healthwatch

NHS Long Term Plan

Healthwatch Derby and Derbyshire

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what would you do?

It's your NHS. Have your say.

Thank you

Healthwatch Derby and Derbyshire would like to thank all participants who gave their time to share their experiences and thoughts of health and social care services in Derby and Derbyshire in relation to the NHS Long Term Plan (LTP).

Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all patients, family, friends and carers who have experienced health and social care services, but nevertheless offer useful insight.

It is important to note that the engagement was carried out within a specific timeframe and are all the genuine thoughts and feelings that patients, families, friends and carers have conveyed to Healthwatch Derby and Derbyshire.

The data within this report should be used in conjunction with, and to complement other sources of data that are available.

Background

With growing pressure on the NHS – an ageing population, more people living with long-terms conditions, and lifestyle choices affecting people's health – changes are needed to make sure everybody gets the support they need.

The Government is investing an extra £20bn a year in the NHS. The NHS has produced a LTP, setting out all the things it wants health services to do better for people across the country.

The LTP sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia.

The Healthwatch network were commissioned by NHS England to support public engagement around the NHS LTP within each Sustainable Transformation Partnership (STP) footprint. Therefore, between March and May 2019, we engaged with people across Derby and Derbyshire about what people think should happen in order to make care better for people in the community.

Locally, our STP is called Joined Up Care Derbyshire (JUCD) and their plan identifies five priorities:

1. Prevent physical and mental ill health and help people to make better lifestyle choices
2. Make sure services are tailored and targeted to people and their communities
3. Make it easy for people to get the right care, when they need it, in the right place for them
4. Health and social care need to work seamlessly
5. Make organisations as efficient as possible

For more information on JUCD please visit: https://www.joinedupcarederbyshire.co.uk/about

Methodology

To collect consistent information across the county, we used a questionnaire developed by Healthwatch England.

The questionnaire was promoted online and our engagement team and volunteers also promoted the questionnaire through attending events and groups.

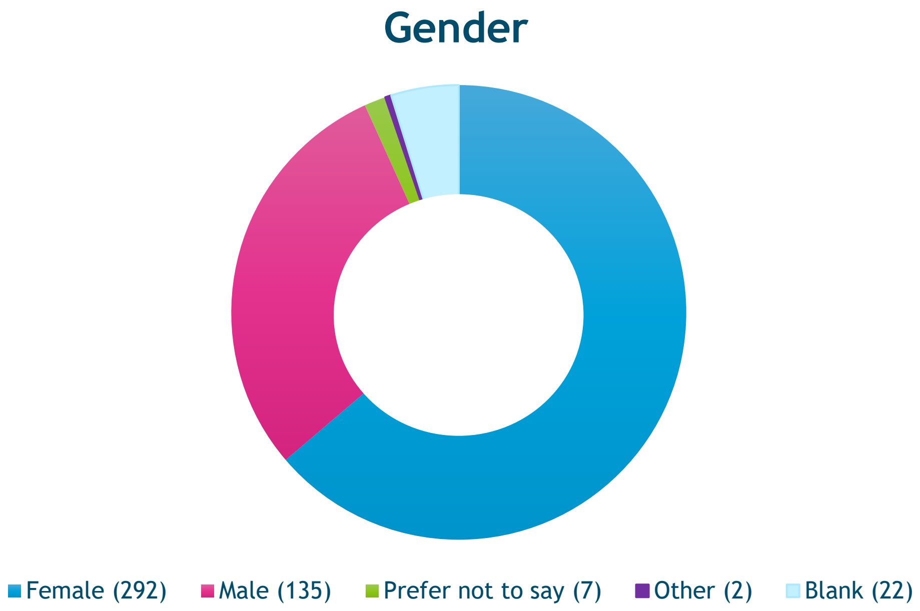
In terms of our engagement, we gathered views through:

- Surveys - we received 458 responses
- Focus groups with the Black Minority Ethnic (BME) Community, a mental health group, a learning disability group and an elderly group.

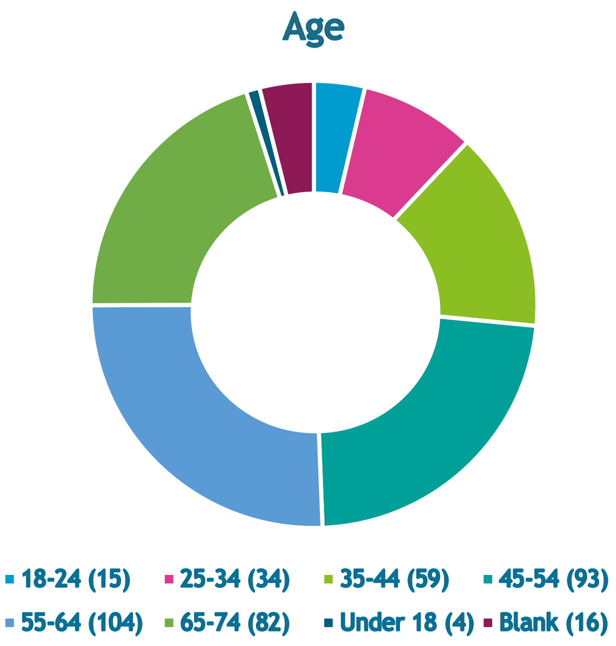
Who we spoke to

The following charts provide the demographics of those who took part in our surveys.

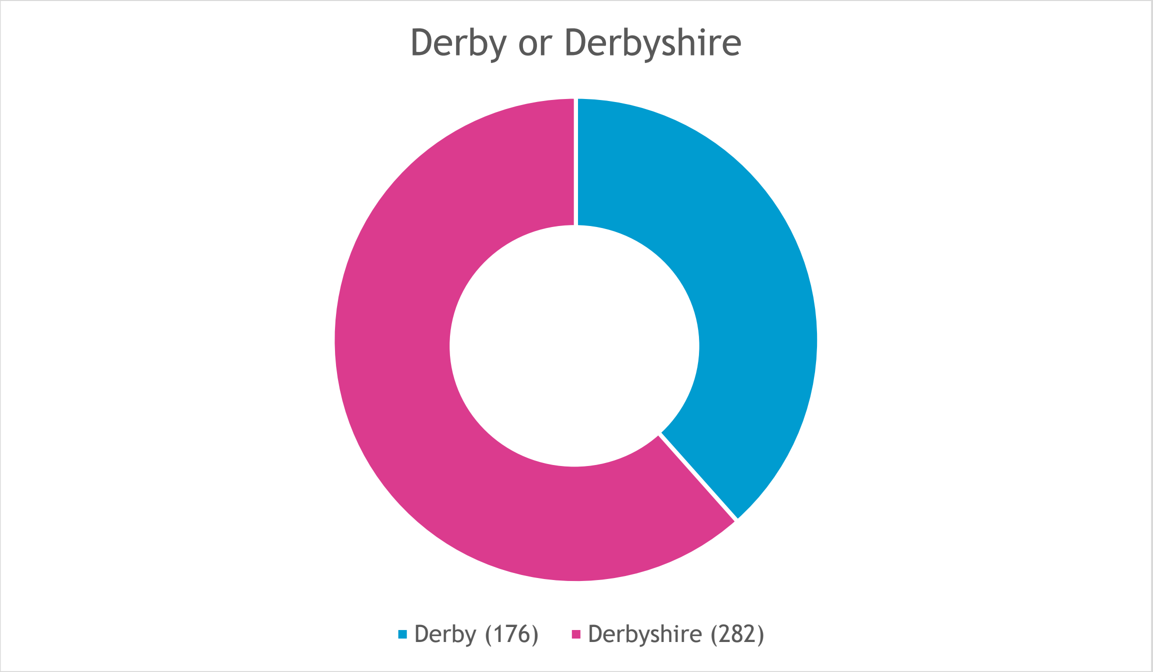
- Gender



- Age



- Derby or Derbyshire resident



Summary of findings

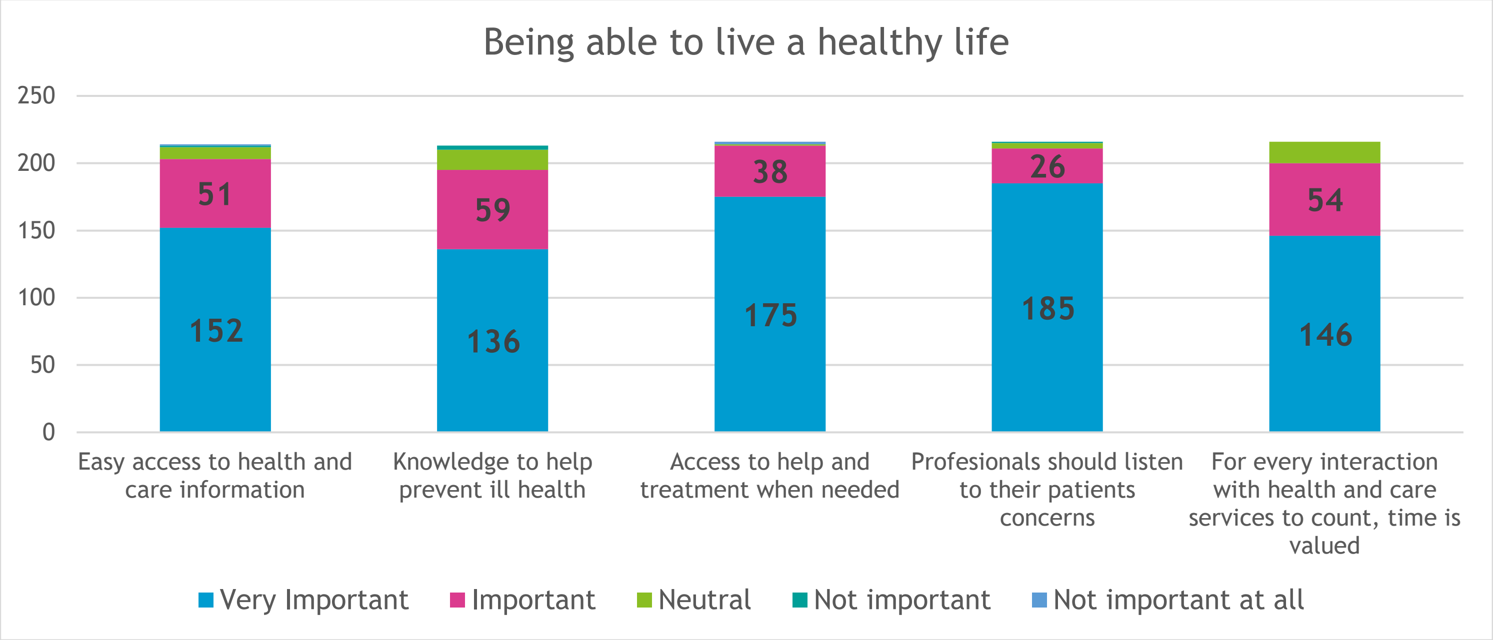
- People want to feel listened to by professionals when they first raise concerns about their health
- Carers want to feel listened to, and included in early conversations (where appropriate), about their loved ones health
- People felt education should be increased around where people can go to access information and advice, as it isn't always necessary to book a GP appointment (i.e. could visit a pharmacy)
- Quick and easy access to the relevant help and treatment was seen to be vital
- It was felt that patients and professionals should make joint decisions on any health or care treatment
- People should receive sufficient information in an understandable format to help them make choices about their health and care treatment
- A high proportion of people found it difficult to access ongoing support once they received their diagnosis
- Support from specialist professionals was highly valued i.e. Macmillan nurses
- Most people explained seeking help for more than one condition was much harder
- The importance of timely communication was seen to be paramount
- It was seen to be important for people to have the confidence to know their personal data is managed well and kept secure
- People want to be able to stay in their own home for as long as possible with the right support
- People want to feel well supported at the end of life.

