

The NHS Long Term Plan

Healthwatch

Lincolnshire

The Lincolnshire Public “Talk About” NHS Long Term Plan

June 2019

wh  **t**

would you do?

It's your NHS. Have your say.

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Executive summary

Lincolnshire is a county with over 760,000 residents (the 4th largest in England), many of our residents are accessing NHS services in neighbouring counties; we border Norfolk, Cambridgeshire, Rutland, Leicestershire, Northamptonshire, Nottinghamshire, North and North East Lincolnshire. We are a county that is a mixture of coastal, urban and rural conurbations with challenges including poverty, isolation, transportation links and seasonal fluctuations in population and a healthcare service that is much challenged.

The purpose of our work and indeed this report is to provide information to the Lincolnshire Health System with regards to what Lincolnshire people feel about the NHS and the Long Term Plan; how people feel it affects them personally and what could be done differently. Furthermore our role was to analyse and include our own insight over many years to add context to these findings which will then be shared with the Health and Care system, and others in the public interest.

What we recognise from this work is that most of the messages coming through are not new, with a focus on communication, access which complimented the desire for a step change in our application of technology, timeliness and efficiency, transport and county infrastructures and of course care closer to home. When shared with the system team it was reassuring to hear that in essence these themes were consistent throughout providing a solid basis for benchmarking and measureable improvement from the public perspective.

However what the report also reinforced is that the general public told us they want to see a more ‘joined up’ approach across all NHS services in and out of county, whether they be primary or acute and greater synergy and demonstrable evidence that the health, public health and social care system are truly working collaboratively.

As a Healthwatch we feel there is a good deal of miss-information and apathy across the county, with patients disengaged, with feelings of little control and inequality of provision and with this in mind there is an urgent need to reenergise and invest in our county for the future.

Background

In the seventy years since the founding of the NHS, life expectancy has increased by around 13 years. But different types of diseases are becoming more common. More people are living with cancer or dementia largely due to increases in life expectancy and falls in the rate of premature death.

With advances in prevention and medical care in the UK, mortality rates for heart and circulatory diseases has declined by more than 75% in the last 40 years. But cardiovascular disease (heart and circulatory diseases) remains the biggest cause of premature mortality and the rate of improvement has slowed, with lifestyle and life expectancy being contributing factors.

Longer-term health conditions also make an increasing contribution to the overall challenge of the system. Mental health, respiratory and musculoskeletal conditions are responsible for a substantial amount of poor health, and place a substantial drain on the NHS and other care services.

According to the latest NHS reports thousands of people in England could avoid an early death from one of the 5 most common killers which are cancer, heart disease, stroke, lung disease and liver disease. The latest Global Burden of Disease study reveals that the slower improvement since 2010 in years-of-life-lost is “mainly driven by distinct condition-specific trends, predominantly in cardiovascular diseases and some cancers”. The NHS has therefore used these findings to help frame the improvement priorities in the Long Term Plan.

On 18th June 2018 the Prime Minister set out a funding settlement for the NHS in England for the next five years. In return, the NHS has been asked to develop a long term plan for the future of the service, detailing their ambitions for improvement over the next decade, and their plans to meet them over the five years the funding covers.

Healthwatch England have worked closely with NHS England to contract local Healthwatch organisations to engage with their local residents via two national surveys, in addition to which locally facilitated focus groups were also included into the mix.

One of the surveys invited people to comment on the main themes of the Long Term Plan whilst the other invited people with long term health conditions to share their experiences of accessing and receiving care from their relevant specialist services.

The surveys asked various questions which linked into the priorities of the Long Term Plan, specifically but not exclusively related to:

- Preventing illness and tackling health inequalities
- Making better use of data and digital technology
- Progress on care quality and outcomes; better care for major health conditions

Lincolnshire residents shared with us over 800 individual comments about their own experience of accessing and receiving health services in Lincolnshire.

These comments range from the very positive and supportive, to the understanding and accepting, through to the harrowing accounts of where services are just not meeting the needs of people and their families, leading to poorer outcomes. The experiences shared

also highlighted some inequalities in accessing health services in the county and whilst there are many, we have included ‘one’ such example under Section 6 of this report called ‘In Focus’.

The purpose of this report is to provide information to the Lincolnshire Health System with regards to what Lincolnshire people feel about the NHS Long Term Plan, how people feel it affects them personally and what could be done differently. This report, by its completion will have been presented to the System Leaders of our health services in Lincolnshire, which includes the STP Programme Team. It is expected that the insight we are able to share will help influence the design and delivery of future health services in our county. Responses to this report and actions from STP are included under Section 8 ‘Next Steps’.

However, what follows is a precis of the findings for Lincolnshire, this not only includes the survey, but other relevant information Healthwatch Lincolnshire feels is both pertinent and contributory to the report, this includes the summaries at the end of each section which states what Healthwatch Lincolnshire thinks is the bigger picture from what people, families, carers, staff and the system generally are telling us.



Specific Objectives

The objectives and timeframes for this work were set out by NHS England and Healthwatch England and can be found below. In Lincolnshire, our engagement and consultations began on the 1 March 2019 and ended on 13th May 2019. During this time we have promoted 2 national NHS Long Term Plan survey’s and facilitated 4 focus groups as well as gathering data from our own information repository. All of this information has been collated to enable Healthwatch Lincolnshire to identify a number of overall themes and trends.

Objective	Healthwatch Lincolnshire performance against objective
250 people to complete the Long Term Plan surveys, there were 2 separate surveys, one condition specific and one general. Local Healthwatch will analyse the results.	We received 309 survey responses from the people in Lincolnshire in total with over 800 free text comments. Results have been analysed and a summary of them included in this report
Identify and summarise existing insight and evidence that is relevant for the Local Plan.	Throughout this report we have referenced Healthwatch Lincolnshire’s own insight and evidence gathered through the public voice, involvement in system activity and our thematic work
<p>Carry out <u>at least two</u> public engagement events or focus groups involving a minimum of ten participants in each:</p> <ul style="list-style-type: none"> • One with the general public • One with a specific group or community sector • The themes and topics for the focus groups will be locally agreed with the STP 	<p>Healthwatch Lincolnshire have facilitated 4 focus groups using a set of questions designed through liaison with our Lincolnshire STP programme team.</p> <p>The groups selected were :</p> <ul style="list-style-type: none"> • Seniors Group - Sleaford (24 people) • Health and Care Students - Boston (11 people) • Stay Safe Group (8 people) • Gainsborough YourVoice@HWL (30 people) <p>In addition we discussed the questions with both:</p> <ul style="list-style-type: none"> • Parkinson’s Group, Louth (22) • Public at HWL Board meeting, Boston
Carry out any other reasonable activities collectively agreed with your STP and co-ordinating Healthwatch.	This focused on 4 STP led Healthy Conversation events during April 2019, where we attended and were able to engage with the public regarding the long term plan, promote the surveys and gather feedback

<p>HW to demonstrate within the final report how the local area has taken and utilised service user findings</p>	<p>This report, has been presented to local STP and also the STP Stakeholder Board. It is expected that the insight we are able to share in this report will help influence the design and delivery of future health services in our county and the STP actions and considerations will be included within Section 8 of this report ‘Next Steps’.</p>
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What we found out ...

Themes and sentiments - at a glance

Overall Themes

- People want to be treated ‘holistically’, not just condition or illness specific
- **Technology needs to be embraced** and developed as a ‘world class’ facility but not assumed that everyone will participate
- **Travel, transport, county road infrastructures** with links in and out of Lincolnshire were a consistent barrier for effective health and care systems
- People want more information, advice and guidance about how to make **better lifestyle choices and an affordable and supportive infrastructure to achieve this**
- People are accepting that some health services might be delivered further from home, but they definitely want their **recovery, recuperation and ongoing healthcare support delivered locally (close to home with continuity of care)**
- **Waiting times** for appointments need to be reduced
- **Diagnosis and test results** needs to be much quicker
- Services need to be much more visually joined up, this also includes ‘strategies’ from any of our statutory bodies that impact on the local population.
- **All communications with people**, both verbal and written need to be consistent, clearer, informative, concise, reliable and appropriate
- **People, families and carers have an important voice** which must be included and acknowledged as an essential part of their health management
- Where people don’t have a voice they don’t want to be disadvantaged, there is **more need for advocacy and support** to navigate the systems for all.

Public Sentiments

When reviewing the public feedback from all sources there were certain sentiments that we interpreted as general overall feelings about the health and care system generally:

- People are confused about our health and care system
- People are confused about how much responsibility for health lies within ourselves.



“Varied services across the county, it’s complicated to understand the difference with them all, the general public don’t know the difference between all services”

- People feel that ‘Dr knows best’ is a culture that is no longer relevant and that the system needs to ‘really’ listen and act in the best interest of the patient
- People are blaming political and financial challenges and using them as an excuse for inequitable standards across the county and country
- People are not engaged, apathetic and ‘bored’ of the spin.

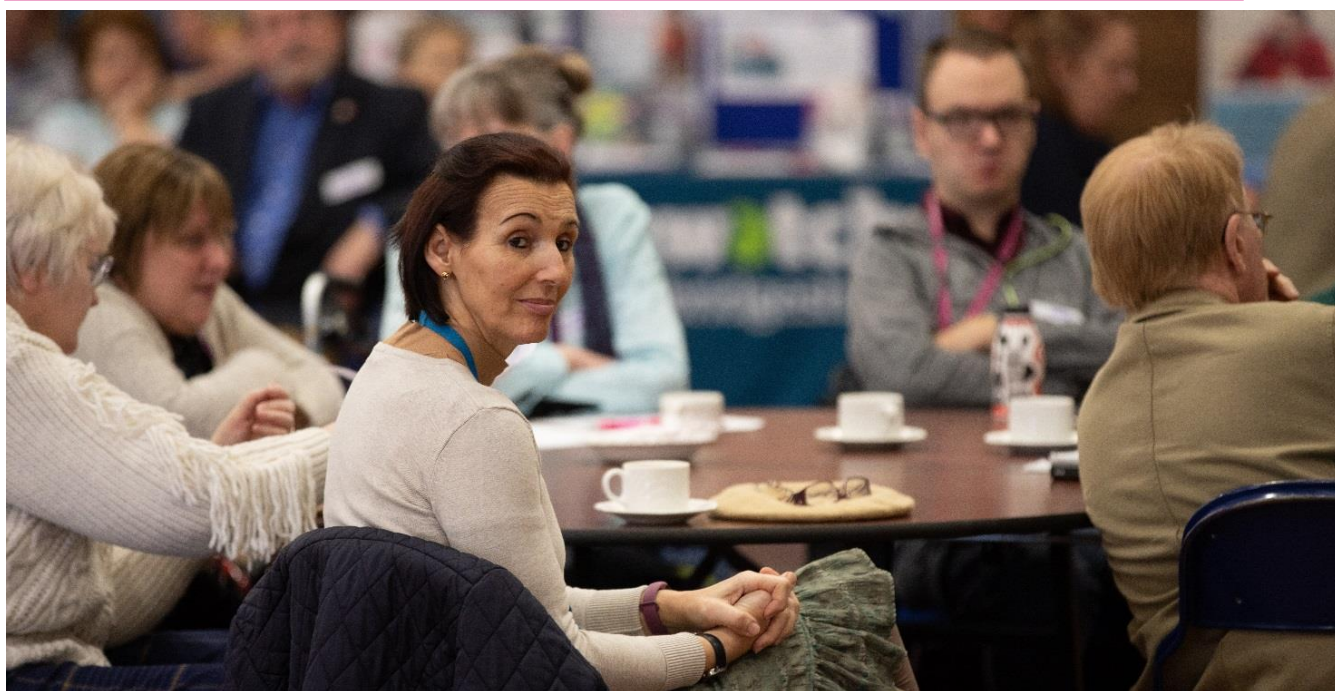


“More interaction if possible; by any way possible; listening from GPs hospitals etc. not informing only”

Two way process of sharing information and dialogue, improving understanding and appreciating there is more than one person in the relationship



“Reduction in central government grants to local authorities, increase in council taxes, reduction in services, such as local buses, longer to travel to towns causing social isolation, an ageing population (no plans for this)”



Expanding on the Themes

Communication

The public were clear that communication was an issue, that irrespective of modality (verbal, written, digital or face to face), the methods need to be clear, providing no ambiguity of what is being conveyed to the reader. That the communication is accessible and is received only once in a way that provides the end user, time, information and a pathway for any clarification to be carried out. The other plea was that the system worked in a synergistic way to ensure that one end of the county was not producing documentation differently to another. That approach is not a good use of time or resources and very challenging to monitor and measure from quality assurance purposes.

The whole person approach

People told us they want to be treated holistically, with respect, listened to and definitely be involved in managing their own health journey.



“My biggest problem is that you have multiple health issues and find continuity of care difficult to access and seeing a number of different doctor’s only acts like a sticky plaster and no one looks at the whole person or even tries to link various problems to find a full diagnosis.”

Technology

Use of technology brought out a mixed reaction. For some people the use of technology was definitely the way forward with a need to bring Lincolnshire into the present day, achieving world class digital care for now or in the future to ease the geographical and financial pressures being placed on 100% face to face contacts. Examples included maximising opportunities for text messaging, Skype consultations, access to records and tests and certainly better online signposting and advice to help manage long term conditions.

“Utilising technology moving forward to interact with people and medical professionals should be a given. After initial investment, the return in time and admin expenses will more than make up for the money spent and make long term savings.”

For other people the idea of using technology for their healthcare needs was appalling. This portion of the community were clear they wanted interaction from a person, and that for many in our county having fast and reliable digital access is still limited.

“Wake up to their being across the UK 6 million people who cannot access, do not have a signal or do not want to use the internet. People need people to talk to. What use is skype to examine a person? We need a skilled caring person. Again fine in theory but I live in the real world.”



Rurality

Rurality is a major issue and this is not just about travel and transport. Other concerns with regards to living in rural areas were related to an increasing level of more distant NHS services making it even harder for people to access, this can be coupled with less preventative and community based support leading to decreasing community cohesion and networks.

Travel infrastructure and public transport are a running theme throughout and continue to be a major problem and concern for people in Lincolnshire. People recognise that this is not in the gift of the NHS, but instead acknowledge that it will be necessary to mobilise a **proactive approach across all statutory bodies, community voluntary sectors and their own communities to drive a cohesive and significant change** for the way Lincolnshire plots and identifies itself on the national map for 2020 onwards.

People wanting **NHS services locally** was a significant theme. However, suggestions such as having specialist services and the **‘more complex’ health needs dealt with in central locations** were much more palatable and in fact preferred if that meant skills and equipment was state of the art and if all rehabilitation/aftercare was much more local.



“Lincolnshire is very rural and care is very sketchy, some excellent, some not so much. We struggle to get an appointment at the GPs, access service etc. We feel second class citizens compared to the bigger towns. Why shouldn’t care be the same throughout the country?”

Waiting times

Waiting times for appointments, assessments and diagnosis was another major theme throughout. Healthwatch Lincolnshire on behalf of people are concerned that we are hearing many incidents where this is impacting on patient’s mental and physical health.



“I need easier access to a GP/health professional and not having to wait several weeks. By the time I have waited several days to see a health professional the condition has deteriorated and my needs then are greater.”

Working together

We know **people are keen to see and experience a more ‘joined up’ approach across both primary, secondary NHS and ALL services in and out of county.** We constantly hear about the plethora of action plans, projects, pilots and strategies to improve the lives of people who live and work in Lincolnshire. In reality what people **don’t** feel they see, is all these joined up and plotted to ensure time, energy and resources are being planned and delivered effectively with the person (patient/resident) at the centre.

From the feedback received in the NHS Long Term Plan national survey alone, we got a real sense that the public are **ready to hear the truth but also wanted reassurance that their voices will be heard** throughout any future consultation period. From a Healthwatch perspective this reflection of the public voice needs recognition, and a response needs to be carried out **at pace** to demonstrate a real system wide commitment to making Lincolnshire a great place to live and work and die well.



4.1 Findings from the NHS Long Term Plan general survey

The following sections provide a breakdown of the public’s feedback from the survey where we received 235 surveys, 212 were used for the analysis. 23 were omitted for varied reasons. This will be followed by a consolidation of where Healthwatch, along with information and data gathered along the way, have interpreted what ‘we feel’ is the bigger picture for Lincolnshire in terms of themes and trends.

4.1.1 What matters most to people in Lincolnshire?

Living a Healthy life

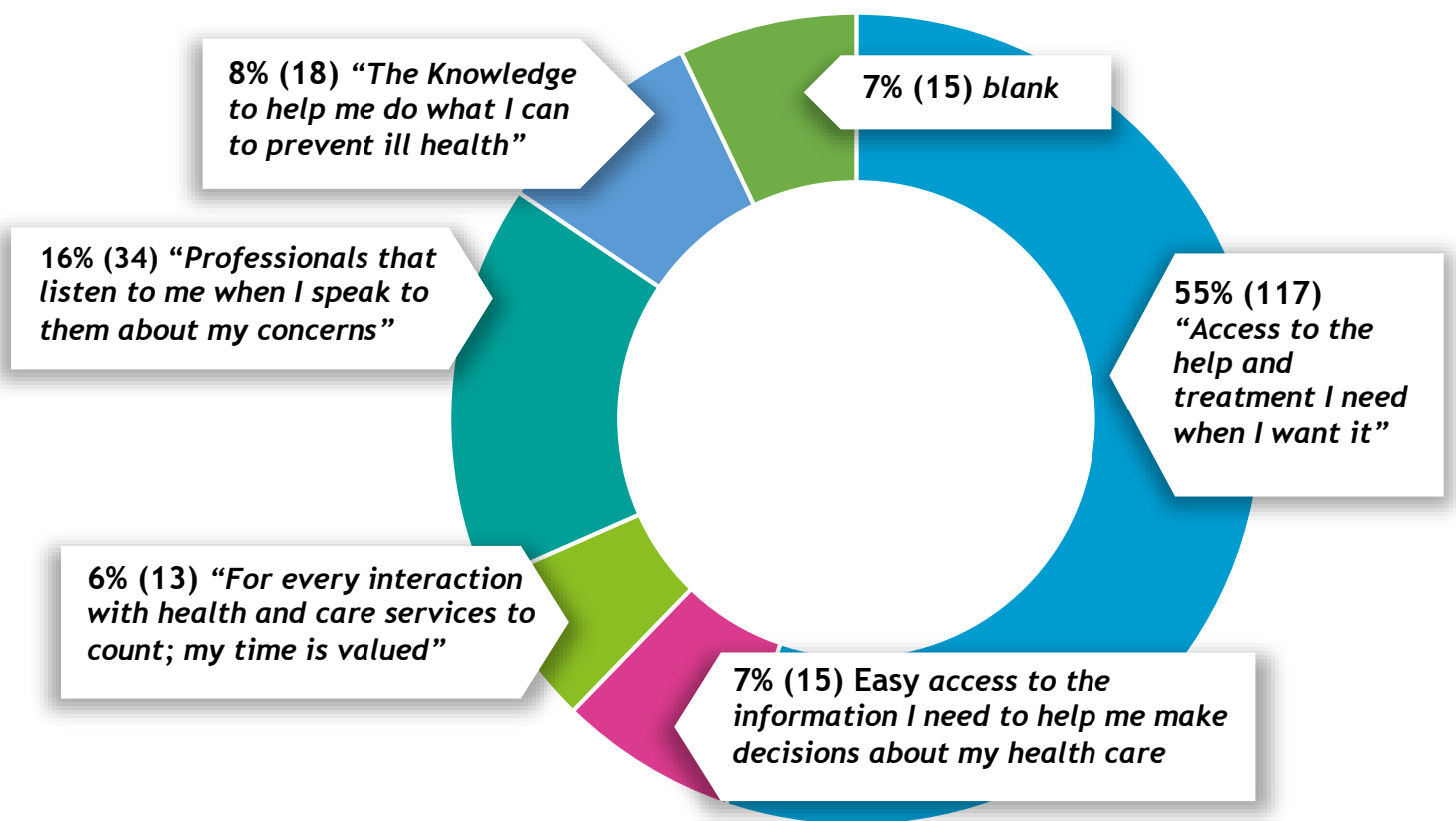


Chart 1, results from Q7 what is most important to you to help you live a healthy life?

