healthwatch

NHS Long Term Plan

What matters to you?

Patient and Public Engagement by Healthwatch Leicester, Healthwatch Leicestershire and Healthwatch Rutland

what would you do?

It's your NHS. Have your say.

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Executive summary

I. Background

The National Health Service (NHS) Long Term Plan (2019) consolidates a shift towards personalised and integrated health and social care, illness prevention and reduced acute hospital admissions with care closer to home for people when possible. NHS England has commissioned Healthwatch nationwide to conduct public engagement to determine what people want from their NHS services. This report will inform local policy makers about what is important to Leicester, Leicestershire and Rutland people and their hopes for future health and care services.

II. Method

A mixed methods approach was taken using surveys, focus groups, semi structured interviews and patients' narratives. People who have often previously been under-represented in public engagement were specifically sought.

III. What matters most to people in Leicester, Leicestershire and Rutland?

All participants

- Choosing the right treatment is a joint decision between the patient and relevant health care professional.
- People want to stay in their own home for as long as it is safe to do so.
- People want to talk to the doctor or other health care professional from wherever they are.
- Timely access to services is important and most patients are prepared to travel for this, if it was not too far or too time consuming.
- When someone is reaching out for help and support through their GP, they want to feel listened to.

People with long-term conditions

- People living with long term conditions want to be able to look after themselves when possible but know that support exists for them when they need it.
- Patients who have been diagnosed with cancer and their carers reported a much better experiences of the NHS than those who have a mental health diagnosis.
- Different long-term conditions create varied challenges and experiences.
- Communications with and information given to patients and carers throughout the illness needs improvement.

- Primary Care services would be improved if the professionals could better inform patients of local support services and had a better understanding of and training about how patients and the whole family experience living with long term conditions.

People with dementia and their carers

- If a patient has family or friends, they are better able to access services.
- People with dementia are more likely to be digitally excluded.
- People with dementia miss the ability to drive.

Young people with learning disabilities and autism

- Clinicians need a better understanding of learning disabilities and autism and the impact the disability has on the whole family.
- Professionals should ensure that the right support is offered when needed.
- People with learning difficulties are also likely to be digitally excluded.
- Getting a diagnosis can be the biggest challenge.

1. How did we do it?

1.1 Introduction

In this section we set out how Healthwatch Leicester and Leicestershire and Healthwatch Rutland worked together, as part of the Healthwatch England project, to engage with the local public to understand what matters most to them when accessing health and care services.

1.2 Context

Over recent years, policy makers have been attempting to remove the historical boundaries between primary care, secondary care and social care. The NHS Long Term Plan, published in January 2019, consolidates this move to 'integrated care'. With an ageing population in England and increasing demands on the NHS, the intention is to focus on keeping people healthy, independent and able to self-manage long-term (chronic) conditions without multiple acute hospital emergency admissions, for as long as possible.

NHS England commissioned the Healthwatch England network to carry out nationwide public engagement to determine what people want from their NHS services now, and in the future and what their experiences have been to date. Healthwatch Leicester and Healthwatch Leicestershire with Healthwatch Rutland were asked to work together to cover the Leicester, Leicestershire and Rutland (LLR) area.
LLR forms the geographical footprint of the local Better Care Together[1] initiative. There are three local authorities: Leicester City, Leicestershire and Rutland. Over one million people live in Leicester city, market towns such as Loughborough, Melton Mowbray or Oakham, large and small villages, hamlets or in isolated rural spots. The population of Leicester City is statistically younger with a wide ethnic and cultural diversity, whereas Rutland has a higher proportion of older age groups but is less ethnically and culturally diverse. The disease burden and health and social care needs are therefore significantly different across the footprint.

Healthwatch Leicester & Healthwatch Leicestershire and Healthwatch Rutland, with added advice from the Better Care Together team, engaged with the public during Spring 2019 and are now pleased to present the results in this report which, we hope, will help inform local health and care policy.

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[1] Also known as the Sustainability and Transformation Partnership

1.3 Method

We used a mixed method approach and widely distributed (online and hard copy) both the Healthwatch England general survey and the long-term conditions survey. To gain deeper and richer interpretations of people's experiences and expectations, we also talked with patients and their carers in 10+ focus groups and semi-structured interviews and used patients' 'stories' about their experiences. Survey data was quantitatively analysed and the focus groups, interviews and 'stories' were subjected to a thematic analysis.

1.4 Who did we talk to?

The surveys were completed and submitted by 597 members of the public.

	Leicester City	Leicestershire	Rutland
General Survey*	150	184	105
Condition Survey*	21	89	48

*full demographic breakdown in appendices 1 and 2

We were aware that there are groups of people who are consistently under-represented in such an engagement, so we specifically sought to include:

- Patients with dementia and their carers.
- Young people (up to age 25 years) with learning disabilities and/or autism and/or additional needs.
- Black and Minority Ethnic groups (BAME).
- Lesbian, Gay, Bisexual, Transgender and Questioning (or Queer) groups (LGBTQ+)

1.5 Promoting the Engagement

We used existing networks to reach out to community groups and explain the work we were doing. The surveys were promoted and made available to be completed online or through face to face engagement and also distributed around public spaces (surgeries, libraries, council buildings etc) in Leicester, Leicestershire and Rutland.

Focus groups and some semi-structured interviews were held across the region to guide a more in-depth discussion about what is important to different groups of people. These were also used as an opportunity to distribute and promote the surveys.

Drop in clinics and workshops were held in targeted areas of Leicester and Leicestershire to engage with people from different ethnic groups.

2. What is important to you?

This section presents the general survey results in which people were asked what is most important for them to receive from their local NHS services. Despite the demographic mix in the LLR population, arguably the most striking result is that, with a few exceptions, the public largely want and attribute importance to the same things. The different questions and responses are now set out under two broad categories: 1. Living a healthy life and 2. Interactions with the NHS. A summary of the results is given at the end.

2.1 Help to live a healthy life

With an increasing population, an ageing demography and people living longer with more chronic illnesses, attempts are being made to reduce the demands on NHS services by encouraging people to live longer and more healthily.

i. What is most important to you to manage and live a healthy lifestyle?

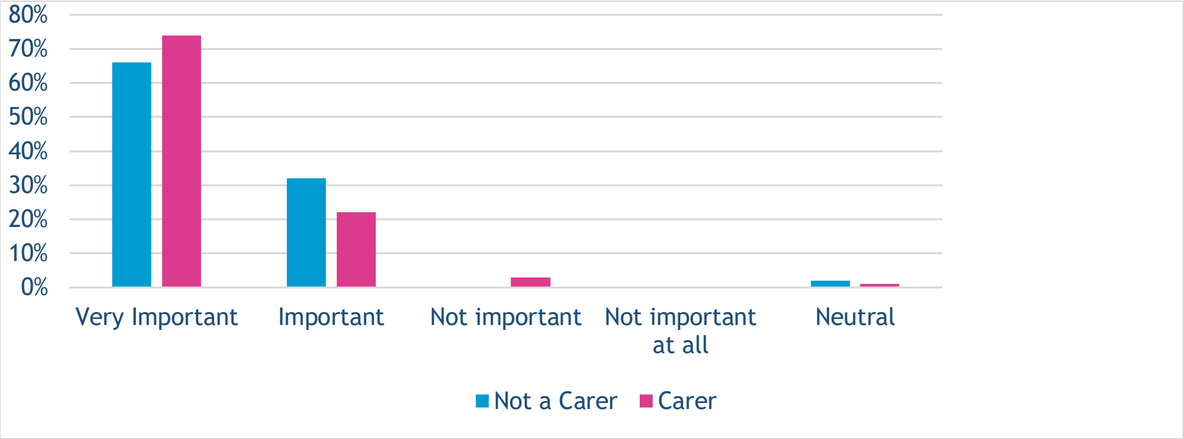
The respondents were asked to rate the following statements and place in order of importance:

- Easy access to information I need to help me make decisions about my health and care.
- Access to help and treatment I need when I want it.
- Professionals that listen to me when I speak to them about my concerns.
- For every interaction with health and care services to count, my time is valued.

The majority of the respondents indicated that the most important to them is: **Access to help and treatment I need when I need it.**

As throughout the general survey, the replies to all the factors were heavily weighted towards ‘important’ or ‘very important’ by all the different demographic groups, but there were subtle intergroup differences as the following table demonstrates:

Chart 1 -% response of carers and non-carers – ‘easy access to information I need’



Thus, a higher percentage of carers in comparison to non-carers thought that easy access to information is ‘very important’ and, conversely, more non-carers rated it as ‘important’. This pattern of difference between ‘very important’ and ‘important’ plays out across other groups. For example:

- Age: All age groups, except 25-34, rated ‘access to help and treatment when needed’ as the most important. Whereas, those between 25-34 considered ‘easy access to information’ was the most important.
- Ethnicity: Most ethnicities rated ‘access to help and treatment when needed’ as most important but the Bangladeshi and Black British ethnic groups rated ‘easy access to information’ as most important.
- Religion: Most religions considered ‘access to the help and treatment when needed’ to be most important except for Buddhists and Jewish, who thought ‘professionals that listen’, and Sikhs, who thought ‘the knowledge to help them do what they can to prevent ill health’ as most important.
- Sexuality: The LGBTQ group were unique in having intragroup differences in their ratings as the following Table 1 demonstrates:

Table 1. Sexuality group responses – Most important to getting help to live a healthy life

Row Labels	Asexual (1)	Bisexual (4)	Gay or lesbian (5)	Heterosexual (342)	I'd prefer not to say (44)	Other (20)	Pansexual (1)
Access to the help and treatment I need when I want it	0%	0%	20%	46%	44%	53%	0%
Easy access to the information I needs to help me make decisions about my health and care	0%	0%	20%	13%	17%	16%	0%
For every interaction with health and care services to count; my time is valued	0%	25%	0%	4%	5%	0%	0%
Professionals that listen to me when I speak to them about my concerns	0%	75%	40%	24%	15%	26%	100%
The knowledge to help me do what I can to prevent ill health	100%	0%	20%	13%	20%	5%	0%
(blank)	0%	0%	0%	0%	0%	0%	0%
Grand Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

Statistical significance cannot be assumed due to the small number of respondents in the LGBTQ group, but Table 1 indicates that:

- Bisexual, Gay/Lesbian and Pansexual participants rated 'having professionals that listen' to them as most important.
- Heterosexual respondents rated 'access to help and treatment when needed' as most important.
- The one asexual respondent rated 'having the knowledge to prevent ill health' as most important.

ii. Managing and choosing the support you need

The respondents were asked to rate the following statements and place in order of importance:

- If I have a long-term condition, I decide how the NHS spends money on me.
- Choosing the right treatment is a joint decision between me and the relevant health and care professional.
- I make the decision about where I will go to receive health and care support.
- I should be offered care and support in other areas if my local area can't see me in a timely way.
- I make the decision about when I will receive health and care support.
- My opinion on what is best for me, counts.
- Communications are timely.