What matters most to people in Derby and Derbyshire?

- **Having what I need to live a healthy life:**

The NHS is not just there to help people when they are ill, but to support people to live a healthy life too.

We asked people to rate how important the following statements were in relation to living a healthy life.



As you can see from the above chart, the top two most important things were:

1. For professionals to listen to patients about their concerns
2. To be able to access the help and treatment when needed.

Furthermore, we later asked people what is the *most* important thing to help them live a healthier life and with very similar results 43% of people felt being able to access the help and treatment when needed was most important along with, 26% of people who felt it was important for professionals to listen to their patients concerns.

Priority	What is most important to you to help you live a healthy life?	%
1.	Access to the help and treatment I need when I want it	43%
2.	Professionals that listen to me when I speak to them about my concerns	26%
3.	The knowledge to help me do what I can to prevent ill health	14%
4.	Easy access to the information I need to help me make decisions about my health and care	9%
5.	For every interaction with health and care services to count; my time is valued	8%

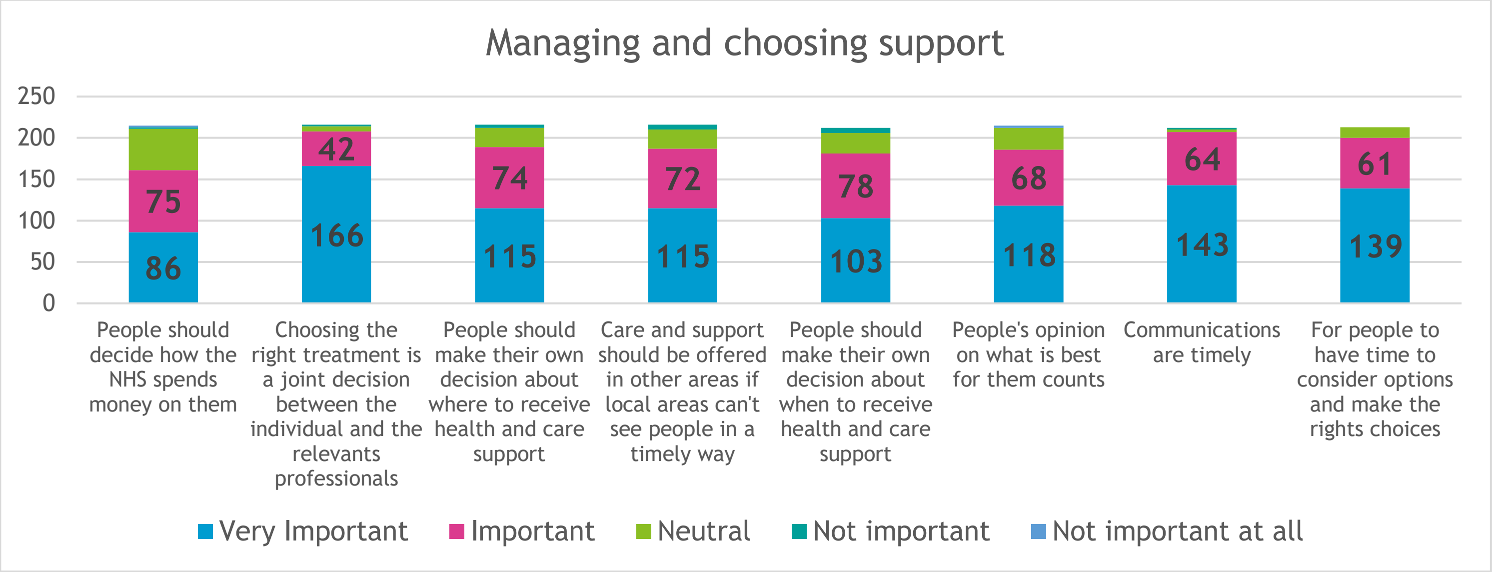
We also asked people to suggest one thing would help them to live a healthy life, the following are a sample of the comments made:

- “Easier access to health access and advice”
- “Access to support when needed”
- “Being able to get an appointment with my local doctor”
- “Information about groups in the community that can help me”
- “Having more support groups”
- “Having local clubs and health facilities that I do not need transport and money to get to”
- “More support on healthy diets”.

➢ Managing and choosing support:

When people are unwell and need support or treatment for their condition, they may need to be properly informed to be able to make choices about their own care and what may work best for them.

We asked people to rate how important the following statements were, in relation to managing and choosing support.



The chart above, shows that the top two most important things were:

1. For patients and the relevant professionals to make joint decisions on any health or care treatment
2. For communication to be timely.

We also asked people what is the *most* important thing to help them manage and choose support with very similar results, 40% of people felt it was important for patients and professionals to make joint decisions on treatment. Communication did not appear as important with only 4% of people listing this as a number one priority for managing and choosing support.

In addition, 16% of people felt they should be offered care and support in other areas if their local area could not see them in a timely way.

Priority	What's most important to you to be able to manage and choose the support you need?	%
1.	Choosing the right treatment is a joint decision between me and the relevant health and care professional	40 %
2.	I should be offered care and support in other areas if my local area can't see me in a timely way	16 %
3.	I have time to consider my options and make the choices that are right for me	10 %
4.	If I have a long term condition I decide how the NHS spends money on me	10 %
5.	I make the decision about where I will go to receive health and care support	9 %
6.	My opinion on what is best for me, counts.	7 %
7.	Communications are timely	4 %
8.	I make the decision about when I will receive health and care support	4 %

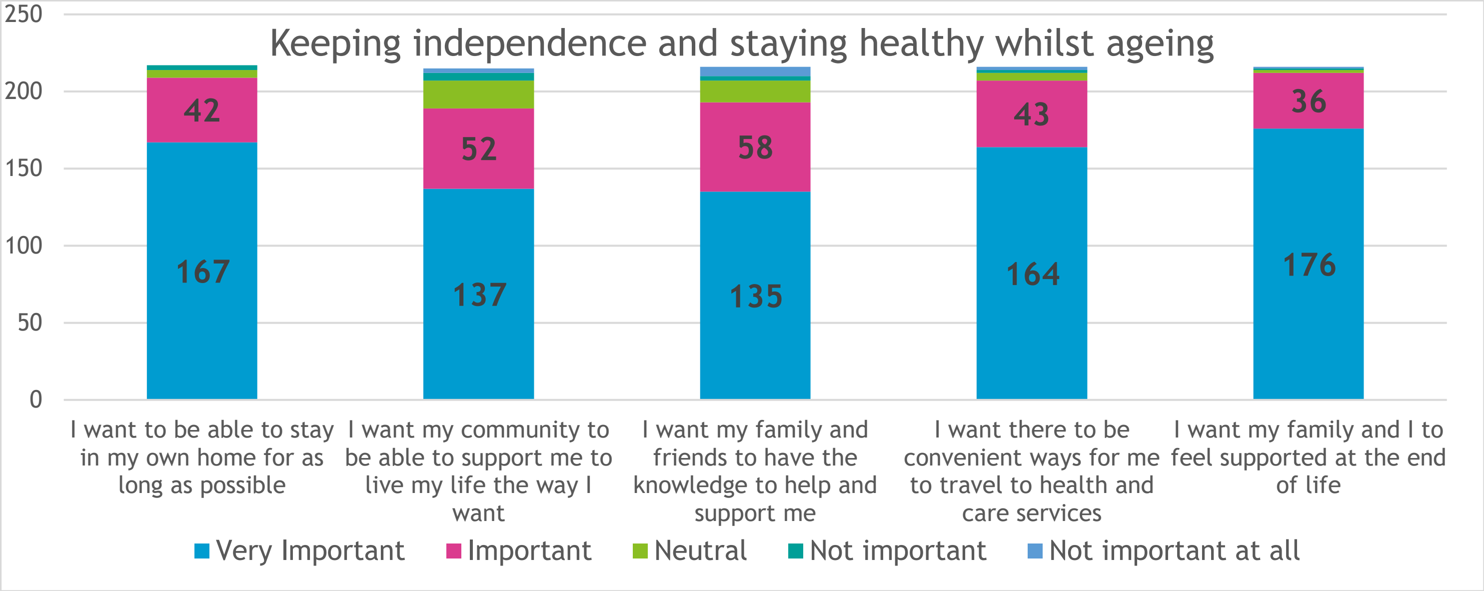
We also asked people to suggest one thing that would help them to manage and choose how the NHS supports them, the following are a sample of the comments made:

- "I have a choice in the specialist that treats me if I am not in agreement with the first specialist"
- "A clear explanation of the condition and the options for treatment, with the risks and potential benefits of each"
- "Understanding from health professionals. Too often seem disinterested"
- "Support offered is flexible and can move away from traditional methods"
- "Sometimes it feels like too much choice is given. Medical staff should be allowed to give clear opinions about what they think will and won't help. Sometimes, particularly when you're ill, you just want to be told"
- "Knowing I'm getting the best advice and not just being given the cheapest option"
- "See a doctor when you want, not have to wait and to have access to good medical advice"
- "Staff respect my choices and decisions and listen carefully to what my needs are and not feeling like I am in a sausage factory".

➢ Keeping independence and staying healthy whilst ageing

The ageing population is placing greater demands on the NHS and it is evident that people want to be able to look after themselves for longer, and the NHS wants to help people to do so.

We asked people to rate how important the following statements were, in relation to keeping independence and ageing healthily.