People were asked to choose what they felt was the most important factor in helping them to live a healthy life. The top choice was the ability to access help and treatment they need, followed by professionals that listen to them when they talk about their concerns.

The public were clear that they want a system that takes into consideration the **timeliness** and **effectiveness** of their actions and how this in turn impacts on people. This covered a plethora of factors from the time it took to access professional advice; be referred and seen for assessment and diagnostics; receiving results and treatment right through to patient and public meaningful involvement in service planning or consultation.

‘Effective’ means for people that ‘the system works towards doing things once and doing them right’, learning from others and not reinventing the wheel for Lincolnshire.



“To access a doctor, on the day and at the time, I need them - not being told none are available and to keep ringing at 8am the next day. This doesn’t work, as I’ve had to wait weeks for an outcome that has left me still injured and still waiting for an MRI and ultrasound to confirm this, for treatment - probably all too late by now!!”

The public were also clear that **communication** was an issue and that irrespective of modality (verbal, written, digital or face to face), the methods need to be clear, providing no ambiguity of what is being conveyed to the reader whether that be patient, carer or family support. They were clear that the communication should always be accessible and is received only once in a way that provides the end user the time, information and a pathway for any clarification to be carried out. The other plea was that the system worked in a synergistic way, for example working together to ensure that one end of the county was not producing documentation differently to another. That approach is not a good use of time or resources and very challenging to monitor and measure from quality assurance purposes.

They were also concerned that they shouldn’t be disadvantaged because Lincolnshire is a large county with a poor transport and road infrastructure, or because the system as a whole cannot work together to deliver health and care in a fully integrated way.



Managing the support I need

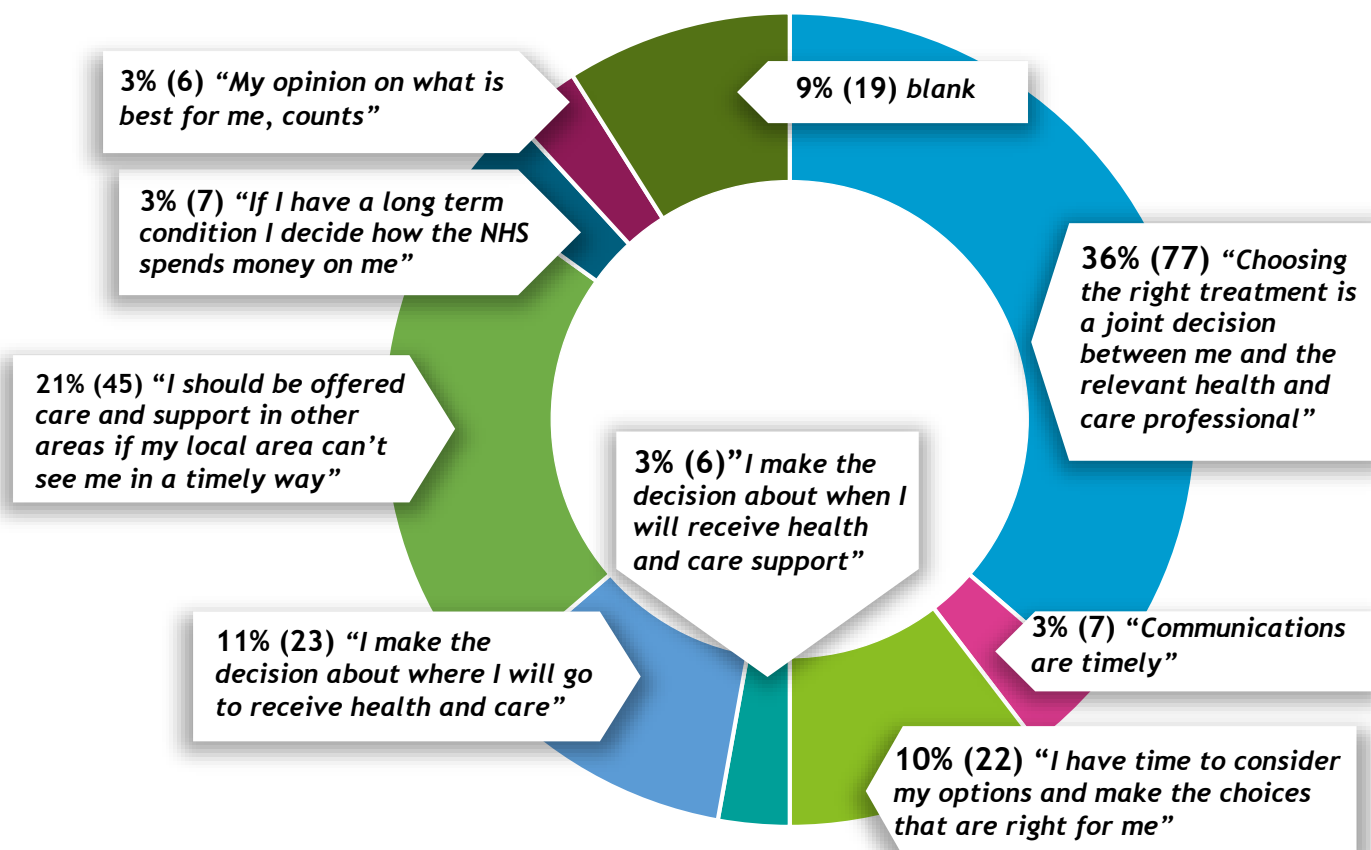


Chart 2, results from Q8 what’s most important to you to be able to manage and choose the support you need?

When asked to choose what the most important thing to them was when it came to managing and choosing the support they need, people’s top choice (36%) was “choosing the right treatment is a joint decision between me and the relevant health and care professional”. It was also important for people to be offered care and support in other areas if the local area can’t see patients in a timely way, this focus also draws on some of the conclusions which can be drawn from the ‘Dr is not always right’ terminology.



“Options clearly laid out at the start of investigations/diagnosis/treatment etc. with the professional recommending a particular course while also giving space for the patient to research things and make an informed decision about progress”

People want to know what their options and choices are but also after they receive this information they would like honest advice on how to make that choice. “Being fully advised of the choices”.

Understanding what matters most to people is important, whether this is due to their age, gender, involving family carers, specialist care needs or just because their wish is to include ‘holistic’ treatments as part of their care/treatment plans.

To help people be aware of options and choice, more than one respondent suggested a system which captured ‘provider profiles’, and comments included those below:

- A “best outcome” table for care providers ranked by how good the outcomes are for a particular condition so may be hospital A for say Heart, Hospital Z for Parkinson’s etc. Not always in your locality. Be prepared to travel to the best (within reason)
- Knowing which providers have got the best results for treating my condition and then having access to these providers
- Being given options as to best places to receive the support I need

Keeping my independence

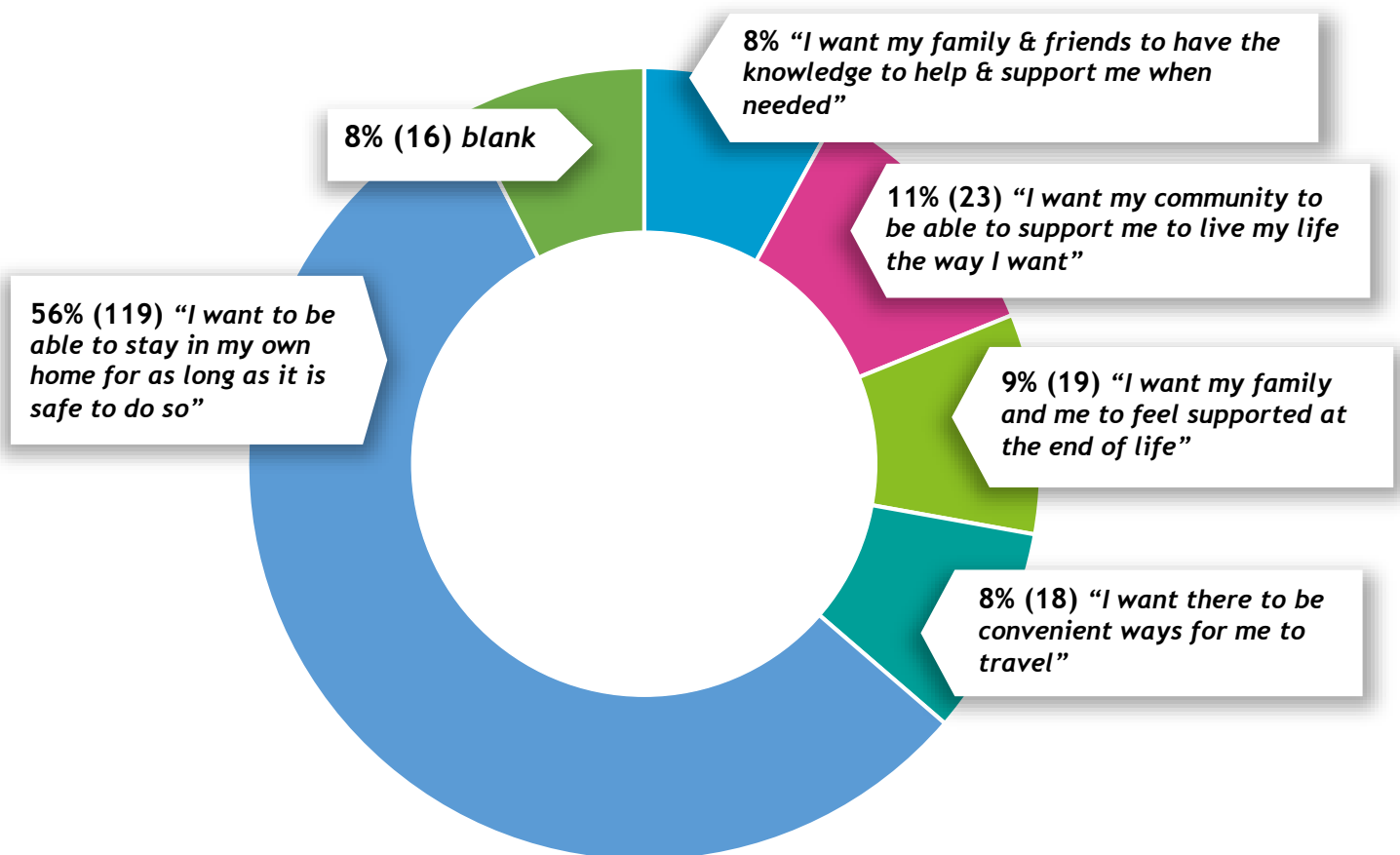


Chart 3, results from Q9 what is most important to help you stay independent and healthy as you grow older?

When asked to choose the most important factor to help stay independent and healthy as they grow older, the top choice (56%) from respondents was “I want to be able to stay in my own home for as long as it is safe to do so”.

A significant number of people felt that a reliable, affordable (and more importantly statutory funded) home care was essential to help them stay independent when the time came for them not to be able to care for themselves. Bring back ‘home help/visitors’ was a suggestion. To support this many people wanted to see care assessments and packages prepared well in advance so care needs can be in place much earlier.

Having lifelines such as ‘facetime’ or direct line access for some people was important. It was felt that if a person’s health is not great a chance to be reassured by a health professional would be beneficial to both the patient and their family *“My nan is 95 lives on her own, I feel that she should get someone other than me to check up on her maybe a nurse phone call every month or FaceTime call with me helping her with technology..”*.

It was felt that keeping active, better education about health and wellbeing (including from an early age) could all help someone to stay at home and out of hospital.



“Workplaces and employers to be much more involved in creating healthy workplaces, supporting and encouraging employee wellbeing”

How I interact with the NHS

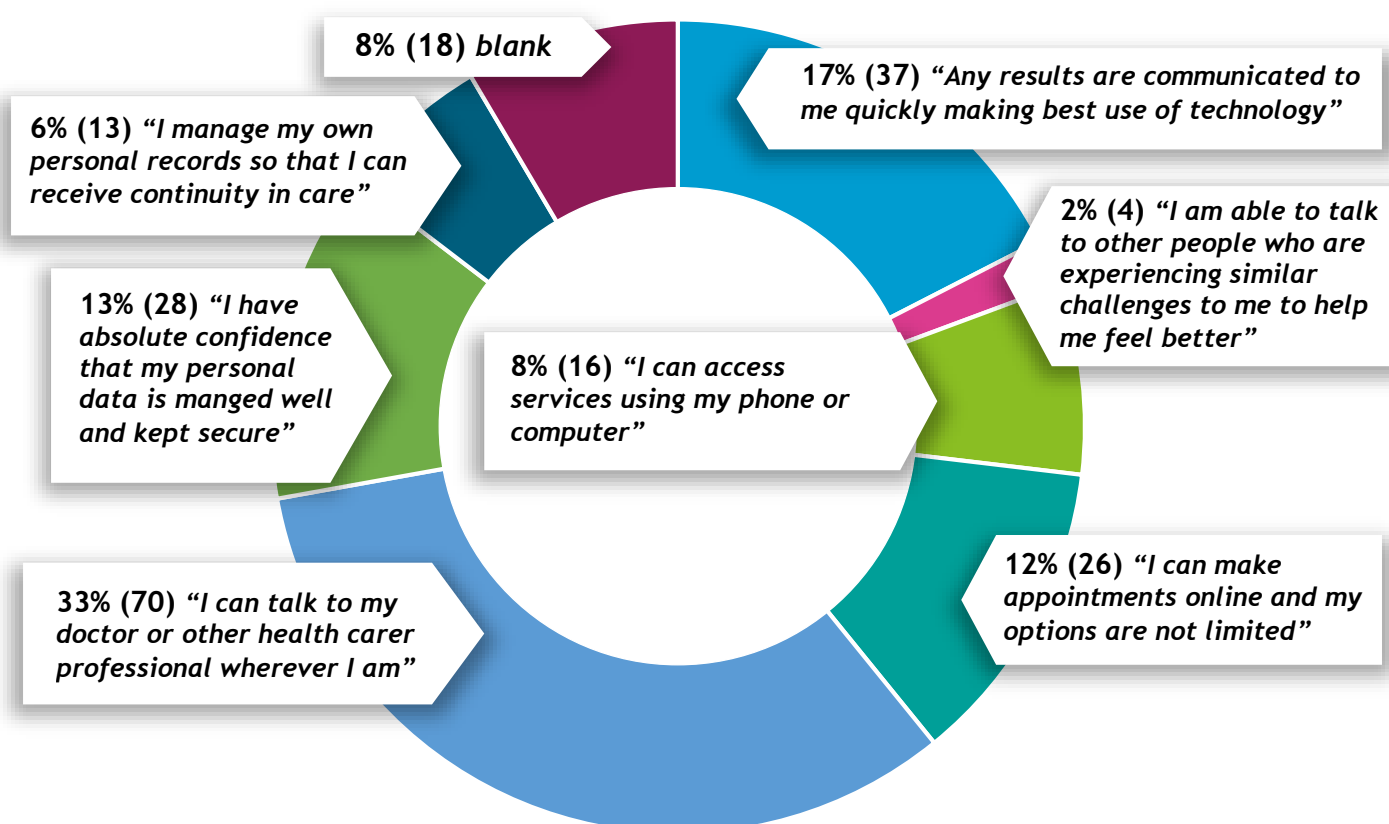


Chart 4, results from Q10 what is most important to you when you are dealing with the NHS?

When asked to choose the most important factor when they interact with the NHS, the top choice (33%) from respondents was *“I can talk to my doctor or other health carer professional wherever I am”*.

People felt there has been an increase in the length of time they are waiting to get help, this was particularly felt at GP level.

17% felt the most important thing when interacting with the NHS was ‘any results are communicated to me quickly making best use of technology’

Whilst the importance of technology was again mentioned, it was also felt people could lose out as technology was impersonal and didn’t allow for the ‘human touch’.

4.1.2 What are the cross cutting themes?

Four cross cutting themes emerged from all areas of the general survey, building a ‘picture’ of a public and patient population that wants to see synergy and pride in its delivery of ‘care’, putting Lincolnshire on the map.

1. Working Together

Statutory Services to Work Together to look at Lincolnshire making it an attractive place to live, work, bring up families and ultimately die. Throughout we saw public feedback on the need for services to work together. Healthwatch have repeatedly heard from residents that they don’t understand why it is not simple and straight forward for the NHS to communicate more effectively with each other and with other statutory bodies (particularly the care sector).

The public generally only see one NHS, they do not see the plethora of Trusts, Social Care and other provision both private and 3rd sector that make up our health services. People within the county are generally proud of where they live and for some, they moved here with the expectation that Lincolnshire would provide a better quality of life for themselves or their families.

What Healthwatch hears is that **Lincolnshire could be so much more, better roads, better attractions, more investment** to make it an attractive place for people to come, visit, live, work and enjoy.



“Local authorities to make it easier to walk and cycle to school and work etc. Cycle lanes, zebra crossings, well-lit pedestrian areas so people feel safe. Dropped curbs for wheelchairs, buggies, bikes and wheelie bags. Benches with arms so older people can stay mobile and walk and have a rest when they need to, and use the arm to push up again to get up”

2. Transport.

Transport was a constant recurring theme. A significant portion of our county rely on public transport which is limited and offers very little by way of simple and efficient travel for the population, even for those car users the lack of routes around the county which offer effective and efficient travel are limited.

“Consider the rural area of Lincolnshire, infrastructure and transport before cutting and centralising services. A vast majority of the people accessing health care are elderly, and this is the group less about to travel distances for treatment.”

“Travel in Lincolnshire is difficult, sparse public transport available, and very expensive. Can take 3 to 4 hours from Grantham areas to Lincoln.”

3. Care Closer to Home

People said they wanted care closer to home, but when this wasn't achievable they wanted the choice to go elsewhere to get the best service in the shortest amount of time, but always with the intention of providing rehabilitation (convalescence and recovery) closer to home. Where routine care was needed; blood tests (for adult and children), INR and sensory impairment checks as examples, they want the system to work together to provide this care closer to home, Healthwatch Lincolnshire considers these views are valid and suggests care closer to home could be achieved through actions such as reconfiguration of services or retraining/upskilling of staff, a good example of this is that children requiring blood tests have to go to hospital rather than having it at their local GP practice as the skills are not available locally.



“I would like to see centres of excellence for my treatment, I don't mind if I have to travel. However, aftercare and rehab should be closer to home.”

“It would be very nice but unfortunately it is not possible. Sometimes you have to go for specialised services further away and then come home for recovery.”

4. Education and Support

Local facilities and programmes to educate and support communities have a healthier life and stay independent for longer is a much needed theme.

Something that resonates with ongoing feedback into Healthwatch Lincolnshire is the need for local support. Communities feel education and support to help them lead healthier lives and contribute to self-care is missing from the current model of providing services, instead they have seen a reduction in Public Health preventative models and less community cohesion.

4.1.3 How do people want services to be delivered?

“Locally and where they can't be delivered locally, people want services that are accessible and supported by fit for purpose transport links, roads and public.”

4.1.4 Healthwatch talks about what key factors will need to occur and contribute to local STP and NHS Long Term Plan

Most of the issues that appear to impact on the general health, wellbeing and independence of our local population including young families, economic migrants and our aging population are not wholly in the gift of the NHS to change.

The pivotal factor which needs to change is the **statutory bodies ‘really’ working together for the ‘greater good’ of our county**, taking responsibility for today and the short to medium, not simply focusing on the long term 5, 10, 15 years' time.

Services in our county have continued to ‘bumble’ along resulting in reduced services, declining budgets, consistent reduction of community sector support and still more and more planning for new homes, with **no apparent joined up thinking about how these people will live in a cohesive environment taking their psychological, physical and economic wellbeing into consideration.**

The general public appears generally apathetic when it comes to ‘transformational’ change, or any change for that matter.