- I have time to consider my options and make the choices that are right for me.

These questions resulted in little difference in the ratings of importance across the groups. With the exception of the variable of 'sexuality', the sentence rated the 'most important' was:

Choosing the right treatment is a joint decision between me and the relevant health or care professional.

The responses with the added variable of 'sexuality' are shown below but, again, should be considered as indications rather than statistically significant due to small numbers in some groups.

Table 2. Sexuality group responses – most important to manage and choose the support you need

Row Labels	Choosing the right treatment is a joint decision between me and the relevant health care professional	Communications are timely	I have time to consider my options and make the choices that are right for me	I make the decision about when I will receive health and care support	I make the decision about where I will go to receive health and care support	I should be offered care and support in other areas if my local are can't see me in a timely way	If I have a long-term condition, I decide how the NHS spends money on me	My opinion on what is best for me counts
Asexual	0%	0%	0%	0%	100%	0%	0%	0%
Bisexual	75%	0%	0%	0%	0%	0%	25%	0%
Gay or Lesbian	20%	0%	20%	0%	20%	40%	0%	0%
Heterosexual	52%	5%	11%	4%	7%	12%	4%	4%
Prefer not to say	51%	3%	8%	3%	13%	8%	5%	10%
Other	28%	0%	6%	6%	28%	11%	17%	6%
Pansexual	0%	0%	0%	0%	0%	100%	0%	0%
(blank)	37%	0%	0%	11%	0%	42%	11%	0%
Grand Total	**50%**	**4%**	**10%**	**4%**	**8%**	**13%**	**5%**	**4%**

As Table 2 demonstrates, whilst 'choosing the right treatment is a joint decision' was most important to bisexual and heterosexual respondents, the asexual respondent considered that 'making the decision about where to receive services' was the most important. The Gay/Lesbian and Pansexual respondents rated 'being offered care and support in other areas' as most important.

iii. If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?

The survey respondents were asked to reply to this question in their own words. 215 responses to this question were received and thematically analysed as follows:

- **Having better access to information. (29 comments)**

"More information about care/treatment so that I can make an informed choice."

"An open forum at a surgery where pre-selected questions could have an answer and advice from patients who have experienced the problems and could voice their ideas and solutions as well as clinical advice."

- **Better GP access. (27 comments)**

"The GP being open in evenings and weekends so I can go without taking time off work. People don't really know what is best for them but I want to discuss my thoughts about my personal health experiences with a professional who listens and then explains why."

"More GPs to alleviate the pressure on surgeries enabling them to support me more efficiently."

- **More local and easily accessible services. (26 comments)**

"Having more facilities to be provided locally. We have a hospital in Melton which is hardly used. A lot of consultations and treatment should be provided here, and we would not be required to travel to other towns."

"More hospital services at Rutland Memorial Hospital."

- **Better patient choice and control. (21 comments)**

"I would like to be more involved in decisions about my health."

"I should be at the centre of my care and given the right information about my illness so I can make the right decision about my illness. Having a named GP is important."

- **Being listened to. (16 comments)**

"Be listened to when attempting to explain a problem"

"Important, they should listen to the disabled child or adult"

iv. Keeping your independence and stay healthy as you get older

The respondents were asked to rate the following statements and place in order of importance:

- I want to be able to stay in my own home for as long as it is safe to do so.
- I want my community to be able to support me to live my life the way I want.
- I want my family and friends to have the knowledge to help and support me when needed.
- I want there to be convenient ways for me to travel to health and care services when I need to.
- I want my family and me to feel supported at the end of life.

Again, most responses were either 'very important' or 'important'. For almost all response groups the most important factor for keeping their independence and stay healthier as they got older was: **To be able to stay in own home for as long as it's safe to do so.** The results are demonstrated in Table 3 below:

Table 3. Percentages of responses rating Very Important/Important or Neutral for maintaining independence

	Very Important	Important	Neutral
Stay in own home	78%	18%	3%
Community able to support	48%	34%	15%
Family and Friends have the knowledge	62%	26%	10%
Convenient ways to travel	66%	28%	5%
Support at end of life	76%	19%	4%

When demographic variables were added there were the following differences:

- The under 18 age group and 'any other white background' groups rated 'convenient ways to travel to health and care services' as most important.
- The 18-24 age group rated 'staying at home' and 'family and friends having the knowledge to give them support' with equal importance.
- African ethnicity group rated 'family and friends' having the knowledge to give them support' as most important.

The higher percentage response for 'neutral' and lower percentage responses for 'very important' and 'important' suggests that people consider 'community support' as less important than the other options. But there was a different response to the importance of community support when ethnicity or sexuality were added as variables as Tables 4 and 5 below demonstrate:

Table 4. Ethnic group responses on ‘Community to be able to support me to live my life the way I want’.

	Very important	Important	Neutral	Not important
African	50%	50%	0%	0%
Any other mixed background	25%	50%	25%	0%
Any other white background	46%	31%	15%	8%
Asian British	48%	29%	19%	5%
Bangladeshi	50%	50%	0%	0%
Black British	100%	0%	0%	0%
Caribbean	50%	42%	8%	0%
Indian	36%	46%	7%	11%
Other	20%	50%	30%	0%
White British	51%	31%	16%	2%
(blank)	38%	43%	10%	10%
Grand Total	**48%**	**34%**	**15%**	**3%**

Black British ethnic group unanimously valued community support but a higher number of the Indian ethnic group than any other ethnic group considered it unimportant.

Table 5. Responses with sexuality as variable to ‘Community to be able to support me to live my life the way I want’.

	Very important	Important	Neutral	Not important
Asexual	100%	0%	0%	0%
Bisexual	75%	25%	0%	0%
Gay or lesbian	20%	40%	40%	0%
Heterosexual	49%	34%	14%	3%
I'd prefer not to say	56%	34%	10%	0%
Other	37%	16%	37%	11%
Pansexual	100%	0%	0%	0%
(blank)	41%	41%	9%	9%
Grand Total	**48%**	**34%**	**15%**	**3%**

The intragroup differences with sexuality as a variable demonstrate that the Gay and Lesbian respondents place less value on community support. The one pansexual and one asexual people attributed the greatest importance to community support. Due to small numbers, statistical significance cannot be assumed and the results should be considered as an indication only.

v. If there was one more thing that would help you retain your independence and live healthily for as long as possible, what would it be?

200 comments were received to this free text question and were thematically analysed with the following dominant themes emerging:

- **More local services and support. (28 comments)**

"To have support and resources available locally to ensure I live an independent life for as long as possible. At the moment it is a 'lottery'."

"Having a variety of support at home or nearby to be able to live independently for as long as possible."

- **Better (online) access to services. (24 comments)**

"Being able to check online for anything the health and care services need to tell me as well as being able to contact them efficiently online when I need them."

"Access to appropriate technology."

- **Social and Community support. (18 comments)**

"I don't think there are enough groups to help myself [sic] and others in my community to improve our independence and health."

"I have had a look at the NHS Long Term Plan and cannot see anything about investment into social care. I think that it will be impossible to significantly improve the health of the populous [sic] unless this is recognised and addressed."

2.2 Interacting with the NHS

Part 2 of the general survey specifically asks people about what is important for them when they are using NHS health and care services.

i. Rate how important the following statements are when it comes to interacting with the local NHS

The respondents were asked to rate the following statements and place in order of importance:

- I have absolute confidence that my personal data is managed well and kept secure.
- I can access services using my phone or computer.
- I manage my own personal records so I can receive continuity of care.
- I can talk to my doctor or other health care professional wherever I am.
- I can make appointments online and my options are not limited.
- Any results are communicated to me quickly making best use of technology.
- I am able to talk to other people who are experiencing similar challenges to me to help me feel better.

The majority of people rated this set of statements as 'very important' or 'important'. Fewer people rated 'being able to talk to other people who are experiencing similar challenges to me' and 'I manage my own personal records' as 'very important' or 'important'. The most important, as shown in the table below, was: **'having results communicated quickly'**.

Table 6. Percentages of responses rating Very Important/Important/Neutral or Not important

	Very Important	Important	Neutral	Not important
Confidence that personal data is managed well	60%	27%	13%	1%
Access services using phone of computer	47%	37%	13%	3%
Talk to Dr or health professional wherever I am	52%	34%	12%	2%
Make appointment online	48%	29%	18%	3%
Results communicated quickly	64%	26%	8%	1%
Able to talk to others	30%	39%	23%	8%
Manage my own records	37%	37%	23%	3%

Adding demographic variables produced slightly different results:

- Age: The under 18s thought 'any results are communicated to me quickly making best use of technology' to be most important. 18-24 years thought 'I can access services using my phone or computer' is most important. 25-34 years thought 'I can make appointments online and my options are not limited' is most important.
- Religion: Most religious groups rated 'I can talk to my doctor or other health care professional wherever I am' as most important, except Muslims and Sikhs who thought 'I can make appointments online and my options are not limited' is most important.
- Ethnicity: Asian British, Indian and 'any other mixed background' ethnic group rated 'I can make appointments online and my options are not limited' as most important. African and 'Others' ethnic group rated 'I have absolute confidence that my personal data is managed well and kept secure' as most important as Table 7 below shows:

Table 7. Ethnicity - Most important for interacting with the local NHS.

