Care Quality Commission

Integrated Care System Brief Report prepared by:

healthwatch
Lincolnshire

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Executive Summary

As part of the Care Quality Commissions (CQC) work to develop a new regulatory assessment for Integrated Care Systems (ICS) in England, Healthwatch Lincolnshire is pleased to present this report which contains detailed information about our engagement approach and findings from both the public and health and care leaders in Lincolnshire

Lincolnshire covers one large geographical ICS footprint which includes both urban and rural conurbations. Lincolnshire has it all from the city of Lincoln with the usual mix of affluence and deprivation, through to coastal complexities and some of the most rural areas in England. Local health Trusts who have struggled for many years, their challenges only exacerbated by the ever-declining workforce, poor travel infrastructures and local expectations of care all gave our work richness and tales to tell.

When starting this work, we were aware that many of our NHS services are still feeling the impact of Covid-19 and only just experiencing green shoot recovery. For many patients, carers and service users, their view of Covid-19 on how they access services has changed from support and understanding, through to concern and often anger about the impact on their health where they feel services are 'not available'.

Throughout the engagement work we completed between April and May 2022, including surveys, group work and one to one interviews, the areas that mattered most to people were being treated holistically (person centred care); more effective and appropriate communication and services being more joined up (talking to one another).

Our health and care leaders told us they were fully committed to embedding patient, carer and service user experiences in service redesign and decision making but recognised there is a lot to be done by everyone to meaningfully achieve this. This was reinforced by the overwhelming response to our public and seldom heard question 'Do you feel your experience of health and social care are activity taken into consideration in helping to shape future services – overwhelmingly the response was NO.

On page 8 of this report, we have included a long list of evidence that we feel would support CQC in its ICS regulatory work, from strategies, to plans, performances, policies and agreements.

Introduction

HWLincs is presenting this report to the Care Quality Commission with the purpose of sharing our overall findings and most importantly key headlines, to support the Commission in its development and approach of regulatory assessment for Integrated Care Systems (ICS) across England. Our remit for this work was to gather insight across the entire Lincolnshire ICS area, with the following three points forming the focus areas:

1. **Leadership** – how ICS decision-makers consider people's lived experience
2. **Integration** – equality and access (care pathways/moving between services)
3. **Quality and safety** - Peoples experiences
    - How does CQC get peoples experience information into this new form of regulation?
    - What types of questions should CQC be asking people to understand their experience of systems?

CQC contract deliverables are:

- To gather and present insight, both quantitative and qualitative, on the agreed focus areas to include engagement and feedback from the:
    - General public
    - Seldom Heard Group of People
    - Health and Care Leaders
- Prepare a comprehensive report which provides expert commentary on these findings by 9 June.
- Make recommendations on how communities can be empowered to engage more effectively with the ICS in their local area.
- Provide examples of how CQC can best gather people's experiences across an ICS area.

About HWLincs and Healthwatch Lincolnshire

HWLincs is a registered charity, set up in April 2013 to deliver the Healthwatch Lincolnshire contract. Since this time, we have successfully delivered not just the Healthwatch contract but other complimentary contracts for organisations such as NHS Lincolnshire and the CQC.

Healthwatch Lincolnshire has strong connections to the partners involved within our Lincolnshire ICS, which includes our seats on the Lincolnshire Clinical Commissioning Group (CCG); ICS Development Board; Quality Patient Experience Committee; Health Inequalities Programme Board; Health Protection Board; Quality Service Review Group (care services); United Lincolnshire Hospital Trust Board and Health Scrutiny Committee, to name but a few, giving us direct access to health and care system leaders.

About the Lincolnshire ICS

There is one ICS covering Lincolnshire with a footprint that includes the identified geographical county of Lincolnshire (excluding North and Northeast Lincolnshire), Lincolnshire ICS includes partners from the following organisations:

- Lincolnshire County Council (including 7 District Councils which together are coterminous with the County Council)
- NHS Lincolnshire ICS Board and Partnership
- Three Lincolnshire based NHS Trusts – (United Lincolnshire Hospitals NHS Trust; Lincolnshire Community Health Services NHS Trust; Lincolnshire Partnership Foundation NHS Trust)
- One NHS Ambulance Trust – East Midlands Ambulance Service
- 85 Lincolnshire GP practices (covered by 16 PCNs)
- Other primary care services e.g., pharmacy
- LinCA - Lincolnshire Care Homes Association, supporting 295 care homes in the county
- Lincolnshire Voluntary Engagement Team (3rd sector grouping)
- Other key partners e.g., Lincolnshire Police
- Healthwatch Lincolnshire

About Lincolnshire

The geography footprint of Lincolnshire is vast and includes a mix of urban, rural and some very isolated rural parts. Urban areas include the city of Lincoln, large towns of Gainsborough, Grantham, Skegness, Boston, Spalding, Stamford and towns such as Sleaford, Louth, Horncastle, Sutton Bridge and Bourne. Close to our city and towns is a significant network of 1,066 smaller villages, some with good infrastructure and access into their nearest town, whilst others are mere hamlets with no shop, amenities and limited public transport.

Key lines of enquiry

The questions below were used by us as an internal framework, providing us with focus for our 'overall' evidence gathering. We felt the following questions would support CQC in its work to develop a regulatory ICS inspection framework.

How does CQC ensure peoples experience of health and care services are considered when regulating ICS?

- Include Experts by Experience or local service users in all inspections
- Extend ICS inspection period (3 to 6 months) to enable more people to engage
- On CQCs behalf, ask local Healthwatch, to gather patient carer and service user feedback from local people, communities, and partners

What types of questions should CQC be asking people to understand their experience of systems?

- Ask people, have you been asked **'What matters to me'?**
- Inviting people to **'Tell us your story'**, 'what has been your experience to date'
- If you shared your experience with a provider, commissioner or other organisation, did you feel your views were heard?

What public feedback information should CQC include when assessing quality of care?

- Complaints – number of, how they are managed and outcomes
- Examples of where services are/are not working jointly for best outcomes
- Patient experience reports from organisations such as Healthwatch or NHS Trusts

What evidence will CQC require from providers and commissioners?

