comments are suggestions for change:

- *I should not have to use You Tube to get information about my condition. This should be given by medical staff.*
- *There needs to be faster communication between doctors - why not use email where they are able to? It would save money.*
- *They are not on top of the existing IT, never mind developing more. All medics should have patient information wherever you go, but they don't. The computer system doesn't work and it cost millions. Need to train staff on its use. They should ask the people using the systems what they need.*



Management of multiple long-term conditions

All the comments made include suggestions for ways to improve the management of all health conditions together:

- *A greater understanding of how one can impact on another.*
- *A holistic approach would be good and not just seeing individual conditions e.g. diabetes in isolation to IPF.*
- *If you are under multiple hospitals you have to co-ordinate and fight for care yourself. I have to carry copies of all my letters, results, etc. to every appointment, e.g. scan done at Tameside Hospital and not available to access at Wythenshawe so have to print out my own copy.*

- *It would be great if one specialist could refer you directly to the other instead of having to go through your GP and long waiting lists.*
- *More detail by a team maybe diagnosing with true facts rather than guesstimate. Make easier access to GPs.*
- *Someone professional to look at all my conditions at the same time when deciding on medication/treatment. Someone to discuss how best to take medicines prescribed in conjunction with other medicines already have.*
- *They change the medication for one condition without thinking about how it might affect other conditions and the medication taken for those.*
- *You have to tell every professional your full history at each appointment.*



Carers

Here are a couple of comments about support which may not be widely known:

- *Carers Centre - Hyde. Given the carer a card with details of their relative on, so if they have a health (or other emergency) themselves, the attending services will know there is someone relying on their care, who will also need looking after.*
- *Carers continue to attend support groups even after the person they care for has passed away.*

There is a strong feeling that professionals need to involve carers more, and more support should be provided. Here are some examples:

- *Carer is not medically trained so information for carer in how to deal with exacerbation etc.*
- *Carer not included in discussions. Patient was too ill to understand what was being said.*
- *DNR asked about at each admission to hospital. They won't use the previous one. It is upsetting for carers. There is no empathy, care or consideration for the health and wellbeing of carers.*
- *It would have been nice for someone to talk to my husband and at least tried to give him support as to my overall recovery.*

- *More honesty on end of life at the beginning.*
- *More information and including carer in all discussions.*
- *No support for carers at hospital, even if you are pushing someone in a wheelchair. The patient feels guilty, especially if their carer is elderly and/or has their own health problems.*



Travel

This question was not included on the survey. It was talked about briefly in the focus groups. The agreement was that, provided you have a car to get there, people are happy to travel up to 15 miles to get the best treatment. However, people with heart and lung disease may not have someone who can take them to appointments. Here are some of the comments:

- *Appointments can be early or late or at weekends. Patient Transport doesn't operate then. Bus pass can only be used after 9.30am.*
- *Miles of Smiles is good.*
- *Patient Transport - you spend a long time hanging around, being picked up very early and then waiting to go home - you can be out of the house all day.*
- *Public transport can be a problem if you don't drive. Parking is atrocious and the costs are too high. It should be the same everywhere and cheap or free.*
- *Public transport takes a long time - hard if you're ill and on oxygen. There is the risk of picking up an infection.*
- *There is not enough disabled parking and it is too far to walk to where you need to be. There is not enough parking generally.*
- *They don't think about people's ability to get there, or where you live when they are setting appointments and times.*
- *Tram to Wythenshawe stops outside but it's a trek up to the hospital and takes a long time.*



Barriers to good care

In the focus groups, discussions included actual experiences of care, what changes people would like to see, and what are the barriers to improving care. Here are some of the areas which were said to be a barrier to getting the care people would ideally like. Other examples are included within earlier sections of the report.