Communication needs to be clear and timely, whether that is our population who have heard talk and speculation for 5 years about a giant health consultation which never happened and who are increasingly disengaged, or whether it is Mr X who has received multiple appointment letters for an operation creating confusion, or Mrs Y who hasn’t had her cytology results and has been waiting for them in excess of 6 weeks but no one can tell her what is happening. From this we see the pattern of **not ‘putting the patient at the centre’** is inextricably linked to our behaviours as a system. Not to mention wasted staff hours and money expended on an inefficient service.



“Better information at each life stage so you do what you can to be in great health for the next life stage. A better joined up approach across the whole community”

Alongside communication, the need to **improve digital technology** to improve access and create equality for people resonated from the local population. It is recognised that not everyone wants to use technology and the desire to sit in front of a professional and see the ‘whites of their eyes’ is still very important for some. However the balance has to be strived for and become a reality sooner rather than later if we are ever going to free up some of our rammed waiting rooms and ever extending waiting lists.

Health and Social Care Secretary Matt Hancock in 2018 set out plans to make the NHS an ecosystem for the best technology available, building on the £20 billion long-term plan to transform health and social care so it can improve treatment and deliver better care for people.

Matt Hancock announced the NHS app will be piloted in 5 areas in England from October 2018 ahead of a national roll-out in December 2018. It was anticipated that people in the pilot areas would be able to download a test version of the app, allowing access to:

- *booking GP appointments*
- *ordering repeat prescriptions*
- *their medical record*
- *111 online access for urgent medical queries*
- *data sharing preferences*
- *organ donation preferences*
- *end-of-life care preferences*

It is May 2019 and we have not as a Lincolnshire population had sight of the digital transformation which will apparently be more economical and provide a better experience for people.

For too many years we have **stripped away the services that have supported people** living in communities and which promoted health and wellbeing. Removal of health based education and skills programs for local people has had a negative impact on knowledge, awareness and access to activities and services which would bring benefits to individuals and communities as a whole.

It wouldn't be unfair to state from the patient experiences we hear as a local Healthwatch that our people receive better communication and digital access to companies like Amazon™ dealing with millions of small providers, than they do from their local health and care services.

Again outside the gift of the NHS, little attention seems to have paid to the population in terms of need. People contacting Healthwatch Lincolnshire often describe what they need is a **generic and accessible advocacy support service**, not only accessible when you fall in a specified characteristic grouping, but available to all.

The next section 4.2 evaluates the condition specific feedback, and comparing and contrasting any anomalies with the general survey.



4.2 Findings from the Condition Specific survey

The second survey produced by Healthwatch England was focussed on people’s experiences of long term conditions. In total we received 74 surveys, 63 were used for the analysis. 11 were omitted for various reasons.

In some cases (illustrated below) the number of responses received did not provide enough thematic data for us to ascertain a clear picture for each condition. However, in respect of those people, carers and families that have responded and the fact that these views are still valued and will provide extra intelligence for commissioners, we have included them along with the analysis in Appendix 6.

<u>The Long Term Condition</u>	<u>Did People Respond</u>	<u>No. of Responses</u>
Cancer	<input checked="" type="checkbox"/>	11
Heart and lung diseases	Insufficient Data	0
Mental Health	<input checked="" type="checkbox"/>	20
Dementia	Insufficient Data	4
Learning disability	Insufficient Data	0
Autism	<input checked="" type="checkbox"/>	6
A long-term condition (generalised)	<input checked="" type="checkbox"/>	22

4.2.1 What matters most to people in Lincolnshire?

When a diagnosis of a life changing, life limiting or longer term condition ‘strikes’; people, families and carers agreed that it really affects ‘everyone’ involved in the care no matter what level that involvement may be.

It is fair to say that the issues that are high on the agenda for those without a long or life limiting condition are similar to those with. However what is noticeable is that people in the long term condition cohort, only really reference transportation in terms of being able to access their care, but where that care is delivered seems almost immaterial, as the right and specialist care was seen as more critical.

4.2.2 What are the cross cutting themes?

Six cross cutting themes emerged from all areas of the condition specific survey building a ‘picture’ of a public and patient population that wants to see proactive, speedy and informative health and care.

- Early diagnosis
- Help to manage and live healthier
- Communication needs to be much clearer
- Appointments - continuity of care professional was very important
- Helping support network to cope and deal the condition
- Family first approach

4.2.3 How do people want services to be delivered?



“Locally, timely, appropriately, efficiently”

Help, Setting and Delivery to Expectations, Closer to Home, Continuity

- More help is needed to help people access ongoing support after diagnosis or assessment.

Overall only **17%** said yes they felt the support they received met their needs and only **26%** said they would describe their overall experience of getting help as positive.

52% of people from the survey said they had other additional conditions or disabilities and of those that had an additional condition **41%** felt it made getting support harder.



“It is an almost impossible goal BUT why cannot primary care and critical care patients records be visible to each branch. My GP cannot see the paper records held at my local hospital for example. This kills the idea of holistic care.”

“I manage my own personal records so that I can receive continuity in care.”

More needs to be done to find out what patient expectations are from an early stage in their contact with health services when diagnosed with a long term condition.

59% of people said the wait to receive initial assessment on diagnosis was slow

56% would describe the time they had to wait between initial assessment/diagnosis and recovery/treatment as slow



“I feel that I am not being listened too or believed that I know how I feel/am feeling and having enforced opinions and views thrust upon me, whereby I can tell that I definitely haven't been listened too - seriously. Some of the Drs I see are totally arrogant and I am dismissed with no proper diagnosis, which I have proved is so, within a very little time, afterwards, meaning I have to revisit and get treatment and my health depreciating, at the same time!!!!”

“Things such as referrals to be carried out in a timely manner. When services in my local area are not appropriate for me e.g. cannot offer the appropriate treatment (particularly mental health treatment). To be given the option of being referred elsewhere.”

“More efficient referral system, less convoluted. It is very tiring having to constantly chase health professionals for urgent treatments and scans.”

- Having some modicum of control so people can manage expectations is clear. More needs to be done with regards to ensuring people have timelines and consistent communications from services when it comes to dealing with assessment, diagnostics, treatment and ongoing care.
- One question in the survey related to how much time people would be willing to travel for diagnosis and specialist treatment was answered subjectively and would of course depend on the respondent’s individual circumstances. However 20/30 minutes to one hour was the preference of the majority. What was clear was that people were not happy to travel 2 hours or more for their care. Whether this would change if the road and transport infrastructure is improved was not built into the questions. Equally, in the analysis and interpretation, the assumption is made that the 2 hours may mean one way or both ways. Finally, we must also appreciate that for some people the pain and discomfort of travel makes long distance quite distressing, not only for the patient but also those around them.
- We noted that generally people were happy to see any medically appropriate health professional who is free immediately. This was most important to them for speedy and efficient diagnosis and explanation of treatment or support options. However, there was a shift of views once the condition required long term support, more people indicated continuity of care professional was very important.

This was confirmed in Healthwatch Lincolnshire’s GP Appointment work (April 2018), people really do value consistency, continuity and familiarity.

4.2.4 Healthwatch Talks about Key factors that will need to occur and contribute to local STP and NHS LTP.

The following provides an overview of what we have learnt from all feedback. For reflections on the qualitative and quantitative data please refer to Appendices 5 and 6.

Something that came out clearly were the mixed experiences of people at first point of contact with the health system, normally the GP Practice. Being able to **get an appointment, being taken seriously, or diagnostics not being carried out when perhaps they should have, all being relevant.**

In order to get earlier detection for people, the pathway for assessment needs to be consistent for all people and where the system can’t currently cope with an increased

throughout this needs to be addressed and managed. Earlier **detection is better than long term health needs and treatments**. Coupled with this was the need to get results and appointments and any necessary care in a timely fashion to **avoid delays** and prevent further deterioration of a patient’s condition, this was to also ensure that the patient’s psychological wellbeing is maintained.

Overwhelmingly, from the comments it appears patient feel that **lessons and learning from the experiences of individual people, family and carers are not being embedded** into the delivery of the service. The system needs to use as many mechanisms and opportunities as possible to listen, learn and put into action constructive feedback.

During treatment, care and beyond, **“joined up thinking”, “a central point of access”, “one person who knows where I am in the pathway”** are all sentiments shared by people, this focus is an ongoing theme throughout the report. Patient’s share that they feel “fobbed off” or ‘it’s not my job’ syndrome is not a helpful approach in managing the patient and family through a complex health and care system. Perhaps more widespread use of Care Portal will help remedy this issue for people, although Healthwatch Lincolnshire feels that the NHS in Lincolnshire, holistically adopting this at pace, is now required.

With so many possible recognised **long term health conditions**, it has not been possible to provide individual results for every long term condition. One main reason is that respondents in the condition specific survey were not asked to specify what their health condition/s were.

The overarching factors which are important to people with specific conditions are consistent including:

- **Delays** - whether this is in getting an initial diagnosis or appointment to see a specialist for treatment and care. Delays are really impacting on patient’s mental wellbeing as well as physical health.
- **Joined up services** - having a team to manage the specialist healthcare needs of individual people particularly those with more than one long term condition is essential. The need for more joined up services also extends to both primary, secondary care, specialist services and social care.
- **Continuity** of specialist care once my condition has been diagnosed - including access to Specialist Nurses and regular check-ups with relevant health professionals.
- **Communications** - both written and verbal needs to be given in a more appropriate, understandable and in some cases respectful way.

4.3 Findings from the focus group engagement

As part of this work we engaged with a number of groups; one health condition specific with the remainder being the general population. We noted that the identified key themes were not that much different from those coming out from the national surveys. Focus groups focussed on Lincolnshire aspects of care and in essence you wouldn't expect to see any significant differences in wants, needs and experiences and this was borne out by the outcomes of the discussions. The following highlights the main areas of importance for local people, the cross cutting themes and how people want their services delivered. For a copy of the focus group questions please see Appendix 7.

4.3.1 What matters most to people in Lincolnshire?

- Better communication between different departments to enable the patient to be considered as a whole person rather than the condition, including a computer system that links everything together.
- Local services with a coordinated approach to appointments for tests and consultations.
- Introduction (re-introduction) of respite beds or half way houses (we note that very recently Holbeach Hospital are moving to focus on re-ablement beds for recovery).
- Improved messages about self-care.
- End the confusion of language for different services for example differences between services, UTC v MIU v A&E - people will just go to what is in their town.
- Improved Mental Health care.

4.3.2 What are the cross cutting themes?

- Communication and information both between patient and service provider as well as between health services themselves
- Access to transport and travel for appointments e.g. almost impossible to get to an early morning appointment if reliant on public transport, give people options.
- Speedier access to appointments (primary and secondary care)
- Improved technology especially around sharing information between departments
- Review and improve mental health service provision
- Concern over distances involved an ability, especially for carers/family members to visit, so that the general wellbeing of a patient can be improved.
- Acknowledging the importance of carers' and family involvement to be given appropriate consideration and attention.

4.3.3 How do people want series to be delivered?



“Locally, promptly, with empathy”

4.3.4 Healthwatch talks about key factors that will need to occur and contribute to local STP and NHS LTP

‘Doing things differently’

- There was mixed support for having to travel further for specialist services, although there was an air of resignation that it will happen anyway. This was particularly relevant to access and cost of travel.
- It is accepted that visitors can aid and assist a patient recovery but for some people visiting will be restricted in view of costs involved, especially with a significant number of people already living in areas of deprivation or with fuel poverty, therefore making an extended hospital visit extremely restrictive.
- However there was a lot of support for respite beds/halfway houses to enable a quicker return to the local area for those who are unable to return home immediately.

‘Preventing illness and tackling health’

- There was strong support for more coordination of appointments and tests and a lot of confusion around the differences between such as MIU and UTCs.
- There was support for different ways of getting those in high risk groups to participate in exercise such as distance markers on paths (especially in parks) and exercise classes just for overweight/obese people.
- It was also felt there is need for a total review of mental health services including more drop in services (charity/community led), and more understanding and empathy from all involved and more support for carers.

‘Making better use of data and digital technology’

- There was strong support for digital consultation for people with mental health conditions and where it could avoid ‘white coat syndrome’
- It was also felt that technology could monitor progress on care quality and outcomes and support better care for major health conditions.
- Reservations were expressed due to unreliability or lack of adequate broadband in Lincolnshire.
- Generally there was a preference for face to face especially on initial consultation.

5. How does the feedback link into the NHS LTP?

The following draws out some of the key priority areas within the NHS Long Term Plan which we anticipate will be picked up through local commissioners and providers via STP to make the commitments for change a reality for Lincolnshire.

We have been clear that the focus of our response will be related to what we know, therefore issues related to estates, workforce and broader implications for fiscal matters are not covered.

The feedback is drawn from different sources and includes:

- The national survey (both general and condition specific)
- Lincolnshire focus groups
- Patient feedback
- Healthwatch knowledge of the Lincolnshire System, including information taken from previous studies.

The following breaks down where possible feedback related to the NHS Long Term Plan Priority Areas of:

- Cancer - see section 4.2 Finding from condition specific
- Maternity and Neonatal
- Cardiovascular, Respiratory, Diabetes and Stroke
- Children’s Cancer Care, Learning Disability, Autism and Mental Health
- Primary Care Networks and Fully Integrated Community-Based Health Care
- Digital Technology



5.1 Condition Specific - Cancer

In cancer care, the NHS Long Term Plan wants to boost survival by speeding up diagnosis. It includes a package of measures to extend screening and overhaul diagnostic services with the aim of diagnosing 75 per cent of cancers at stages I or II by 2028. A review of cancer screening programmes and diagnostic capacity will also be undertaken to report back in the summer. In 2020, a new waiting time standard will be introduced requiring that most people get a clear ‘yes’ or ‘no’ diagnosis for suspected cancer within 28 days of referral by a GP or screening.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
In some types of cancer we see the county performing well, but this is not a consistent message across all cancer sites.	More consistent approaches to recognising and reacting to early symptoms from medical professionals
We see a lot of time and effort being directed towards living with and beyond cancer programmes for recovery.	People tell us that their psychological welfare is not catered for during most parts of their cancer journey.
We see agencies such as Macmillan working with partners to improve cancer services, but this is only one partner, particularly in palliative and EoL care.	People feel they become part of the system with no personalisation and can be made to feel guilty because of the fragility of services.
	Preventative cancer care programmes have been decommissioned by Public Health creating a reduction in awareness and education in our communities.
	The transparency and contingency planning in terms of cancer assessment, diagnostic and treatment with fragile services is not evident, for example we are seeing and hearing about patients with extended waits for assessment and diagnosis rather than being offered care outside of the county.
	Our performance year on year for is not an improving picture which impacts on staffing, opportunities and investment.

5.2. Maternity and Neonatal

Among a range of commitments in the NHS Long Term Plan, continuity of care during pregnancy, birth and after birth will be improved, bed capacity in intensive neonatal care will increase in areas where this is currently lacking and mental health services and other support for pregnant women and new mothers will be improved.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
The changes that have been made so far to the maternity provision has been positive and not had any negative connotations.	Physical environments are low quality in many of the service areas.
Lincolnshire has developed maternity voices to listen to the voice of the mother, families and carers.	

5.3. Cardiovascular, Respiratory, Diabetes and Stroke

The plan sets out a number of actions to improve detection and care for people with cardiovascular disease (CVD) and respiratory disease, prevent diabetes and improve stroke services. The aim is to prevent up to 150,000 cases of heart attack, stroke and dementia over the next 10 years.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
The Stroke Assisted Discharge Service is a pathway that works well for those people who are less acute and require less intervention but instead need more by way of reablement.	Our lifestyles and education add to the challenges around these conditions.
	Referral/transfer of services for out of county people could be timelier in terms of information about additional support services.

5.4 Children’s Cancer Care, Learning Disability, Autism and Mental Health

The NHS Long Term Plan is specific in its commitment to improve outcomes for children with cancer, increase support for children with learning disabilities and autism and improve children and young people’s mental health services.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
CAMHS has an outstanding CQC rating	Despite CAMHS CQC rating we are still hearing from CYP or their parents/carers that a child was not accepted into the service despite suicidal tendencies or other severe signs and behaviours
Development of the Health Check booklet was seen as a positive activity along with some of the commissioned work in 2018 for the promotion of LD health checks.	Health checks can support on going health and care monitoring, however we know that the development of health checks across our system for those with LD has been slow in developing to ensure continuity, consistency and coverage of the county’s population.
We have a managed care network and mental health concordat looking at the integration and commissioning of mental health.	Statutory bodies, people, families and staff all continue to tell us that policies and procedures are not joined up, people are unsure of mental health pathways, it is under commissioned to meet the growing need and people are left without support in the community. The crisis team would appear to be inaccessible for those in most need and our self-harm and suicide rates continue to rise.
	Despite all the strategies and the ‘talk’ about assessment and diagnosis and subsequent support for children on the autistic spectrum, specifically dyspraxia, we don’t seem to have tackled the reality that families cannot get the support needed because the diagnostics are not available, and schools are reported to not act without a diagnosis, a clear examples of systems not working together.
	Adults requiring autism assessments can often find it challenging to go to the prescribed centre, and there seems to be little flexibility to support assessment out of county even when it is more accessible to the patient. Example of not putting the person at the centre.

5.5 Primary Care Networks and Fully Integrated Community-Based Health Care

The plan suggests that primary care networks will be managing local population health from 2020/21 with the investment in and development of, multidisciplinary teams in primary and community hubs to develop an integrated and community based care model. The assessment of the population planning will be part of that process but must ensure the patient voice is considered with greater emphasis on patient centred care.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
<p>We know that we have gone some way in Lincolnshire into developing the Neighbourhood Teams or as we now term it Integrated Neighbourhood Working (dropping the need for teams)</p>	<p>Easier access to GP appointments - we regularly hear about people waiting 3-4 weeks for an appointment More consideration of infrastructure from local planning authorities when granting approval for large developments or even small developments in more rural locations</p>
	<p>A consistent approach to INW with the same cohorts of the population so comparisons and learning can be quickly achieved.</p>

5.6 Digital Technology

The NHS Long Term Plan was clear in its intentions to ensure that each patient would have a ‘right’ to access GP consultations in ways other than face to face using digital interfaces, this goes far beyond the capacity to book and cancel appointments on line and order repeat prescriptions.

What works well in Lincolnshire?	What could be better for Lincolnshire Residents?
<p>Its intentions to do things differently.</p>	<ul style="list-style-type: none"> • Improving community access to Broadband which is fast and reliable • Support for those on low incomes to access digital technology • More training and development for communities to change hearts and minds in terms of benefits to digital health and support. • Better use of contracting with providers to ensure that use of digital technology is an ‘expectation’ rather than a ‘nice to do’.

6. In Focus

People who responded to the NHS Long Term Plan condition specific survey shared with us their individual experiences of accessing and receiving healthcare services. Some of the experiences shared enabled us to identify where people in Lincolnshire were experiencing inequalities in services. Below gives examples why in their ‘own words’ Lincolnshire people feel they are receiving unequal treatment because:



They live in a rural community...

Cancer - *“No local support in rural coastal community, visited mobile Macmillan unit an hour away to get advice and support. Not good 4 weeks after breast surgery.”*

Autism - *“Many support groups are in the ‘County Town’ of Lincolnshire and therefore inaccessible if you happen to live at one end of the county - it’s not always easy/possible to access a nearer service in a neighbouring county.”*

Regarding travel times - *“It is not possible to travel more than 30 mins because of disability, pain and mobility issues. I was recently offered a quick hospital appointment for cardiology at hospital that was over 1hr away, with no direct bus or train route to it. I had no one to drive me as it was 9am appointment. Which would have meant me getting a taxi which would have been prohibitively expensive. I had no option but to arrange for local hospital appointment which took a further three months get and that was an urgent referral because I keep falling and knocking myself out ending up in A&E!”*

Lincolnshire’s limited offer of services for...

MS - *“Very little support for MS in Lincolnshire. Only one nurse, my treatment is in Nottingham so my MS Nurses are in Nottingham a very long journey when you need to see them.”*

Diabetes - *“Initially my child who has Diabetes managed to get all the help they required but after that it’s sort of dropped off as the diabetes nurses left their posts and were*

not replaced. Currently Lincolnshire people in our area go to East Riding if it is in an emergency situation with regards to diabetes nurses. As I understand this really does need addressing as Diabetes is going to be more prevalent in society I worry about my young child and the infrastructure in place to help them.