- **Engagement strategy** – with performance against action plan
- **Communications strategy** – with performance against action plan
- **Accessible Information Standards (AIS) Strategy** – and examples of where these are being met
- **Patient feedback** – what systems are in place to show feedback is joined up across ICS. In an effective ICS, it will be vitally important not to focus just on the performance of individual services but also the efficiency and effectiveness of the interface between services and providers
- **Equality Impact Assessment** – examples from service redesign as a minimum
- **ICB Board performance reports** – these should be provided and collated for a 12-month period to enable monitoring of performance
- **Whistleblowing policy** – including examples of information shared which should be logged on a register
- **Never event/Serious Incident logs** – should provide evidence of how these are dealt with, how lessons learned are shared

  Care plans e.g., Anticipatory Care Plans, Advanced Care Planning – examining a random selection of plans to check if these are appropriately in place, include the persons own desired outcomes and are up to date.
- **Waiting times for diagnostics, elective care** – including number of people on the lists, how people are triaged to ensure 'high risk' patient needs are being dealt with.
- **ICS partner agreements** – these would demonstrate real 'commitment to integrated working' from all providers, commissioners and stakeholders involved in local ICS.

Summary of Public Engagement

From the results of our surveys, one to one interviews and group work, we were able to summarise the following areas as **'what matters most to the public'**:

People want to be treated holistically – this was a theme that was highlighted repeatedly, one that is important to people for better outcome/s

- They want services to wrap around their needs
- People want patient centred care to be delivered
- People want everyone involved in their care to access one central source for their 'patient and service user record' and this should include access by them as a patient.

People want better communication – problems with communication is a theme we have consistently heard for a long time. The impact of poor communication on patients and carers should never be ignored:

- People want better communication between services and departments
- People want better communication between patient and services
- People want to be provided with appropriate communication methods e.g., for deaf people

Better co-ordination between services – people told us that lack of coordination results in them having to continually repeat themselves, wait longer for additional support services or just not be recognised:

- Patients receiving cross border health and care do not feel they are always joined up, in places like Lincolnshire this is quite a significant problem. This issue may also be relevant for areas which is covered by more than one ICS.
- Patients expect more liaison between services to ensure they do not have to keep repeating themselves
- People want a more seamless experience between GP and hospital, hospital and community health, community health and care

People want services to meet their healthcare needs, they want to be able to access services and be heard

- People want more face-to-face appointments. Whilst there was some acknowledgement of the benefits with online access or consultations, we could not ignore the outpouring of sentiments shared with us around currently lack of face-to-face appointments especially with GP services
- Long waits for services are impacting people
- More work needs to be done to ensure services are meeting the needs of everyone. Inequalities in receiving services still exist for some people such as the homeless, people living in rural communities or people with sensory disabilities
- Inequalities to access some services such as NHS dentistry or neurology in our county
- Overwhelmingly people told us that they did not feel listened to or were given enough opportunities to share their experiences

> **One of** the most compelling comments from **a** health and care leader **we heard was “do we [clinicians] ask people** what matters to **them, or do we just ask, “what is wrong with you?”**

Summary of Health and Care Leaders Engagement

Whilst we believe the patient, carer and service user feedback provides the most important evidence to CQC, we recognise that another important element of this work is to hear from our health and care leaders, as it is they who will be shaping our health and care services now and in the future.

From the responses we received, it was reassuring to hear that all the health and care leaders agreed that our health and care service user experiences MUST be embedded and at the heart of their decision making.

Between 25 April and 25 May 21 health and care leaders told us about their views against the following three questions:

1. **What would it take for Lincolnshire to be the most advanced ICS in England where public experience clearly influences decisions?**

   What they told us:

   - For Lincolnshire ICB to lead the way, they need to set an example for the whole system to follow by truly putting people at the heart of decision making. This would include (but not exclusively) such activities as having lived experience stories at all strategic meetings and recruiting patient representatives to sit on all relevant boards and committees
   - The creation of an overarching Engagement Platform. One that brings together all experiences, encourages wider gathering of experiences, and provides useful analysis of results which will be used by decision makers
   - Need to change the culture and language to ask people 'what matters to you' rather than 'what is the matter with you'
   - Create 'service redesign and decision making' patient involvement/provider collaborative opportunities. This would include support and training leading to participants to be meaningfully involved in planning, design, improvements and

monitoring. The process should include a mechanism for continuous patient and user feedback to support ongoing service improvements.

2. **What do you consider effective and inclusive involvement of 'patient, carer and service user' would look like as part of a CQC regulatory inspection?**

    - ICS can provide evidence to CQC as to their widespread public engagement and involvement at all levels. This engagement must include marginalised communities and seldom heard people
    - CQC should follow a patient or service user journey (especially where they have a long-term condition or require support from multiple health and care services), not just during inspections but continue this over a longer period (beyond inspection). This would enable CQC to benchmark changes against patient, carer or service user lived experiences. This statement is one that we have shared with CQC previously as important to service users, the fact that it has been raised with us again and by a different audience provides real credibility to the statement.
    - Inspections should be extended over a longer period of time e.g., 3 – 6 months, enabling local people more opportunities to meet with CQC Inspection Teams and feed into 'Engagement Platforms'
    - Experts by Experience or local service users should always be invited to be part of CQC inspection
    - CQC should not focus on just the volume of feedback/experiences gathered, but also on how the ICS is 'joining up' experiences from across the system and then how it is:
        - a) using them to influence decisions and overcome issues and challenges being faced by users.
        - b) communicate decisions and improvements back to users. (i.e., you said, we did…)
        - c) evaluate the impact of any decisions or changes to pathways/services

3. What do you think needs to be done to make user experiences embedded and at the heart of decision making in Lincolnshire?

- Develop a framework across the ICS using multiple organisations to ensure user experience helps shape improvements in delivery
- Create a consolidated information system into which all patient and public experiences about all services in the ICS can be entered and analysed. Such a system would provide decision makers with experiences and feedback not only on individual services and providers, but also be capable of more easily identifying the challenges and issues service users face moving along pathways and between different services & providers.
- Integrated Care Partnership (ICP) develops a strategy that formally and informally seeks to hear, gather, showcase and embed the voice of users.
- Go to people, not expect people to come to you
- Enable lots of ways people can feedback
- Learn ‘how to’ from other sectors and organisations
- Complete a needs assessment by whole system
- Create an environment where patient/user experiences are treated as a priority by all stakeholders

We would like to take this opportunity to thank our NHS Lincolnshire CCG Executive, Lincolnshire Health and Wellbeing Chair, Chief Executives from the three NHS Lincolnshire Trusts, Chair of LinCA and VCSE colleague who contributed to this work. We appreciate the time they took out of their busy days to complete the survey and meet with Healthwatch Lincolnshire.