- *Care not joined up. People are not talking to each other between departments.*
- *Changing medications when they are working already.*
- *Doctor not chasing to check that referrals have been made.*
- *GP appointments are not available. Not enough emergency appointments.*
- *Lack of liaison.*
- *Medications which are too costly are withdrawn.*
- *Referrals not made when urgent.*
- *Some drugs are only available when you reach a certain stage (per NICE guidelines) but then you can be too bad for it to be effective.*
- *Support for carers needs to be available.*

Other comments

Here is a selection of generalised comments which have not been included elsewhere in the report:

- *Idiopathic lung fibrosis (IPF) not many people know about it (public)*
- *NHS doing a wonderful job under difficult circumstances.*
- *Pulmonary Fibrosis has a very low profile. COPD is more well-known and P.F. gets lost.*
- *Should have a flag on your medical record, so when you get an exacerbation of your symptoms you don't have to battle with the receptionist to get an appointment/medication/home visit.*
- *Stop wasting money with wrong medication, wrong diagnosis, long waiting times when people get worse before their treatment can start.*
- *There is no End of Life pathway for pulmonary fibrosis.*

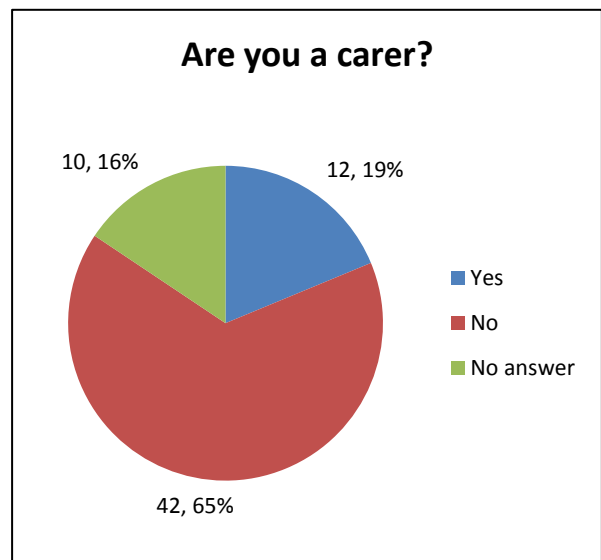
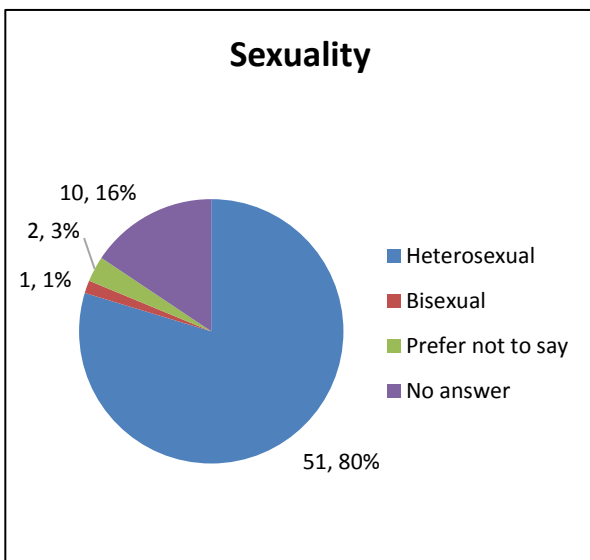
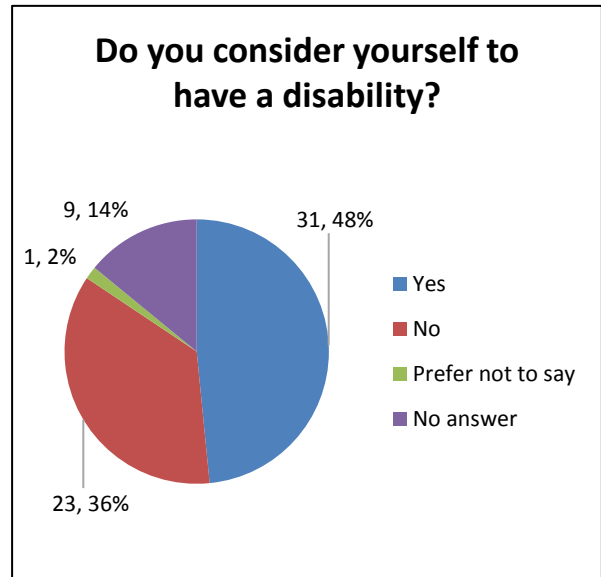
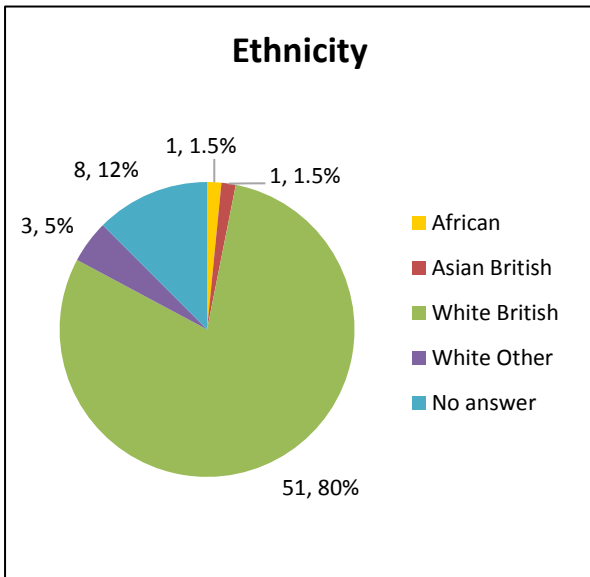
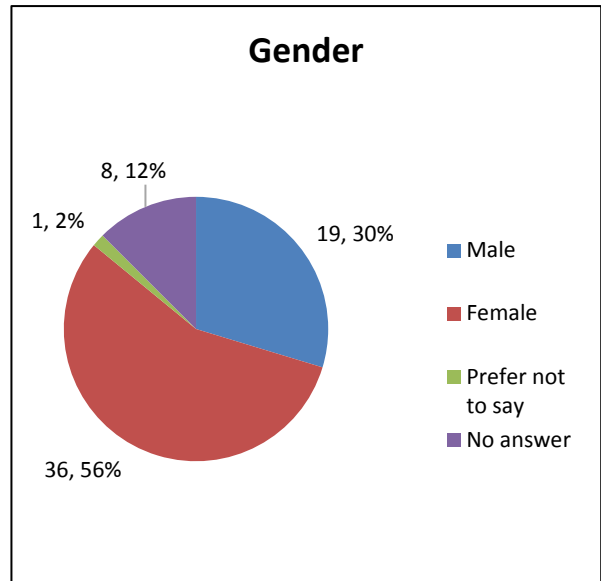
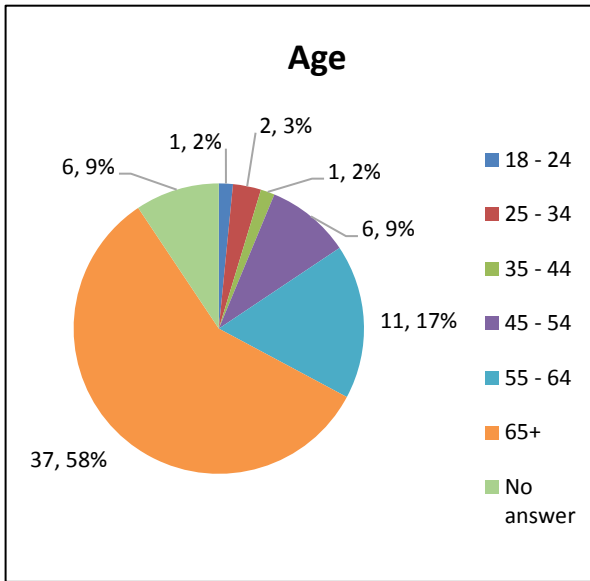
- *There should be a set of processes across everywhere for the journey of your diagnosis - setting the expectations of what could/should happen, so you are clear what to do at each stage.*