Diabetes - *“There are quite simply not enough Diabetes trained nurses to go around you are waiting a long time to get in this condition is life-threatening you seriously need to pour more money into it.”*

Cancer - *“Getting the GP to take notice was the 1st obstacle, then long waits for hospital consultations and then sent to neighbouring county for tests and they said my husband should have been referred to them initially for quick treatment.”*

Adult neurology - *“My partner has recently had a heart attack, is being treated for cancer and just received notification that they need to be urgently referred to neurologist as they most likely have a degenerative neurological condition. Only problem is we have been told by our doctor that we are not able to get an appointment anywhere to see a consultant neurologist, we are so concerned about any delays and I am concerned the stress of waiting caused their heart attack (experience taken from Healthwatch Lincolnshire IMP database).”*

They felt their age was an issue...

Dementia - *“Dementia services all over the UK are aimed at those over 65 (presumably due to the condition being most prevalent in this age group). However, my mother was diagnosed with early onset Alzheimer’s at the age of 53. She is now 56 and the services we are able to access are greatly limited due to the age bracket. The needs of those diagnosed younger are vastly different than those aged 65 and over. There is next to no specific support available to those of us caring for younger dementia sufferers and very little in way of services for the people diagnosed. Myself and my father have felt the services offered to older people are largely very accessible and varied but my mother is reluctant to engage with services geared for those. There needs to be more awareness of dementia affecting younger people and services to support this massive diagnosis and the impact it will have on their lives and those of their loved ones.”*

Autism - *“We felt our child was not disabled enough for the local parent supporting parent group, and now they are almost 14 there is no parent group to support us with this age.”*

Autism - *“All the support for Autism stops at age 16 when the child leaves school. My son is 24, has no support and has a mental age of 15 yet child benefit stopped. Children with learning disabilities should be regarded as younger with regard to support.”*

Diabetes - *“I appreciate the pot of money can only go so far but juvenile diabetes type one seems to be more commonplace now through no fault of their own this really does need addressing if you look after them in younger life they are less likely to rely on the NHS for help during the middle years and so surely it is money well spent.”*

7. Engaging people in health service delivery

This section of the report is used to summarise any findings that Healthwatch have received about how people would like to be engaged as part of any health and care service transformation.

Engaging people is considered to be an enabler of service change and improvement within the Long Term Plan so what might good and appropriate engagement look like?

When considering this we not only looked to the feedback from the general and condition specific survey, but also considered the views of those taking part in the focus groups. We also recognised what we know in Lincolnshire from patient feedback as part of the service change and transformation that has already taken place and where people have shared their views on this with us.

What was the feedback	What was done well	What could have been improved
Drip fed messages but no realisation of action, no consultation, no listening.	Raised the profile of the need for transformation of Health and Care to gain public interest.	Just about everything in terms of managing expectations and delivering on statements of promise.
Demonstrate that the voice of the patient is heard.	Raise the profile of the proposed changes and improved awareness for the public about the misuse of emergency and urgent services.	Raised expectation that the public voice would be heard and considered when in reality for the public the outcomes have not changed. More demonstrable evidence that the system is listening is needed.
Commissioners and providers need to share clear and precise details related in changes to services, a need to know basis is not good enough and leads to rumour and patient discontent and anxiety.	Sent out early communication to people to make them aware of intentions of change, an example of this would be the Pain Management Service.	Having a joined up approach to patient messages, this was clearly not evident between the staff on the ground and the commissioners, the understanding and the patient interaction was damaging. Did not capitalise on the opportunity to communicate with people digitally by responding to feedback as it arose on social media.
	Care Portal provides an opportunity for patient care to be managed effectively.	This should be made mandatory for all and not a choice as this dilutes the effectiveness of a system development.

From the Focus Groups we established that there was support for ongoing involvement in the way health and care was being developed in the county. The patient population felt they were not best placed to decide the exact methodology to be used. However what was useful was their considered views of where these interactions with the Lincolnshire public should take place.

Feedback from focus groups on how and where they would like to engage included the comments below:

- Go to places where the public are e.g. shopping malls, pubs, garden centres and community events
- Visit the elderly/schools/colleges/work places to get opinions from seldom heard groups
- Let health groups be more involved, such as Parkinson’s
- Carers voice needs to be listened to
- Carers and family should be present as at the time of appointment or assessment, it is not possible to remember or say everything so the presence of family is important
- Know your community
- Centralise resources
- Key (positive) messages to people telling them what is available, how to access it and pathways
- Are voices really being listened to and acted on
- Public meeting, focus groups
- All views however collated should be heard
- Looking for more interaction by any means possible; more listening from GPs hospitals, consultants, social care needs to be a two way process of sharing information and dialogue, improving understanding and appreciating there is more than one person in the relationship
- Not just information giving, listening clinics, provision of appropriate information or supported signposting (social prescribing).
- Text messages to feed back
- Token voting system in surgeries

8. Next Steps

We engaged with our local STP throughout this process and shared the report and presented the findings. This section provides a response from system leaders in terms of how the views of the public from this piece of work will be incorporated into the final plans for Lincolnshire.

Their commentary was as follows:

How the work Healthwatch fits with the broader public engagement the STP is doing?

“Throughout 2019, Lincolnshire’s NHS has been conducting ongoing engagement with staff, the public, patients, their representatives and our partners, in order to best understand feedback and views upon the changes that our local health system needs to make in the coming years. We have worked closely with Healthwatch, as development work around the long term plan has happened, in order to ensure that the simultaneous engagement we are doing links from the perspective of learnings, as well as in the minds of the public, to retain simplicity and understanding. This has meant we have hosted Healthwatch at our own events throughout the year, and that we have reported outcomes from our engagement to them through our STP Stakeholder Board, to help progress our mutual understanding of feedback.”

Which of Healthwatch findings stand out?

“

1. ***Travel, transport, county road infrastructures with links in and out of Lincolnshire were a consistent barrier for effective health and care***

This has been a consistent and important concern for the public, throughout this period of engagement and beyond. We are working with partners who manage the counties travel and transport to ensure these concerns are considered as progression is made.

2. ***Technology needs to be embraced and developed as ‘world class’ but not assumed that everyone will participate***

In our rural county, this is often cited as a consideration, but with the reservation that poor connection speeds, and reluctance to adopt IT solutions may slow progress.

3. ***People are accepting that some health services might be delivered further from home, but they definitely want all their recovery, recuperation and ongoing healthcare support local (close to home with continuity of care)***

This message has also been strong from our own engagement work, similarly focused upon the acceptance that specialist care may require greater travel, but frequent and routine appointments should be delivered as close to home as possible.”

Does the STP have plans to investigate any elements further?

“Yes. Our Healthy Conversation 2019 engagement work will continue throughout the year, and within this, we are developing more detailed public and staff workshop sessions to explore the key themes we are hearing are important, and progress thinking around them with this input. We are also embarking upon a significant piece of co-production work with stakeholders and partners across Lincolnshire in our Integrated Community Care programme which will consider many of the care closer to home themes that have been raised.”

What is the timeline for producing their local plan?

“We will be guided by national, mandated timelines. The current thinking is that we will continue our engagement process over the summer of 2019, with localised plans developed in conjunction with our public and partners by the autumn.”

What role do they see public engagement playing in the future in terms of tracking progress against the plan?

“We have already adopted a routine of sharing our ‘you said, we did’ evidence and reporting through various internal and external routes (online publication, System Executive Team, Lincolnshire Health Scrutiny Committee etc.). This allows anyone to see what feedback we have heard and how it has impacted our continued service analysis and development, and will continue as we reach the stages of changes and improvements occurring.”

9. Methodology

The methodology Healthwatch Lincolnshire used to enable us to present the findings in this report include:

- Healthwatch England NHS Long Term Plan General Survey - a copy of this survey is in Appendix 1. Alongside answering a number of questions with selected tick box responses, respondents were invited to add ‘free text comments’. This report contains summarised analysis of these free text comments as well as detailed information in Appendix 2 and 3. This survey was promoted both nationally and locally by Healthwatch England and Healthwatch Lincolnshire via social media and other media opportunities. Interested people had an option to complete the survey both digitally and in paper format (large print and other accessible versions of the survey were also provided by Healthwatch England). We received data relating to 235 completed surveys (no personal information was requested). However the analysis contained within this report where stated relates to these responses.
- Healthwatch England NHS Long Term Plan Condition Specific Survey - a copy of this survey is in Appendix 4 which covered 7 different health themes. Alongside answering a number of questions with selected tick box responses, respondents were invited to add ‘free text comments’ to their response. This report contains summarised analysis of these free text comments as well as detailed information in Appendices 5 and 6. This survey was promoted both nationally and locally by Healthwatch England and Healthwatch Lincolnshire via social media and other media opportunities. Interested people had an option to complete the survey both digitally and in paper format (large print and other accessible versions of the survey were also provided by Healthwatch England). We received data relating to 74 completed surveys (no personal information was requested).
- The analysis contained within this report where stated relates to these responses.
- Healthwatch Lincolnshire facilitated 4 focus group meetings as follows:
 - Gainsborough, yourvoice@hwl event, 30 people attended.
 - Boston, Health and Care Students, 11 people attended
 - NK Seniors Group (Sleaford), 24 people attended
 - Stay Safe; Gainsborough, Mental Health Group, 8 people attended (condition specific group)
- We facilitated 2 further discussion opportunities which enabled us to test out early focus group questions and promote Healthwatch Lincolnshire’s involvement in engaging and consulting on NHS Long Term Plan. One of the opportunities was at the Healthwatch Lincolnshire Board meeting in public with around 25 members of the public in attendance. Some very helpful feedback was acknowledged and acted upon to ensure any final focus group questions did not contain any misleading questions. The second discussion opportunity was with a Parkinson Group in the county, this provided a very useful ‘sounding board’ to ascertain whether our focus group questions were right for public audiences.

- Focus groups continued: A summary of the feedback received from our focus groups is included in this report. Focus group questions were designed to be relevant to Lincolnshire. A full list of the questions can be seen at Appendix 7.
- Healthy Conversations 2019, we attended 4 events (in Boston, Skegness, Louth and Grantham) facilitated by NHS colleagues in Lincolnshire. This offered us an opportunity to ‘meet the public’ with the purpose of discussing the NHS Long Term Plan, inviting them to complete paper copy surveys and signposting them to the online survey.
- Healthwatch Lincolnshire information bank - this includes evidence over the years we have collated, reports including our Escalation Papers, thematic reports, IMP (Information from Patient Experience Programme) and through our representatives attending around 40 health and care meetings every month.

10. Acknowledgements

We would like to list those that have contributed either directly or indirectly to the production of this report:

- 309 general surveys were completed
- 74 condition specific surveys were completed
- 73 individuals who took part in the focus groups
- Healthwatch Lincolnshire Trustees, Volunteers and Staff
- Lincolnshire STP Senior Leadership Team
- Lincolnshire STP Communications and Engagement Leads
- NHSE England and Healthwatch England who instigated the England wide activity and provided support
- *Acknowledgements specifically to the following engagement groups:*
 - NK Seniors (Sleaford)
 - Stay Safe group, Gainsborough
 - Boston College Health and Care students
 - Parkinson Society, Louth
 - Public and professionals attending Healthwatch Lincolnshire’s @yourvoice event (14th April 2019)
 - Public and professionals attending Healthwatch Lincolnshire’s board meeting in public

Appendices

No.	Name of Appendix	Description	Page No.
1	General Survey Questionnaire	Copy of the NHS Long Term Plan General Survey questions which were distributed nationally and produced by Healthwatch England	43
2	General Survey Quantitative Results	Healthwatch Lincolnshire evaluation, results and tables which reflect the results of the quantitative questions within the NHS Long Term Plan General survey produced by Healthwatch England	54
3	General Survey Qualitative Evaluation of Free Text	Healthwatch Lincolnshire Qualitative evaluation for free text questions within the NHS Long Term Plan General survey, individual free text comments are available a upon request	61
4	Condition Specific Survey Questionnaire	Copy of the NHS Long Term Plan Condition Specific survey which was distributed nationally and produced by Healthwatch England	73
5	Condition Specific Survey Quantitative Results	Healthwatch Lincolnshire evaluation, results, tables which reflect the results of the quantitative questions within the Condition Specific Survey produced by Healthwatch England	81
6	Condition Specific Qualitative Evaluation of Free Text	Healthwatch Lincolnshire Qualitative evaluation Qualitative evaluation for free text questions within the Condition Specific NHS Long Term Plan produced by Healthwatch England, individual free text comments are available a upon request	91
7	Lincolnshire based questions used with focus groups	Healthwatch Lincolnshire facilitated focus groups using questions which specifically related to Lincolnshire, these questions were designed and agreed with STP partners.	104

Appendix 1

General Survey Questionnaire

healthwatch

NHS Long Term Plan

The survey

questions

whot

would you do?

It's your NHS. Have your say.

About this survey

With growing pressure on the NHS - an ageing population, more people living with long-term 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 Long Term Plan, setting out all the things it wants health services to do better for people across the country. Now your local NHS needs to hear from you about what those changes should look like in your community.

The Long Term Plan 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.

Your local NHS needs to hear from you about what it should do to make care better for your community.

- How would you help people live healthier lives?
- What would make health services better?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

Share your views and help make care better.

Survey 1 - people’s general experiences of health and care services

1. Do you consent to Healthwatch using your responses?

Yes (If yes, go to Q2)

No (If no, go to end of survey)

2. Pick the area that best describes where you live

2b Who are you responding on behalf of?

Yourself

Someone else

Having what I need to live a healthy life

The NHS isn’t just there to help you when you’re ill, but to support you to live a healthy life too. Tell us what you think local services could do to help you stay well.

3a) Rate how important the following things are to you when it comes to living a healthy life:

	Very important	Important	Neutral	Not important	Not important at all
<i>Easy access to the information I need to help me make decisions about my health and care</i>					
<i>The knowledge to help me do what I can to prevent ill health</i>					
<i>Access to the help and treatment I need when I want it</i>					
<i>Professionals that listen to me when I speak to them about my concerns</i>					
<i>For every interaction with health and care services to count; my time is valued</i>					

3b) If there was one more thing that would help you live a healthy life, what would it be?

Being able to manage and choose the support I need

When you are unwell and need support or treatment for your condition you need to be properly informed to make choices about what works best for you. Tell us what local services need to do to make this a reality.

4a) Rate how important the following things are to you when it comes to managing and choosing the support you need:

	Very important	Important	Neutral	Not important	Not important at all
<i>If I have a long term condition I decide how the NHS spends money on</i>					
<i>Choosing the right treatment is a joint decision between me and the relevant health and care professional</i>					
<i>I make the decision about where I will go to receive health and care support</i>					
<i>I should be offered care and support in other areas if my local area can't see me in a timely way</i>					
<i>I make the decision about when I will receive health and care support</i>					
<i>My opinion on what is best for me, counts.</i>					
<i>Communications are timely</i>					
<i>I have time to consider my options and make the choices that are right for me</i>					

4b) If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be?

The help I need to keep my independence and stay healthy as I get older

Our ageing population is placing greater demands on the NHS. We know that people want to be able to look after themselves for longer, and the NHS wants to help you do so.

5a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

	Very important	Important	Neutral	Not important	Not important at all
<i>I want to be able to stay in my own home for as long as it is safe to do so</i>					
<i>I want my community to be able to support me to live my life the way I want</i>					
<i>I want my family and friends to have the knowledge to help and support me when needed</i>					
<i>I want there to be convenient ways for me to travel to health and care services when I need to</i>					
<i>I want my family to feel supported at the end of life</i>					

5b) 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

How you interact with your local NHS

The NHS wants to adapt to make it easier for people to access support they need, when they need it.

6a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

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

6b) If there was one more thing that you think need to change to help you to successfully manage your health and care, what would it be?

Tell us what is most important

Out of the statements below, we want you to pick the one that you feel is most important to you.

7. What is most important to you to help you live a healthy life? [pick one]

- Easy access to the information I need to help me make decisions about my health and care
- The knowledge to help me do what I can to prevent ill health
- Access to the 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

8. What's most important to you to be able to manage and choose the support you need? [pick one]

- 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

9. What's most important to you to help you keep your independence and stay healthy as you get older? [pick one]

- 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 expect there to be convenient ways for me to travel to health and care services when I need to

I expect that my family and I will feel supported at the end of life

10. What is most important to you when interacting with the NHS [pick one]

I have absolute confidence that my personal data is managed well and kept secure

I can access services using my phone or computer

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 manage my own personal records so that I can receive continuity in care

I am able to talk to other people who are experiencing similar challenges to me to help me feel better

11. If you have any further comments please write them below.

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

12. Your age

Under 18

45-54

18-24

55 -64

25-34

65-74

35-44

75+

13. Your ethnicity

- | | |
|---|---|
| <input type="checkbox"/> African | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Arab | <input type="checkbox"/> White British |
| <input type="checkbox"/> Asian British | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other white background |
| <input type="checkbox"/> Black British | <input type="checkbox"/> Any other mixed background |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Other |
| <input type="checkbox"/> Gypsy or Irish Traveller | |

14. Do you consider yourself to have a disability?

- Yes
- No
- I'd prefer not to say

15. Are you a carer?

- Yes No

16. Do you have:

- a long term condition Neither
- multiple conditions

17. Which of the following best describes you?

- | | |
|---|------------------------------------|
| <input type="checkbox"/> Heterosexual | <input type="checkbox"/> Asexual |
| <input type="checkbox"/> Gay or lesbian | <input type="checkbox"/> Pansexual |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Other |

18. Your gender

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Other |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to say |

19. Your religion

Buddhist

Christian

Hindu

Jewish

I'd prefer not to say

Muslim

Sikh

Other

No religion

Appendix 2**General Survey Quantitative Results****3a) Rate how important the following things are to you when it comes to living a healthy life:**

	Very Important		Important		Neutral		Not Important		Blank	
	n	%	n	%	n	%	n	%	n	%
Easy access to the information I need to help me make decisions about my health and care	147	69%	48	23%	4	2%	1	0.5%	12	6%
The knowledge to help me do what I can to prevent ill health	136	64%	55	26%	7	3%	1	0.5%	13	6%
Access to the help and treatment I need when I want it	194	92%	6	3%	0	0%	0	0%	12	6%
Professionals that listen to me when I speak to them about my concerns	185	87%	14	7%	0	0%	0	0%	13	6%
For every interaction with health and care services to count; my time is valued	150	71%	44	21%	6	3%	0	0%	12	6%

People who responded to the questions above, indicated they considered all 5 areas in table 3a were very important or important to them. However, within this level of importance ‘Access to the help and treatment I need when I want it’ and receiving their healthcare from ‘Professionals that listen to me when I speak to them about my concerns’ were topmost in peoples priority. These views match with the information Healthwatch Lincolnshire receive on a monthly basis with significant number of people concerned about long waits for appointments, test results and treatment at both primary and secondary provider levels.

At the bottom of the important ratings was having ‘knowledge to help me do what I can to prevent ill health’. As people we have for a long time looked to the NHS to provide all our healthcare needs and pick up the pieces when things are going wrong regardless of how well we have looked after our own body. Most people recognise the importance of what our own lifestyle choices might do to our health, but as one respondent noted *“stopping smoking and limiting alcohol consumption are “givens” but easier to talk about than to achieve”*. Let’s face it the health and fitness industry is one of the biggest in the world, but for many people the stresses and strains of everyday living results in us making some unhealthy choices about smoking, drinking alcohol, diet and exercise.