The chart above, shows the top two most important things were:

1. For people to feel supported at the end of life
2. To be able to stay at home for as long as possible.

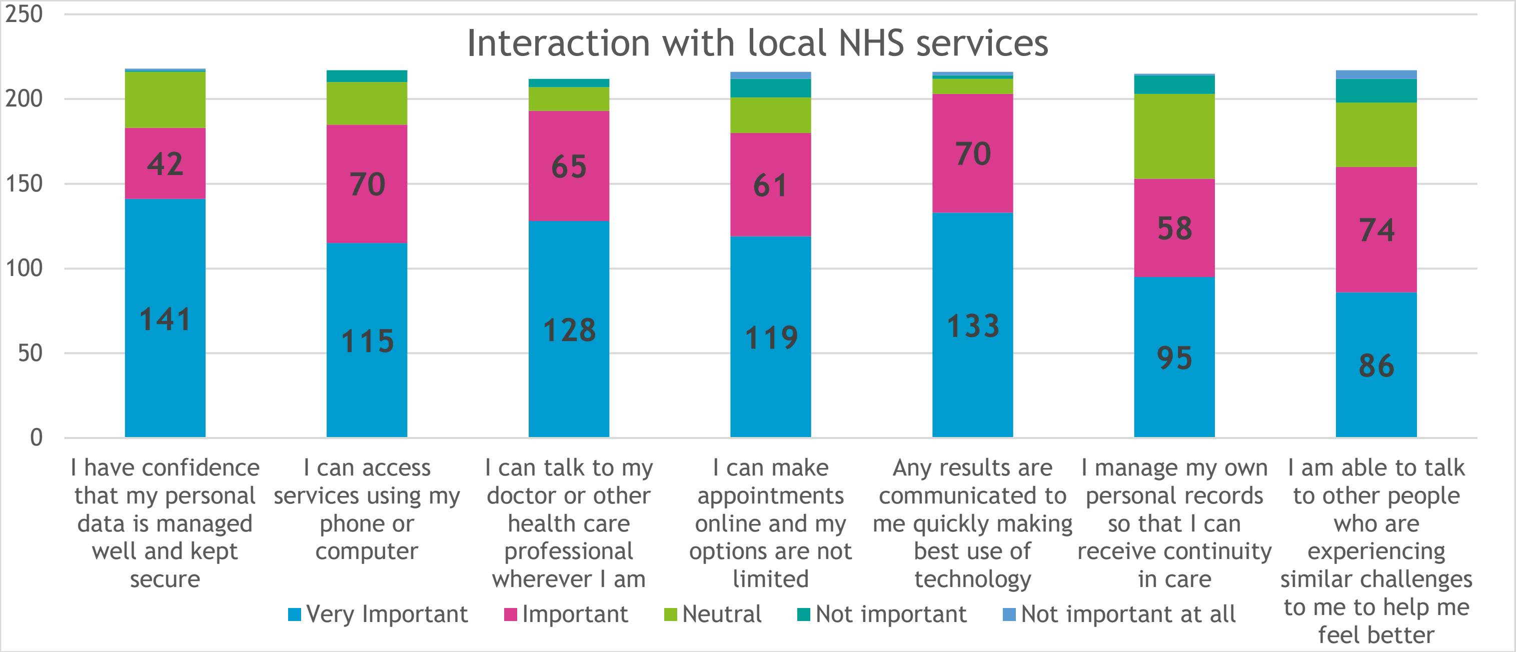
We also asked people what is the *most* important thing to help them keep their independence and stay healthy, 56% of people felt the most important thing was to be able to stay at home for as long as possible. The second most important thing was that 14% of people wanted there to be convenient ways to travel to health and care services.

Priority	What's most important to you to help you keep your independence and stay healthy as you get older?	%
1.	I want to be able to stay in my own home for as long as it is safe to do so	56%
2.	I want there to be convenient ways for me to travel to health and care services when I need to	14%
3.	I want my family and me to feel supported at the end of life	13%
4.	I want my community to be able to support me to live my life the way I want	10%
5.	I want my family and friends to have the knowledge to help and support me when needed	7%

➢ Interaction with local NHS services

It is important for the NHS to adapt to make it easier for people to access support they need, when they need it.

We asked people to rate how important the following things were, when interacting with local NHS services.



The chart above, shows that the top two most important things were:

1. To have confidence that personal data is managed well and kept secure
2. Results are communicated quickly, using best use of technology.

We also asked people what is the *most* important thing when interacting with local NHS services, 40% of people felt being able to talk to a doctor or health professional regardless of where they were was the most important thing and 23% felt feeling confident there personal data was being managed well and kept secure was most important.

Priority	What is most important to you when interacting with the NHS?	%
1.	I can talk to my doctor or other health care professional wherever I am	40%
2.	I have absolute confidence that my personal data is managed well and kept secure	23%
3.	I can make appointments online and my options are not limited	13%
4.	Any results are communicated to me quickly making best use of technology	13%
5.	I can access services using my phone or computer	5%
6.	I manage my own personal records so that I can receive continuity in care	4%
7.	I am able to talk to other people who are experiencing similar challenges to me to help me feel better	2%

We also asked people to suggest one thing that would help them to retain their independence and live a healthier life for as long as possible, the following are a sample of the comments made:

- “Properly regulated home help services not quick calls that do nothing to really help you. NHS should run home help services”
- “More funding for care at home”
- “More help at home when I need it”
- “Provision of 24 hour care if needed. This is too demanding for family and friends to cope with”
- “Stay in my own home as long as possible”
- “To have the support and facilities to still be able to do activities”
- “Homecare services are provided for me at the time I want them and not when it suits the provider e.g. being put to bed at 6pm because there are not enough staff to do this later in the evening and vice versa in the morning”.

Focus group - older people and healthy ageing

We undertook a focus group with ten older people in Derby City about ageing healthily.

The group were asked about what they thought worked well, what didn’t work very well and what could have been easy to improve in terms of health and care services in Derby city.

Many participants explained how they currently stay healthy, through eating healthily and undertaking light exercise.

The following are the main themes that emerged from the focus group:

➢ Carers

Carers explained the importance of feeling listened to by health and care professionals in respect of their loved one. It was felt that in terms of hospital visiting hours, carers should be able to visit outside of the ‘standard times’ to be able to offer help and support. However, it was felt that hospital staff are not always aware of the visiting policies for carers.

In addition, carers commented on how important it is for health and care professionals to really understand their caring role and ensure they are included within the care of the cared for. One carer explained, “Some GPs worked really well with me as a carer, I felt part of a team”. Another said, “Excellent recognition for me as a carer”.

It is important to ensure there is flexibility offered to carers to be able to share their concerns or update health and care professionals on their loved one. One carer said, “Telephone calls to GPs takes far too long – I needed an email address to communicate as a carer”.

How should carers be involved and supported?

1. “We need to be treated as equal expert partners”
2. “Carers will increase in numbers so must be seen as part of the solution, not lip service”
3. “Total involvement is vital”
4. “Carer must be supported”.

➢ Pharmacy and medication

It was felt that more people should be aware they are able to ask for advice from a pharmacist, rather than having to always go to their GP.

Participants also felt it was good that you are able to now order prescriptions online to be sent to pharmacy.

➢ Information

It was highlighted how important it is for people to receive sufficient information to be able to make choices about their health and care treatment.

Information should be forthcoming and in a way that patients and carers understand, which would lead them to be able to make more informed choices. Majority of the participants would like information provided by their GP but also expressed a necessity of continuity of care with the same doctor which would also improve communication.

Participants felt that information should be provided by:

- A GP
- GP receptionists to be trained and supported to share signposting information
- Friends and family
- To have a drop in centre
- Internet and NHS website
- Over the phone.

➢ Joined up care

Participants explained the importance of ensuring different services communicate with one another. One person explained, “Poor communication between hospitals and social care services caused unnecessary anxiety and ultimately delayed discharge”.

➢ GP appointments

Participants commented on how it is becoming increasingly difficult to book a GP appointment. It was felt that access to GPs should be improved and to ensure people have a named GP so there is continuity in care.

➢ What matters most to people

1. To be able to see a specialist
2. For staff to be trained and have the relevant knowledge.

➢ Feeling supported

Participants wanted to be supported by a range of professionals and services, but generally by the most relevant one to them. Ideally they would like this to take place close to home but also realise that isn’t always possible regarding specialist advice and treatment.

Some participants felt that a wider range of services could be delivered at home but also appreciated that this might not be possible due to a number of factors.

➢ Engagement in system wide changes

Participants explained they would want to be engaged in any potential cuts or changes to services.

Generally people want to be engaged in a timely manner, particularly about changes to, or closures of services. They want to be informed about the benefits to them of the changes. Where they have been asked about their experience or opinion, they would like to have feedback.

Focus group – Black Minority Ethnic (BME) community

We undertook a focus group in Derby City with 12 members of the community who identified themselves as Black African, Indian, Black Caribbean and Asian British.

The purpose of the event was to discuss the general experiences of health and social care with the local BME community to find out what works well and what could be improved.

The following are the main themes that emerged from the focus group:

➢ GPs

A number of participants explained their difficulty of being able to book a GP appointment.

It was felt that the early morning, or evening appointments are often given out to those who could visit their GP within the day, making it more difficult for people who work to be able to get an appointment outside of the ‘standard’ hours.

Some participants felt that staff particularly GP receptionists can ‘speak down’ to patients and be ‘a bit condescending like a child’. It was also explained, that receptionists are usually the first person people come into contact with and there can be language barriers for those where English is not their first language. It was noted that this also happens at other services such as the walk-in centres.

In addition, one participant explained, “111 service was not helpful, was asking me to repeat self over and over. So hung up and went A&E”.

➢ Engagement in system wide changes

Participants explained they would want to be engaged with any changes and/or closures to local services. One participants said, “I would like to know what they are and why they are needed [the changes]”.

It was explained that individuals should be aware of why changes are needed and to be advised of all alternatives.

Another participant explained, “Where there is a major change everyone in the city should be written to and given chance to comment. The wishes of local people should count and be fed back”.

➢ What matters most to people

1. Education across all areas
2. Good communication
3. Joined up care
4. Early assessment, diagnosis treatment
5. Personalised care
6. Services closer to home
7. For professionals to be understanding of individual’s faith/language.

Feedback around specific conditions

Cancer services in Derby and Derbyshire

In terms of our specific conditions survey 39 participants completed the cancer survey.

Assessment, diagnosis and treatment

Accessing help for cancer

38% of participants felt supported when they first tried to access help. Experiences of whether support met people's need varied across the county. Some participants explained they had an 'excellent' experience of treatment from the start, whilst others explained they had to be more persistent to receive a diagnosis and access the relevant support.

In terms of overall experience of accessing help, 42% of participants explained they had a positive experience, and 39% explained it was average.

The top themes were:

1. People want to feel listened to and taken seriously when sharing initial concerns with a GP
2. To have a quick response time between referrals, initial assessments and diagnosis
3. To have time to talk through the diagnosis with professionals and learn about the support available
4. To have more joined up care.

Sample of comments:

- "Named professional and his team repeatedly did not spot the mole as being skin cancer, this went on for several years and I had to go private to get it diagnosed"
- "It took more than one attempt to get a referral for a mammogram and biopsy"
- "I had a quick referral, support from specialist nurses and enough space to process the diagnoses. The initial contacts were all great"
- "Perhaps having someone to talk things through after consultations"
- "Not quick enough. Departments not joined up in terms of talking to each other"
- "Different staff and departments had various levels of concern, there needs to be a more linked up response"
- "I think maybe additional appointments for just talking would be good as all the medical stuff is thrown at you, and you need time to process that"
- "In my case I felt mostly well supported. I have no complaints. However I did feedback to staff that although it was important to focus on my physical recovery I was hardly ever asked how I was feeling. My head was a mess and felt totally screwed up. I have since received psychological support in a group situation which was very helpful"
- "Although the GP referral was quick and the follow up, we were not advised as to what support we could get from other agencies including financial support. We needed to research this ourselves".