You can read more feedback from Leader’s survey and CCG Executive meeting in appendix four

Methods of Engagement

To ensure we offered opportunities to as many Lincolnshire residents as possible, between 11 April and 19 May 2022, we organised a wide range of engagement activities including:

- Public online survey – available from 11 April to 19 May 2022
- Distribution of 500 public hard copy surveys to 17 organisations, including community hubs and sensory groups

- Seldom Heard online survey – available from 22 April to 15 May 2022
- Seldom Heard hard copy survey – made available on request

- 20 group activities – 17 of which were face to face (which included one specifically arranged focus group) and 3 were held virtually

- 4 one to one interview with individuals from Seldom Heard Group

- Leaders online survey – available from 25 April to 25 May 2022
- Leader's meeting – 19 May 2022

Summary table of activities including number of people engaged	
Activity	Number of responses or people attended/involved
Public survey	295 responses (3 removed before analysis)
Seldom Heard survey	521 responses
19 Group Activities	Involving 250+ people (a small number of the activities had several people attending as more of a drop-in)
One focus group	5 people
4 x one to one interview	4 people
Leader's survey	13 responses
Leader's meeting	8 people

A full list of the activities we completed is in appendix one

- **Between 5 April and 19 May 2022, we engaged with over 1,000 people**
- **Free text responses shared with us via the public and seldom heard survey resulted in over 2,500 qualitative comments.**

Our selected Seldom Heard Group

Our selected seldom heard group included people who have Myalgia Encephalomyelitis (ME), Fibromyalgia, Epilepsy and Multiple Sclerosis (MS).

Our rationale for selecting people with these neurological conditions was because we understood from feedback which is received by our Healthwatch that this group of people are likely to have required diagnosis and ongoing support through the healthcare pathways, providing us with direct opportunities to gain experience more about their experiences. We are also aware that in Lincolnshire these services are not always available. We felt that people within this group could have a relevant story to share with us.

Previous engagement we have had with people with conditions such as fibromyalgia is that they regularly feel 'seldom heard' knowing that it can take a long time for them to receive a clinical diagnosis.

We were initially surprised by the significant number of people completing the seldom heard survey, but on reflection this did confirm what we had already suspected, that they felt 'unheard'.

Demographics from public and seldom heard surveys

The table below provides a breakdown of the demographic data collected from the public and seldom heard surveys. From this data we can summarise the following points:

- Following the pattern of our experience to date, more women than men completed the survey
- Whilst we had people aged from 16 to 80+ completing the survey, people between the ages of 25 to 64 made up the largest group
- Ethnicity data followed the general population make up for Lincolnshire i.e., ethnic population is still in the minority, so the largest group of people responding came from white background (British/English/Northern Irish/Scottish/Welsh)
- The data for location of respondent's indicated we received quite an even spread across the county, with slightly higher numbers coming from East Lincolnshire. This reflects not only East Lincolnshire's larger population size but also suggests that we have received feedback from some of our most rural and challenged communities.
- We had quite high numbers of people responding with a disability and/or long-term condition, some of this should be attributed to the higher number of respondents to our seldom heard survey.
- In addition to the data shown in the table, we met with people from smaller market towns of Stamford, Spalding and Bourne attending focus groups and met with people from areas further east such as Louth and Boston.

Demographic	General Population	Seldom Heard	Combined
Gender			
Woman	68%	95%	87%
Man	29%	4%	13%

Non-binary	1%	0.4%	0.5%
Age			
16 to 17	0%	1%	1%
18 to 24	1%	0.4%	1%
25 to 29	18%	39%	31%
50 to 64	29%	48%	41%
65 to 79	34%	10%	19%
80+	3%	1%	6%
Ethnicity			
White: British / English / Northern Irish / Scottish / Welsh	84%	91%	88%
White: Any other background	3%	4%	4%
Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic groups background	0%	2%	1%
White: Irish	3%	1%	1%
Any other ethnic group	1%	1%	1%
Mixed / Multiple ethnic groups: Black African and White	0%	0.4%	0.2%
Location			
Boston Borough	13%	9%	11%
East Lindsey District	24%	21%	22%
Lincoln City	7%	10%	9%
North Kesteven	10%	14%	13%
South Holland	20%	12%	15%
South Kesteven	18%	16%	17%
West Lindsey	8%	16%	13%
Outside of Lincolnshire	1%	2%	2%
Carer			
Yes, I consider myself to be a carer	17%	18%	18%
Disability			
Yes, I consider myself to have a disability	25%	64%	49%
Long-term condition			
Yes, I consider myself to have a long-term condition	53%	82%	73%

Engagement Findings

The following pages provide information gathered from our engagement activities including group work, one to one interviews, public and seldom heard surveys.

Summary of feedback from seldom heard group activities

Key points raised during the group activities told us that people want:

- To be treated holistically
- For their condition to be recognised – person centred care
- Specialist medical support to help them manage their condition e.g., specialist health professional
- Not to have to repeat themselves throughout their healthcare journey
- Better and more relevant information, in suitable formats
- Communication to be more effective and relevant
- To be asked 'what is important to me' and 'what is my goal'

Further information from group activities can be read in appendix two

Summary of feedback from one-to-one interviews with four 'self-selecting' individuals from our seldom heard group

Key points raised during the interviews told us that people want:

- To be treated holistically
  - This includes additional support needs such as counselling to help people come to terms with what is often 'life changing' diagnosis
- Care to be patient centred
- Care to be consistent across services
  - Accountability of care
- Ongoing support
  - To know that specialist support is available in times of crisis or for reassurance
- Information –
  - At point of diagnosis

    - Central point for patient records that can be accessed by all services and the patient/responsible carer
- To be heard – communication comes out repeatedly as an issue
    - Between services
    - With patient and their carers

A detailed *write up of each one-to-one interview is in appendix three*

Survey findings

Pages 20 to 38 provide quantitative and qualitative analysis from the public and seldom heard surveys. It is important to note that we received more than 2,500 free text responses through the surveys. If required these comments can be shared with you to provide additional context, please contact HWLincs to request enquiries@hwlincs.co.uk .