4a) Rate how important the following things are to you when it comes to managing and choosing the support you need:

	Very Important		Important		Neutral		Not Important		Not Important at all		Blank	
	n	%	n	%	n	%	n	%			n	%
If I have a long term condition I decide how the NHS spends money on me	79	37%	83	39%	32	15%	5	2%	2	1%	11	5%
Choosing the right treatment is a joint decision between me and the relevant health and care professional	149	70%	46	22%	8	4%	0	0%	1	0.5%	8	4%
I make the decision about when I will receive health and care support	102	48%	75	35%	21	10%	2	1%	2	1%	10	5%
I should be offered care and support in other areas if my local area can't see me in a timely way	126	59%	59	28%	13	6%	2	1%	1	0.5%	11	5%
I make the decision about where I will go to receive health and care support	122	58%	58	27%	18	8%	3	1%	1	0.5%	10	5%
My opinion on what is best for me, counts	106	50%	72	34%	22	10%	1	0.5%	1	0.5%	10	5%
Communications are timely	155	73%	44	21%	1	0.5%	0	0%	0	0%	12	6%
I have time to consider my options and make the choices that are right for me	128	60%	69	33%	6	3%	0	0%	0	0%	9	4%

From table 4a above we are able to identify the following:

When managing and choosing support overall people rated all areas as very important or important to them. However, from this we can identify that:

Communications are timely is very important and this reflects what Healthwatch Lincolnshire hear every month from people, carers and service users. Whether this is receiving only one appointment letter, information in easy understandable formats (and that includes results of tests, through to verbal communications with medical staff.

Choosing the right treatment as a joint decision with healthcare professionals and having time to consider options and choices were the next most important areas. People want to be much more involved in their own healthcare needs and should be encouraged to do so. Medical staff need to understand this is not just about empowering people but helping them to better understand their own health needs could help them to manage their conditions or recover from surgery or short term illnesses far better.

It may surprise some that people were not averse to being ‘offered care and support in other areas if my local area can’t see me in a timely way’. People tell Healthwatch Lincolnshire that being treated quickly is very important to them, they become very stressed by long waits for tests, treatment and surgery. However, we need to also recognise that for some people living in rural areas, public transport and travelling to services out of county is often very challenging.

Slightly less importance was put on ‘my opinion on what is best for me counts’ reflects the fact that many people still value the opinions of a trained professional.

Whilst people are keen to be involved in ‘where’ their treatment is going to take place but they feel less able to influence when this will be. Perhaps people are now becoming ‘used’ to longer wait for healthcare.

People who responded should they have a long term condition did not feel so able to decide ‘how the NHS spends money on me’. Healthwatch Lincolnshire feels more needs to be done to help the public understand NHS finances both in terms of overall budget constraints and cost of individual services through to what is a Personal Health Budget and how can I use it.

5a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

	Very Important		Important		Neutral		Not Important		Not Important at all		Blank	
	n	%	n	%	n	%	n	%	n	%	n	%
I want to be able to stay in my own home for as long as it is safe to do so	180	85%	23	11%	1	0.5%	1	0.5%	0	0%	7	3%
I want my community to be able to support me to live my life the way I want	121	57%	63	30%	18	8%	2	1%	0	0%	8	4%
I want my family and friends to have the knowledge, to help and support me when needed	121	57%	66	31%	13	6%	2	1%	0	0%	10	5%
I want there to be convenient ways for me to travel to health and care services when I need to	148	70%	46	22%	4	2%	2	1%	0	0%	12	6%
I want my family and me to feel supported at the end of life	175	83%	22	10%	4	2%	1	0.5%	0	0%	10	5%

Once again most people who answered these questions felt that all areas were very important or important to them. Not surprisingly ‘staying in my own home’ was rated as the most important to people, very few of us want to believe anything other than this.

Alongside staying in your own home, people wanted to know that both they and their loved ones will be given the right support when the times comes, this is something that we should all be reassured is automatically in place.

Travelling to healthcare services again comes out as an important issue, and this is a long running and key theme for many people in Lincolnshire.

Community support has been mentioned previously, 57% of respondents to this question felt this was very important and a further 30% important to them

6a) Dealing with the NHS?

When you need something from the NHS, how important is it...

	Very Important		Important		Neutral		Not Important		Not Important at all		Blank	
	n	%	n	%	n	%	n	%	n	%	n	%
I have absolute confidence that my personal data is managed well and kept secure	134	63%	54	25%	15	7%	1	0.5%	0	0%	8	4%
I can access services using my phone or computer	101	48%	71	33%	23	11%	5	2%	3	1%	9	4%
I can talk to my doctor or other health care professional wherever I am	124	58%	59	28%	15	7%	3	1%	1	0.5%	10	5%
I can make appointments online and my options are not limited	120	57%	53	25%	27	13%	4	2%	0	0%	8	4%
Any results are communicated to me quickly making best use of technology	134	63%	59	28%	9	4%	1	0.5%	1	0.5%	8	4%
I manage my own personal records so that I can receive continuity in care	91	43%	62	29%	41	19%	8	4%	0	0%	10	5%
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	60	28%	70	33%	57	27%	12	6%	2	1%	11	5%

Once again a majority of people considered all of the areas in table 6a to be very important or important, but more people did select a neutral stance to these questions telling us that:

Results from Q7) - What is most important to you to help you live a healthy life?
(Graphically represented)

	n	%
Easy access to the information I need to help me make decisions about my health and care	15	7%
The knowledge to help me do what I can to prevent ill health	18	8%
Access to the help and treatment I need when I want it	117	55%
Professionals that listen to me when I speak to them about my concerns	34	16%
For every interaction with health and care services to count; my time is valued	13	6%
Blank	15	7%

Managing the support I need

(Results from Q8) - What is most important to you to be able to manage and choose the support you need? (Graphically represented)

	n	%
If I have a long term condition I decide how the NHS spends money on me	7	3%
Choosing the right treatment is a joint decision between me and the relevant health and care professional	77	36%
I make the decision about where I will go to receive health and care support	23	11%
I should be offered care and support in other areas if my local area can't see me in a timely way	45	21%
I make the decision about when I will receive health and care support	6	3%
My opinion on what is best for me, counts	6	3%
Communications are timely	7	3%
I have time to consider my options and make the choices that are right for me	22	10%
Blank	19	9%

Keeping my independence

(Results from Q9) - What most important to you to be able to keep your independence and stay healthy as you get older?

	n	%
I want to be able to stay in my own home for as long as it is safe to do so	119	56%
I want my community to be able to support me to live my life the way I want	23	11%
I want my family and friends to have the knowledge to help and support me when needed	17	8%
I want there to be convenient ways for me to travel to health and care services when I need to	18	4%
I want my family and me to feel supported at the end of life	19	9%
Blank	16	8%

How I interact with the NHS

(Results from Q10) - What is most important to you when interacting with the NHS? (Graphic)

	n	%
I have absolute confidence that my personal data is managed well and kept secure	28	13%
I can access services using my phone or computer	16	8%
I can talk to my doctor or other health care professional wherever I am	70	33%
I can make appointments online and my options are not limited	26	12%
Any results are communicated to me quickly making best use of technology	37	17%

I manage my own personal records so that I can receive continuity in care	13	6%
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	4	2%
Blank	18	8%

Q11 - free text ‘If you have any further comments’

General Survey Demographic data (don’t think we need to include any of this in the main report if we do it should only be in appendix)

All of these can be looked at and filtered to see if any particular group has any significant different responses from other groups in terms of long term plan

Q12 Age

Blank	1	0.5%
-------	---	------

	n	%
Under 18	3	1%
18 - 24	3	1%
25 - 34	10	5%
35 - 44	11	5%
45 - 54	31	15%
55 - 64	67	32%
65 - 74	63	30%
75+	24	11%

Q15 Carer - Are you a carer?

	n	%
Yes	42	20%
No	167	79%
Blank	3	1%

Q13 Ethnicity

White British	175	83%
Asian British	2	1%
Other	1	0.5%
Any other white	4	2%
Blank	30	14%

Q16 Long term condition

	n	%
No	82	39%
Yes, I have	90	42%
Yes more than one	35	17%
Blank	5	2%

Q14 Disability - Do you consider yourself disabled?

I’d prefer not to say	9	4%
Yes	70	33%
No	132	62%

Q17 Sexuality

	n	%
Bisexual	7	3%
Gay or Lesbian	3	1%
Heterosexual	171	81%
I’d prefer not to say	21	10%
Other	3	1%
Blank	7	3%

Q18 Gender

	n	%
Male	67	32%
Female	136	64%
Prefer not to say	7	3%
Other	1	0.5%
Blank	1	0.5%

Q19 Religion

	n	%
Buddhist	4	2%
Christian	127	60%
Hindu	3	1%
I'd prefer not to say	16	8%
No Religion	56	26%
Other	3	1%
Blank	3	1%

Q2b Yourself or someone else

	n	%
Someone else	11	5%
Yourself	200	94%
Blank	1	0.5%

Appendix 3

General Survey Qualitative Evaluation of Free Text

In question 3b, respondents were invited to tell us - If there was one more thing that would help you live a healthy life, what would it be? We received 149 free text responses to this question and are therefore unable to include all of them, below is a summary of the responses:

The overall themes from people about ‘Easy access to the information I need to help me make decisions about my health and care’ concerns and views included:

- The type of information people would like to access to help them make healthy lifestyle choices included knowing where to go, how to use online services to find the right information, receiving the information in a clear and consistent way, counselling and support for dieting and weight management, receiving professional help but also being involved with planning and control of their weight, smoking cessation or other health lifestyle management journey.
- For some people it was their role as a carer that was most important to them and in particular having help and support to find out what they are entitled to financially is really important.
- Communication is a big issue. People are beginning to be much more open to the idea of new communication methods to enable ‘live chat’ or skype consultations. However, they do still want their information in easy to read, easy to find and up to date formats.
- People also want more opportunities to talk face to face with professionals “*Having someone to listen and explain in layman’s terms*” said one respondent.

The overall themes from people about ‘Knowledge to help me to what I can to prevent ill health included a range of suggestions including:

- Better and More health and wellbeing education is needed on person wrote, “*Better education on the basics - “move more eat less for example” without fads and fashions such as odd diets*”. More cookery lessons was a request and certainly one person wished this had started when they were ‘*at school*’.
- More awareness at an early age about how to live a healthier lifestyle.
- Online support - knowing where to go to get easy to access information which is clear and consistent.
- People also had a lot of other really good ideas about what services would help them to live a healthier life:
 - Services that are more ‘joined up’. “*Being healthy isn’t just about the NHS, it’s what sits around it*”.

- Someone to monitor health and lifestyle regularly and provide advice
- Affordable fitness classes and access to local swimming pools. One suggestion was *“Easier access to appropriate organised Public Health/NHS exercise--this tends to be sparse in Lincolnshire”* and another *“ease of access to services relating to weight loss that do not cost a fortune!”*.
- Better and more available public transport. For instance Healthwatch Lincolnshire asked ‘if someone from a rural community wanted to access their nearest municipal sports centre after work, would public transport be available to them to get home afterwards?’
- Annual health check (MOT) for people over 65
- *“More availability in rural areas for keeping the more mature healthy, exercise, social, lifestyle and companionship”*.
- *“Not everyone lives in Lincoln”*.

The overall themes from people about ‘Access to the help and care I need when I want it’ concerns and views included:

- People want good local reliable, timely and accessible services, this includes 24 access to A & E services.
- Waiting for routine GP appointments was an issue and this is something that Healthwatch Lincolnshire hear about on a daily basis and is a big concern to people. One person wrote *“Easier access to a GP/health professional, and not having to wait several weeks. Living with a long term condition is part of what I do, but sometimes all I need is a quick phone call or a short visit to my practice to talk to someone about what is normal and what I can do. By the time I have waited several days to see a health professional the condition has deteriorated and my needs then are greater. My surgery seems to be telephone consultation averse.”* Healthwatch Lincolnshire has raised concerns for some time about the impact of waiting times for routine and follow up appointments on people overall health, particularly for people with long term conditions. Prevention by keeping a patient’s condition manageable could be the difference in many cases between keeping them at home or the need to admit to hospital and provide additional intervention such as social care support.
- Some concerns were shared that people felt centralising healthcare in rural areas where there is no public transport and long distances between towns could lead to endangering lives.

The overall themes from people about ‘Professionals that listen to me when I speak to them about my concerns and views included:

- Being treated holistically is important to people *“as an elderly person with multiple health issues I would like some professionals to look at me as a whole person and not just discuss one issue”*. This is something Healthwatch Lincolnshire has recently highlighted due to incidents where a people diabetes was not recognised properly when they were in hospital for surgery.

- People want to be listened to and not patronised. Communication is very important, the number of times Healthwatch Lincolnshire hears from people that they leave the consultation room ‘none the wiser’.
- One patient mentioned they would like to have *“Dialysis from a chair rather than very painful dialysis from a bed, I have severe lower limb ischemia and need to keep my feet in a dependant position to allow gravity to supply small amount of blood/oxygen to my foot/feet”*. Whilst very specific this is all about personalising care to the needs of people.

The overall theme from people about ‘Every interaction with health and care services to count; my time is valued only provided small number of free text comments.

- Having an opportunity for longer GP appointments for people with multiple health issues was raised.

In question 4b, respondents were invited to tell us - If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be? We received 109 free text responses to this question and are therefore unable to include all of them, below is a summary of the responses:

The overall theme from people about ‘If I have a long term condition I decide how the NHS spends money on

- Whilst we only received a small number of comments about people’s views on how NHS money should be spent, equal access for everyone in our county is certainly important. One person wrote *“Knowing that it isn’t a postcode lottery on how my condition is managed. There should be equal access to the same level of service wherever I live”* which is a very telling comment. Healthwatch Lincolnshire is aware that due to current commissioning and at times provider arrangements in Lincolnshire, there is definitely some inequalities in how and where healthcare services are delivered in Lincolnshire. On behalf of people we are very pleased that our 4 Clinical Commissioning Groups are merging to ensure commission, healthcare long term plans and sustainability will be designed and delivered with our counties needs in mind and not just ‘centrally available’ in Lincoln city and our larger towns.

The overall themes from people about ‘Choosing the right treatment is a joint decision between me and the relevant health and care professional’ concerns and views included:

- It is clear that people want easy access to healthcare professionals advice particularly in areas of specialisms and understand this does not always need to be in person and can be with a Specialist Nurse rather than a consultant. People value the advice a specialist will give them in helping them manage their condition. One person wrote *“With long Term conditions, someone at the end of a phone line who has specialist knowledge of various conditions. Does not have to be a Doctor but*

a Healthcare professional. From past experience, questions arise that could be simply answered without bothering a GP. We now have Healthcare Assistants specialising in Diabetes, Heart problem for e.g. in surgeries, why not extend this further. I am sure Doctors time would be saved”, this comment demonstrates how patient’s past relationships with medical staff is changing.

- People want continuity from their healthcare professionals particularly where they are making joint decisions with them about their health, *“once you have seen a consultant/specialist you are able to maintain contact with that person/department for that condition rather than ‘go see your GP if you have further problem. This just means further delays in seeing GP, delays in referral process/waiting for appointment whilst all the time you have additional concerns or worries about your health”*. The importance of continuity having appointments with the same doctor, specialist nurse, consultant etc is something that Healthwatch Lincolnshire has identified on many occasions. Our GP Appointment work in 2018 really highlighted this as an area that concerns people as they felt lack of continuity had an impact on not only their health but also their mental wellbeing.
- Receiving clear, concise, honest advice and information from healthcare professionals also appears important for people. There is also a need for healthcare professionals to openly discuss with the patient their options for diagnostics, treatment and care to enable them to consider what they feel is best for them *“Options clearly laid out at the start of investigations/diagnosis/treatment etc with the professional recommending a particular course while also giving space for patient to research things and make an informed decision about progress”*. Putting people at the heart of their healthcare needs is a mantra we hear, this needs to be embedded as a given as people are becoming much more receptive to wanting choice and control.

The overall themes from people about ‘I make the decision about where I will go to receive health and care support’ included:

- For this question we received the largest number of free text comments and almost overwhelmingly from this people want to continue accessing their services locally, this was very important to many respondents *“Local, local and local. Not 50 miles away. We need local services or a fleet of transport options”*. There was also a comment with regards to the importance of visitors being able to spend time with their loved one when they are in hospital as an ‘important part of the patient’s recovery’.
- Not surprisingly concerns about travel around a vast rural county is also an issue for many *“Travelling out of Lincolnshire is not an option for people who have low incomes”* and *“To consider the rural area of Lincolnshire, infrastructure and transport before cutting and centralising services. A vast majority of the people accessing health care are elderly, and this is the group less about to travel distances for treatment”*, were just two of the comments.
- Having more knowledge about ‘choice of hospitals’ is also something people would be keen to have, this would help them in understanding where best to go for

specialist treatment or maybe to avoid significant waits, one respondent wrote *“more info about choice of hospitals for specific services - for a patient individual issues and circumstances need considering when hospitalisation is required”*.

The overall theme from people about ‘I should be offered care and support in other areas if my local area can’t seem in a timely way’ was:

- Although we did not receive a lot of responses to this question 87% of the people who responded indicated this is very important or important to them. In Lincolnshire many people are required to travel out of county to specialist services such as neurology so this is not something new. However, with pressures on our counties services leaving many very fragile, and possible plans to consolidate some services onto one site the reality is that in future people will be required to travel to other areas for their care and support, one respondents comments acceptance of this but a plea to ensure recovery was closer to home recognises this issue *“I would like to see centres of excellence for my treatment, I don't mind if I have to travel. However, aftercare and rehab should be closer to home”*. We must always keep in mind the impact travelling longer distances has on a patient’s health, a person’s finances and challenges in a rural county with accessing regular reliable public transport.

The overall theme from people about ‘I make the decision about when I will receive health and care support’ was:

- Fewer comments were shared about this theme. We suspect many people have become used to ‘waiting’ for their appointment or treatment date. Whilst in many cases this is not such a problem, when people are waiting significant periods of time this can have an impact on their mental wellbeing, especially for lifesaving treatment. Over the past 6 years Healthwatch Lincolnshire has received numerous calls from people who are scared about what will happen to them as their operation or consultant’s appointment has been cancelled more than once. One patient contacted us who needed major lifesaving surgery, they had 5 operation dates cancelled and they actually said *“I may not live long enough to share my experience with anyone so thank you Healthwatch I have at least been able to tell someone”*, thankfully we were able to intervene and reassure the patient that we had checked and their 6th planned date was confirmed as a definite. What people really want is honesty. If waiting times are long for whatever reason, they want to know. This helps them plan their lives over the next 3 - 6 months or longer. There is nothing worse than not knowing when the letter will drop through the post box with that all important date, one person wrote *“Correct time scales if it is going to be 29 plus weeks say so that the patient can possibly go elsewhere or go private”*.