Multiple conditions

A total of 46% of participants explained they had another long-term condition or disability in addition to their cancer diagnosis. 53% of people explained that seeking support for more than one condition made getting support much harder, compared to 12% of participants who said it made getting support easier.

Length of time to receive initial assessment, diagnosis and treatment

In terms of the wait to an initial assessment or diagnosis, there appeared to be an equal split between responses and it would seem that most participants were seen within the standard timeframe (two weeks).

For treatment, 36% of people explained this happened quite quickly, compared to 28% of people who explained they were left to wait.

Sample of comments:

- “Two weeks which is standard and the hospital squeezed me in, I was very grateful”
- “I was not under a consultant so I had to keep calling the hospital to chase the biopsy and scan results”
- “To get to see a consultant approximately six weeks”
- “Two weeks between diagnosis and getting the results”
- “There were lots of tests and x-rays which needed doing so all this takes time to organise”.
- “I didn’t have to wait long at all, from diagnosis to operation to treatment, it was all organised and followed on, and the treatment is still on going too. Thank you, Derby Royal, you do the NHS proud”
- “Ten days from scan to diagnosis and two weeks for chemotherapy”.

➢ Referral to a specialist

86% of participants explained they were referred to see a specialist and 42% of participants described the length of time between their initial appointment and seeing the specialist as quite quick.

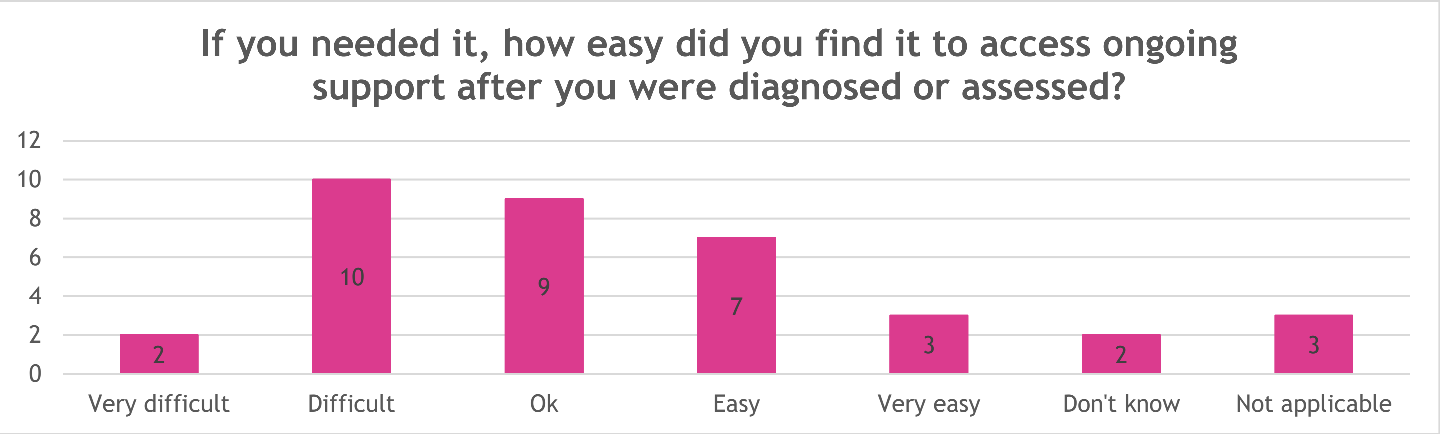
It would appear that most people were seen very quickly and did seem to be left waiting.

Sample of comments:

- “Not long at all. It was very well organised”
- “Two to three weeks”
- “I didn’t have any long waits, everything seemed to flow”
- “The medics had difficulty deciding which team should him, hence he came under three different consultants before one of them decided to go ahead and begin treatment”.

The provision of ongoing care and support

We asked people about the provision of the care and support they experienced following a diagnosis of cancer.



As demonstrated in the above chart, 33% of people explained they had difficulty in accessing ongoing support following their cancer diagnosis.

➢ Access to further health and care support

After being diagnosed or assessed, 36% of participants explained they had not been offered access to further health and care support.

In terms of aspects of support for people diagnosed with cancer that worked well, Macmillan nurses were highly valued, it also appeared extremely important for people to have a named contact for if/when they had any questions about their diagnosis or any aspect of their care.

Sample of comments:

- “The specialist nurses were incredibly helpful, but so stretched that it was hard to contact them”
- “Specialist nurses answered all questions”
- “Seeing the same consultant”
- “Access to a qualified breast care nurse, I used the telephone helpline to ask questions and seek reassurance or just check that what was happening to me was normal, they always rang me back and it gave me confidence which helped my recovery”
- “To have an allocated nurse and consultant”.

➢ Support meeting expectations

41% of participants felt the support options met their expectations, compared to 21% who felt the support did not meet their needs.

Many people explained that they would have liked more avenues to access support and to have the opportunity once the diagnosis had ‘sunk’ in, to have a follow up appointment in order to be able to ask questions and really understand the treatment.

Sample of comments:

- “Can access advice over the phone, e.g. is it OK to have a shingles vaccination?”
- “It was there if I needed it, I think maybe a follow-up with a nurse would have been good after the initial diagnosis as it is hard to take it all in at one appointment”
- “I needed more understanding about the other difficulties that I face. If I had not had the support of my family I would have found it very difficult to access and understand my treatment”
- “As mentioned before it took a long time to find out what services were available (through trial and error) and to understand at what point in the process we could access these”
- “Fast, clear, accurate information received”
- “All professionals involved were caring, sensitive and compassionate. No improvements identified”
- “Voluntary services were excellent in signposting to useful contacts”.

➢ Improvements to health and care support

In terms of aspects of support for people diagnosed with cancer that could be improved, the following were highlighted:

1. Continuity of care
2. Follow up appointments and for professionals to stay in touch as circumstances change
3. More help to find the right information

Sample of comments:

- “Able to see the same consultant”
- “It would have been great if the GP followed up with another review meeting as I am now five months into treatment”
- “To have more information available”
- “As the illness developed we were asked on several occasions, ‘Is there anything else you need?’. As a lay person, we didn’t know what was available, or what we might need”

- “All information has to be sought out, we have not had one person to whom we could address out concerns or ask questions”
- “Information. They just presumed I knew stuff”.

Communication

In terms of communication, 47% of people felt they received consistent communication from support services compared to 29% who felt communication was not consistent.

Long-term conditions e.g. diabetes, arthritis in Derby and Derbyshire

In terms of our specific conditions survey 77 participants completed the long-term condition survey.

Assessment, diagnosis and treatment

Accessing help

30% of people felt supported when they first tried to access help. The main theme was around the importance of GPs taking initial concerns seriously and listening to their patients.

Overall, 42% participants rated their experience of accessing help as positive, compared to 32% of participants who explained they had a negative experience.

Sample of comments:

- “When the symptoms for what we now know to be rheumatoid arthritis started at the age of 19 I don't feel my GP took it seriously enough, possibly because of my age. Eventually I went for x-rays and blood tests
- “GP's don't have time to discuss a health problem. The usual response is to increase and take more of the prescribed tablets instead of discussing other 'new' meds”
- “I had to wait over 12 months for a lung function test, although I had been to my GPs repeatedly”
- “My GP told me I was too young for hip replacement and would not send me an x-ray I paid to see an orthopaedic consultant who told me I needed a replacement ASAP”.

Multiple conditions

A total of 68% of participants explained they had multiple long-term conditions. 51% of people explained that seeking support for more than one condition made getting support much harder, compared to 8% of participants who felt it made getting support easier.

One participant explained, “I was not listened to, my appointment with the consultant was rushed, I do not feel I have had an accurate diagnosis, the care is not consistent, other conditions are not taken into account when deciding on my care, I still do not think I am on the correct medication”.

Length of time to receive initial assessment, diagnosis and treatment

43% of participants felt it took a long time to receive their initial assessment or diagnosis.

In terms of treatment, 34% of participants explained they had to wait quite a while between their initial assessments and to receive their treatment, compared to 26% of participants that felt this happened very quickly.

Sample of comments:

- "It was seven or eight months before I got Fibromyalgia diagnosis. I understand it can't be diagnosed until had the symptoms for three months. However, there were then delays with the consultant's report which delayed me getting my work ill-health pension. Also not having a diagnosis meant my work colleagues were sceptical about why I wasn't back at work"
- "It was months and months of seeing various GPs all of whom were dismissive of the symptoms before we finally got the referral to a consultant"
- "To receive first diagnosis it took more than a year of constant pushing for answers"
- "From initial identification of a problem there was a long wait for diagnosis which wouldn't have been possible if I hadn't done my own research and fight for a referral to a specialist".

➢ Paying privately for a diagnosis

A number of participants explained the delays around referrals to specialists and the difficulties with getting a diagnosis for some long-term conditions. Therefore, many participants paid for a private assessment to speed up the process.

Sample of comments:

- "I ended up going for a paid-for private consultation"
- "I wasn't getting anywhere with the NHS hospital so my mum paid for me to go to a private hospital when I received a diagnosis"
- "It was ok because I paid for it".

➢ Referral to a specialist

71% of participants explained they were referred to see a specialist and 19% of people described the length of time between their initial appointment and seeing the specialist as very quick compared to 40% of people who describe the length of time as long.

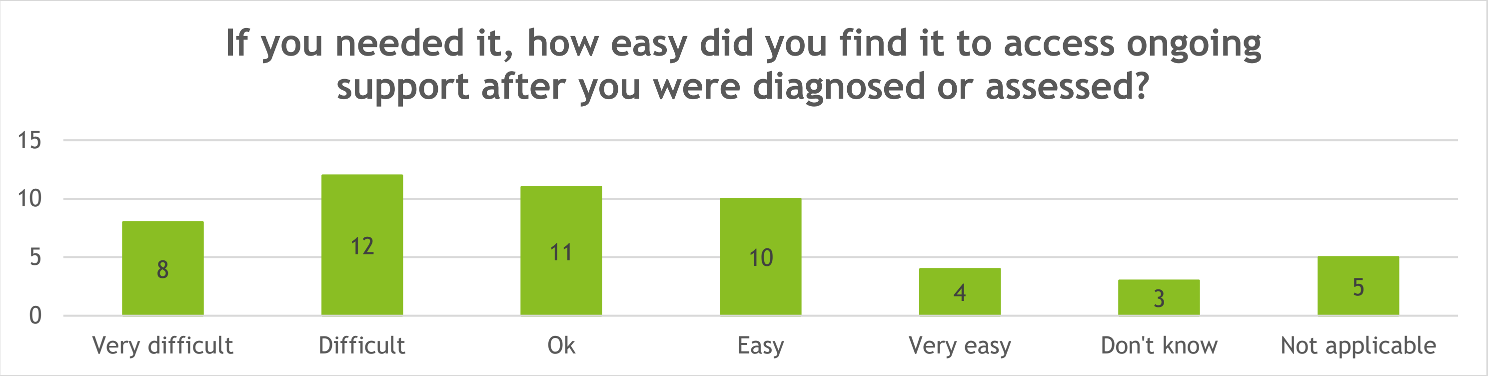
Some participants explained they were seen 'within weeks' whilst others were left waiting several months.