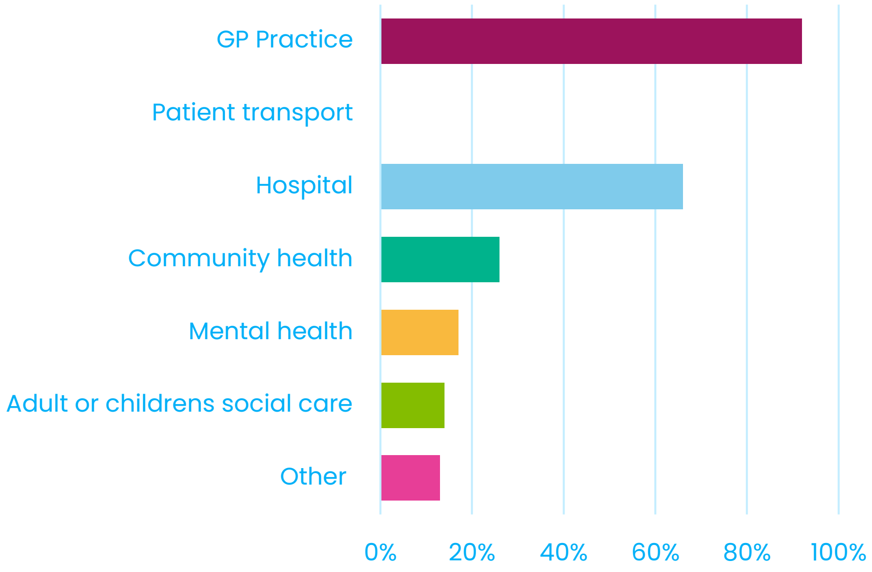
General Population

We received 295 responses to our general population survey. Three of the completed surveys were removed due to the fact they were returned as blank or duplications.

Q1] Are you filling in this survey for yourself or for someone else?

- 82% (239) of the responses received were a person's own views
- 18% (51) of the responses were the views of a friend/relative or carer of the cared for.

Q2] Please tell us which services you have needed to access in the past year?



The table shows that GP services and hospitals received the highest number of responses. It is worth noting that a small number of respondents had only accessed one service i.e., GP Practice.

Q3] How well as a Lincolnshire resident are you supported by health and care services? (Respondents were invited to select from strongly disagree through to strongly agree)

- Only **27%** of responders 'agreed strongly' or 'agreed' they felt supported by health and social care services in Lincolnshire.
- **26%** of people felt they have health and care support that enables them to live as they want
- **30%** said they felt in control of planning their care and support if they need it

The above statistics suggests this question would be a useful one to ask the public, via organisations like Healthwatch, prior to ICS inspection and then benchmark before each subsequent inspection

Q4] Tell us what currently works well with the health and social care services that are supporting you? (Free text responses)

For many people, GP access was praised and the use of new digital systems such as askmyGP and E-consult were valued, along with the ease of renewing online prescriptions.

District Nurses and mental health professionals were also praised for the support given. It appears the best care was received where services wrapped around the patient and their needs, providing individual person-centred care.

"District nurse service very good when Hospital did not admit me after a fall in a public toilet. nurses visited for several weeks to dress my wounds."

"I have been supported well by my mental health care workers being always there when I've needed them regardless of Covid19"

"Excellent service and care from my GP, and I also receive excellent care from the CMHT."
"I am well supported by my GP and practice I have regular telephone calls from my consultant to discuss blood results and scans."

"Ask my GP and the NHS app to order prescriptions is awesome. The nurse at my GP is brilliant too"

"Heart failure nursing team is a great idea to monitor mum's medication and blood pressure etc. I love the fact she is visited in her home for this. And the liaison between hospital, nursing team and doctors has been impressive."

Q5] Tell us how health and social care services could better to support you?

From the free text responses, we can summarise the main themes as:

a) Better communication
b) Acknowledgement of condition
c) Better access to GP services – as they are the first port of call and entry to other services
d) Seeing and treating the person holistically
e) Services talking to each other
f) Cross border services working closer
g) Addressing Equality of access

The following pages (numbers 18 to 21) include a selection from the many free text comments we received concerning the above points.

a) Communication

Healthwatch Lincolnshire has recently (2022) completed a piece of work covering the impact of **substandard or inappropriate communications by providers to patients** as this is an area that we hear about time and again. We have shared the summary report with our NHS and Social Care colleagues for their input and consideration. It appears areas such as Accessible Information Standards is an area that would benefit from more input.

> *"COMMUNICATION is the main problem with delivery of services. Communication between professionals; communication between disciplines or agencies; and communication with patients is not effective. It is so often left to the patient to chase up issues. There seems to be a total lack of processes or systems which are in place and followed. Efficient working seems to depend on an individual thinking through a problem and figuring a possible solution, rather than clear, unambiguous processes which are easily accessible to all staff. It seems remarkable, in the twenty-first century, that technology has not been used to ensure that information is updated and easily accessed by staff."*

Healthwatch Lincolnshire has recently (2022) completed a piece of work covering the impact on substandard or inappropriate communications by providers to patients. We have shared the summary report with our NHS and Social Care colleagues for their input and consideration.

b) Acknowledgement of condition

In both the public and seldom heard surveys we received a lot of comments from people asking for people to help and treat them with more **understanding of their condition/s**. Also, that all services involved in delivering a person's healthcare needs **liaise to support best outcomes.**

> *"To be acknowledged as a disabled person and the problems that arise from that would help and for all of the different providers to communicate and to inform me and each other of the help that could be offered."*
>
> *"Access to specialised support from people who actually understand the condition and not from a child who has done a half day online course!!"*
>
> *"Someone who understands my illness & what I deal with, someone I can talk to about my conditions & to cope/manage on a daily basis."*

In both the public and seldom heard surveys we received a lot of comments from people asking for people to help and treat them with more understanding of their condition. Also, that all services involved in delivering a person's healthcare needs liaise to support best outcomes.

c) Better access to GP Services

A lot of respondents told us they were worried, upset and even in some cases angry about the current issues with access at many of our GP services. People felt very frustrated with things like the **length of time it takes to get through on the telephone** to reception through to **lack of face-to-face appointments**.