The overall themes from people about ‘My opinion on what is best for me counts’ is:

Overwhelmingly about being treated with dignity and respect, being listened to and acknowledged as a person, not a number. We feel it important to share the comments that were made as they individually portray the above:

- being listened to and feel like a person and not just another number
- respect my engagement with alternative/complimentary medicines and therapies
- Treating me with respect, I am intelligent and have studied my condition, but there is a tendency for doctors to ignore what I say and for nurses to call me darling, sweetheart and cupcake, I hate this.
- All staff in the NHS should be able to stop and listen to any concerns, try to understand and if necessary point me in the right direction.
If it involves another department, why can't a referral be made then rather than the constant passing back to GP. Time wasting.
- The opinion of close relatives who do not see me on a regular basis or, indeed, know my day to day living needs should NOT be taken into account over my own assessment (assuming that I have not been diagnosed with advanced senile dementia of any kind). Healthwatch Lincolnshire would also like to point out that we have examples of where family carers voices were not listened to, carers often the only voice speaking up for the patient.
- Understanding of my personal needs & requirements.
- I'm MADE TO FEEL THAT I DO MATTER, not just another person.
- Prove they listen to my comments by acting on them
- It's very important that the individual is heard

The overall themes from people about ‘Communications are timely’ really focused onto the following:

- *“Communication timely Communication accurate Communication sincere”*
- Use of technology - better use of IT and Smartphones, more information online
- Better communications between providers eg GPs and hospitals is something that Healthwatch Lincolnshire has heard before *“Better communication of patient notes between hospitals, GPs and other health professionals. e.g. Consultant at hospital cannot access test results done at different hospital. With patient's consent this access should be quick and easy via secure computer system. Many duplicate tests done and time wasted”*.
- More time available for listening to people
- People want to be kept informed and involved in communications about them.
- People being able to access their records easily
- Reducing administration errors
- Timely communications for appointments and results, *“Receiving hospital letters and results quicker”*

The overall themes from people about ‘I have time to consider my options and make the choices that are right for me’ highlighted the following:

- People want to know what their options and choices are but also after they received this information they would like honest advice on how to make that choice. *“Being fully advised of the choices”*.
- Understanding what matters most to people is also important, whether this is due to their age, gender, involving family carers, specialist care needs eg eating disorder or just their wish to include ‘holistic’ treatments as part of their care plans.
- To help people with their options and choice more than one respondent suggested a system that captured ‘provider profiles’ would be really helpful as follows:
 - *A “best outcome” table care providers ranked by how good the outcomes are for a particular condition so may be hospital A for say Heart, Hospital Z for Parkinson’s etc. Not always in your locality. Be prepared to travel to the best (within reason)*
 - *Knowing which providers have got the best results for treating my condition and having access to these providers*
 - *Being given options as to best places to receive support I need*

What other free text comments were made:

- Recognition that we have a number of specialist GPs, nurses and other healthcare professionals in the county. Suggestion was made that people regardless of which GP practice they are registered with, should be able to access this help in the community rather than having to go into hospital. Also, that staff trained in these specialisms could help to *“re-energise and redirect [them] to perform better and get the best out of their team”*.
- One person would like to see more ‘community support’, we are looking to Neighbourhood Teams and Social Prescribing to start to mobilise more access to activities in our rural communities.
- A number of people commented that they recognise difficulties with workforce recruitment, pressures on staff due to high demand and challenging performance targets and feel this often impacts on people due to the amount of time that can be spent with them. Healthwatch Lincolnshire hears from people and carers often with concerns when people are having long waits in hospital for help with things like personal care.

5b) In question 3b, respondents were invited to tell us, ‘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’, below is a summary of the 105 free text responses we received:

The overall themes from people about ‘I want to be able to stay in my own home for as long as it is safe to do so’ told us:

- A significant number of people felt that reliable, affordable (and more importantly statutory funded) home care was essential to help them stay independent when the time came for them not to be able to care for themselves. Bring back ‘home help/visitors’ was a plea. To support this many people wanted to see care assessments and packages prepared ready so care needs can be in place much earlier.
- Having lifelines such as ‘facetime’ or direct line access for some people was important. It was felt that if a person’s health is not great a chance to be reassured by a health professional would be beneficial to both the patient and their family *“My nan is 95 lives on her own I feel that she should get someone other than me to check up on her maybe a nurse phone call every month or FaceTime call with me helping her with technology I feel its call assumes the family will support her etc”*.
- It was felt that keeping active, better education about health and wellbeing (including from an early age) could all help someone to stay at home and out of hospital.
- For a small number of people they had no family to rely on and felt that staying well enough to live independently in their own home was their only option. *“Somewhere in between a hospital and home - a place of respite to recover in. This is to ensure people who live alone have the care they need post-surgery/procedure between leaving hospital and being well enough to look after themselves at home”* was a very helpful comment made by one respondent and relevant respite facilities should be made available and discussed with the patient as part of discharge options.

The overall themes from people about ‘I want my community to be able to support me to live my life the way I want’ told us:

People definitely want access and support to their local services such as:

- Venues for exercise
- Patient groups
- Opportunities for social contact
- Day centres (a plea to bring them back)
- Community/cottage hospitals and District Nurses

The overall theme from people about ‘I want my family and friends to have the knowledge to help and support me when needed’ was:

- The small number of views shared in the survey about this issue were very similar to those about staying in my home. Telephone lifelines that would reassure families that support is in place, particularly those living far away *“Access to a local phone service where I would be able to talk to an intermediary about any fears/problems I may be experiencing. I only have a daughter & her family in the area & she lives an hour way. There are, now, no other relatives apart from 1 cousin who lives in London”*. Healthwatch Lincolnshire does receive calls from concerned relatives where they are living over an hour away and want to know what ‘lifelines’ there

are in Lincolnshire to help both their relative and them with both everyday issues and in times of crisis.

The overall themes from people about ‘I want there to be convenient ways for me to travel to health and care services when I need to’ include:

- Travel and transport throughout the survey responses is a significant issue for our population in Lincolnshire. Including this is not raising anything new to anyone, however we should ask ourselves has the time has come to recognise that much more needs to be done as a ‘county’ to enable our healthcare services to operate without this burden. Some people feel aggrieved about possible changes to the location of health services and rightly so. If they are living in an isolated village with little or no public transport service, they struggle to get to the nearest GP Practice which can be several miles away. Respondents wanted to see improved road, rail and transport networks; access to very local testing for some health needs rather than having to travel 40 miles or more *“Access to medical care at LOCAL centre not having to travel 40+ miles to hospital for routine tests. Public transport often non-existent in rural areas”*; one person was even keen to see services ‘come to them’.

The overall theme from people about ‘I want my family to feel supported at the end of life’ was:

- A mixed response between wanting to stay at home with the right support available, through to being able to be in control by ending their life (*“Euthanasia if I do wish”*) to not wishing to involve family considering this would make them a burden on others *“I do not want to be forced to stay at home if I am too ill to look after myself and ruin the lives of my family trying to look after me or trying to cope with 15 minute visits from uncaring carers. The strain of caring can destroy lives, marriages and health”*.
- One person did comment that they felt *“Dignity in death as well as life is important to me, I do not want to be a financial burden to anyone (NHS or family) should I become bed bound or in palliative care”*, we are sure many other people agree with this sentiment.

Other comments made by people to question 5b can be summarised under the following areas:

- Funding for NHS needs to be available to enable local services to continue
- No to centralisation (in Lincoln)
- Available and timely appointments (mainly GP) when I need them
- More training for staff in areas such as dementia and learning disabilities
- Better conditions for care staff

6b) If there was one more thing that you think need to change to help you to successfully manage your health and care, what would it be?

The overall theme from people about ‘I have absolute confidence that my personal data is managed well and kept secure’ is:

- That people want to have easy access to their records. They want to be confident if they ask to read what has been written about them they are not left with the feeling that they are being an inconvenience. One person wrote *“More open conversations and easy access to records. I have never felt confident enough to ask to see my records”* and another said *“Having access to my own health care records so that I can make decisions with full knowledge of what health care professionals put in my records”*.
- We had one comment only that lack some confidence in how data is managed and that was due to a personal circumstance of lost data. We were surprised that more people did not comment about data management but hope this is due to the fact that with the introduction of GDPR most people assume their personal records are being stored and managed appropriately.

The overall theme from people about ‘I can access services using my phone or computer’ was:

- There was a mixed response within the free text comments on the use of phone and computer to access services. For some people they were keen to use Video and Skype as a way of being able to consult with health professionals, reducing the need to travel as much, for others they were keen to remind us that not everyone in Lincolnshire has access to reliable IT and mobile services, with one comment to remind us of this being *“Note that there are 7 million people who do not have either have access, a signal or skills to use the internet. These people MUST not be discriminated as a result. This is increasingly taking place”*. There was also a feeling that face to face access remained important, *“I use technology but would prefer to see someone face to face”*.

The overall theme from people about ‘I can talk to my doctor or other health care professional wherever I am’ included:

- Increase the length of time people currently feel they are waiting to get help, this was particularly felt at GP level.

- Access to specialist help such as MS nurses, which one person mentioned was lacking in Lincolnshire.
- Whilst the importance of technology was again mentioned, it was felt people would lose out as technology was impersonal and didn't allow for the 'human touch'.

The overall theme from people about 'I can make appointments online and my options are not limited' was:

- It was clear from the free text responses we received people want online appointment systems to be more accessible and easier to use. They also want more opportunities to be able to cancel, change or book their appointments online, this includes more online appointments available. Whilst we appreciate that many GP surgeries are now offering people full online access this is not the case for all and we would recommend this is address as soon as possible. *“Appointments system needs to work - it does not at present and “I can't make appointments online at my doctors” and I can't access my own records either”* were just two of the comments made.
- Need to be able to access specialist services were mentioned again. This is clearly an area that is important to people and is certainly something that would help people manage their conditions on a daily/weekly and monthly basis.

The overall theme from people about 'Any results are communicated to me quickly making best use of technology' was:

- Some of the messages we heard were clearly about how systems are not working together for the best interests of people. People are confused why primary and secondary care services do not 'talk to one another', leaving time delays for people receiving treatment and results. This was raised for both in-county and out of county services. *“Communication between services - there is a lack in organisation, e.g people having travelled a long distance after being referred say to a hospital not of their choosing find the notes etc have not been sent resulting in a further appointment and more time travelling”*.
- Communicating results is also a big issue. Healthwatch Lincolnshire often hears from people with concerns as to how and when they should be receiving their test results. They do not always realise they need to contact their GP surgery to find out. *“Swift action to test results that g.p surgeries are not doing. Results are not given to people and symptoms are not being treated”* was a replicated theme. Healthwatch Lincolnshire would ask that people are made fully aware when and how any tests results will be communicated back to them.

The overall theme from people about ‘I manage my own personal records so that I can receive continuity in care’ was:

- People would like an opportunity to review their own records and most importantly be part of the process *“all updates to medical records and treatment paths to be signed off with me”*.
- People also felt they should have easier access to their own records *“Computer access to my health records so wherever I am I can access my own data and records”*. This would also help with communicating test results. For example if a patient was able to log into their own records they could have a note on their files which confirmed test result feedback and any suggested follow up. This would mean more onus on the patient to take more responsibility for their own health.
- One person felt they wanted an opportunity to be more involved in their personal health information *“I think people should have opportunity to comment on information provided on their personal record; if the information is missing, incorrect or incomplete”*.

The overall theme from people about ‘I am able to talk other people who are experiencing similar challenges to me to help me feel better’ included suggestions such as:

- People felt they would benefit from more patient support groups in Lincolnshire eg replicate the Healthy Minds Group in Mablethorpe, set up more patient groups covering a wide range of health needs and a request that PPGs are fully active and accessible at all GP Surgeries in the county. *“Support groups are random at present and nobody knows where to find them. This is especially important for dementia cases and their carers”*.

Other comments

Whilst many other comments were made, they continued on the themes already highlighted but we did feel the following comment provided some interesting views:

*“Better information at each life stage so you do what you can to be in great health for the next life stage. A better joined up approach across the whole community:
-Workplaces and employers to be much more involved in creating healthy workplaces, supporting and encouraging employee wellbeing.
-Local authorities to make it easier to walk and cycle to school and work etc. Cycle lanes, zebra crossings, well-lit pedestrian areas so people feel safe. Dropped curbs for wheelchairs, buggies, bikes and wheelie bags. Benches with arms so older people can stay mobile and walk and have a rest when they need to, and use the arm to push up again to get up”*.

Appendix 4

Condition Specific Survey Questionnaire

healthwatch

NHS Long Term Plan

The survey
questions

whot
would you do?
It's your NHS. Have your say.

About this survey

With growing pressure on the NHS - an ageing population, more people living with long-term 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 Long Term Plan, setting out all the things it wants health services to do better for people across the country. Now your local NHS needs to hear from you about what those changes should look like in your community.

The Long Term Plan 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.

Your local NHS needs to hear from you about what it should do to make care better for your community.

- How would you help people live healthier lives?
- What would make health services better?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

Share your views and help make care better.

Survey 2 - NHS support for specific conditions

1. Do you consent to Healthwatch using your responses?

Yes (If yes, go to Q2)

No (If no, go to Q27)

2. Pick the area that best describes where you live

3. Please select the condition you would like to tell us about

Cancer

Learning disability

Heart and lung diseases

Autism

Mental Health

Long-term condition e.g. diabetes, arthritis

Dementia

4. Who are you responding on behalf of?

Myself

Someone else

5. Has the condition you are telling us about started within the last three years?

Yes

No

Your experience of getting help and support

6a. When you first tried to access help, did the support you received meet your needs?

Yes

No

Somewhat

Not applicable

6b Tell us whether the support met your needs and how it could have been improved

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

Very positive

Positive

Average

Negative

Very negative

Don't know

8. Do you have any other/additional conditions including long term conditions or disabilities?

Yes

No

9. If so, how would you describe the experience of seeking support for more than one condition at a time?

It made getting support easier

No difference

It made getting support harder

I don't know

Not applicable

The health and care support you received after initially seeking help

10a. How would you describe the time you had to wait to receive your initial assessment or diagnosis?

- Very slow
- Slow
- Ok

- Fast
- Very fast
- Don't know

10b. Please tell us more about the length of time you waited

11a. How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?

- Very slow
- Slow
- Ok

- Fast
- Very fast
- Don't know

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

Yes (*Go to Q13*)

No (*Go to Q15*)

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

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

15. Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

Yes (*If yes, go to Q16*)

No (*If no, go to Q17*)

16a. How would you describe the time you had to wait between the initial appointment and seeing the specialist?

- Very slow
- Slow
- Ok

- Fast
- Very fast
- Don't know

16b. Please tell us more about the length of time you waited

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

- Very easy
- Easy
- OK
- Difficult

- Very difficult
- Don't know
- Not applicable

18a. Did the support option you were offered meet your expectations?

- Yes
- No

- Somewhat

18b. Please explain how the care did or did not meet your expectations and how it could have been improved.

19a. During your whole experience of getting support did you receive timeline and consistent communication from all of the services that you came into contact with?

- Yes
- No

- Somewhat

19b Please explain how the care did or did not meet your expectations and how it could have been improved.

Time spent travelling to access support and care

20. What is your main means of transport?

- | | |
|--|----------------------------------|
| <input type="checkbox"/> Own car | <input type="checkbox"/> Bicycle |
| <input type="checkbox"/> Another person’s car (getting a lift) | <input type="checkbox"/> Taxi |
| <input type="checkbox"/> Bus | <input type="checkbox"/> Other |
| <input type="checkbox"/> Train | <input type="checkbox"/> |

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

- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Less than 30 minutes | <input type="checkbox"/> 1-2 hours |
| <input type="checkbox"/> 30 minutes to 1 hour | <input type="checkbox"/> Over 2 hours |

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

- | | |
|--|--|
| <input type="checkbox"/> Under 30 minutes | <input type="checkbox"/> From one to two hours |
| <input type="checkbox"/> From 20 minutes to one hour | <input type="checkbox"/> More than two hours |

Your expectations at each stage of your care

23. What is most important you?

	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don’t mind
When first seeking help			
When you first received a diagnosis and explanation of treatment or support options			

During your initial treatment or support

During your long term support

Supporting you to have more control over your own care

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

A lot of support
 Some support

I don't need support
 Don't know

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

26. If you have any further comments please write them below

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

13. Your age

Under 18
 18-24
 25-34
 35-44

45-54
 55-64
 65-74
 75+

14. Your ethnicity

- | | |
|---|---|
| <input type="checkbox"/> African | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Arab | <input type="checkbox"/> White British |
| <input type="checkbox"/> Asian British | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other white background |
| <input type="checkbox"/> Black British | <input type="checkbox"/> Any other mixed background |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Other |
| <input type="checkbox"/> Gypsy or Irish Traveller | |

15. Do you consider yourself to have a disability?

- | | |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> I'd prefer not to say |
| <input type="checkbox"/> No | |

16. Are you a carer?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

17. Do you have:

- | | |
|--|----------------------------------|
| <input type="checkbox"/> a long term condition | <input type="checkbox"/> Neither |
| <input type="checkbox"/> multiple conditions | |

18. Which of the following best describes you?

- | | |
|---|------------------------------------|
| <input type="checkbox"/> Heterosexual | <input type="checkbox"/> Asexual |
| <input type="checkbox"/> Gay or lesbian | <input type="checkbox"/> Pansexual |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Other |

19. Your gender

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Other |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to say |

20. Your religion

- | | |
|------------------------------------|--|
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Christian | <input type="checkbox"/> Other |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> No religion |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> I'd prefer not to say |
| <input type="checkbox"/> Muslim | |

Appendix 5**Condition Specific Survey Quantitative Results****Long-term plan - Specific Condition Survey**

69 Responses - 3 were removed due to duplication - 66 responses

(Q3) Please select the condition you would like to tell us about

	n	%
Cancer	11	17%
Heart & Lung diseases	3	5%
Mental Health	20	30%
Dementia	4	6%
Learning Difficulties	0	0%
Autism	6	9%
Long term conditions	22	33%

(Q4) Who are you responding on behalf of?

	n	%
Myself	34	52%
Someone else	32	48%

(Q5) Has the condition you are telling us about started within the last three years?

	n	%
Yes	27	41%
No	38	58%
Blank	1	2%

(Q6) When you first tried to access help, did the support you received meet your needs?

	Yes		No		Somewhat		Not applicable	
	n	%	n	%	n	%	n	%
All conditions (66)	11	17%	33	50%	20	30%	2	3%
Autism (6)	0	0%	4	67%	2	33%	0	0%
Cancer (11)	3	27%	6	55%	2	18%	0	0%
Dementia (4)	0	0%	3	75%	1	25%	0	0%
Heart and Lung (3)	2	67%	1	33%	0	0%	0	0%
Long term conditions (22)	4	18%	7	32%	10	45%	1	5%
Mental Health (20)	2	10%	13	65%	5	25%	1	5%

(Q7) How would you describe your overall experience of getting help?

	Very Negative		Negative		Average		Positive		Very positive	
	n	%	n	%	n	%	n	%	n	%
All conditions (66)	18	27%	17	26%	14	21%	12	18%	5	8%
Autism (6)	2	33%	3	50%	1	17%	0	0%	0	0%
Cancer (11)	2	18%	3	27%	2	18%	2	18%	2	18%
Dementia (4)	2	50%	1	25%	1	25%	0	0%	0	0%
Heart and Lung (3)	0	0%	0	0%	0	0%	2	67%	1	33%
Long term conditions (22)	4	18%	4	18%	6	27%	7	32%	1	5%
Mental Health (20)	7	35%	7	35%	4	20%	1	5%	1	5%

(Q8) Do you have any other/additional conditions including long term condition or disabilities?

	Yes		No	
	n	%	n	%
All conditions (66)	34	52%	32	48%
Autism (6)	3	50%	3	50%
Cancer (11)	2	18%	9	82%
Dementia (4)	3	75%	1	25%
Heart and Lung (3)	3	100%	0	0%
Long term conditions (22)	15	68%	7	32%
Mental Health (20)	8	40%	12	60%

(Q9) If so, how would you describe the experience of seeking support for more than one condition at a time?

	Made it easier		Made it harder		No difference		Don't know		Not applicable	
	n	%	n	%	n	%	n	%	n	%
All conditions (34)	2	6%	14	41%	15	44%	2	6%	1	3%
Autism (3)	0	0%	1	33%	2	67%	0	0%	0	0%
Cancer (2)	0	0%	0	0%	1	50%	1	50%	0	0%
Dementia (3)	0	0%	2	67%	1	33%	0	0%	0	0%
Heart and Lung (3)	1	33%	0		2	67%	0	0%	0	0%
Long term conditions (15)	1	7%	9	60%	4	27%	1	7%	0	0%
Mental Health (8)	0	0%	2	25%	5	63%	0	0%	1	13%

Waiting times

(Q10a) How would you describe the time you had to wait to receive your initial assessment or diagnosis?

	Very Fast		Fast		Ok		Slow		Very slow		Don't know	
	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	2	3%	8	12%	15	23%	20	30%	19	29%	2	3%
Autism (6)	0	0%	0	0%	1	17%	3	50%	2	33%	0	0%
Cancer (11)	2	18%	1	9%	2	18%	3	27%	3	27%	0	0%
Dementia (4)	0	0%	1	25%	0	0%	1	25%	2	50%	0	0%
Heart and Lung (3)	0	0%	3	100%	0	0%	0	0%	0	0%	0	0%
Long term conditions (22)	0	0%	3	14%	4	18%	8	36%	5	23%	2	9%
Mental Health (20)	0	0%	0	0%	8	40%	5	25%	7	35%	0	0%

(Q11a) How would you describe the time they had to wait between initial assessment/diagnosis and recovery treatment?