Sample of comments:

- "Very slow to gain access to a rheumatologist"
- "I waited few months in between specialists"
- "Months in between appointments and tests".

The provision of ongoing care and support

We asked people about the provision of the care and support they experienced following a diagnosis of a long term condition.



As demonstrated in the above chart 38% of people explained they had difficulty in accessing ongoing support following their diagnosis of a long term condition.

Access to further health and care support

After being diagnosed or assessed, 61% of people said they had not been offered access to further health and care support.

In terms of aspects of support for people diagnosed with a long-term condition that worked well, the overwhelming theme was having access to specialist nurses.

Sample of comments:

- “RA specialist nurse”
- “Having direct access to nurses who had dealt with their inpatients in morning they always ring back as soon as they can. Also having support of voluntary organisation dealing solely with my condition has been vital”
- “Diabetes nurses were amazing support and allowed me to pop and see them with any questions and this has always continued”
- “Specialist nursing support, this was initially visits in my home every six months. Then this went to six monthly phone calls and sporadic clinic invites. This service has progressively deteriorated”.

Support meeting expectations

29% of participants felt the support options met their expectations, compared to 39% who felt the support did not meet their needs.

Many people explained that they were initially unaware of the support available and would have liked to have been signposted, or made aware of the support available.

Sample of comments:

- “Was not offered any support at all, just continual cancellations”
- “I found out about a local support group by chance. It would have been better to have been signposted to them by my GP”
- “I wasn't offered any other support, despite being in constant pain and having difficulty walking, no-one had suggested I may be eligible for a Blue Badge and I don't like to waste an appointment to discuss this”
- “There is absolutely no follow up care”
- “There has been no continuity of care, I was handed leaflets to read but did not have a conversation, I was not given the opportunity to ask questions or give an opinion, I was made to feel like I was a burden”
- “I didn’t get offered any help. I accessed some support myself but it didn’t help much”
- “I felt a bit isolated, although I had weekly treatment, it was difficult to talk about my concerns”.

Improvements to health and care support

In terms of aspects of support that could be improved for people living with a long term condition, the following were highlighted:

1. Promote the types of support available
2. Increase education around different long term conditions
3. Provide services closer to people’s home.

Sample of comments:

- “Ensure that newly diagnosed patients are aware of the support network - have newsletters of the support group readily available”
- “Increase knowledge and understanding”
- “Bring follow up services out of centralised unit”
- “Localise service to provide closer to home”
- “All services are not always very clear about what they are providing and who and why it is being provided. Understanding is not always checked”
- “Provide life long course”.

➢ Communication

31% of participants felt they received consistent communication from support services compared to 43% of participants who felt they did not receive consistent communication.

Prevention and/or early intervention

In terms of prevention, some comments suggest the importance of early education to ensure people know how to live a healthy life and try and prevent certain long term conditions.

Sample of comments:

- “Medication was generally effective and repeat visits for check-ups when needed were able to provide enhanced treatment for glaucoma. Education on diet and exercise to prevent diabetes was excellent”
- “Support to prevent diabetes was excellent after I was diagnosed by my surgery as pre-diabetic. We need to continue/do more if possible to educate patients in how to live healthier lives in order to prevent long-term conditions from developing so that the NHS doesn't have to pay to treat them. We need to take more responsibility for our own health”.

Autism in Derby and Derbyshire

In terms of our specific conditions survey 14 participants completed the autism survey.

Assessment, diagnosis and treatment

➢ Accessing help

In terms of how well supported people felt when they first tried to access help, 57% of people felt their needs were not met.

Overall, 58% participants rated their experience of accessing help as negative.

The main theme was that parent/carers often had to be persistent with services and ‘fight’ for a diagnosis.

Sample of comments:

- “Mental health support for my 15 year old son has been abysmal. He was diagnosed at four years old as autistic and has been pushed from pillow to post. He's cut his own throat”
- “No clear referral pathway between health, social care and education”
- “We were just sent away like we were bad parents and advised to do yet another parenting course. In our first meeting we felt rushed and were asked to just pick our main couple of concerns to talk to them about. We had many. We felt like our concerns were not taken seriously”.

Multiple conditions

A total of 82% of participants explained they had another condition or disability in addition to their autism diagnosis.

33% of participants explained that seeking support for more than one condition made getting support much harder compared to 22% that said it was much easier.

Length of time to receive initial assessment, diagnosis and treatment

67% of participants felt they had to wait a long time to receive their initial assessment or diagnosis.

In terms of treatment, 60% of participants explained the slow process between their initial assessment and receiving treatment.

Sample of comments:

- “We expressed concerns when our son was two years old. It took five years before a diagnosis was made”.

Referral to a specialist

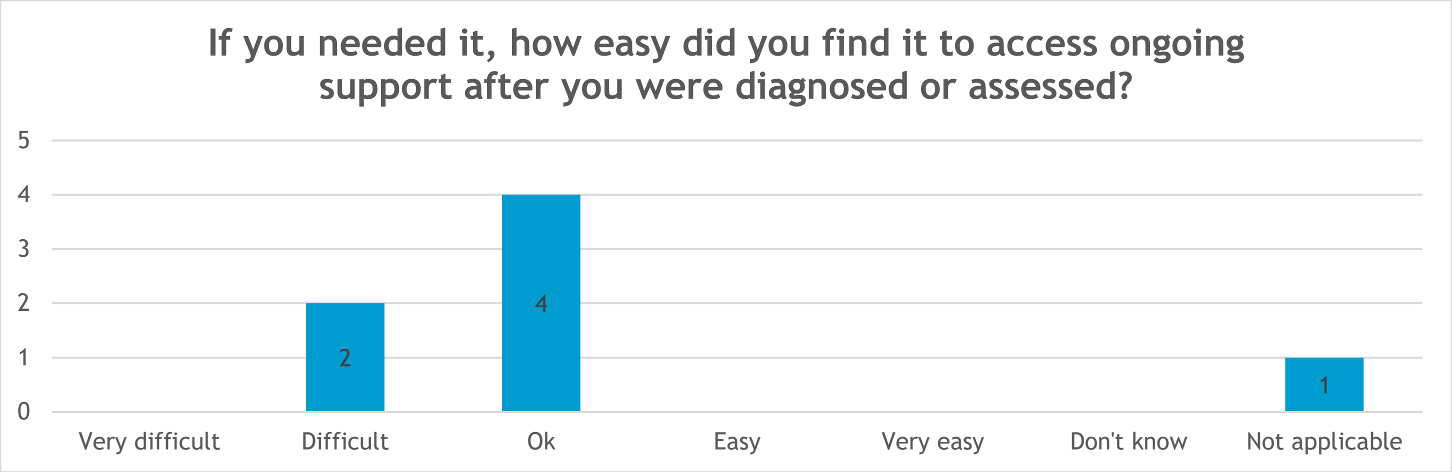
50% of participants explained they were referred to see a specialist. 33% of people described the length of time between their initial appointment and seeing the specialist as fast compared to 33% of people who describe the length of time as slow.

Sample of comments:

- “We saw a paediatrician when our son was in reception aged four. We were then discharged even though we still had concerns and did not feel we were being listened to. We then struggled on for a couple of years until he was nearly six and had to see another doctor following our son having periorbital cellulitis who, when I discussed the problems, wrote a letter to the paediatrician team requesting another appointment to be made to see him again. After this he was seen in about one year”
- “It took almost two years for my son to see a community paediatrician to get a diagnosis of ASD. During this time he couldn't properly access education as he was running around… he just could not cope. His difficulties quickly came home too. The waiting times are not acceptable in anyway shape or form. Since then I have been sent on parenting course and he has been issued with medication for the co-morbid ADHD. However, no one will help him with his anxiety which is what causes his sleep difficulties and is what often fuels his behaviours. So yes and no regarding his needs being met”.

The provision of ongoing care and support

We asked participants about the provision of the care and support they experienced following a diagnosis of autism.



As demonstrated above, 67% of people explained they had difficulty in accessing ongoing support following their autism diagnosis.

➢ Access to further health and care support

After being diagnosed or assessed, 83% of participants explained they had not been offered access to further health and care support.

In terms of aspects of support for people diagnosed with autism that worked well, a number of parent/carers explained how beneficial and helpful they found the educational course to be.

Sample of comments:

- “On receiving diagnosis we were handed a file full of leaflets etc of other sources we could try and approach for help, which in itself was overwhelming. We were then advised we could attend parenting courses to help understand the diagnosis and methods to help support our son. A pack full of leaflets wasn't helpful, a more personalised service would have been helpful. The courses on the other hand were very good”
- “Got sent on courses to manage son’s ASD and ADHD and school got more help”.

➢ Support meeting expectations

67% of participants explained that the support they were offered did not meet their expectations. It was explained that people would have liked for someone to sit and go through what support was available, rather than be handed a number of leaflets.

Sample of comments:

- “We didn't really understand where we went from being told the diagnosis. Just lots of information in leaflets to look at. We needed support at home etc. I would have liked a more personal approach or someone personally going through things with you would have been more beneficial”
- “More child centred support is needed it needs to be more accessible as I can't attend courses as I have no support and I have a ten month old”
- “Children and young adults living with higher functioning autism are expected to get on with their life without any further intervention. It is difficult to then reassess the services required when a problem arises. The result is that the general public don't understand your difficulties, your family understand but are unsure how to support, and your GP has no access for further assessment/help”

- "Tell me what I'm entitled to, see if I need it and provide it, otherwise you're just leaving a now identified vulnerable person to get worse until they either figure out how to ask and get put on a waiting list and eventually get help or something bad happens to them that actually lands them in A&E, with the crisis team".

Improvement to health and care support

In terms of aspects of support that could be improved, the following was highlighted:

1. More education course for parent/carers at convenient times

Sample of comments:

- "Some of the courses were just a few hours split over a couple of days which meant taking lots of time off work. We personally would rather have done it on a day or had an option to attend classes in the evening as we both work"
- "More work with the actual child who is suffering".

Communication

25% of people felt they received consistent communication from support services compared to 50% of participants that felt communication was not consistent.

Dementia in Derby and Derbyshire

In terms of our specific conditions survey 24 participants completed the dementia survey.