Row Labels	Any results are communicated to me quickly making best use of technology	I am able to talk to other people who are experiencing similar challenges to me to help me feel better	I can access services using my phone or computer	I can make appointments online and my options are not limited	I can talk to my doctor or other health care professional wherever I am	I have absolute confidence that my personal data is managed well and kept secure	I manage my own personal records so that I can receive continuity in care
African	13%	0%	0%	13%	0%	75%	0%
Any other mixed background	0%	0%	25%	50%	0%	25%	0%
Any other white background	15%	0%	15%	8%	54%	8%	0%
Asian British	5%	5%	0%	38%	33%	10%	10%
Bangladeshi	0%	50%	0%	0%	0%	50%	0%
Black British	0%	0%	0%	0%	100%	0%	0%
Caribbean	17%	0%	8%	8%	33%	25%	8%
Indian	14%	0%	7%	32%	18%	25%	4%
Other	10%	0%	10%	10%	30%	30%	10%
White British	18%	4%	9%	12%	37%	13%	6%
(blank)	11%	6%	11%	17%	33%	22%	0%
Grand Total	**16%**	**4%**	**9%**	**15%**	**35%**	**16%**	**5%**

ii. If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?

169 free text comments were received for this question.

- **Better GP access - Less time-restricted access to a GP and fewer delays for appointments. (31 comments)**

"A GP surgery that doesn't discriminate against those who work full time so that I can get an appointment either early morning or late afternoon and without having to book 3 weeks in advance."

"Appointments that are longer than 10 minutes, so I feel listened to and understood, not rushed and fobbed off."

- **Access and handling of patient records. (24 comments)**

"For pity's sake let us know what tests show. I have to have regular blood tests, but I go to the hospital and they haven't received the results. I go to the doctors and they say yes, they have the results but won't fill in the details in my book for methotrexate treatment. Then I go to the hospital and get told off because I'm not getting my book filled in. Could test results be put on the website where we go to order repeat prescriptions?"

"All NHS services to be able to access records from systems recording patients' experience - paramedics use links to Leicester Royal Infirmary but not Leicester City General."

- **Choice and Control – how people feel most comfortable in their interactions. (14 comments)**

"Option to speak face to face with relevant person – not on computer, and only by phone is my choice."

"Being able to speak to real people when not sure."

At the end of the survey respondents were invited to leave any further comments. We received 134 responses. Whilst there were 8 comments on the survey structure itself the following themes about health and care services also emerged:

- **GP appointments – frustration with getting appointments and waiting times. (19 comments)**

"Make it possible to get an appointment without having to phone at 8am every morning for days on end until one is available and please, please, please, get medics to LISTEN to us - we know how we are feeling; we know when we are having problems."

"To be able to access a GP for non-urgent medical conditions in less than 3-4 weeks. With the growth of the population in Rutland the medical provision is sadly lacking."

- **More community support. (11 comments)**

"I want a greater emphasis on non-medical ways of staying healthy. I am motivated to stay active and stay engaged with the world as I age, but I see so many people who are not and just go to the doctor or pharmacy for a pill to treat their aches, pains, feeling miserable. Healthcare professionals should be more informed and robust about signposting people to available local activities and organisations before any medication is prescribed to make the patient responsible for their own health and well-being."

"Support from the community is very important to my mental health. I liked answering this survey because it's important to get people's opinions."

- **Better communication – with patients and across health and care services. (9 comments)**

"Communication is really the key with health care. The largest number of complaints are often to do with poor information or communication. The use of medical jargon is still being used which can be frightening and confusing. An extra minute with a Doctor or health care worker to check the understanding of what has been said can really make a difference. Putting patients in contact with support groups can also be very helpful."

"Living in one CCG area, getting primary care in another and secondary care in a third makes it important that provision of care and availability of records are not artificially constrained by CCG boundaries."

2.3 Summary of general survey findings

The general survey results show that what is important to the public is:

- Access to help and treatment when needed
- Having some choice and control in interactions with health and care professionals
- Being able to stay at home for as long as it is safe to do so
- To have better access to GP appointments
- For the NHS to bring care closer to home with enhanced use of local hospitals and other facilities
- To have big improvements in communications – between patients and professionals, between professionals, between GPs, departments, hospitals and trusts.

Somethings less highly valued by most:

- Community support to retain health and independence
- The ability to manage own personal records

3. Living with a long-term condition

The NHS Long Term Plan specifically focusses on several named long-term conditions that will influence ongoing policy for health and care services nationally and locally. This is with the aim of helping people to keep well, independent and at home for as long as possible. For the long-term condition survey we specifically targeted community groups for people living with these named conditions. Here, we define 'those living with' as patients, their significant others and/or their carers. Also, it is important to note that the survey included all long-term conditions. Therefore we sought responses from patients, their families or carers with:

- Autism
- Cancer
- Dementia
- Learning disabilities
- Heart and lung disease
- Mental health
- Any other long-term conditions – e.g. arthritis, diabetes.

The results are set out in 4 sections: 1. The experiences of getting care and support; 2. Transport and travel to access health and care services: 3. What people's expectations are at each stage of the illness trajectory; 4. What support people need to stay well and out of hospital. The section is concluded with a summary of the main findings.

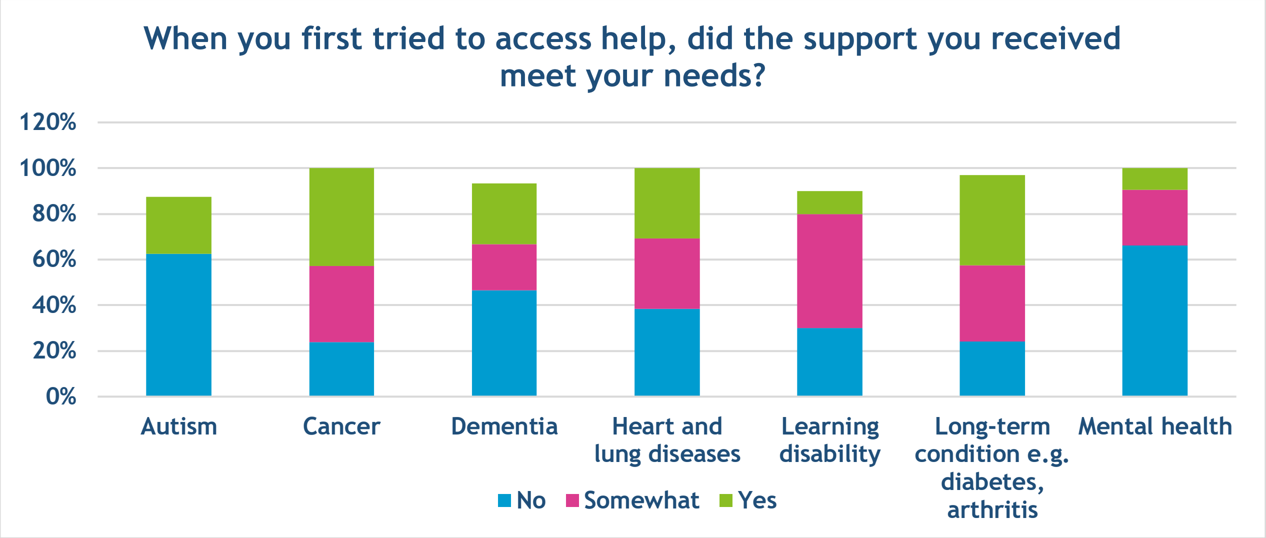
3.1 Experiences of getting help and support

This part of the survey asks people about their experiences of getting support – from the first contact with the health and care services, through assessment, diagnosis, treatment and for ongoing care.

i. When you first tried to access help, did the support you received meet your needs?

The services did not always meet the needs of people with long-term conditions when they first tried to access help. This was more often the case for people with a mental health condition or autism. Although a small sample, Leicestershire has the highest percentage of respondents (55%) saying their needs are not being met compared with 26% of Rutland patients and 45% of Leicester patients.

Chart 2



When considering the percentages of all responses, 44% said their needs are not being met and 23% of those have mental health conditions.

ii. Tell us whether the support met your needs and how it could have been improved.

Free text responses were invited and emerging dominant themes were:

- **Improved communication when support was first sought. (35 comments)**

> *"My GP was very dismissive. They refused to refer on even though the Educational Psychiatrist had written asking for further investigation". (Leicestershire - Autism)*

- **Better professional knowledge of all long-term conditions and awareness of carers' and patients' rights to support in primary care settings. (14 comments)**

> *"You can't self-refer to any services; even something like CBT. Also, most depressives feel worse at night, advice is 'go to your A & E' - as if that's likely. It would be wonderful if there was a meeting place for people with mental health issues, a community setting with a garden, coffee shop maybe, with staff to talk with, group support sessions. A safe place where you can go, and just be, and be accepted […] and supported. Standard advice is 'reach out to friends and family' but that seldom works, people are scared and respond with platitudes like 'get a hobby". (Leicestershire - Mental Health)*
>
> *"We struggled to get anyone to listen and when we finally had a referral we had to go to Leicester". (Rutland – Autism)*

- **Better professional knowledge of support available. (8 comments)**

> *"Increase therapy for patients who have had a stroke for example. A carer told us, 'there is no additional support for speech and therapy which would be really useful'. There is a general feeling that once you have had the initial treatment there is no follow-up care or care in the community" (Carers Focus Group – Loughborough).*
>
> *"I feel that my partner has been abandoned by the NHS. He had Alzheimer's Disease for 7 years and I didn't know anything or that I could claim for help. He should have had this six years ago and no one told me anything. I took him to the GP two years ago, asking for more help and the doctor just turned to him and said, "you're alright aren't you?" So, I didn't get any support and we've not been back". (Carers support group – Melton Mowbray)*

iii. How would you describe your overall experience of getting help?

There were variations in the overall experience of getting help between those that had been diagnosed in the past 3 years and those that had been diagnosed longer than 3 years ago. The following Table 8 demonstrates that, except for the 'negative' experience, there has been a slight decrease in 'very positive' and 'positive' and an increase in 'very negative'. This suggests that those people more recently diagnosed with a long-term condition are less satisfied with their overall experience of getting help than those who were diagnosed more than 3 years ago.