	Very Fast		Fast		Ok		Slow		Very slow		Don't know	
	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	3	5%	12	18%	12	18%	19	29%	18	27%	2	3%
Autism (6)	0	0%	0	0%	3	50%	1	17%	2	33%	0	0%
Cancer (11)	2	18%	3	27%	2	18%	1	9%	3	27%	0	0%
Dementia (4)	0	0%	1	25%	0	0%	1	25%	1	25%	1	25%
Heart and Lung (3)	0	0%	3	100%	0	0%	0	0%	0	0%	0	0%
Long term conditions (22)	1	5%	4	18%	3	14%	10	45%	3	14%	1	5%
Mental Health (20)	0	0%	1	5%	4	20%	6	30%	9	45%	0	0%

(Q12) After being diagnosed or assessed, were you offered access to further health and care support?

	No		Yes		Blank	
	n	%	n	%	n	%
All conditions (66)	34	52%	31	47%	1	2%
Autism (6)	3	50%	3	50%	0	0%
Cancer (11)	4	36%	7	64%	0	0%
Dementia (4)	3	75%	1	25%	0	0%
Heart and Lung (3)	3	100%	0	0%	0	0%
Long term conditions (22)	13	59%	9	41%	0	0%
Mental Health (20)	11	55%	8	40%	1	5%

(Q15) Were you referred to a specialist?

	Yes		No	
	n	%	n	%
All conditions (66)	41	62%	25	38%
Autism (6)	3	50%	3	50%
Cancer (11)	10	91%	1	9%
Dementia (4)	2	50%	2	50%
Heart and Lung (3)	3	100%	0	0%
Long term conditions (22)	15	68%	7	32%
Mental Health (20)	8	40%	12	60%

(Q16) How would you describe the time you had to wait between the initial appointment seeing the specialist?

	Very Fast		Fast		Ok		Slow		Very slow		Don't know		Blank	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (41)	6	15%	9	22%	8	20%	9	22%	7	17%	1	2%	1	2%
Autism (3)	0	0%	0	0%	3	100%	0	0%	0	0%	0	0%	0	0%
Cancer (10)	2	20%	4	40%	0	0%	2	20%	1	10%	0	0%	1	10%
Dementia (2)	0	0%	1	50%	0	0%	1	50%	0	0%	0	0%	0	0%
Heart and Lung (3)	2	67%	1	33%	0	0%	0	0%	0	0%	0	0%	0	0%
Long term conditions (15)	2	13%	3	20%	5	33%	4	27%	1	7%	0	0%	0	0%
Mental Health (8)	0	0%	0	0%	0	0%	2	25%	5	63%	1	13%	0	0%

(Q17) If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

	Very Easy		Easy		Ok		Difficult		Very Difficult		NA	
	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	3	5%	6	9%	13	20%	21	32%	18	27%	5	8%
Autism (6)	0	0%	0	0%	1	17%	4	67%	1	17%	0	0%
Cancer (11)	2	18%	2	18%	0	0%	3	27%	3	27%	1	9%
Dementia (4)	0	0%	0	0%	1	25%	2	50%	1	25%	0	0%
Heart and Lung (3)	1	33%	0	0%	2	67%	0	0%	0	0%	0	0%
Long term conditions (22)	0	0%	3	14%	5	23%	6	27%	6	27%	2	9%
Mental Health (20)	0	0%	1	5%	4	20%	6	30%	7	35%	2	10%

From the above data we can ascertain that more is needed to help people access ongoing support after diagnosis or assessment.

(Q18) Has the condition you are telling us about started within the last three years?

	Yes		No		Somewhat		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	14	21%	34	51%	13	20%	5	8%
Autism (6)	0	0%	5	83%	1	17%	0	0%
Cancer (11)	4	36%	4	36%	2	18%	1	9%
Dementia (4)	0	0%	2	50%	1	25%	1	25%
Heart and Lung (3)	1	33%	0	0%	2	67%	0	0%
Long term conditions (22)	7	32%	9	41%	4	18%	2	9%
Mental Health (20)	2	10%	14	70%	3	15%	1	5%

From the above data we can ascertain that more needs to be done to find out what patient expectations are from an early stage in their contact with health services.

(Q19) During your whole experience of getting support did you receive timeline and consistent communication from all of the services that you came into contact with?

	Yes		No		Somewhat		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	9	14%	31	47%	25	38%	1	2%
Autism (6)	0	0%	3	50%	3	50%	0	0%
Cancer (11)	1	9%	5	45%	4	36%	1	9%
Dementia (4)	0	0%	3	75%	1	25%	0	0%
Heart and Lung (3)	1	33%	0	0%	2	67%	0	0%
Long term conditions (22)	4	18%	9	41%	9	41%	0	0%
Mental Health (20)	3	15%	11	55%	6	30%	0	0%

From the above data we can

ascertain that more needs to be done with regards to timeline and consistent communications from services

Support and control over my own care

(Q24) What level of support do you want from NHS to help them stay healthy?

	A lot of support		Some Support		I don't need support		Don't know	
	n	%	n	%	n	%	n	%
All conditions (66)	14	21%	42	64%	6	9%	4	6%
Autism (6)	0	0%	6	100%	0	0%	0	0%
Cancer (11)	3	27%	5	45%	2	18%	1	9%
Dementia (4)	1	25%	3	75%	0	0%	0	0%
Heart and Lung (3)	0	0%	3	100%	0	0%	0	0%
Long term conditions (22)	5	23%	14	64%	1	5%	2	9%
Mental Health (20)	5	25%	11	55%	3	15%	1	5%

Travelling to access support and care

(Q20) What is your main means of transport?

	Own Car		Another person's Car		Bus		Train		Taxi		other		Blank	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	41	62%	16	24%	3	5%	2	3%	1	2%	2	3%	1	2%
Autism (6)	4	67%	1	17%	0	0%	0	0%	0	0%	0	0%	1	17%
Cancer (11)	8	73%	2	18%	0	0%	1	9%	0	0%	0	0%	0	0%
Dementia (4)	0	0%	4	100%	0	0%	0	0%	0	0%	0	0%	0	0%
Heart and Lung (3)	3	100%	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%
Long term conditions (22)	14	64%	6	27%	1	5%	1	5%	0	0%	0	0%	0	0%
Mental Health (20)	12	60%	3	15%	2	10%	0	0%	1	5%	2	10%	0	0%

(Q21) How much time would you be willing to travel for to receive a quick and accurate diagnosis?

	1-2 hours		30mins - 1 hour		Less than 30mins		Over 2 hours	
	n	%	n	%	n	%	n	%
All conditions (66)	13	20%	32	48%	16	24%	5	8%
Autism (6)	2	33%	2	33%	2	33%	0	0%
Cancer (11)	1	9%	6	55%	0	0%	4	36%
Dementia (4)	1	25%	3	75%	0	0%	0	0%
Heart and Lung (3)	1	33%	2	67%	0	0%	0	0%
Long term conditions(22)	6	27%	11	50%	5	23%	0	0%
Mental Health (20)	2	10%	8	40%	9	45%	1	5%

(Q22) How much time would you be willing to travel to receive specialist treatment or support?

	1-2 hours		30mins - 1 hour		Less than 30mins		Over 2 hours	
	n	%	n	%	n	%	n	%
All conditions (66)	18	27%	34	52%	10	15%	4	6%
Autism (6)	4	67%	2	33%	0	0%	0	0%
Cancer (11)	1	9%	8	73%	0	0%	2	18%
Dementia (4)	1	25%	3	75%	0	0%	0	0%
Heart and Lung (3)	1	33%	2	67%	0	0%	0	0%
Long term conditions (22)	7	32%	10	45%	4	18%	1	5%
Mental Health (20)	4	20%	9	45%	6	30%	1	5%

(Q23) What is most important to you?*When first seeking 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		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	6	9%	16	24%	32	48%	12	18%
Autism (6)	2	33%	0	0%	2	33%	2	33%
Cancer (11)	0	0%	4	36%	6	55%	1	9%
Dementia (4)	1	25%	1	25%	1	25%	1	25%
Heart and Lung (3)	0	0%	1	33%	2	67%	0	0%
Long term conditions (22)	2	9%	7	32%	10	45%	3	14%
Mental Health (20)	1	5%	3	15%	11	55%	5	25%

When you received a diagnosis and explanation of treatment or support options

	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		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	8	12%	19	29%	23	35%	16	24%
Autism (6)	1	17%	2	33%	1	17%	2	33%
Cancer (11)	0	0%	4	36%	6	55%	1	9%
Dementia (4)	2	50%	0	0%	1	25%	1	25%
Heart and Lung (3)	0	0%	1	33%	2	67%	0	0%
Long term conditions (22)	3	14%	10	45%	6	27%	3	14%
Mental Health (20)	2	10%	4	20%	9	45%	5	25%

During your initial treatment or 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		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	9	14%	16	24%	25	38%	16	24%
Autism (6)	2	33%	0	0%	2	33%	2	33%
Cancer (11)	0	0%	4	36%	6	55%	1	9%
Dementia (4)	1	25%	2	50%	0	0%	1	25%
Heart and Lung (3)	0	0%	1	33%	0	0%	2	67%
Long term conditions (22)	6	27%	7	32%	10	45%	5	23%
Mental Health (20)	2	10%	2	10%	9	45%	5	25%

During your long term 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		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	6	9%	36	55%	10	15%	14	21%
Autism (6)	1	17%	3	50%	0	0%	2	33%
Cancer (11)	1	9%	6	55%	3	27%	1	9%
Dementia (4)	0	0%	3	75%	0	0%	1	25%
Heart and Lung (3)	0	0%	1	33%	0	0%	2	67%
Long term conditions (22)	4	18%	13	59%	3	14%	2	9%
Mental Health (20)	0	0%	10	50%	4	20%	6	30%

In answering questions 23 for the 4 areas identified a larger proportion of people considered seeing any medically appropriate health professional who is free immediately was most important to them for diagnosis and explanation of treatment or support options and also during initial treatment or support. However, there was a shift of views once the condition required long term support, more people indicated they would rather see a health professional they would normally see even if it meant they would have to wait. This was confirmed in Healthwatch Lincolnshire's GP Appointment work, people really do value consistency, continuity and familiarity.

Demographics

Age

	Under 18		18 - 24		25-34		35-44		45-54		55-64		65-74		75+	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	1	2%	1	2%	4	6%	5	8%	18	27%	19	29%	12	18%	6	9%
Autism (6)	1	17%	1	17%	0	0%	1	17%	2	33%	1	17%	0	0%	0	0%
Cancer (11)	0	0%	0	0%	0	0%	2	18%	1	9%	5	45%	1	9%	2	18%
Dementia (4)	0	0%	0	0%	1	25%	0	0%	1	25%	1	25%	0	0%	1	25%
Heart and Lung (3)	0	0%	0	0%	0	0%	0	0%	0	0%	0	0%	3	100%	0	0%
Long term conditions (22)	0	0%	0	0%	0	0%	0	0%	7	32%	7	32%	5	23%	3	14%
Mental Health (20)	0	0%	0	0%	3	15%	2	10%	7	35%	5	25%	3	15%	0	0%

Do you consider yourself to have a disability?

	Yes		No		Id prefer not to say		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	30	45%	32	48%	3	5%	1	2%
Autism (6)	4	67%	2	33%	0	0%	0	0%
Cancer (11)	1	9%	10	90%	0	0%	0	0%
Dementia (4)	0	0%	4	100%	0	0%	0	0%
Heart and Lung (3)	3	100%	0	0%	0	0%	0	0%
Long term conditions (22)	13	59%	6	27%	2	9%	1	5%
Mental Health (20)	9	45%	10	50%	1	5%	0	0%

Are you a carer?

	Yes		No		Blank	
	n	%	n	%	n	%
All conditions (66)	16	24%	48	73%	2	3%
Autism (6)	3	50%	2	33%	1	17%
Cancer (11)	1	9%	10	90%	0	0%
Dementia (4)	1	25%	3	75%	0	0%
Heart and Lung (3)	2	67%	1	33%	0	0%
Long term conditions (22)	4	18%	17	77%	1	5%
Mental Health (20)	5	25%	15	75%	0	0%

Ethnicity

	White British		other		Any other white British		Blank	
	n	%	n	%	n	%	n	%
All conditions (66)	56	85%	2	3%	2	3%	6	9%
Autism (6)	5	83%	0	0%	0	0%	1	17%
Cancer (11)	7	64%	1	9%	1	9%	2	18%
Dementia (4)	4	100%	0	0%	0	0%	0	0%
Heart and Lung (3)	3	100%	0	0%	0	0%	0	0%
Long term conditions (22)	17	77%	1	5%	1	5%	3	14%
Mental Health (20)	20	100%	0	0%	0	0%	0	0%

Sexuality

	Asexual		Bisexual		Gay or lesbian		Heterosexual		Id prefer not to say		Other		Blank	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
All conditions (66)	1	2%	1	2%	1	2%	52	79%	7	11%	1	2%	3	5%
Autism (6)	0	0%	0	0%	0	0%	4	67%	2	33%	0	0%	0	0%
Cancer (11)	0	0%	0	0%	0	0%	7	64%	1	9%	1	9%	2	18%
Dementia (4)	0	0%	0	0%	0	0%	3	75%	1	25%	0	0%	0	0%
Heart and Lung (3)	0	0%	0	0%	0	0%	3	100%	0	0%	0	0%	0	0%
Long term conditions (22)	1	5%	1	5%	1	5%	16	73%	2	9%	0	0%	1	5%
Mental Health (20)	19	95%	0	0%	0	0%	0	0%	1	5%	0	0%	0	0%

Appendix 6

Condition Specific Qualitative Evaluation of Free Text

70 people in total completed the NHS Long Term Plan Condition Specific survey. In some cases the number of responses received does not in the opinion of Healthwatch Lincolnshire provide reliable and robust enough data for us to ascertain a clear picture of themes and trends for each condition selected. However, in respect of those people, carers and families that have responded, we have included an overview of responses for Autism and Dementia, as we considered there was learning from patient and carer experiences that could be acknowledge from the comments shared.

Many of the free text responses shared with Healthwatch Lincolnshire in the NHS Long Term Plan Condition Specific Survey included very detailed accounts of a person's experiences of accessing and receiving health services for their long term condition.#

We have summarised the free text responses by condition over the next few pages.

Autism - 6 respondents

In summary what matters most to people about Autism services are:

- Getting a diagnosis of autism much earlier. The belief is that this would not only help the child and their family better understand the illness but also importantly this would support the child's early years educational and social development.
- Services must work 'together' much more.
- Ongoing support should be available to parents and carers both 'peer to peer' and by a professional.

Assessment, diagnosis and treatment

- Respondents were asked 'if you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?' 4 of the 6 felt it was difficult, one felt it was very difficult and one person indicated they were ok with this. No one selected very easy or easy, which confirms not only what we are hearing as a Healthwatch about Autism services in Lincolnshire but also the summary of responses below.
- From all the responses we received it was clear that families (parents) felt the time it takes to receive full diagnosis for their child's autism was far too long and that in some cases these waiting times were really impacting on their child's educational development. One parent commented "*It was only at the end of 2017 that he got a new diagnosis of autism. He has since been able to move from mainstream to SEN school and now is soaring*" another said in response to diagnosis "*I am still waiting after 4 years*".
- There was also a clear opinion that health and education should work much closer/better to help identify, refer and diagnose autism in children. One Parent commented "*Took a long time to eventually get a referral for a diagnosis*

assessment - GP sent us to school nurse and nurse said needed GP referral so it went back and forth for a few months”.

The provision of ongoing care and support

- None of the respondents selected ‘yes’ to the question ‘did the support option you were offered meet your expectations? With 5 of the 6 respondents saying No and only one felt they ‘somewhat’ did.
- Concerns about how children are supported once they turn 16 years of age ie transition between child and adult services. Healthwatch Lincolnshire is concerned that having gone from full and regular support from health services to suddenly be left at such a young age with little or no support can have a real impact on children and their families.
- The Earlybird course and regular appointments with a Clinical Psychologist were both valued by families as support that worked well. However, it was felt that *“Review after Earlybird course and signposting to relevant local organisations”* would have helped improve the support that is available to families.
- Some respondents felt there is a need for more ongoing support for parents *“There is little support for parents of children with autism. The NHS part was ok but the Portage/Social Care was non-existent”*. One parent felt support such as local parent supporting parent groups would be one solution. Another considered more teaching professionals given the right training as *“parents desperate for help but there is no one to give it”* would be a great help, particularly for high functioning children with autism.
- Cancelled appointments - often result in length of time between appointments being extended well beyond the recommended time periods eg 6 monthly due to cancelled appointments extended to 12 to 18 months in-between seeing a consultant.

Prevention and/or early intervention

- None of the respondents felt they had control over their own care
- Annual Health Checks for any person who has a Learning Difficulty as well as Autism is certainly a service that is recognised as important, particularly to help prevent or identify any potential other health conditions.
- A sensory library would be very useful.
- Autism clinics where families can ‘talk to an expert’ annually was also a suggestion.

Healthwatch Lincolnshire work on Autism

In September 2018 Healthwatch Lincolnshire circulated one of our Escalation Papers on the subject of Autism. An extract of this paper is below:

‘we [Healthwatch Lincolnshire] are experiencing an increase in concerns raised with us by families and professionals around the challenges and often distressing inability to access assessment and diagnosis of conditions within country specifically autism and dyspraxia. We recognise that services are not always commissioned or available in county and that people may need to travel. However in this instance feedback is that access is also not available out of county meaning that people, families and professionals are not getting the best outcome.

We are aware that CAMHS excludes **the diagnosis**/treatment of Autism Spectrum Disorder (ASD), Tourette’s syndrome, Dyslexia, Dyspraxia and other neurodevelopmental disorders of childhood, but does not clarify what is the appropriate pathway.

Also we note that LCHS states that currently the Occupational Therapy Service is not commissioned to see children who have a diagnosis of Developmental Co-Ordination Disorder (DCD, also known as Dyspraxia) **or to assess for this condition**, but does not clarify what is the appropriate pathway.

We are aware of the good work emerging around the services offered post assessment and diagnosis, however the concerns within the escalation paper are specific to the needs of families and people needing assessment and diagnosis.

We are aware that the autism strategy has been in place for a number of years, in which we as a Healthwatch contributed to patient and family voice. However the practical application of this strategy appears not to address the wider needs of local people which could and potentially will impact their whole lives if not addressed early and may also prevent equity and equality of access and use of, services including education’.

Since our paper was distributed we have received 2 responses from the Lincolnshire Clinical Commissioning Groups, both acknowledging that the current Autism service ‘does not meet best practice standards and that the current pathways for diagnosis and ongoing care are fragmented’. On behalf of children and young people with Autism and their families we were pleased to also receive the news that the Women and Children’s Commissioning Board are leading work to consider how children and young people have access to timely diagnosis and support’.

Cancer - 11 respondents

In summary what matters most to people about cancer services are:

- People must be proactive in what is happening with their diagnosis, results, treatment and care. It is clear that with time delays and blocks in the system people need to be proactive in their involvement in what is happening, every step of the way.

- Many respondents who had experienced cancer felt there was a definite concern with regards to primary care [GP] professionals in both early detection of cancer and how they acute and community based cancer services are joined up.
- Communications should be provided with the patient and their carer's requirements uppermost.
- From the information we received especially in question 26 'further comments', there is a lot of learning through listening to 'experts by experience'. This should be implemented, not just offering Friends and Family Tests, feedback forms and the like but setting aside resources to enable sitting down with people to listen, learn and discuss.