Assessment, diagnosis and treatment

Accessing support

In terms of how well supported people felt when they first tried to access help, 46% of participants felt their needs were not met compared to 38% who did.

Overall 25% of participants rated their experience of getting help as positive compared to 50% who described their experience as negative.

Experiences varied, some participants felt their needs were met from the start, whilst others felt they had received the diagnosis and were just provided with information leaflets and no further support.

Sample of comments:

- "Very little support, medication was prescribed and lots of leaflets were given but no actual personal support"
- "Mum was an inpatient and diagnosed with vascular dementia and normal pressure hydrocephalus. As I am a nurse it was expected I was able to care for her every need and no offer of help was offered. Still, to-date, me and my family care for Mum at home. This is having a massive impact on all of our well-being and quality of life. I also work full time …"
- "My dad had vascular dementia and was also registered blind. There was very little support for his needs. We eventually received some support from the local community older adult mental health team but this was of little help, especially at times of crisis when Dad's behaviour became challenging. They were able to offer support to the main carer but the advice, certainly around future care of my dad was limited. We were also very keen to keep him at home as his illness progressed but were not supported with this and he ended up passing away in a nursing home which is what none of us wanted.

Dementia is a distressing and life changing condition for those dealing with having the condition and their carers"

- "My husband was diagnosed with Alzheimer's last July. I felt that I was just told the bad news and left to deal with it with little advice or guidance"
- "No, as a carer and on behalf of my mother, I don't believe they were well met initially. Although we knew the disease would inevitably progress, we were not kept informed of just how far it had progressed by the staff in the day unit where Mum used to go. When they eventually did include us, we were essentially told we had two weeks to find more suitable accommodation than the managed housing where Mum was situated and that she could no longer attend the day unit, as she was making other people in the group uncomfortable. We were not expecting that response at that time"
- "We haven't been offered any support at all".

➢ Multiple conditions

A total of 52% participants explained they had another long term condition or disability in addition to their dementia diagnosis.

58% of people explained that seeking support for more than one condition made getting support no different, however 25% explained it make getting support harder.

➢ Length of time to receive initial assessment, diagnosis and treatment

47% of participants explained they had to wait a long time to receive their initial assessment or diagnosis.

However, it would appear the initial assessment happened fairly quickly and it was the diagnosis that for some participants took a long time to receive.

In terms of treatment, 47% of participants were OK with the timeframe between their initial assessment and receiving treatment and 33% explained it took a long time.

Sample of comments

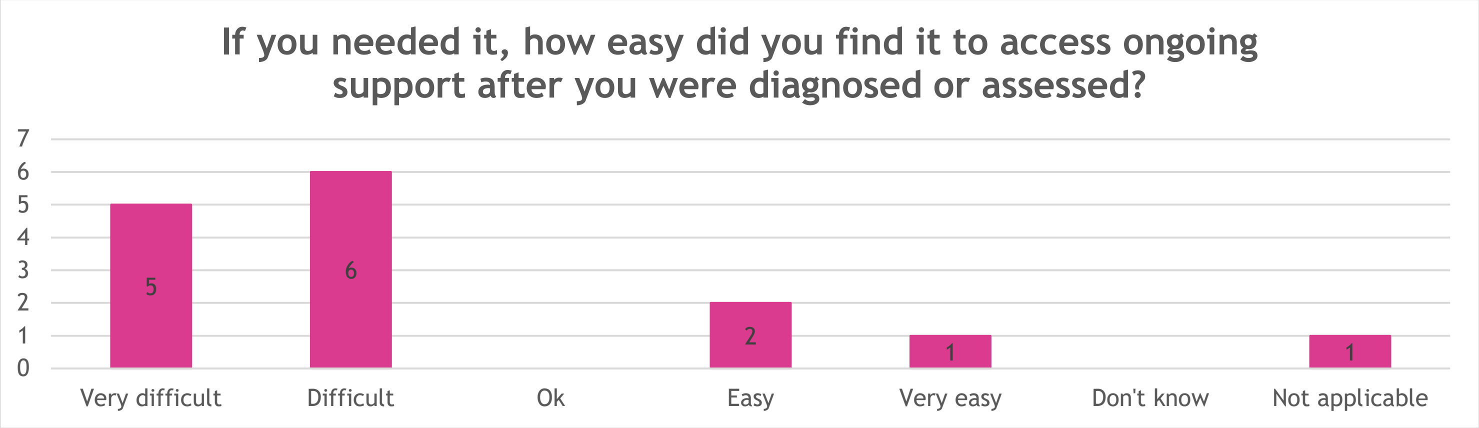
- "Initial assessment within a week"
- "The appointment was made to assess the situation within a week, the support took a few weeks to sort out"
- "We had to visit my wife's GP twice, before he was convinced by my daughter and I something was not right, so from memory, it was a few months"
- "Unable to recall exactly, but over six months"
- "It took three years to get the diagnosis for my wife and then there was no follow up. She still has no contact with social services or with a community psychiatric nurse. I'm not even sure they are aware of her".

➢ Referral to see a specialist

63% of participants explained they were referred to see a specialist, 33% of participants described the length of time between their initial appointments and seeing the specialist as OK, comparted to 21% who felt it was a long wait.

The provision of ongoing care and support

We asked participants about the provision of the care and support they experienced following a diagnosis of dementia.



As demonstrated in the above chart, 73% of people explained they had difficulty in accessing ongoing support following their dementia diagnosis.

➢ Access to further health and care support

After being diagnosed or assessed, 63% of participants explained they had not been offered access to further health and care support.

In terms of aspects of support for people diagnosed with dementia that worked well, participants explained they had a better experience when support was readily available and they were made aware of local support/education groups.

Sample of comments:

- "Support for the family, extra support for the customer, they have both got their own support worker"
- "Initially we were helped by the Alzheimer's Society, but also Derbyshire Council and we never really had to ask for help ourselves"
- "Dad attended a music group which he enjoyed but his sight impairment made it difficult for him to access other services which he would have enjoyed - a gardening group"
- "The living well programme and Chesterfield care group which provided day care for my mum".

➢ Support meeting expectations

64% of participants explained that the support they were offered did not meet their expectations.

Sample of comments:

- "The support was very helpful to the customers and their families, but some of the support was refused from the customer as they didn't like going to places where they didn't know anyone in case they got very confused"
- "Lack of continuity between services"
- "Different healthcare professionals and organisations did not communicate. No one communicated properly with the family"
- "When Mum was admitted to hospital this was often a disappointing experience. Even though I had filled in the 'this is me' profile in great detail I could tell the staff hadn't read it. They concentrated on getting her better physically but didn't seem to grasp the fact that her health and wellbeing were linked. She often didn't eat or drink unless prompted and food and drinks were often left on her tray untouched. She was very low in

mood and desperate together to go home. Discharge was often delayed even when she was physically well enough to go home because the communication between services was poor”
- “Hard to speak to the relevant person who often lacks experience and knowledge different contacts tell you different things. We rely on peer support”.

Improvements to health and care support

In terms of aspects of support that could be improved, the following were highlighted:

1. More support to help people stay active
2. Make breaks for carers more accessible
3. Promote and raise awareness of the local support groups which are seen to be invaluable.

Sample of comments:

- “Nothing”
- “Support taking the customers out, walking, meeting to have chat and maybe a drink, extra support for families like someone going round to sit with them whilst they had time to their selves”
- “Not having drop-in appointments for elderly man with dementia. Better to schedule contact with his official carers so we could check appropriate time and someone would be in”
- “Everything was OK”
- “Subsidised day care places would be really beneficial as it gives carers a break and the person (in this case my mum) had a purpose to get up for. She loved meeting her friends at the group and she had something to talk about when she got home her whole mood improved on the days she went to the group”
- “Previous dementia support service was really good. I have early symptoms of memory impairment and now I can't access support because I don't have a diagnosis which I think is totally wrong”
- “Appropriate follow up groups ran in the same way as the sessions attended”
- “Support is very patchy and you need to be in a dementia crisis to access anything of note. Various local groups and charities outside the NHS have been a much greater help”.

Communication

21% of participants felt they received consistent communication from support services compared to 64% of participants that felt they did not receive consistent communication.

Heart and lung disease in Derby and Derbyshire

In terms of our specific conditions survey 20 participants completed the heart and lung disease survey.

Assessment, diagnosis and treatment

Accessing help

In terms of how well supported people felt when they first tried to access help, there appeared to be an equal split with 35% of participants feeling their needs were met and 35% of people who felt their needs were not met.

Overall, 35% of participants rated their experience of accessing help as positive.

The main theme was that many participants did not receive support immediately after being diagnosed with a heart or lung condition. Some participants were told there was no cure, whilst others felt that people should be offered a lifelong programme of support.

Sample of comments:

- “I was told I had COPD and there was no cure”
- “Diagnosed with long-term heart disease and angina. No initial on-going support just the knowledge of having a long-term health condition. Some years later GP referred me to local government 12 month scheme to improve diet and reduce weight, it worked but then stopped and I felt isolated again. Currently on six week NHS scheme as GP advised. I am now borderline diabetic. For years I am identified within the health authority as having a life-long health condition and being at risk, yet the only support provided has been piece-meal, reactive and short lived. What I need is a recognised personal life long programme of support to help keep me on the right track, help build my confidence to improve and maintain my overall health and well-being”
- “The practice needed to have better knowledge and skill, and did not encourage self-management”
- “I had had a heart attack and as I was deteriorating fast I requested an urgent assessment fully supported by my doctors. A date was given for three months later. I went private and immediately treatment was given which was successful”.

➢ Multiple conditions

A total of 80% of participants explained they had another condition or disability in addition to their diagnosed heart or lung condition.

44% of people explained that seeking support for more than one condition made getting support much harder, compared to 31% who explained it made no difference.

➢ Length of time to receive initial assessment, diagnosis and treatment

50% of participants felt they had to wait a long time between the length of time people had to wait to receive their initial assessment or diagnosis.

In terms of treatment, 25% of participants explained the slow process between their initial assessment and receiving treatment.

Sample of comments:

- “Long waiting time about 3-4 months”
- “Typically 3-4 weeks from diagnostic test to results being available. Often longer if only available with an appointment that could be many weeks later”
- “Four weeks”.