Table 8. Overall experience of getting help

	Did condition start in last 3 years?	
Overall experience of getting help	**No**	**Yes**
Very positive	15%	14%
Positive	21%	20%
Average	28%	27%
Negative	22%	16%
Very negative	13%	22%
Don't know	1%	0%
Grand Total	**100%**	**100%**

When analysing the responses by condition type, there is a noticeable difference. People with cancer reported more positive experiences of getting help and people with mental health conditions reported more negative experiences as the following table demonstrates:

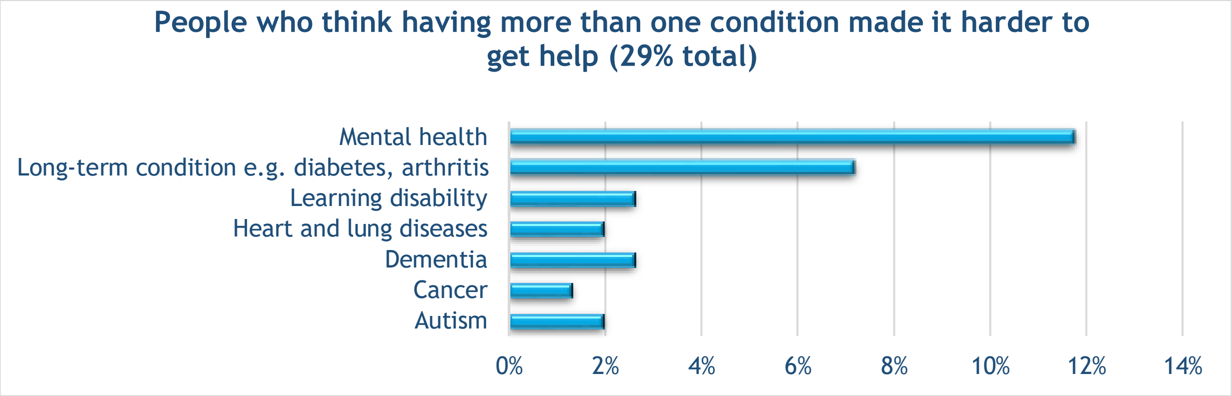
Table 9. The overall experience of getting help with the added variable of 'condition'

Overall experience of getting help by condition	Don't know	Very negative	Negative	Average	Positive	Very positive
Autism	100%	4%	13%	2%	0%	4%
Cancer	0%	12%	6%	7%	13%	35%
Dementia	0%	8%	6%	17%	6%	13%
Heart and lung diseases	0%	4%	13%	2%	13%	13%
Learning disability	0%	8%	0%	7%	13%	4%
Long-term condition e.g. diabetes, arthritis	0%	4%	19%	29%	35%	13%
Mental health	0%	60%	42%	36%	19%	17%
Grand Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

iv. How would you describe the experience of seeking support for more than one condition at a time?

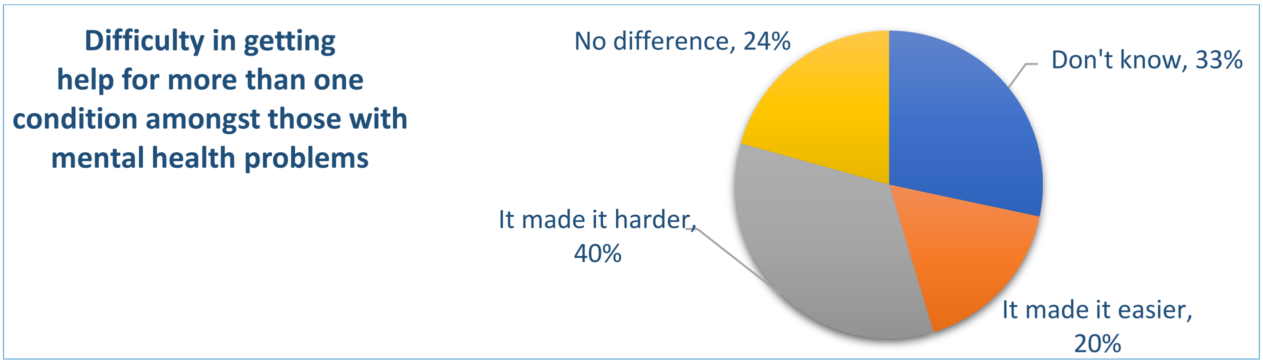
Of all the people with more than one condition, 29% said that it made it harder to get help and 12% of these were those with mental health conditions. Those with cancer as their declared primary diagnosis and another condition experienced the least difficulties as Chart 3 shows:

Chart 3



These results prompted a more in-depth examination of the experiences of mental health patients. The results in chart 4 show that 40% of those people with mental health conditions found it more difficult to get health and support if they had another condition.

Chart 4



v. How would you describe the time you had to wait to receive your initial assessment or diagnosis?

The ratings for experiences of the time waiting for an assessment and diagnosis were more negative than positive and more noticeably negative amongst those in Leicestershire compared with the other two areas as shown in Table 10.

Table 10. Comparing the experiences of time delays across geographical areas

Experience of the time between assessment and diagnosis by area	Leicester	Leicestershire	Rutland
Don't know	5%	2%	9%
Very slow	24%	41%	20%
Slow	33%	19%	15%
Ok	33%	23%	37%
Fast	0%	9%	11%
Very fast	5%	6%	9%
Grand Total	**100%**	**100%**	**100%**

The results in the following Table 11 correlate with those in Table 9 and confirm that, when rating their overall experience of getting support, those with cancer had the least time delay and this was replicated across all three areas. Those with mental health conditions had to wait longer for an initial assessment and/or diagnosis.

Table 11. Comparing the experience of time delays by the different conditions

Experience of time between assessment and diagnosis by condition	Don't know	Very slow	Slow	Ok	Fast	Very fast
Autism	43%	8%	0%	5%	0%	0%
Cancer	0%	6%	6%	16%	23%	60%
Dementia	0%	10%	3%	23%	0%	0%
Heart and lung diseases	0%	8%	6%	11%	15%	0%
Learning disability	14%	6%	0%	9%	15%	0%
Long-term condition e.g. diabetes, arthritis	0%	16%	39%	23%	15%	20%
Mental health	43%	46%	45%	14%	31%	20%
Grand Total	100%	100%	100%	100%	100%	100%

*% of row total

Respondents were then invited to write in more detail about the length of time they had waited to receive an initial diagnosis or assessment:

"Appointments continually changed. Different places, different people." (Rutland - Mental health)

"It was around 2 weeks." (Rutland - Cancer)

"Still not sorted now. Struggled since 2009." (Leicestershire - Mental Health)

"After many, many, months of fighting for a diagnosis I was told that I had Young Onset Alzheimer's, that it progressed quickly, and my life expectancy was 5 - 8 years. I was then asked if I had any questions. That was the end of the support I received." (Dementia focus group - Rutland)

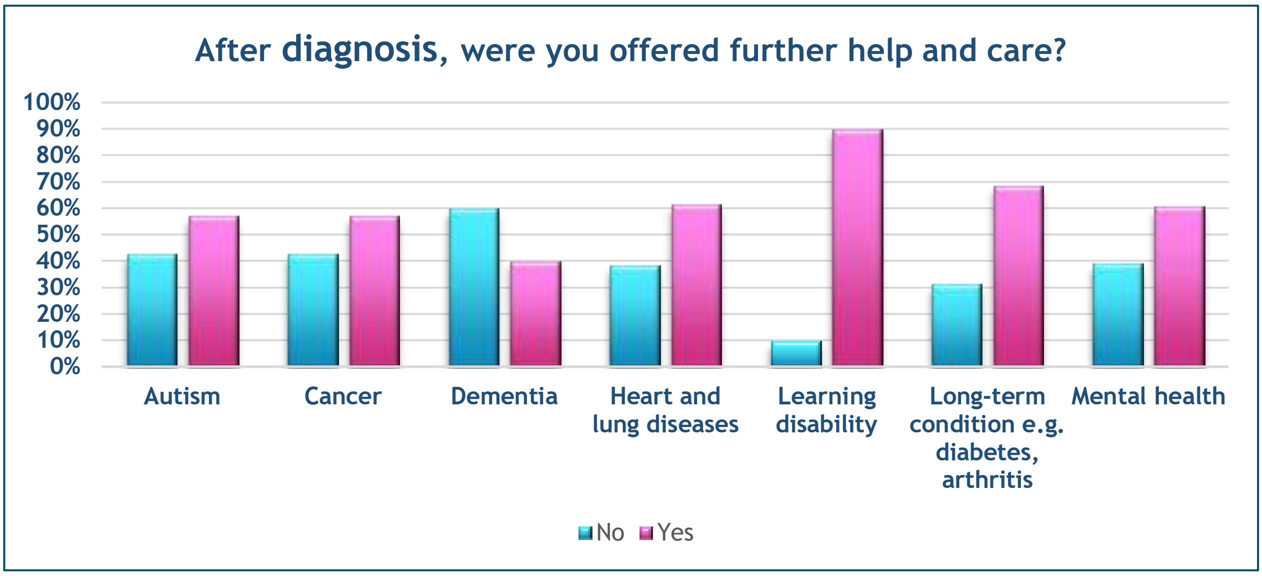
vi. How would you describe the time you had to wait between your initial assessment/ diagnosis and receiving treatment?

The survey then moved from the first experiences of seeking help to the time after assessment and diagnosis and the wait for treatment. The variation in experiences across different conditions was repeated; those people with mental health conditions had a noticeably more negative experience than those with cancer.

vii. After being diagnosed or assessed, were you offered access to further health and care support?

All conditions showed a higher percentage of respondents who were offered access to further health care and support except people with dementia.

Chart 5



viii. If you accessed support, what aspects worked well?

63 people gave a free text reply to this question. Most stated that condition-specific services based either in the hospital or in the community worked well. Over 50% of the comments commended their specialist nurse or treatment.

> *"Excellent support from the medical health professional. Computer program enabled me to engage with support materials and these were assessed on a regular basis by the Medical health professional with feedback and encouragement."* (Leicestershire – Dementia)
>
> *"O.T. assessment & equipment supplied for the house and installation of home alarm."* (Rutland – Dementia)

ix. If you accessed support, what aspect could be improved?