Assessment, diagnosis and treatment

- If there seems to be something 'not quite right' with our health the first place we will present ourselves to get checked out is at our GP Surgery. This is the point where if relevant, we expect our cancer care journey to begin. For our respondents this experience was a real mixture of everything from being taken seriously which led to quick diagnosis and treatment, through to a patient not being taken seriously with the result that long delays lead to something much more serious. From this we can deduce that some people in Lincolnshire may experience inequalities in how they are accessing cancer services due to how they are treated initially by primary care professionals.
- For some people they experienced delays due to the hospital system. Waiting for cancer scan and test results, clinic appointment and referrals to specialists all not only lead to increased stress but avoidable delays in getting to surgery and ongoing treatment.

The provision of ongoing care and support

- Respondents felt there is more that needs to be done about co-ordinating services, one person wrote a really helpful suggestion which was "*Improvements could be made by all the relevant support services coordinating their care through a central organisation who could hold the people details and see who's been referred to assist them. Then the patient would have one contact number and the allocation of services could be facilitated through that*", another respondent referred to this as more "*joined up thinking*" is required.
- Communications were highlighted as very important to people and carers. This was from the excellent specialist nurses and organisations such as Macmillan and Mare Curie, through to improving administration (more than one person commented on this) and how sensitive and difficult information is shared with a plea that some consultants could be a bit 'more sensitive'. The question when asked of respondents 'During your whole experience of getting support did you receive timeline and consistent communication from all of the services that you came into

contact with?', provided a very mixed response with 1 person (9%) saying yes, 5 people (45%) saying no and a further 4 (36%) saying somewhat, this tells us that more needs to be done in this area.

- Local support is also important to people, people recognise that some of their support is often based a long way away from where they live, suggestion that someone 'on the end of a telephone would be very beneficial'. Many people wanted this access to professional help to answer the "*many questions we had*". There was much praise for Macmillan services which were valued as an important part of the support available.
- Fully involving families was also a very important area of support for people with cancer, one person wrote "*take a whole family approach to cancer: everyone is affected*" and this really brings home the impact of serious and life threatening illness on everyone in the family unit.

Prevention and/or early intervention

- Throughout the survey, no person commented about how they felt the prevention agenda would have affected them or their loved ones with their cancer experience. Within this report we have already highlight the need for much better education, advice, guidance and support to Lincolnshire people with regards to what is meant by prevention and self-care and ways in which they can help themselves.
- With regards to early intervention, this is clear, getting diagnosis early, receiving test results on time and starting treatment as soon as possible is what matters most to people, in Lincolnshire there is definitely issues with all of these areas.
- One respondent helpfully offered the following solutions:

With regards to cancer you need to have:

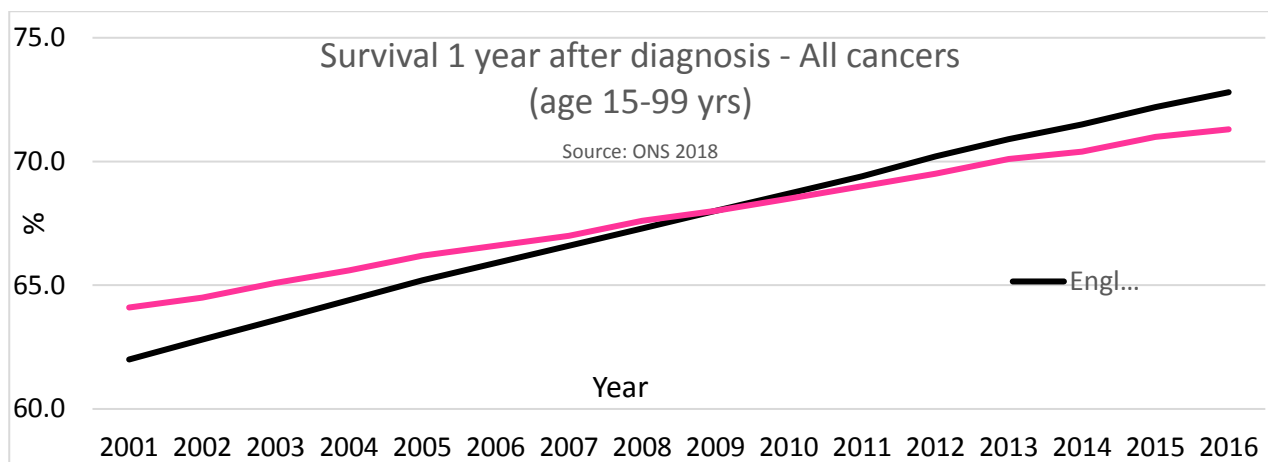
- Rare cancer pathways: immediate referral to specialist national centres on suspected rare cancers so as not to compromise possibility of cure
- Properly trained, up to date oncological dieticians (extremely poor and ill informed at LCH and hospice)
- lead clinician who maintains contact with patient and family throughout the whole treatment, not just 'factory style' treat and drop
- palliative nurses and teams trained to identify and support family carers from the start
- a human approach to palliative and end of life care from clinicians
- identify the support needs of the family including children affected
- take a whole family approach to cancer: everyone is affected.
- Cancer leads to monitor early diagnosis and treatment/ outcomes of cancer in working age adults; to monitor early diagnosis and treatment / outcomes for rare cancers.
- make sure the patient and family know what to do in an emergency
- make sure the family caring also understand the medication so they can assist properly in a crisis

- make sure the family know what to do if travelling out of the county (even in the UK) and what to do in the event of a medical crisis (health records were not nationally accessible electronically in 2015)

Healthwatch Lincolnshire work on Cancer

Healthwatch Lincolnshire has been raising concerns about cancer performance in Lincolnshire for 6 years. During this time whilst we have been told ‘much is being done to improve the services’ performance has declined. Once people are in the cancer service pathways they tell us the care they receive is exemplary, but delays in appointments, diagnostics and test results are concerning for all.

The graph below shows the performance of one year after diagnosis survival rates in Lincolnshire. We can see from this graph that in 2001 Lincolnshire was performing much better than the England average for cancer services. However, by 2009 performance was beginning to decline and has since only declined further.



Access to services differs greatly in Lincolnshire and really depends on where someone lives as well as how far they are able to travel. For example, a person living in Spilsby with suspected breast cancer who is not able to drive, may have no option but to wait for diagnostics, results and a consultants appointment at Pilgrim Hospital, Boston, possibly resulting in a breach of performance referral and treatment times, this coupled with a difficult journey from home to hospital using public transport creates a real problem. Whereas a person living in Stamford with Peterborough City being their nearest hospital, will not only most likely face reduced waiting times for diagnostics, results and a consultants appointment, and their journey will almost certainly be quicker. Both of these areas in Lincolnshire are less than 15 miles from their nearest hospital but the experiences of public transport and road network will be very different.

In both May 2018 and April 2019 Healthwatch Lincolnshire prepared Escalation Papers on cancer services.

The first paper focused on 62 day treatment from urgent GP referral and the second was concerning patient experience of cancer pathway care and treatment.

Why did we focus on 62 day treatment from urgent GP referral, what did our paper say - 'For over 3 years Healthwatch Lincolnshire has received information which confirms Lincolnshire people are not receiving treatment for cancers within the national recommended requirements. Our organisation has raised on numerous occasions concerns about performance for cancer services in Lincolnshire. We appreciate there are over 200 types of cancer with some more common than others, and we are keen to know which cancer services are directly attributed to the under-performance of the 62 day wait for treatment.

According to BBC Health site <http://www.bbc.co.uk/news/health-41483322> Lincolnshire performance figures for March 2018 were as follows:

United Lincolnshire Hospital Trust	England
75.5%	84.8%

- United Lincolnshire Hospitals NHS Trust ranked 121 out of 133 trusts
- The national target is that 85% of people should begin treatment within 62 days of urgent GP referral

It is widely known that treatment for cancer should be at the earliest possible opportunity to ensure people have the best chance of a positive outcome. Any delay in treatment will surely lead to potential risk of harm and it is Healthwatch Lincolnshire's role on behalf of people to raise this as a serious issue'.

Why did we focus on patient experience of cancer pathway care and treatment, what did our paper say - 'As a local Healthwatch we have, on many occasions raised and questioned, the level of access and care given to cancer people within the county. We are aware of the fragility of many services, however, we feel assurances provided do not echo the patient experience, for example the Living with and Beyond Cancer Strategy for Lincolnshire states that "everything we do will place the person at the centre", this is not the reality for many people who have contacted us previously and this is not the reality for the patient we will cite in this case.

Delays in cancer care and treatment could potentially cause harm to the people. Not supporting and communicating with the patient (and family members) effectively can potentially cause psychological harm'.

A response from Lincolnshire West CCG to our first paper was received in July 2018 and gave us detailed information to each of our questions. Whilst our Healthwatch recognise, acknowledge and commend the amount of work that is happening to improve cancer services in Lincolnshire, from patient feedback and national performance data, it appears cancer services in the county are still very fragile. As our most recent paper has only just been circulated (May 2019), we acknowledge that we do not expect a response to date. However, we are pleased to report that at the May 19 NHS Quality Surveillance Group meeting for Leicestershire, Lincolnshire and Northamptonshire, our Cancer Escalation Paper was presented and discussed.

Dementia - 4 respondents

Due to the small number of responses we received with regards to dementia services, we have not been able to complete any meaningful analysis of the data. However, from the free text responses received we have summarised as follows:

- Families felt that much earlier dementia diagnosis would help both the person with dementia and their family cope much better with everyday activities.
- More support and information for families on how to help their loved one with dementia is required, one person wrote *“When we enquired as to support for early onset Alzhiemers/Dementia we were told there wasn’t any specific service through out Lincolnshire”*. This support should be appropriate and offered to people of all ages, including people diagnosed at ‘early onset’.

Caring for someone with dementia can be a very demanding and isolating role. One person wrote *“If a carer is disabled they cannot access any support. No one has come to the home to see how she can cope or to see how frail my dad is. If I wasn’t around I think things would be far worse. I have had to work on my mum to seek help for her mental health (still awaiting a gp appointment with a wait of over 2 weeks) as I feel she is at breaking point. There needs to be assessments of safeguarding to protect carer and those being cared for”*.

Long Term Conditions - 22 respondents

With so many possible long term conditions it has not been possible to provide individual results for every long term condition. One main reason is that respondents in this national survey were not asked to specify what their health condition/s are. However, during the free text comments some people have indicated their long term condition, so when summarising these results we may refer to conditions if we have included respondent comments.

In summary what matters most to people about Long Term Conditions are:

- Delays - whether this is in getting an initial diagnosis or appointment to see a specialist for treatment and care. Delays are really impacting on patient’s mental wellbeing as well as physical health.
- Joined up services - having a team to manage the specialist healthcare needs of individual people particularly those with more than one long term condition is essential. The need for more joined up services also extends to both primary, secondary care, specialist services and social care.
- Continuity of specialist care once my condition has been diagnosed - including access to Specialist Nurses and regular check-ups with relevant health professionals.

- Communications - both written and verbal needs to be given in a more appropriate, understandable and in some cases respectful way.

Assessment, diagnosis and treatment

- Delays in initial diagnosis - it seems this does depend on many factors including, the condition itself, what other conditions a patient has that may 'mask' or delay diagnosis and where they live ie which hospital they will be referred to. One person said *"Because I have more than one health condition it varies. I have five different specialist. Times vary for each department. Cardiology was reasonable but took three months. Eye clinic was immediate, within a few hour but it was an emergency. Audiology can take up to four months. Rheumatology up to three months, pain clinic keep cancelling so been over six months"*. Many people said they were very distressed by long delays before they could get diagnosed, in some cases they felt 'fobbed off', in others the delays in fact resulted in a deterioration of their condition.
- Travel issues - people understand that getting to health appointments is their responsibility. We hear a lot of concerns about travel and transport in Lincolnshire but we must always remember the patient that due to their health conditions feel unable to drive themselves to their appointment and therefore reliant on public or private transport. If the appointment they are offered is over one hour's drive away, the cost of a 2 way taxi fare will be financially high. People then have the choice to either endeavour to get to that 9am appointment which is a long way away and will cost them an extreme amount of money, or wait over 3 months for an appointment at their local hospital. This is exactly what happened to one respondent, they had no option but to wait for a local appointment and in the 3 months they waited their condition deteriorated to such as degree they ended up in A & E.

The provision of ongoing care and support

- Specialist nurses - people value the support offered in the community from Specialist Nurses such as diabetes, Parkinson's and MS Nurses but feel there is not sufficient numbers of them in Lincolnshire to provide the help and support needed. Healthwatch Lincolnshire is aware that access to Specialist Nurses is often a 'postcode lottery', resulting in inequalities of provision for ongoing care and support. With conditions such as diabetes on the rise Healthwatch Lincolnshire would recommend funding to provide more Specialist Nurses to help people manage their conditions at home, keeping them out of hospital or requiring regular trips to their GP.
- One suggestion was that better use of technology would enable people with more than one long term condition can have a point of contact with each department via iPad or Smartphone. The suggestion is that this would enable specialist advice to be offered quickly and could help with those people living in very rural areas requiring help to manage their condition.

- Joined up care - is especially important, this would result in people being treated holistically rather than conditions in isolation, to respondents this was a real issue with one person writing *“I have complicated health needs, more than one condition. There is no joined up care to manage them. None of them [hospitals] talk to each other so there is fractured care”*. Healthwatch Lincolnshire considers that delivering ‘person focused’ care and support through opportunities such as Neighbourhood Teams managing care as a team, wrapping services are the person is essential. Where managed and co-ordinated care is happening it works really well for people with one person telling us *“Once the care and support was being coordinated by the one Consultant it was so much smoother - the person coordinating kept everything in control and good communication developed. That key person is crucial!”*.
- Appointments issues seem to be a very regular occurrence, cancelled appointments can cause a lot of upset for people who have had to organise transport to attend clinics. In some cases cancellations have resulted in very long gaps between the ongoing support people receive. Respondents commented more than once that they had to chase appointments and treatment which they felt left them very anxious and stressed. Having access to urgent appointments for treatment and care was also something respondents mentioned was very important to them.
- Written communications such as leaflets and lists of contact numbers whilst can be helpful for some people, others are too unwell or overwhelmed to make best use of them, as one respondent put *“Yes but this was a piece of paper with contact numbers on. The patient was too unwell to make contact themselves and comprehend what they needed to do”*. Healthwatch Lincolnshire recommends a policy of checking to see what communications methods will be most appropriate for every patient. More than one person felt that very often the way in which verbal information was communicated was ‘abrupt and inconsiderate’ leaving them feeling a burden, confused and alone.
- No regular or ongoing support offered - many people who respondent with a long term condition did feel they were not offered any ongoing support and were just ‘left to live with it’, resulting in them feeling they are alone with their health problems. For some minor conditions this might be acceptable but for many of our respondents they were talking about conditions such as thyroid (under or over active), autoimmune, rheumatology, MS and diabetes. Many people commented that they live with constant chronic pain leaving them unable to sleep.
- Involvement of families and carers in healthcare needs, this might include providing confirmation of diagnosis and treatment in written formats to enable people to share with and refer back to carers and family at a later date.
- People want continuity in their ongoing care and support, this really means remaining with one specialist.

Prevention and/or early intervention

- People want more information about how to keep active and diet without causing further harm due to their long term conditions.
- Being offered regular check-ups was mentioned on several occasions, people felt this would help them better manage their condition.

Mental Health - 20 respondents

In summary what matters most to people about mental health services are:

- Waiting times, whether this is for assessment, diagnosis, treatment or ongoing support people felt that the length of time they or their loved ones have to wait is not acceptable.
- Length of time initial treatment/support is offered, is considered to be problematic. In most cases we are told the 6 week period of support is not meeting the needs of people with mental ill health.
- The need to make services more person centred and where relevant include families and carers in this process is very important in keeping the patient safe.

Assessment, diagnosis and treatment

- **Waiting times** - overwhelmingly people felt that the time they had to wait for assessment, diagnosis and treatment was far too long. Many commented that during this time they faced personal crisis either for themselves or loved ones including suicidal thoughts.
- **Medication** - prescribed by GP as first stage of treatment there was a feeling from respondents this should not be the solution. People felt they would have preferred an assessment prior to being offered any medication. In some cases medication made things worse with one family saying *“Given wrong medication for depression, 6 months of hell and 3 suicide attempts. The last one in hospital saw the lad committed for a fortnight whilst medication sourced”*.
- **Assessments and diagnosis for specialist services** - such as eating disorders and veterans was mentioned as an issue for people. One person told us *“My husband was seen by the crisis team at home a couple of times then referred on to the Veteran's MH team. However at that point this was not fully up and running and the subsequent wait for this service to start left us with no support, effectively it felt like they had washed their hands of him. This took over a year to properly start treatment with the complex cases veterans service. I ask you would someone who had had a stroke be left untreated for a year? Unlikely and if one applies parity of esteem on conditions someone left suicidal with complex PTSD deserves better as this was a life threatening condition”*.

- **6 weeks of treatment** - (including counselling or Group Information Sessions) - from the people that responded where they had experienced Group Sessions there was no positive comments made with the feeling that this method of support potentially does more harm than good. The view is that one to one rather than Group Information Sessions would be better. Additionally, many felt that 6 weeks of support from any service for people with mental health illnesses is just not long enough.
- **Person centred** - it was clear from many people that they felt the system was designed to expect people to follow a set 'process' of waiting, 6 weeks of support, medication and then no more support for some time. Services need to recognise that as one person put it "not 'one size fits all'". Additionally, suggestions to keep people and families 'in the loop' and also to provide a telephone contact for times when support is most needed.

The provision of ongoing care and support

- **After an initial 6 week period support for many people ends** - Many people commented that this was just not good enough, their problems had not miraculously gone away "*The course lasted for only 6 weeks and was not helpful. Counselling should be available a lot sooner and should last for more than the basis 6 weeks*", was one of the comments made. There was a plea for more available counsellors.
- **Too much reliance on patient and their families** - to push for help, this is particularly an issue for anyone with mental ill health that have no family network around them. For many people having to make the first contact with services creates a barrier so great they cannot cope, this can often lead their illness to spiral downwards.
- **Timely support** - the feeling is that this needs to be immediate, waiting times are far too long for people with a mental health condition.
- **Inequalities in services across the county** - it was recognised that availability of ongoing support will depend on where a person lives and that rural areas of Lincolnshire are under-resourced. One person suggested that more Healthy Minds Groups like the one in Mablethorpe should be set up.
- **Support for families and carers** - is essential in helping the patient with mental ill health, quite often it is families and carers that are left in despair trying to manage difficult situations on a daily (sometimes hourly) basis. One respondent felt that "*carers have to swim with their own resources or sink accordingly*".

Prevention and/or early intervention - suggestions from respondents

- Annual reviews to include an MOT checklist
- Provide up to date relevant information
- Provide simple clear advice about where to seek help

- Provide information about a people' rights in regard to care and treatment
- Have mental health teams based in all GP surgeries
- Ensure CRISIS teams are resourced to enable immediate access and support

Appendix 7

Lincolnshire based questions used with focus groups

1. The NHS Long Term Plan encourages close working between health and social care teams. What are your views on ways in which health and social care services in Lincolnshire could work more closely together?
2. What are your views on having most of your healthcare closer to home but more specialised healthcare services further away?
3. What are your views on digital and technological opportunities for accessing healthcare and managing your health condition? For example if you were offered a digital 'wearable' device to help you manage a long term condition would you be interested in it? Or if you had the chance to have an E-consultation or remote consultation (via the internet) with a specialist how would you feel about this?
4. Evidence shows that there is a direct link between the lifestyle choices we make and how healthy we are including our potential life expectancy. There is a new Integrated Lifestyle Support Service being developed in Lincolnshire which will support people who need help to stop smoking, reduce alcohol intake, increase physical activity and maintain a healthy weight? Is this a service you feel is beneficial? And if yes in what format would you prefer to receive it e.g. one to one with a consultant or group sessions with other people?
5. What is your view on all the different treatment options for accident and emergency care eg 111 (CAS), Urgent Treatment Centre, Minor Injuries Unit, A&E? Do you understand what they all do and when you should access them?
6. What are your views on how mental health services need to be delivered to improve people's care on a day to day basis?
7. How do you think people, carers, service users and the public should be involved in helping to inform, influence, improve and redesign our healthcare services for Lincolnshire?

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