➢ Referral to a specialist

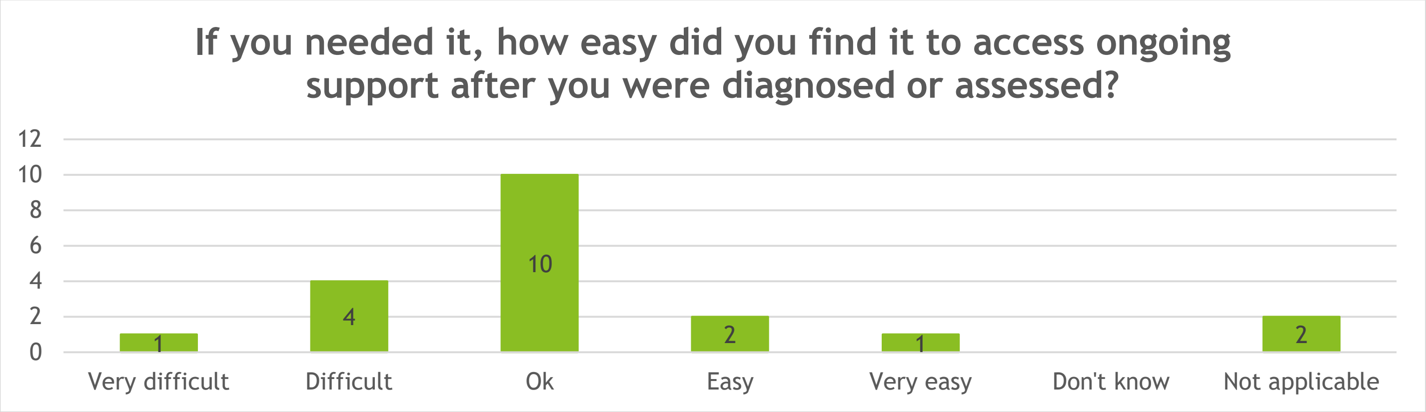
80% participants explained they were referred to see a specialist. 33% of people described the length of time between their initial appointment and seeing the specialist as fast compared to 38% of people who describe the length of time as OK.

Sample of comments:

- “Almost same day”
- “7-8 weeks”
- “As I was admitted as an emergency specialist help was soon provided”
- “About three months”.

The provision of ongoing care and support

We asked people about the provision of the care and support they experienced following a diagnosis of heart or lung disease.



As demonstrated in the chart above, 25% of people explained they had difficulty in accessing ongoing support following a diagnosis of a heart or lung condition.

➢ Access to further health and care support

After being diagnosed or assessed, 70% of participants explained they had been offered access to further health and care support.

In terms of aspects of support for people diagnosed with a heart or lung condition that worked well, a number of people highlighted the support offered by their GP.

Sample of comments:

- “The nurses taught me how to cope with my condition, what the long term prognosis was and exercises to help me”
- “Mum’s GP referred her for rehabilitation for several weeks which helped her see others that had problems of a similar nature and got her access to OT and physio”
- “I’ve had a great deal of support from my present GP practice as they know my condition and react quickly if I start to suffer with chest infections etc”
- “Support via the GP”
- “Derby chest clinic and excellent support from my GPs”.

➢ Support meeting expectations

35% of participants explained that the support they were offered did meet their expectations and 53% felt it sort of met their expectation. It was explained that people would like that they would have liked more someone to sit and go through what support is available, rather than be handed a number of leaflets.

Sample of comments:

- “I had to find out myself what help was available”
- “I have a life-long health condition, I received a time-limited support package and felt abandoned once that support was removed”
- “When I left hospital I had follow on treatment, but it was a bit confusing and not joined up”.

➢ Improvement to health and care support

In terms of aspects of support that could be improved, the following were highlighted:

1. More joined up care

Sample of comments:

- Better communication after leaving hospital as some participants felt this was "disjointed"
- "Staff are very busy and have little time, clearly higher staff levels are required".

Communication

44% of people felt they received consistent communication from support services compared to 28% of participants that felt communication was not consistent.

Learning disabilities in Derby and Derbyshire

In terms of our specific conditions survey seven participants completed the learning disability survey.

Assessment, diagnosis and treatment

Accessing help

In terms of how well supported people felt when they first tried to access help, 57% of people felt their needs were 'somewhat' met.

Overall, 71% participants rated their experience of accessing help as average.

Sample of comments:

- "Long waiting list for speech and language therapy"
- "Lack of information about what support was available. Not informed respite was available until we found out for ourselves".

Multiple conditions

A total of 71% of participants explained they had another condition or disability in addition to their learning disability.

50% of participants explained that seeking support for more than one condition made getting support much harder compared to 25% that said it was much easier.

Length of time to receive initial assessment, diagnosis and treatment

71% of participants felt they had to wait a long time to receive their initial assessment or diagnosis.

Furthermore, 43% of participants explained the slow process between their initial assessment and receiving treatment.

Sample of comments:

- "It took over a year"
- "We were not kept informed of the waiting time. The letters were not easy to understand when I got an appointment"
- "It took months for the people who could make an assessment and diagnosis"
- "Fairly quickly once educational professionals became involved".

➢ Referral to a specialist

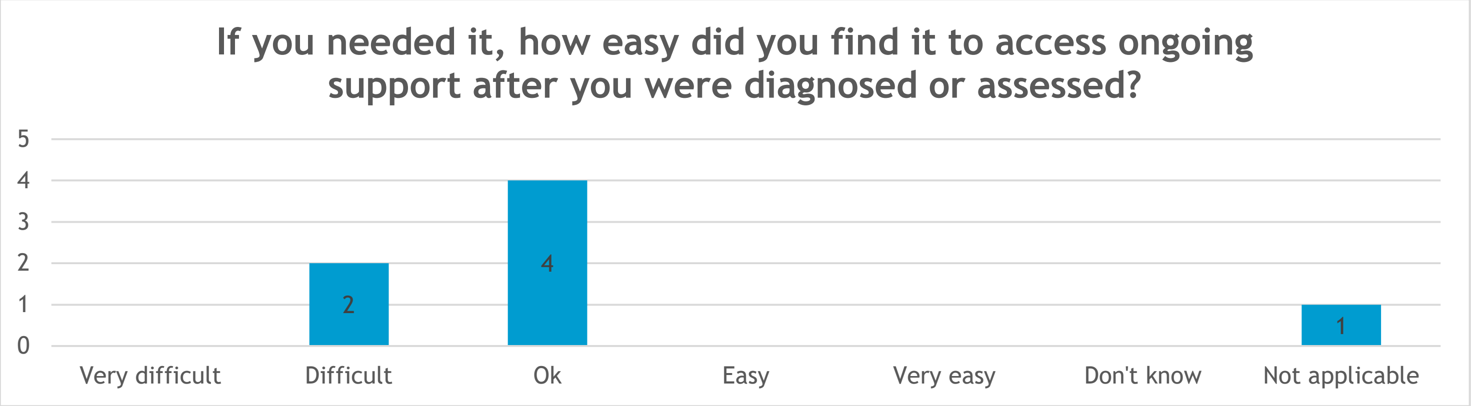
71% participants explained they were referred to see a specialist. 50% of people described the length of time between their initial appointment and seeing the specialist as ‘fast’ compared to 25% of people who describe the length of time as ‘slow’.

Sample of comments:

- “ We waited over a year”
- “It went very well but more staff training needed”
- “During the initial admission to hospital various consultants became involved”
- “It was quick because we went privately”.

The provision of ongoing care and support

We asked participants about the provision of the care and support they experienced following a diagnosis of a learning disability.



As demonstrated in the above chart, 57% of people explained they had difficulty in accessing ongoing support following a learning disability diagnosis.

➢ Access to further health and care support

After being diagnosed or assessed, 57% of participants explained they had not been offered access to further health and care support.

In terms of aspects of support for people diagnosed with a learning disability that worked well people liked therapy sessions.

Sample of comments:

- “Time with therapist”
- “Support in education. Speech and language therapy was all good”.

➢ Support meeting expectations

43% of participants explained that the support they were offered did not meet their expectations. It was explained that people would have liked someone to sit and go through what support is available, rather than be handed a number of leaflets.

Sample of comments:

- “Sometimes letters arrived a long time after”

- “Sometimes I did not receive letters on future appointments”
- “When surgery was required we had the support of the learning disability specialist nurse at the hospital. This was key, it was wonderful. The whole experience (which was mixed NHS and private) was wonderful”.

Improvement to health and care support

In terms of aspects of support that could be improved, the following were highlighted:

- “More time available with therapist”
- “Staff training around learning disabilities”
- “Behavioural advice and support, managing behaviour and outbursts, mental health support”.

Communication

50% of people felt they received consistent communication from support services compared to 16% of participants that felt communication was not consistent.

Focus group - learning disabilities

We undertook a focus group with 11 people with learning disabilities in Derbyshire.

We used to questionnaire to help guide a conversation with participants. The following are the main themes that emerged from the focus group:

Many participants explained how they currently stay healthy and manage their condition.

1. Keeping fit: Seven doctors explained to people how they should keep fit, with many recommending swimming and walking as good exercises to participate in
2. Eating healthy: One participant explained they had a booklet about healthy eating, whilst another four participants explained they had just been told
3. High blood pressure: None of the participants were told how they could help with blood pressure.

One participant explained, “Sometimes doctors talk about how diets and some food can help me keep fit, they tell me to eat lots of fruit and vegetables but I do not listen as I do not like vegetables”.

Participants felt that health professionals could do more to help people living with a learning disability to make better life style choices.

All participants felt it was very important to feel listened to by health and care professionals and not to feel rushed. One participant explained, “It would be good if the doctor or nurse could spend more time talking to people, I often feel rushed”.

Participant’s made the following suggestions:

- Don’t speak so fast
- Make sure additional time is available for appointments
- Ensure information is available in easy read
- Check that people understand what is being said.

Mental Health in Derby and Derbyshire

In terms of our specific conditions survey 60 participants completed the mental health survey.

Assessment, diagnosis and treatment

Accessing help

In terms of how well supported people felt when they first tried to access help, 53% of participants felt their needs were met and 17% of people who felt their needs were not met.

Overall, 35% of participants rated their experience of accessing help as positive.

The main theme was around long waiting times to access mental health support and it was felt support should be offered at point of access, not when the situation has worsened. Furthermore, therapy was seen to be positive, however many felt that they didn't have enough sessions for them to be really beneficial.

Sample of comments:

- "I had psychotherapy but this was short term and ended before I really got the full benefit of the process, I needed more sessions with the therapist"
- "Counselling is restricted to a certain number of sessions. It can help short term but not long term. Even CBT can lose effectiveness over time and people could really benefit from "top ups" or more mental health safe spaces/unbiased peer support groups"
- "An appointment with my GP to discuss the issue resulted in being given a self-help leaflet without any questions being asked, this was basically phone numbers. I followed the instructions and eventually had an assessment and was offered an appointment with a therapist which resulted in four totally useless hour-long sessions were I was expected to open up about my issues but offered no help or guidance whatsoever. At my last appointment I explained that this wasn't helping and was "discharged". I am now back to square one and don't know what to do. I realise that mental health is a massive, widespread problem and if this is the sort of brick wall people are faced with, I am not surprised at the increasing number of self-harm and suicides happening"
- "Access to mental health professionals is scarce and hard to access unless you have a more severe mental health condition such as schizophrenia. People are slipping through the net. There needs to be a specialist professional triage system with easy access. A GP will only recommend antidepressants and counselling and this is insufficient for some"
- "The waiting list for my suicidal son to access the mental health team was over six weeks, it took a suicide attempt before he got any help and once they deemed him no longer a risk the support disappeared resulting in a second attempt".