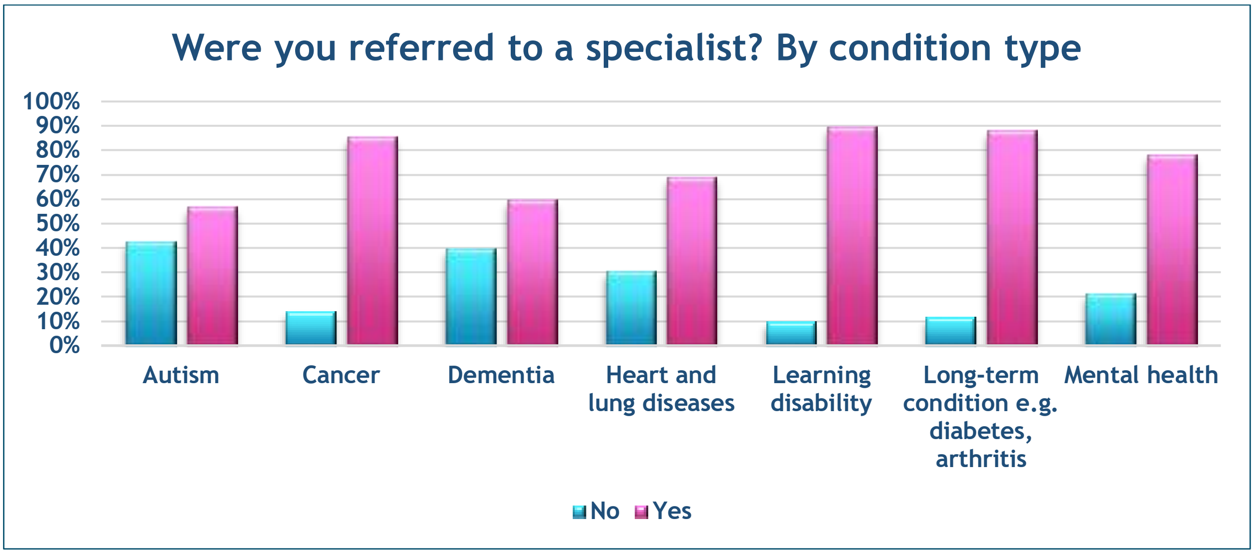
50 free text replies were received for this question. The most common response was that nothing could have been improved (8 comments).

With no other dominant theme emerging, 4 people would have liked quicker access to support and 4 would have liked quicker access to treatment.

x. Were you referred to a specialist?

All conditions reported a higher percentage of people saying they were referred to a specialist however there was still a relatively high percentage of people with autism or dementia who said they were not referred to a specialist.

Chart 7



As Table 12 below shows, the time taken to see a specialist correlates with earlier results. Those with mental health conditions waited the longest and those with cancer waited the least.

Table 12. Time taken to see a specialist sorted by condition

Time to see a specialist	Don't know	Very fast	Fast	OK	Slow	Very slow
Autism	11%	0%	0%	0%	7%	6%
Cancer	11%	63%	21%	11%	33%	0%
Dementia	0%	0%	14%	11%	13%	3%
Heart and lung diseases	0%	13%	7%	11%	0%	8%
Learning disability	22%	0%	14%	11%	0%	3%
Long-term condition e.g. diabetes, arthritis	11%	13%	29%	39%	13%	23%
Mental health	44%	13%	14%	18%	33%	57%
Grand Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

*% of row total

The respondents were then invited to say more about the length of time they waited to see a specialist. The contrast between the mental health and cancer patients is further reflected:

> *"Same day as admission." (Leicester – Cancer)*
>
> *"I saw my surgeon within a week of diagnosis." (Leicestershire – Cancer)*
>
> *"6 weeks." (Rutland – Mental Health)*
>
> *"Usually 15 months." (Leicester - Mental Health)*

xi. If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

With ever increasing significance for the results, more people with mental health conditions found it 'very difficult' or 'difficult' to access ongoing support. Cancer patients reported the greatest ease. The full results for all conditions are shown in Table 13.

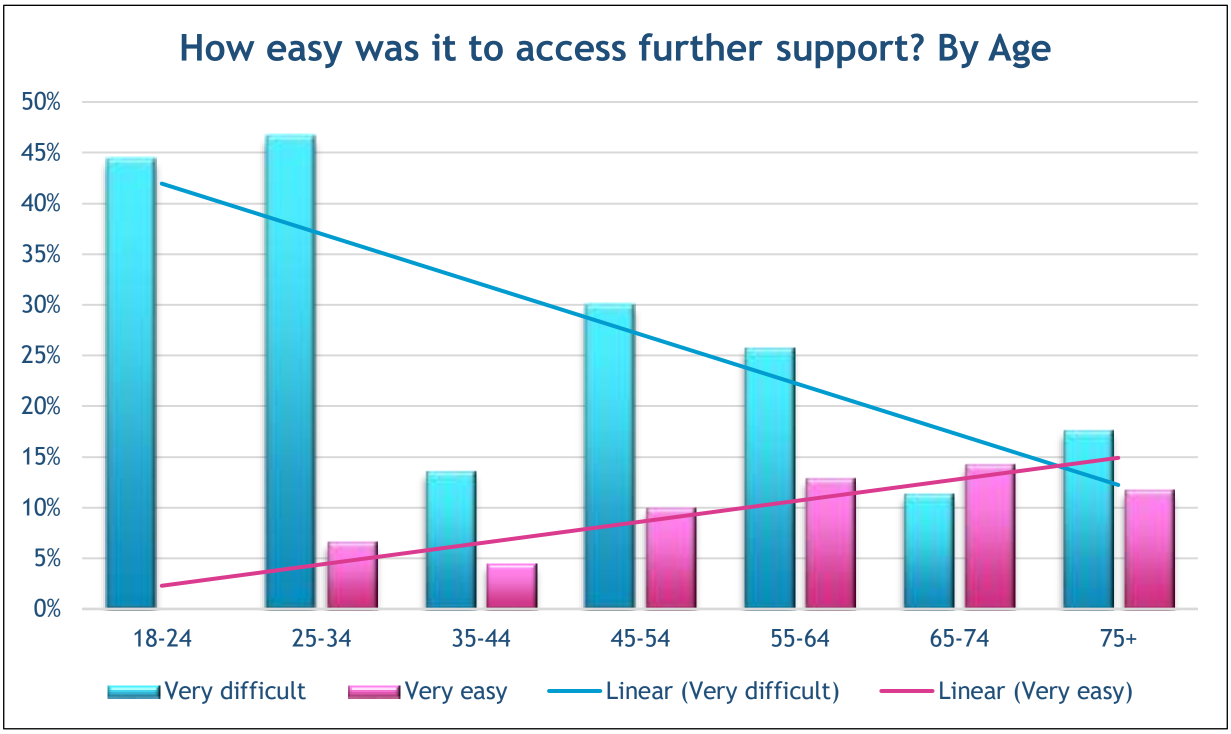
Table 13. How easy was it to access support?

How easy was it to access further support	Don't know	Very difficult	Difficult	OK	Easy	Very easy
Autism	0%	13%	13%	13%	0%	13%
Cancer	0%	14%	24%	19%	14%	29%
Dementia	0%	27%	13%	27%	13%	0%
Heart and lung diseases	8%	8%	31%	15%	23%	0%
Learning disability	0%	20%	10%	30%	10%	10%
Long-term condition e.g. diabetes, arthritis	3%	20%	17%	31%	14%	11%
Mental health	4%	33%	37%	8%	8%	6%
Grand Total	**3%**	**23%**	**25%**	**19%**	**12%**	**10%**

***% of row total**

When adding the variable of age, the results indicated that the younger the respondent, the worse their experience or, perhaps, the higher their expectations. Conversely, elderly patients are more satisfied with their experience or they might have lower expectations than younger patients. This is demonstrated in the following Chart 7.

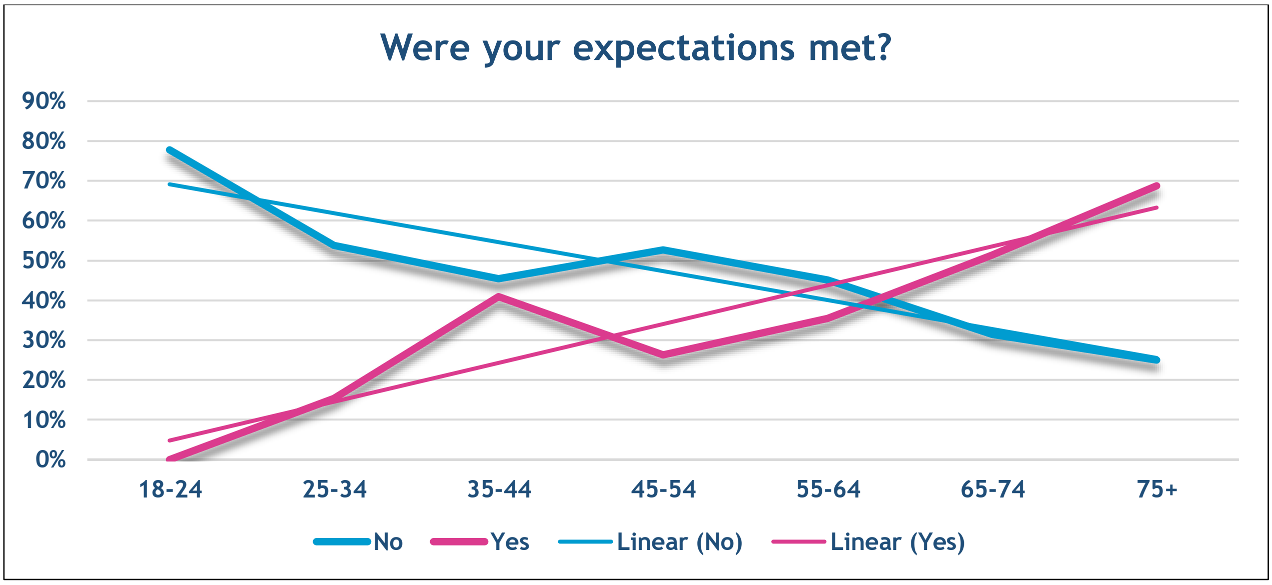
Chart 7.



xii. Did the support option you were offered meet your expectations?