"I feel badly let down as a Lincs resident, being sent to A&E in Cambridgeshire but Lincs will not approve any treatment that has been approved by three separate Cambridgeshire Consultants. I'm beyond furious as I've been in considerable pain since April 2020."

"Having a diagnosed serious heart condition, needing to urgently get to see a GP, I tried to use for the first time askmyGP only to find it has been switched off by 8.30am, so I telephoned to book an appointment, only to be 50 in the phone queue. By the time I was able to get through no appointments left for that day. The thought of having to do this all again the next day was sole destroying".

"As a retired GP my wife and I retired to an apartment in [East Lincolnshire town] LITERALLY 200 yards from a GP surgery. When we tried to register with this surgery we were told that we were 'outside their area' – the TRUE reason being that if accepted we would not be dispensing patients. As our health has deteriorated we have tried to register with them again on TWO occasions AGAIN being refused – we are NOT difficult or demanding patients – but we are both disabled and have had to register 7 miles away".

d) Seeing and treating the person holistically (are services joined up)

We particularly heard about this issue from respondents in our seldom heard survey, people want recognition that their health and care needs are **joined up** and when they are receiving healthcare services that people **are aware of their holistic needs**.

"Better transgender and non-binary inclusion. Possibly specialist services (endocrinology, etc) located in Lincolnshire rather than having to travel to London"

"Listen respect listen again talk a plan through together what my needs are not how I fit into a box of thousands of other people with the same condition".

"Tell the patients more. I have had more than one referral that I thought was for one thing, only to get to the hospital and I've actually been referred for something else and not been told.

"A holistic approach to health and wellbeing, improvements made in communicating with patient and their carer/relative. Improve sharing of medical information across the health and care professional and with social care (where required). Listen to the patient and their carer/relative when issues arise before they end up being a bigger problem which results in admissions for the patient. Coordinating the care by having a lead clinician".

e) Services talking to each other

It is clear from the responses received those patients expect services to liaise on their behalf, not only to ensure the **patient does not have to keep repeating themselves** with each service they visit, but more importantly so that services **understand the patient holistic needs**. With much more integrated working between services from July 2022 onwards, there most likely will be additional increased expectations to support improved experiences and outcomes.

"Better communication between the health professionals. Seeing the person and not the condition and not working in silos! Looking at the bigger picture and the impact that everything has on the health of the person. The last few years, our biggest problem has been getting the GP and the health professionals to listen to us. It has been an ongoing battle to fight for things. Urology, for example has been ongoing over a number of years resulting in a poor health outcomes for my parent. Lack communication and liaising with each other and lack of communication with the person. Being continuously let down by the Primary Care Team."

"More planning and person focused services. Less bland aspirations and more outcomes. Stop treating the public as fools. More honesty and compassion."

f) Cross Border services working closer

Significant number of Lincolnshire patients are referred to out of county hospital and specialist services so, the importance of knowing they are **treated in one county but can come 'home' to recuperate and receive localised support services** is essential.

"The whole system is disjointed, you never know who is responsible for what. It is very easy to be forgotten once out of hospital. There is no regular checking up of a patient".

"I feel badly let down as a Lincs resident, being sent to A & E in Cambridgeshire but Lincs will not approve any treatment that has been approved by three separate Cambridgeshire Consultants. I'm beyond furious as I've been in considerable pain since April 2020".

"Being in South Holland they have contracts with Cambridgeshire and Norfolk services to allow us to move between the services quite nicely".

.

"It might work great for others in the north of the area but I seem to have medical records at [four different hospitals] which I thought would have been coordinated by my GP in Lincolnshire".

g) Equality of access

Equality of access continues to be an issue for some people either due to communication issues, personal circumstances such as poor mobility, rurality, lifestyle or because services are just not as readily available

"There are lots of people who will not access this survey because they are homeless. Neither health and social care or mental health services are working for them. There is little in the way of assertive outreach (except in Lincoln city) and the system does not work for them. Giving them an appointment several weeks later is no good for someone who is in survival mode day to day. They then get DNA' d and taken off the list after a single appointment. There has to be more than this and a better approach to working with people. They aren't 'hard to reach', the system is too hard"

"Be able to see a GP face to face in a reasonably time. Be able to see my results even if bloods are through the hospital, people living in different areas can".

"I think the CQC are doing more to 'kick things into gear' than any comments that patients seem to come up with. Eg I have an electric wheelchair. If my husband wasn't with me, I couldn't get up (so called) drop kerbs at hospitals and GP surgeries or even open doors. Surgeries and hospitals are severely lacking for wheelchair users and patients with mobility problems".

"Too many appts with different people, who don't appear to talk to each other. I have mobility issues and travelling for appts is difficult. I've recent been to [hospital] for an appt, where I had to wait over an hour, just to find the consultant didn't have the results he needed to talk to me! Even different GPs at [my surgery] don't give the same advice/care. They ring me, even though they know I can't hear them properly and I don't understand what they are saying. They're supposed to ring my daughter. I find it all very confusing/ frustrating and sometimes upsetting".

Q6] Do you think health and care services work well together enabling you to (Respondents were invited to select from strongly disagree through to strongly agree)

- only **19%** of people indicated they felt access to services is there when they need them.
- **14%** of respondents felt able to move between services easily
- **28%** of respondents understand what is happening with their health and care
- **46%** of respondents felt they are treated with respect and dignity
- **31%** of respondents felt able to manage and deal with their health in a way that makes sense to them

Q7] Tell us what currently works well about how health and care services work together in Lincolnshire (Free text responses)

Whilst sadly 'nothing' was a common theme, with many people feeling unable to share with us what they felt was working well, it is important to highlight that people did praise the support they have received from individual staff, specific departments and third sector organisations such as Age UK.

“I genuinely can’t think of anything”

“I find Age UK in Park Street Lincoln, are excellent in keeping me informed of the support and care that is available. They have all the leaflets on the different benefits and help that is there. Marvellous! Thank you, Age UK.”

“Stop smoking team, very good. My GP and team are very good.”

“Referrals from GP to specialist care is very good, you don't need to see a GP for this, but you do need to know you are going to get to the right help when you need it most”

“When it works well such as the Care for the Elderly Team, it makes a huge difference to the overall health and wellbeing of the person. It also means less visits to the GP and reduces admissions into hospital.”
“Warfarin clinic is first class”.