Multiple conditions

A total of 42% of participants explained they had another condition or disability in addition to their mental health condition.

60% of people explained that seeking support for more than one condition made getting support much harder compared to 40% who explained it made no difference.

Length of time to receive initial assessment, diagnosis and treatment

56% of participants felt they had to wait a long time between the length of time people had to wait to receive their initial assessment or diagnosis.

Furthermore, 56% of participants explained the slow process between their initial assessment and receiving treatment.

Sample of comments:

- "Between experiencing an issue and visiting the GP it was almost a year before any practical help was forthcoming, during which time the problems were exacerbated. Earlier intervention would have greatly helped my situation"

- “I was contacted very quickly by Trent PTS although the wait between first contact and appointment could have been quicker”
- “It was only a few weeks. Luckily there was support from family”
- “It was a couple of weeks, this was manageable for me but for someone in dire need of help is totally unacceptable”
- “Had an initial diagnosis then got put on a waiting list which can take approx. Three months just to get CBT therapy”
- “My GP sent me for assessment after the third time I saw him then I had to wait about eight weeks to see someone as appointments were cancelled”
- “Well over a year before diagnosis”.

➢ Referral to a specialist

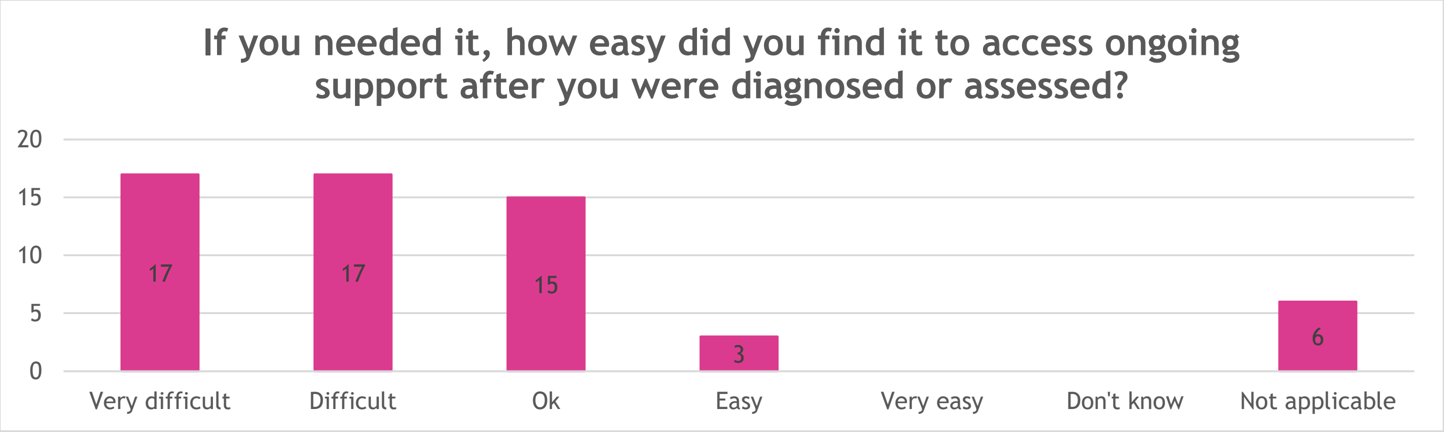
58% participants explained they were referred to see a specialist. 44% of people described the length of time between their initial appointment and seeing the specialist as fast compared to 44% of people who describe the length of time as OK.

Sample of comments:

- “Almost a year, during which my situation was made worse”
- “He was seen here within about two months of a hyper episode. Because he was already on a mood stabiliser this was not unreasonable, but in the meantime he was having problems with working”
- “About six months”
- “Three months”
- “It took six months, in which time I had attempted suicide nine times and my weight had dropped to a BMI of 12.1”
- “Saw psychiatrist in reasonable time to begin with, it took over a year to be given a permanent psychiatrist though”
- “Very quickly. Am very satisfied with appointment made and received”
- “Had to be admitted to acute hospital prior to receiving help, then appointments are often cancelled and rearranged with up to a nine month wait for each review”.

The provision of ongoing care and support

We asked people about the provision of the care and support they experienced following a diagnosis of a mental health



59% of people explained they had difficulty in accessing ongoing support following a diagnosis of a mental health condition.

➢ Access to further health and care support

After being diagnosed or assessed, 60% of participants explained they had been offered access to further health and care support.

In terms of aspects of support for people diagnosed with a mental health condition that worked well, many people explained how important it is to be able to have someone to talk to about their concerns and most people explained how helpful counselling and therapy were.

Sample of comments:

- “CBT, counselling”
- “The support was the therapy, nothing else was offered”
- “CBT was helpful although the first few weeks you kind of resist as it opens up the wounds you have been trying to hide”
- “Flexible appointments”
- “Ongoing counselling”
- “As the NHS wasn’t helpful, my GP did recommend I self-referred to First Steps Eating Disorders who were quick to assess me and equally quick to start providing me with a range of support”
- “Enablement worker who visited me after leaving my hospital”
- “I have accessed support including Talking Therapies Telephone Support. This was useful as I knew that I could talk to someone once a week about my problems and they gave me ways of helping with my anxiety and ways to help improve my sleep”
- “Online support via charity and telephone support lines”
- “I had good support from my CPN and psychiatrist. We talked through all my issues”.

➢ Support meeting expectations

50% of participants explained that the support they were offered did not meet their expectations and 25% felt it sort of met their expectation. A number of participants explained they would have liked to have been referred for support, rather than receive medication to help with their mental health.

Sample of comments:

- “The support options were limited and eventually I went back on antidepressants”
- “Medication was seen as the ‘be all and end all’ after diagnosis. Support was practically non- existent in the rural area I lived and nothing was offered despite requesting to be seen out-of-area, where support services could be accessed”
- “He was just discharged, no offer of continuing support”
- “Only certain therapies available, a wait for those that were. A postcode lottery”
- “Counselling is only available during office hours, my daughter works full time”
- “There was no ‘care’ during my appointments, I was expected to talk about my problem but there was no interaction or discussion”
- “No support other than medication was offered after seeing the psychiatrist. No talking therapy was offered despite my history clearly indicating that it had been very useful in the past”.

➢ Improvement to health and care support

In terms of aspects of support that could be improved, the following were highlighted:

Sample:

- “More therapists, more nurses, more psychiatrists so that a relationship is built up between patients and professionals so that the trust is there enabling patients to feel able to open up”

- “More mental health workers, so people who have lower levels of serious mental illness can have access to talking therapies. Probably more NHS run support groups too”
- “Talking therapy. I just want to talk every week in therapy with someone”
- “The BMI needs to be adjusted to come in line with NICE as were impacted by post code lottery”
- “Having quicker access to actual support services would be beneficial. However, I appreciate that demand dictates supplies”
- “By the time you feel you are making any progress the support is cut off to make room for the next person. You can leave feeling only half fixed”
- “Access to therapy”
- “A longer period of counselling for those with serious mental health conditions”
- “Changed CPN too often and seemed to get lost when first CPN left, could easily have dropped out of the system here”
- “Continuity of care”.

➢ Communication

42% of people felt they received consistent communication from support services compared to 60% of participants that felt communication was not consistent.

Focus group - Mental Health

We undertook a focus group with 15 people with a mental health condition.

The group were asked about what they thought worked well, what didn’t work very well and what could have been easy to improve in terms of health and care services in the county.

The following are the main themes that emerged from the focus group:

➢ GPs

A number of participants felt there was little or no awareness/understanding of mental health within GP surgeries. One person explained, “If you show signs of getting agitated you are asked to leave or the police are called”

It was felt by the group that there was a need for more training for all staff within GP surgeries around mental health so they can be more understanding and offer support if required.

Participants felt they were treated differently by health and care professionals due to their mental health condition with some explaining they felt “patronised”.

➢ Lack of joined up care

It was felt that there was a lack of clear communication, and professionals do not always seem to talk to one another. One participant explained, “You are passed around a lot from one service to another”.

Another participant provided an example, “GP should be able to contact psychiatrists to discuss medication. I spoke to my GP about medications only to be advised that I would have to discuss this with the psychiatrist. My next appointment with the psychiatrist was in three months’ time, this was not acceptable. Why can’t a GP contact a Psychiatrist?”

A suggestion was made for there to be a process or system in place to support professional to share information.

➢ Helpful information

The group explained how important it is for information to be clear, some participants added the importance of being able to be able to talk to someone face to face first and the receive literature or more information to take home and read.

The group explained that they would like information on the following:

- Keeping well
- Self help
- Support groups
- The condition, including what impact it can have and how it can be managed
- Medication, including possible side effects, what to do if the medication isn't working, what alternatives are available and how to ask for a medication review.

➢ What matters most to people

1. To receive care closer to home
2. To have choice
3. To receive clear information following diagnosis.

Sample of comments:

- "I would like to access services as close to home as possible, mental health can make it difficult to travel and go to unfamiliar places"
- "Getting the correct treatment is the most importance, but you should be able to access if locally"
- "I would like to be able to choose who you see and where you see them, but it should also be timely"
- "Prepared to wait for diagnosis if treatment is exceptional"
- "Once there is a diagnosis, you need clear information that is verbal and written and you need to access treatment quickly and locally".

Engaging people in health service delivery

As mentioned within the main body of the report, people want to feel genuinely engaged in any potential cuts, or changes to services. They want to feel fully informed of the benefits and it was felt this should always be carried out in a timely manner.

Next steps

Response from Joined Up Care Derbyshire (JUCD)

We would like to thank Healthwatch Derbyshire and Derby for conducting their public engagement around the NHS Long Term Plan to support Joined Up Care Derbyshire, Derbyshire and Derby's Sustainability and Transformation Plan (STP) to consider 'what matters most to the residents of Derby and Derbyshire' in relation to health and care services.

Joined Up Care Derbyshire has a number of different workstreams, each of which is considering how best to implement the ambitions outlined in the NHS Long Term Plan, and take forward current priorities to improve the health and care of Derbyshire's residents, to ensure they have the best start in life, stay well, age well and die well. To do this each workstream is currently talking to a wide range of stakeholders and drawing on existing intelligence, which will then feed into a refreshed STP Plan which will reflect feedback from a wide range of stakeholders, including patients, carers, young people, and the general public.

The report produced by Healthwatch significantly adds to this intelligence and the findings are currently being considered by the programme leads for each workstream to inform their submissions to the refreshed STP Plan. We would particularly like to say that we found the structure of the report helpful in terms of identifying key areas for focus in each of the programme areas, as this will support the programme leads to incorporate the findings into their final plans.

A draft STP Plan, covering our local ambitions for health and care services in Derbyshire and Derby for the next 5 years, is due to be submitted to NHS England on the 27th Sept, and the final version is expected to be published on the 15th November following extensive stakeholder/public engagement.

Vikki Taylor

STP Director

Joined Up Care Derbyshire