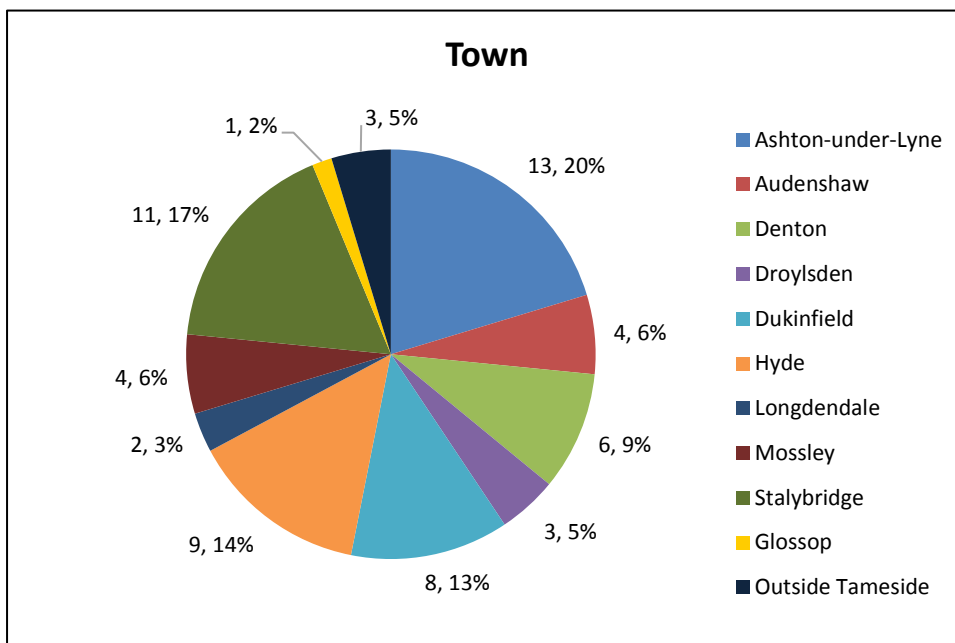
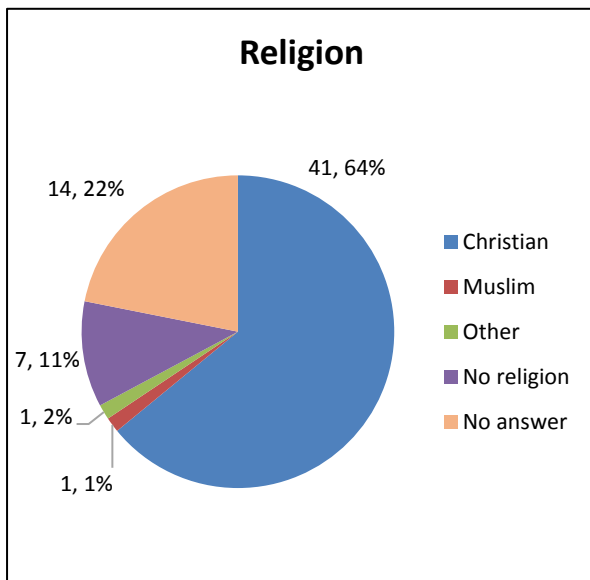


THIS WAY

- *They only ask about whether you have ever smoked. What about people who worked in the cotton mills, or engineering, etc.? What about all the secondary smoking in workplaces, bars, public transport, etc. before the changes to Health and Safety laws?*

Demographics





The graphs above show the demographic responses from the surveys.

Please note that the people who attended the focus groups also completed the surveys, so the following details are for information only, and are not to be added to the data in the graphs above.

Focus group demographics:

Age	1 = 45 - 54 years	3 = 55 - 64 years	11 = 65 years +
Gender	5 = male	10 = female	
Ethnicity	15 = white British		
Disability	11 = yes	4 = no	
Sexuality	15 = heterosexual		
Carer	6 = yes	9 = no	
Religion	10 = Christian	1 = no religion	

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- Healthwatch Tameside staff