“My cardiologist, GP and cardiac rehab team have worked well together, all other services i.e., diagnostics have not”

8] How do you think health and social care services could work better together to support you or others in Lincolnshire? (Free text responses)

A main theme from responses suggests better communication between departments and services, more collaborative working and a shared patient/service user record system (Care Portal in Lincolnshire)

“More communication between departments and with patient”

“Quicker communication between departments”

“They need to work together … too many agencies not sharing … not sure why I have to fill forms out Like this when the problem is not at my end”

“Shared language Less signposting and referral”

“II do not find services communicate well between them I have to say things more than once. I feel that staff are on a knife edge and this often comes over as frustrated with patients, I often don’t know what I need best to help me deal with my health, this is why I look to services and their people to give me the right advice”

"Talk to each other. Services quote obviously do not communicate. Getting prescriptions delivered is now a nightmare. I've been discharged from hospital without meds and I've had meds changed by consultants and my surgery doesn't get to know. If I didn't have my daughter to sort these things out for me, I'd probably be dead by now!"

"One key issue is the availability of clear, documented information about a patient's care, test results, medication and interactions with medical/clinical/social care professionals. This should be across care settings, disciplines and districts. At present, it is left to a patient or their carer to remember what has happened to them. Either, patients need to be in charge of their own health and social care records, or these need to be on a shared platform."

"One system, one record, a willingness to collaborate effectively with multiple services in a timely way."

"One shared information system, honesty with the public about what is happening, listening more to what patients and service users are saying and learning from this"

"Better case management, integrated approach, with jointly reviewed & resourced care plans. I had to ask my go to consider me for specialist services. Great online 6 week explanatory/ basic ME management info. Nothing for 2 + years …"

"Main hub with online information about the service users needs and issues. Everyone could add to it and comment about what works, patient can also add to it any issues they are having. Obviously, it would need constant monitoring but the more information gathered would enable more appropriate services could be offered. At the moment no one seems to talk to anyone else."

Q9) How well are you supported by health and care social care staff in your area, if you need them? (Respondents were invited to select from strongly disagree through to strongly agree)

- **25% (1 in 4) people felt supported by people who listen carefully, so they know what matters to them**
- **25% (1 in 4) people felt supported to make decisions**
- **27% said they have considerate support delivered by skilled and knowledgeable people**

The above results are disappointing and suggest this is an area that is important for our health and care providers and commissioners to focus on. People want to know they are listened to, that their personal choices and needs are understood, that they are part of any decision making about the healthcare they receive.

Q10) Can you give one or two examples of how well health and social care staff support you?

"I have been very impressed during the covid pandemic at how helpful the vaccination staff have been + how convenient the COVID sites are."

"Support me with medication, make sure I am safe, door locked etc."

"GP talking to me as an adult and giving me choice and control over the decisions around my health."

"I have excellent help from my local GP and practice nurse."

"With depression and my mental health they gave me the best resources online and ways to deal with everyday life. I was also able to talk to a nurse practitioner."

"Diabetic nurse is great have such good advice and is always there when I need her."

"The nurse at my local surgery, once I'd finally been prescribed the correct medication, gave me a follow up phone call to make sure the dose was working and that I was ok on the medication."

"Before undergoing a colonoscopy I had everything explained and I felt put at ease by the Staff."

"My GP is knowledgeable about my needs and my cardiologist and cardiac team coordinate very well to ensure they are working together."

The above positive responses demonstrate that despite the many negative comments we received, there is still a lot of people who feel they have been able to successfully access support from their healthcare services.

Q11) What could health and social care staff do to better support you and others in Lincolnshire?

From the free text responses, we received clearly previously mentioned themes including the importance of people being treated holistically, better two-way communication, and better information are all important.

“Disability awareness. Allow more time for appointments for autism. My son has to overcome anxiety by asking/checking so needs extra time.”

“A holistic approach to health and well being, improvements made in communicating with patient and their carer / relative. Improve sharing of medical information across the health and care professional and with social care (where required). Listen to the patient and their carer/relative when issues arise before they end up being a bigger problem which results in admissions for the patient. Coordinating the care by having a Lead clinician.”

“Actually talking to someone would help”

“See patients Listen Assess not judge And see pepole as a condition instead of a person”.

“Linked up knowledge and understanding of a patients condition and it effect on lifestyle and mental health. I understand that in today's economy, time and funding is a major factor in the social care and medical services, however, treating the patient with a bit of dignity and time to talk about, their medical concerns and how they are coping would go a long way to help with their condition.”

“People don’t listen to me. People speak too quickly and get irritated when I don’t understand them. This upsets me”.

“share information better Be clear on what to expect from services Think about their language – use workds I understand”.

"Improve communication. Listen to the persons needs instead of completing check list format. We are people with individual needs, not robots."

"Communicate with the patients and actually hear what we say instead of just listening and ignoring."

"A&E staff need to more empathetic and listen to the needs of patients. Diagnostics and waiting times need to be improved."

"Keep patients updated Don't just leave them stuck on waiting lists no support. Currently having 2 do 2 hour round trips for my daughters medication at Grantham hospital, why can't these prescriptions be sent to pharmacist. More help and support with mental health and actually take time to listen."

"Keep in touch, review my situation, help or guidance with difficulties, information. Take my condition seriously, and appropriately service support it. And provide community advocates the support individuals to access resources to ensure some quality of life."

"People don't listen to me. Sometimes their accents are so strong I can't understand them. People speak too quickly and get irritated when I don't understand them. This upsets me."

Q12) Do you get information and advice about health and social care services in Lincolnshire? (Respondents were invited to select from strongly disagree through to strongly agree)

Once again, the negative results of this question suggest that more needs to be done to address how patients receive timely, relevant information and advice. With the inclusion of social prescribers across Lincolnshire, many third sector organisations providing information and support to their service users and availability of Connect to Support Connect to Support Lincolnshire | Lincolnshire we feel that Lincolnshire should be able to co-ordinate a more positive approach.