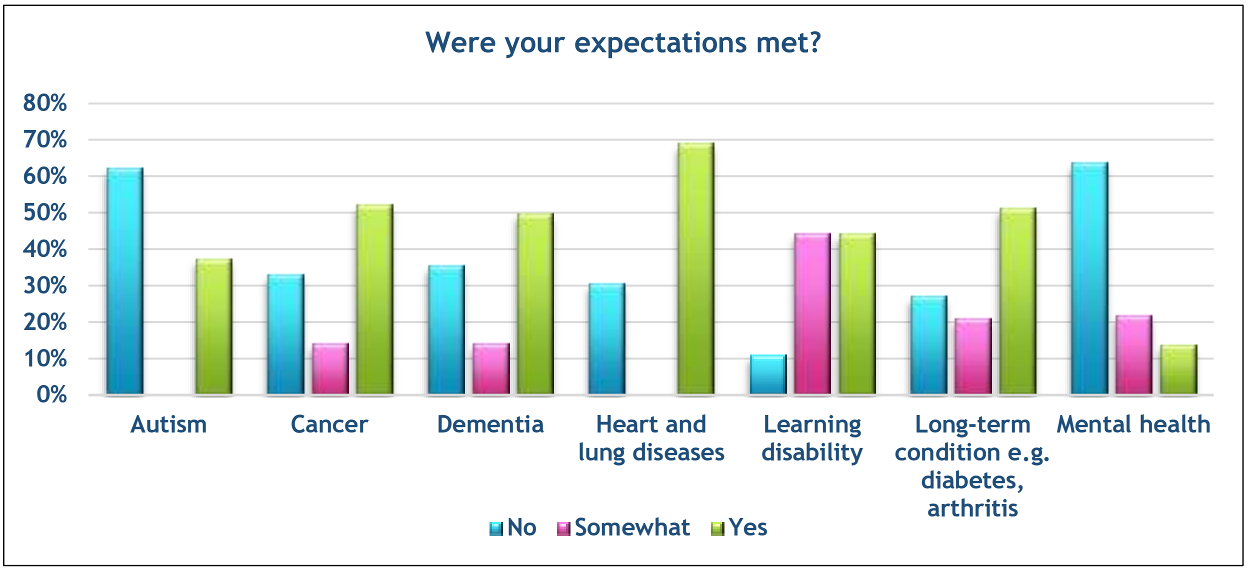
The suspicions about younger and older people having differing expectations in section (3.1.xi after Table 13) seem confirmed by Chart 7 above and Chart 8 below:

Chart 8



Again, more people with mental health conditions and those with autism said their expectations were not met. The highest reports of expectations having been met were from those with heart and lung conditions as Chart 9 reveals.

Chart 9



81 (57 not met/ 24 met) respondents then described in their own words how their expectations of support had not been met or could be improved.

By analysing the comments left, the main reasons given for expectations not being met or how expectations could have been improved are -

- **Expectations would have been met if support was greater or more consistent (13 comments)**

"GP has never offered me follow up appointments to see how I am and if my medication is helping me and certainly has never suggested I have blood tests to check that the medication is not affecting me physically - they just keep on prescribing the tablets!" (Rutland - Mental Health)

"I was discharged after the SCAD and heart attack with absolutely no advice. I'm 6 months on and have still not seen the specialist, got to wait until end of July. They referred me for cardiac rehab but that still has not happened and they won't even put me on the three month waiting list so it's going to be over a year since the heart attack before I get to rehab, so at the minute, I am vegetating at home as I have been given absolutely no support whatsoever. Not even a leaflet about SCAD, which I managed to source myself from SCADUK." (Leicestershire-Heart and lung disease)

- **Expectations would have been met had communications been better. (10 comments)**

"We had to catch up with a lot of information ourselves - no updates or information on what is being done." (Leicestershire - Mental Health)

"Non-expert GP made a decision without listening to our family lived experience or evidence from other professionals." (Leicestershire - Autism)

- **Expectation would have improved if there hadn't needed to chase up on support/service - (6 comments)**

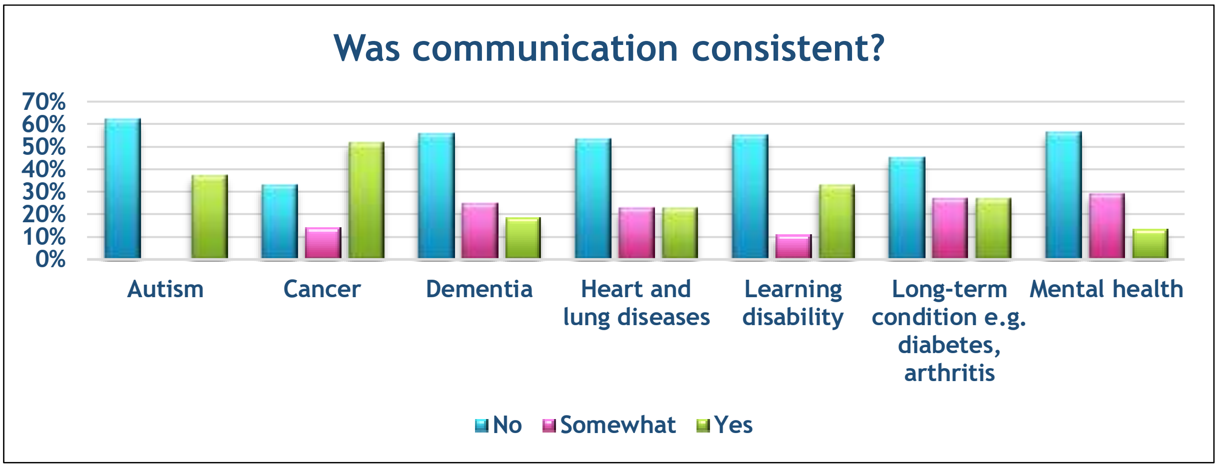
"98% of the time there has been no problem but, on a few occasions, and they really are only a few, I have had to chase people up to get information that they should have provided to me in the first place." (Leicester – Type 1 Diabetes)

"I had to chase counselling by telephone and was often transferred to the wrong place or person, very frustrating and hard when you have had to pluck up the courage to bare your heart & soul to explain what it is you are after, not everyone I spoke to was trained in mental health and you could hear the awkwardness down the phone." (Mental Health – Leicestershire)

xiii. During your whole experience of getting support did you receive timely and consistent communication from all the services that you came into contact with?

Cancer is the only condition where more patients had a positive experience of consistent communication. There was no geographic or demographic bias within the cancer cohort.

Chart 10



3.2 Transport and time spent travelling to access support and care

The focus of this section is on transport and travelling to access health and care services. 55% of respondents travelled in their own care and 24% in another person's car when accessing support and care. Individual conditions were examined. That is, 79% of the people surveyed were dependent on private cars rather than public transport or other means. A higher percentage of people with learning disabilities travelled in another person's car. For all other conditions, a higher percentage of people travelled in their own cars.

i. How much time would you be willing to travel for to receive a quick and accurate diagnosis?

30 minutes – 1 hour was the most common response for each mode of transport. With the exception of bicycle travel, there was a general unwillingness to travel for more than 2 hours. This was the same for all condition types, demographics and areas.

Table 14. Willingness to spend time travelling

How much time would you be willing to travel	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Another person's car	27%	46%	19%	8%
Bicycle	0%	0%	0%	100%
Bus	17%	44%	28%	6%
Own car	13%	49%	21%	17%
Taxi	33%	67%	0%	0%
Train	50%	50%	0%	0%
Grand Total	**18%**	**47%**	**20%**	**13%**

ii. How much time would you be willing to travel to receive specialist treatment or support?

Table 15. Willingness to travel for specialist support by condition

Travel for specialist support	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Autism	13%	50%	25%	13%
Cancer	10%	43%	29%	19%
Dementia	0%	60%	27%	13%
Heart and lung diseases	15%	23%	38%	23%
Learning disability	0%	80%	10%	10%
Long-term condition e.g. diabetes, arthritis	12%	44%	38%	6%
Mental health	23%	45%	23%	9%
Grand Total	14%	47%	28%	12%

Irrespective of condition, the majority of people are willing to travel up to one hour to see a specialist and people with heart and lung disease are slightly more willing to travel for longer. This indicates that people are prepared or expect to travel further and for a longer time to see a specialist. It is important to note that, as Rutland has no acute hospitals within its boundaries, patients must travel out of county to Leicester, Peterborough, Grantham, Nottingham or Kettering. It is unsurprising, then, that travel and transport figured highly in the Rutland public's concerns when asked about transport to health and care services. Without access to a private car and with limited public transport, getting to any of the acute hospitals can take many hours. Even if patients do have access to private transport, at peak travel and parking times a relatively short journey across country lanes and congested city roads can take longer than the 30-60 minutes the survey respondents were willing to accept.

3.3 Your expectations at each stage of your care

Section 3.1 asked those living with long term conditions about specific experiences. This section concentrates on the expectations people had, how they were met and their hopes and expectations for the future as they pass along the illness trajectory. There is a particular focus on determining whether people value speedier appointments without the continuity of a familiar health and care professional or whether they prefer to see professionals they know but have to wait longer to do so.

i. What is most important to you when first seeking help?

Table 16. Who people prefer to see

Who would you want to see when first accessing help	Don’t mind	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	50%	13%	38%
Cancer	15%	5%	80%
Dementia	13%	44%	44%
Heart and lung diseases	8%	33%	58%
Learning disability	30%	30%	40%
Long-term condition e.g. diabetes, arthritis	24%	21%	55%
Mental health	13%	37%	50%
Grand Total	**19%**	**28%**	**54%**

54% of people would rather see any professional who is available immediately rather than wait to see someone they normally see at this stage. However, more people with autism said they don’t mind and people with dementia had no preference.

ii. What is most important to you when you first receive a diagnosis and explanation of treatment or support options?

Once a diagnosis has been made, people’s opinions about the value of speedier appointments at the expense of seeing a familiar health and care professional have minimal changes except for those with learning disabilities as the following Table 17 shows:

Table 17. Who people prefer to see when they first receive a diagnosis and future options

When you’ve been diagnosed	Don’t mind	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	42.86%	28.57%	28.57%
Cancer	5.00%	45.00%	50.00%
Dementia	18.75%	43.75%	37.50%
Heart and lung diseases	0.00%	50.00%	50.00%
Learning disability	20.00%	60.00%	20.00%
Long-term condition e.g. diabetes, arthritis	17.65%	32.35%	50.00%
Mental health	14.58%	45.83%	39.58%
Grand Total	**14.97%**	**42.86%**	**42.18%**

Again, a higher percentage of people with autism said they 'don't mind'. There was a marked increase in the percentage of people with learning disabilities saying they would prefer to see the health professional they normally see even if they have to wait. People with undefined long-term conditions still prefer to see any health professional more quickly. For the rest of the conditions, there were small percentage difference between the two options of seeing a known profession and waiting or seeing an unknown professional more quickly.

iii. What is most important to you during your initial treatment or support?

Table 18. Who people prefer to see during initial treatment/support

During initial treatment	Don't mind	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	57.14%	28.57%	14.29%
Cancer	5.00%	35.00%	60.00%
Dementia	12.50%	43.75%	43.75%
Heart and lung diseases	8.33%	33.33%	58.33%
Learning disability	20.00%	70.00%	10.00%
Long-term condition e.g. diabetes, arthritis	21.88%	15.63%	62.50%
Mental health	12.77%	59.57%	27.66%
Grand Total	15.97%	41.67%	42.36%

A comparison of Tables 16 (first seeking support) and 17 (first diagnosis) with Table 18 (first treatment) demonstrates that people's expectations change as they progress along the illness trajectory from diagnosis to treatment. At the first treatment stage, those with cancer, dementia, heart and lung illnesses and undefined conditions now showed a greater preference for speed rather than seeing someone they know. Those with learning difficulties and mental health conditions now show a greater preference for familiarity than speed. Those with autism show a greater tendency not to mind.

iv. What is most important to you during your long-term support?

When asked about expectations of long-term support, the responses show more shifts in expectations.

Table 19. Who people prefer to see during long term support

Ongoing support	Don't mind	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	50%	50%	0%
Cancer	5%	50%	45%
Dementia	6%	75%	19%
Heart and lung diseases	9%	55%	36%
Learning disability	10%	60%	30%
Long-term condition e.g. diabetes, arthritis	21%	48%	30%
Mental health	11%	72%	17%
Grand Total	14%	61%	26%

Comparing Tables 17 (first diagnosis), 18 (first treatment) and 19 (long-term support) shows that the total of 'don't minds' remains very similar. However, there is, from first diagnosis to long-term support, an increase in people preferring to see the professional they normally see and be prepared to wait (up from 42.86% to 61%). This was most marked in people with dementia (up from 43.75% to 75%) and people with mental health conditions (up from 45.83% to 72%). People with all conditions, except those with learning disabilities demonstrated a lower preference over the illness trajectory for seeing any professional sooner. Those with dementia, learning disabilities and mental health conditions all showed a reduced percentage in 'don't mind' from 'first treatment' to 'long term support'. This suggests that people living with long term conditions build up effective (and, possibly, affective) relationships with 'their' professionals over the illness trajectory. Continuity of care is obviously valued by patients and their families or carers.

3.4 Supporting you to have more control over your own care

Central aims of the NHS Long Term Plan are 'personalised care' (care for the whole person according to individual needs and preferences and not just a specific illness) and helping those with long term conditions to stay well for as long as possible, manage their conditions themselves and avoid acute hospital emergency admissions. This following section therefore focusses on the support people want from the NHS to achieve these aims.

i. What level of support do you want the NHS to provide to help you stay healthy?

63% of respondents said they wanted ‘some support’ and 26% wanted 'a lot of support'. There was no variation across different demographics or areas. Table 20 shows the results in full:

Table 20. The level of support people want to stay healthy

Level of Support	A lot of support	Some support	Don't know	I don't need support
Autism	33%	56%	0%	11%
Cancer	19%	67%	5%	10%
Dementia	20%	67%	7%	7%
Heart and lung diseases	15%	62%	8%	15%
Learning disability	40%	50%	0%	10%
Long-term condition e.g. diabetes, arthritis	21%	79%	0%	0%
Mental health	32%	54%	6%	8%
Grand Total	**26%**	**63%**	**4%**	**7%**

100% of the people with unspecified conditions wanted ‘some support’ or ‘a lot of support’. The second highest need for support was expressed by those living with dementia. 77% of patients with heart and lung conditions expressed the lowest need for ‘a lot of support’ or ‘some support’ and were the biggest group to say they did not need support.

ii. What could the NHS do to help you stay healthy or manage any condition you have?

97 people responded to this free text question and the following themes emerged from their replies:

- **Better access to services – less delays or waiting times. (14 comments)**

> *“Make it possible to get an appointment and even more so, to be able to see the same doctor each time. We have over a dozen doctors at our practice and you are lucky to be able to get an appointment with anyone, yet alone someone you have seen before. Same at the hospitals, you see someone different every time. There is absolutely no continuity of care so how on earth can the doctors understand what is happening?” (Leicestershire – Heart and Lung)*
>
> *“Work with me to help me integrate the medical care I need into my ‘normal’ life. I have a life limiting condition but I want to live the life I have, not spend all my time waiting for medical care of one sort or another.” (Rutland – Cancer)*

- **Supporting local activities - better access to non-medical help and support. (13 comments)**

> *“To give support positively for a good change such as lifestyle and wellbeing.” (Leicestershire – Autism)*
>
> *“Signposting to local facilities to support or encourage me to remain healthy and increase my wellbeing. In order to signpost, the NHS needs to be aware of all the local activities and this is something that Public Health could amass and provide.” (Leicestershire – Dementia)*

- **Better training for staff - better understanding of the patients and their condition. (11 comments)**

> *“Provide more training and information for lesser known conditions, especially those that are 'invisible illnesses' and provide more support to the patient going through the experience, it seems those with invisible illnesses don't get the time and effort.” (Leicestershire - Long Term Conditions E.g. Arthritis, Diabetes)*

iii. If you have any further comments, please write them below

The survey finished by inviting free text comments. 64 comments covering a wide range of themes were received. Some of these emerging themes include:

- **More local support. (5 comments)**

"Living on the border of 3 counties I didn't know where to go for help. Carers' groups do not exist in villages, so you have to travel. You have to be able to drive, sometimes, 40 miles just for 1 hour carers' session. Dementia is tiring but living in rural areas means you are isolated and ill-informed; all adding to the stress." (Leicestershire – Dementia)

"Far too few children's mental health and psych [sic] services. It's appalling in our area." (Leicestershire – Autism)

- **Better access to services. (5 comments)**

"We feel a lot of time is wasted attending appointments and then finding we have to repeat them because the person has left or is on long-term sick. We have assessment after assessment and little practical action. If we had a personal budget for physio/SALT we could have effective block bookings rather than consistently starting and stopping and being reassessed." (Rutland – Learning Disabilities)

- **Positive experience – patients sharing their personal positive experience. (5 comments)**

"The care I have received and continue to receive is exceptional. My consultant works with me to provide me with the best quality of life I can have. I am very lucky, but I am very aware that other people have found it to be frightening and overwhelming to have a rare cancer without sufficient support. There is nothing more unnerving than to have to call out a paramedic or get admitted to A&E to have the medical professional treating you admit they have never heard of the condition you have!" (Leicestershire - Cancer)

3.5 Summary of the long-term conditions survey findings

- People who have mental health conditions receive a slow and unsatisfactory service throughout their illness trajectory. They are most likely to want to see the same health and care professionals even if they have to wait longer.
- People with cancer receive the quickest and most satisfactory service.
- People want health and care professionals to have more knowledge about their illnesses, local support services and a greater understanding of the impact of their illnesses on their families.
- People in Leicestershire have to wait longer to get a diagnosis than those in Rutland and Leicester city.
- All the respondents, except those with cancer, want communications to be improved.
- Patients with long term conditions build relationships with health and care professionals and value continuity of care.
- Most people with long-term conditions want some or a lot of support; especially those with dementia and unspecified long-term conditions; but people with dementia are least likely to be offered ongoing care and support. Those with heart and lung conditions require the least support.
- People are prepared to travel up to one hour to access health and care services but will make somewhat longer journeys to see a specialist.
- Younger people find it harder to access health and care services and their expectations of doing so are not being met.
- Those who have been diagnosed with a long-term condition in the last three years consider they have had a less satisfactory service than those who were diagnosed more than 3 years ago.

4. Focus groups, interviews and patients' stories

In this section, attention switches from the two surveys with standardised questions and choice options to the thematic analysis of data collected from focus groups, semi-structured interviews and patients' stories. These were intended to complement the surveys by providing rich detail about people's experiences and expectations of the NHS. The participants came from the following groups:

- Carers
- Young people (up to age 25 years) with learning disabilities and/or autism and/or additional needs
- Those living with dementia
- Hospital outpatients

4.1 Carers and caring

Carers told us that being a carer can be described as '*a labour of love*' which involves minimal financial reward and long hours. Specifically, many carers in the dementia interviews and in one patient's story alerted us to the extra burden placed on them by the responsibility for ordering, storing and administering medications to patients. The carer role is often accompanied by a sense of personal loss: loss of career and salary expectations; loss of previous relationships with significant others – often due to the mental and/or physical ravages of illness; loss of a former identity; and loss of a social life. There is a sense of injustice in that: there are few concessions for carers; their own health is often considered by NHS professionals to be secondary to that of the patients; the carers' allowance is tax deductible; and carers think that hospitals, sometimes dangerously, discharge patients before they are ready to go home because they know that the carers are there to '*pick up the pieces*'. In addition, carers felt that professionals, sometimes erroneously, might dismiss their own very valid opinions and give primacy to the patients' opinions about their care and support needs. Carers did, however, praise their inclusion in hospital patients' drink rounds and hospitals' 'carers' pamphlets.

4.2 Transport

Hospitals are also criticised for inadequate attention to carers' needs in car parks and, in particular, the University Hospitals of Leicester inconsistent policy of charging carers with 'blue badges' for car parking at the Royal Infirmary but not at Glenfield Hospital or the General Hospital.

Transport problems were particularly felt in Rutland and in the County by dementia patients and their carers, many of whom are elderly. All the dementia patients spoke sadly of their inability to continue driving. They were heavily dependent on their carers or social networks to drive them to appointments and social activities.

One group of carers usefully suggested that a ‘park and ride’ scheme for the Leicester hospitals would solve a lot of travel problems.

4.3 Social and community support

Rutland has 3 groups for young people with disabilities: Youth Chaos (ages 11-25 years, for special educational needs and disabilities); Disabled Youth Forum (run by Rutland County Council for young people, aged 14-25 years, with a variety of disabilities to facilitate their feedback to local services and facilities); Out of Hours Club (a voluntary organisation arranging social events and outings for those 18 years and over).

Dementia patients and their carers in Rutland spoke highly about their specific social groups: the Memory Café organised by Age UK; Rutland Reminders (a singing group); Active Rutland (swimming and walking); Rutland Community Ventures (arts activities).