- **22% of people felt they can get health and care information and advice that helps them plan their life**

- **22% of people said they can get information and advice that is accurate, up to date and provided in a wat that they can understand**

Q13) What currently works well about how you get information and advice about health and social care services in Lincolnshire? (Free text responses)

Clearly from the responses we received people looked to online as a place to go to for information and advice. Many people told us they value digital access but do feel there is a place for receiving both online and face-to-face support.

"Via NHS app the info is up to date."

"My GP [record] on app and ordering repeat medication on the app."

"Online resources and social media."

"Local noticeboards and leaflets, often via chemists, as GP surgeries less accessible 111 call positive in past."

"Pages online NHS website is up to date with different information about any illnesses or important updates."

"By talking to people / Social media groups, who have experienced the care system and can help me understand and know what questions to ask."

"Digital services are great, we need more of them, they enable me to get advice when I need it."

"Nothing, have to research everything myself online."

Q14) How getting health and social care information and advice in Lincolnshire could be improved? (Free text responses)

Providing up to date and relevant information is always a challenge. It takes a lot of staff time to keep information current and relevant (consistent).

One problem is that for many people they will only access information when they ‘need it’ which is often in a crisis or difficult time in their lives. Also, the way people want to receive information is so personal, for some it is online or through social media, some via traditional media, whilst others want to access information in public places or directly from the people who are delivering their healthcare services.

“In local papers Television Radio.”

“All in one place and easy to understand.”

“There are currently too many points of contact and each professional has their own opinions which results in lack of consistency. Consistent information should be made available to meet the needs of people with different requirements for accessing this - for example, online, via a helpline, in writing. However, the key issue is consistency. We need to get away from the message you receive being dependent on who you speak to today. It should be about systems and processes and not individual opinion.”

“Communication by the combined services to be on the same level and follow up contact to make sure the patient understands and action is taken to enable the care support is put in place where needed.”
“More email services as not everyone wants to talk on phone.”

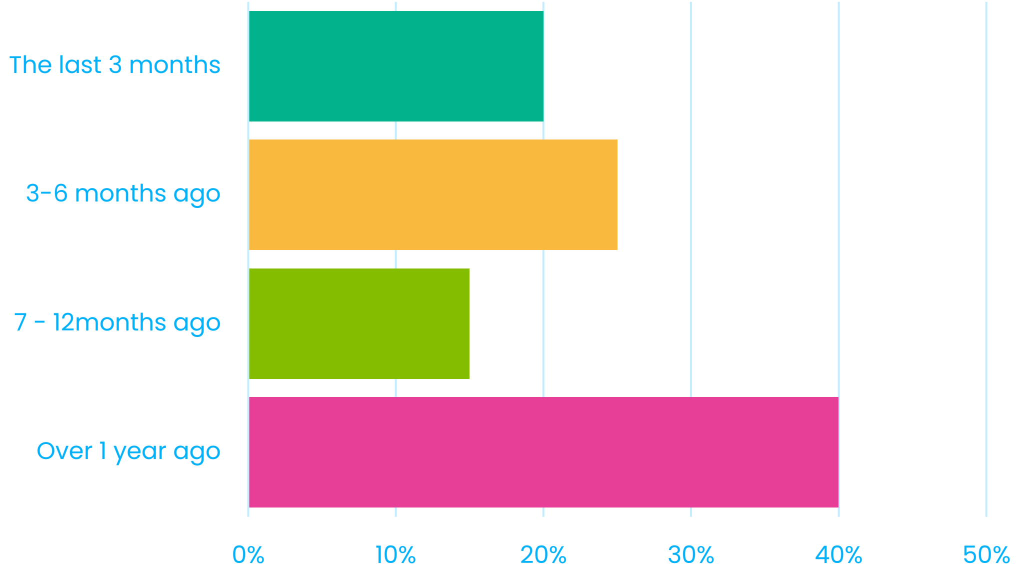
“Phone and email contact awful; NHS ACCESSIBLE INFORMATION STANDARD not only ignored but deliberately undermined by different and incompatible communication practices.”

“Make information available in social outlets. Bring the information out into the community instead of burying it in some remote office. Hold information stands in shopping areas at regular intervals.”

> *"Ask the person how they want their information and in what format. Ensure that this feels person centred and not a tick box exercise. Many older people, my parent included are often made to feel that they are a burden to the NHS (health and care). Too many professionals still make the older person feel that this condition is because they are older and do not do enough to support the person to self manage. Many people need to know that the health and care is there when they really need it and do not need to feel that they are a burden."*

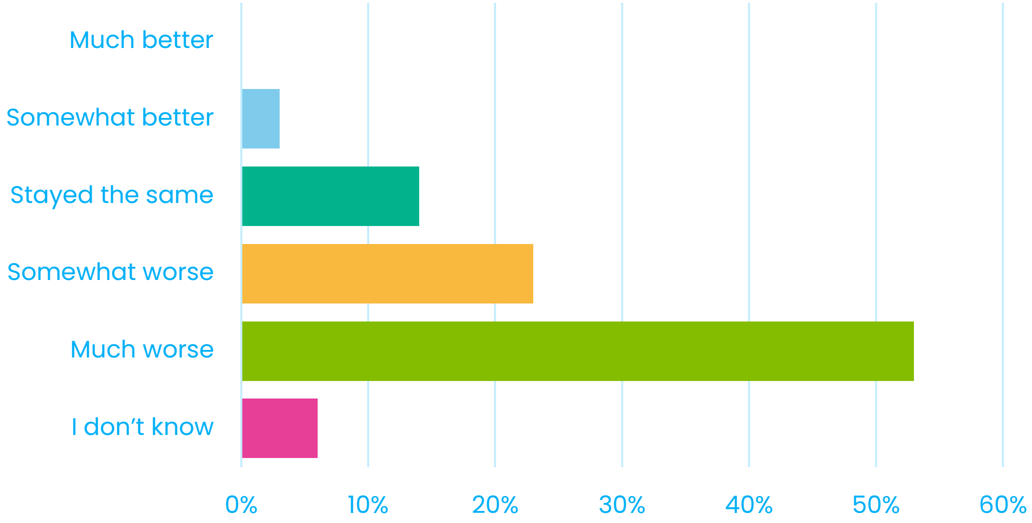
Q15) With the experiences you have shared, what time frame do your answers above relate to:

Interestingly, from the responses, we found there was no difference with the sentiments and themes expressed between those experiences in the last 3 months and those of over 1 year ago.