The Carers Centre Leicestershire and Rutland (CLASP) caters for all carers in LLR and holds several workshops a week which are usually held in Leicester. There are also several Carers Support Groups in Leicester and Leicestershire. In Rutland, there are several organisations including Rutland Rotoract Family Support Drop-in sessions and Age UK Rutland Carers Support Groups.

In common with the survey responses, many of the participants thought they had been ill informed by NHS professionals about the groups, support services and benefits available to them and often ‘*just happened to find them*’.

> *“Most young people wanted a lot more communication about services available to them, but they want it in a way they could understand. They also wanted more people to tell them about activities they could take part in. These people, they think, should be people they know.” (Rutland learning disabilities focus group)*

Participants variously informed of their involvement in other social activities and community support: church groups; friends, family and neighbours; the Admiral nurses in Rutland; a local chemist in Leicestershire who was prepared to do blood tests; and group therapy for children with ADHD[2].

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[2] Attention deficit hyperactive disorder

Despite the lower ratings given in the survey for the importance of community support, this seems much valued by the participants, with carers, particularly, saying there is '*a need to speak to somebody who is not a professional'*.

4.4 Speaking to professionals and professionals' communication

Speaking to health and care professionals is often necessary and can be very stressful.

Getting through on the telephone to GP surgeries is difficult and securing a GP appointment can be a '*very major stress'*. Whereas Melton Mowbray carers thought their GP practice should employ more specialist nurses, one Loughborough carer said she '*did not like seeing nurse practitioners as she felt they were not adequately qualified to deal with issues that should be addressed by the GP*' An example of difficulties with surgery appointments was provided by a carer who was given appointments for blood tests for himself and his wife, who has dementia, on the same day but some time apart. They had to decide whether to make two journeys or sit and wait in the surgery!

Many participants also complained about waiting to see a specialist. For example, one carer waited for 6 months for his wife to be seen by an incontinence nurse and another was still waiting some 6 months after being referred to an allergy clinic. The young people with learning disabilities also expressed the distress and anxiety they experience as they are '*passed around*' different specialists with, for them, little or no tangible outcome.

Communications between different hospitals, between GP's and hospitals and between hospitals, GPs and patients/carers are often fraught with difficulty. This was more so when, as often happens in Rutland, patients go outside of the LLR footprint (system) for primary or secondary care. There is a sense that organisational systems '*do not talk to each other'* across the boundaries.

One of the patients' stories tells about the difficulties for the University Hospitals of Leicester in securing a full medical history from an out-of-county-hospital where treatment had been commenced. Another patient talks of his frustration as he has to travel from one of the Rutland villages to Haematology outpatients at Leicester Royal Infirmary just to be told that his blood results are within normal limits. He asks why Haematology cannot just make the results available to him and his GP on his electronic record. A third patient was told she must travel some 20 miles to Leicester Royal Infirmary to have her dressing changed when it could easily have been done locally in Oakham.

4.5 The use of technology

The dementia interviews and learning disabilities focus groups draw attention to the issue of digital exclusion. Although simple gadgets like panic alarms or monitoring equipment provide considerable reassurance, computers and other technology are often too difficult to operate for those with cognitive impairment:

> *"From the Out of Hours Club – most can use a phone and make and receive calls. Fewer can use their phones for texts. Even fewer use their phones, tablets or computers to browse the Internet. However, ¾ of the group have email addresses." (Rutland – learning disabilities volunteer)*
>
> *"We did think about using Alexa (Amazon Echo) to remind Mum but somebody told us it would muddle her up even more. We are interested in Hive but have not really looked into it. That might be for the future." (Rutland – dementia patient carer)*

4.6 Summary of the findings from the focus groups, interviews and patients' stories

- Carers often feel they are undervalued, are experiencing many losses, work long hours and have many responsibilities. They value hospital, GP, social and community support but would welcome more and better signposting to it. The management of medications is problematic.
- There are illness-specific social groups available in Rutland for young people with learning disabilities and additional needs and for people with dementia which seem highly valued.
- Transport to access health and care services can be problematic, especially for those in rural areas. One worthwhile suggestion is that of the introduction of a 'park and ride' scheme from Leicester city outskirts to the Leicester hospitals.
- All groups would value more information from NHS professionals about benefits, social groups and support services etc.
- Communications with the NHS and between NHS services are poor, cause extra anxieties and need to be improved.

5. Conclusion

This engagement has provided a snapshot of the public's opinions and experiences of, and expectations and aspirations for, our NHS. The results of each survey and major themes arising from focus groups, interviews and patients' stories have been summarised at the end of their respective sections. It is therefore not our intention to summarise them again here – but, rather, to reflect on how these results might be used, how they can help shape Leicester, Leicestershire and Rutland health and care services and what questions might arise from the results.

5.1 How can the results be used?

Firstly, this report will be published and distributed across the Leicester, Leicestershire and Rutland footprint for health and care commissioners and providers, local authorities, policy makers and the general public. We hope that, in turn, readers will use the public's voice to guide them in preserving the best of our local NHS, to make improvements for all of us where needed and to transform where safe, advantageous and manageable.

Secondly, the results of the Leicester, Leicestershire and Rutland Better Care Together footprint will combine with the results from all other Healthwatch areas and provide the Government with a national snapshot of what the public want from the NHS.

5.2 How can these results shape local health and care services?

In Leicester, Leicestershire and Rutland we are in the midst of big changes. Plans for both a community services redesign and new buildings for the University Hospitals of Leicester are developing. Changes in senior managers in commissioning and provider teams are being made. The movements towards an Integrated Care System are underway. Our GP practices have been organised into Primary Care Networks and we will soon be experiencing new ways of care delivery in primary care with new professional groups in our surgeries. These include social prescribers, clinical pharmacists, physician associates and paramedics. Within this significant time of change, this report provides evidence of what the public want. Healthwatch can therefore use these results to represent the public voice and work with, and, yet, when necessary, critically challenge, commissioners and providers of health and care services in order to seek continued improvement for the local population.

5.3 What questions arise from the results?

So many questions have been asked in this project that it is essential to consider whether the results, in turn, have raised questions. The answer is undoubtedly, 'yes' as we now list some that we have and which will, hopefully, provoke further debate:

- How does this latest Healthwatch project fit in with the broader engagement the Better Care Together team have been doing and intend to continue?
- Which of Healthwatch results have the greatest significance?
- Does the Better Care Together team have plans to investigate any elements of this work further?
- Could the Better Care Together team now set out their timeline for producing their local plan?

And

- If so, what role does the Better Care Together team members see public engagement playing in the future in terms of tracking the progress of this plan?

STP response to report

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Appendix 1 – Demographic breakdown of General survey responses

Row Labels	Leicester	Leicestershire	Rutland
18-24	6	8	2
25-34	30	11	5
35-44	17	16	6
45-54	17	21	15
55-64	25	36	22
65-74	25	47	18
75+	13	35	30
Under 18	7	1	3

Row Labels	Leicester	Leicestershire	Rutland
African	8		
Any other mixed background	2	1	1
Any other white background	6	3	4
Asian British	14	6	1
Bangladeshi	2		
Black British			1
Caribbean	9	3	
Indian	26	2	
Other	5	3	2
White British	68	159	92
Disability	**Leicester**	**Leicestershire**	**Rutland**
I’d prefer not to say	81	77	56
No	38	59	28
Yes	21	38	18
Are you a carer?	**Leicester**	**Leicestershire**	**Rutland**
No	126	130	88
Yes	15	47	13
Grand Total	**141**	**177**	**101**

Carer	**Leicester**	**Leicestershire**	**Rutland**
No	37%	38%	26%
Yes	20%	63%	17%

	Leicester	Leicestershire	Rutland
No	81	77	56
Yes I have a long term health condition	38	59	28
Yes I have more than one long term health condition	21	38	18

Sexuality	**Leicester**	**Leicestershire**	**Rutland**
Asexual	1		
Bisexual	1	3	
Gay or lesbian	2	2	1
Heterosexual	111	143	88
I'd prefer not to say	13	24	7
Other	11	6	3
Pansexual		1	

Sex	**Leicester**	**Leicestershire**	**Rutland**
Female	87	120	66
I'd prefer not to say	6	8	2
Male	48	50	33
Other		1	

Religion	**Leicester**	**Leicestershire**	**Rutland**
Buddhist	1	2	1
Christian	51	103	56
Hindu	13	3	
I'd prefer not to say	9	7	12
Jewish		1	
Muslim	26	1	1
No religion	29	57	27
Other	10	5	4
Sikh	3		
Grand Total	**142**	**179**	**101**

Appendix 2 - Demographic breakdown of Respondents of Conditions survey

Your age			
	Leicester	**Leicestershire**	**Rutland**
18-24	4	3	2
25-34	1	8	6
35-44	1	19	4
45-54	3	12	5
55-64	5	16	10
65-74	6	18	11
75+		11	7
Under 18			1
Grand Total	**20**	**87**	**46**
Your ethnicity			
	Leicester	**Leicestershire**	**Rutland**
African	2	1	
Any other white background	2	3	2
Asian British	1	2	1
Black British			2
Gypsy or Irish Traveller		1	
Indian	1		
Other		1	
White British	14	78	40
Grand Total	**20**	**86**	**45**
Do you consider yourself to have a disability?			
	Leicester	**Leicestershire**	**Rutland**
I'd prefer not to say	1	7	2
No	10	42	20
Yes	9	38	23
Grand Total	**20**	**87**	**45**
Are you a carer?			

	Leicester	Leicestershire	Rutland
No	16	61	35
Yes	3	21	9
Grand Total	**19**	**82**	**44**
Which of the following best describes you?			
	Leicester	**Leicestershire**	**Rutland**
Bisexual		2	1
Gay or lesbian		3	
Heterosexual	18	69	36
I'd prefer not to say	2	11	3
Other			1
Grand Total	**20**	**85**	**41**
What gender do you identify as?			
	Leicester	**Leicestershire**	**Rutland**
Female	15	54	27
I'd prefer not to say	1	2	
Male	4	31	17
Grand Total	**20**	**87**	**44**
Which, if any best describes your religious beliefs?			
	Leicester	**Leicestershire**	**Rutland**
Buddhist		3	1
Christian	11	46	31
Hindu		1	
I'd prefer not to say	1	10	3
Jewish	1		
Muslim	1		
No religion	5	24	9
Other	1	1	
Sikh		1	
Grand Total	**20**	**86**	**44**

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