Q16) How do you feel that the COVID-19 pandemic has affected your experience of health and social care in the past 12 months?

Not surprisingly, respondents overwhelmingly felt the impact of Covid-19 has affected their experience of accessing and receiving health and care services in the past 12 months.



"Each service makes one feel guilty for troubling them when you are aware they are very busy. People tend not to seek help. During the pandemic some areas have worked very professionally but local surgeries could have been more prominent."

"I feel that certain sections of the Health Service have used the pandemic as an excuse to 'work from home' and only offer a part-service i.e. Dentists has not been able to help with toothache but has been doing check-ups! What is that all about?"

"Lack of face-to-face GP appointments and interactions with clinicians has resulted in serious problems being missed. It took eight contacts with various GP/A&E/UTC/Out of Hours services between December and February for it to be picked up that my husband who has many red flags (heart transplant patient who is immunosuppressed and also has myeloma) had a serious infection which had turned into sepsis and endocarditis. Communication breakdowns both through this period and after diagnosis led to unacceptable delays in treatment. Accountability seems to be something alien to people working in these areas. Because of such fragmented systems, individuals will not even be aware of the mistakes that they made."

“Not listened to concerns brushed aside. Forced out of A & E when I should have stayed in due to quote "we need that bed, why is she still here" Also a good nearly 2 years into investigating my heart, when an appointment was finally made the tests to accompany weren't ordered and therefore caused further delay.”

“I had a baby in September 2020. Services were impacted hugely and we missed out on so much. Partners not allowed to attend scans yet made to wait ages in a clinic with strangers to see 2 midwives sat next to each other, with no clear indication for having 2 present. No point to the appointment as I was told I was there for a vaccine I didn't want so signed to say I was declining then left. Rules all over the place but many didn't make sense. Health visiting services making a quick phone call. Children's centre groups not running even when restrictions changed so they would have been allowed.”

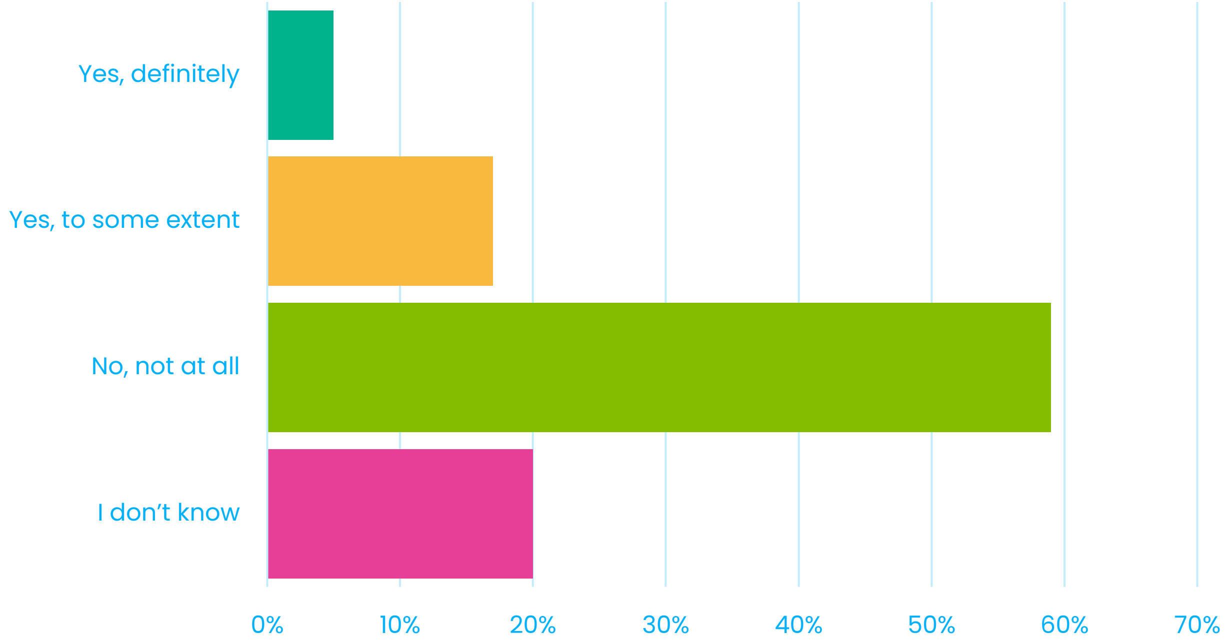
“GP surgeries are not even answering the phones, I am a leukaemia patient in remission and dread when I need to speak to my GP, it is near impossible and extremely stressful when staff are dismissive, obviously they're stressed but this is not the patient's fault.”

“No access to services. Gatekeeping. Appointments cancelled but not rescheduled. Services reluctance to operate normally again.”

“Access to the GP - extremely difficult. Being dismissed and told to go to A+E unnecessarily. Conditions that were minor not being dealt with at Primary Care level that then develop to be more serious and results in more hospital visits / admissions than needed. The person is then unwell and takes longer to recover. Issues not being addressed and resulting in serious consequences.”

Q17) Do you feel as a Lincolnshire resident your experiences of health and social care are actively taken into consideration in helping to share future health and social care services?

It is clear from the response that people do not feel listened to, this is definitely an area that should be addressed by our ICS leaders and one of the questions that should be raised by CQC when inspecting the ICS systems in England "Demonstrate how you listen to, collate, analyse and act on user experiences of health and care services"



“There is no requirement for health services to be publicly accountable and as such public engagement situations do not need to take into account the wishes of the wider local population. Legislatively this needs to change.”

“I fill out a lot of local surveys and see improvement on what I have suggested.”

“All decisions made are not putting customers at the centre. They are made regarding resources available eg Money.”

“Various parts of NHS LINCS engagement pay far too little attention to a] the hard to reach- isolated; poor; not on internet etc b] travel problems for the car-less.”

“I have never seen or experienced anything to suggest my views regarding specific experiences are wanted! I have very specific suggestions on improving services I or my family have accessed, but never being asked for these.”

“Certain groups such as homeless people are excluded completely by systems challenges. Working professionals also have l in tied input. Our GP has a PPI group but it’s imprisonment to be involved unless you’re retired or don’t work full time. Therefore they think they’re doing fine with things but they’re completely missing the experiences of working professionals.”

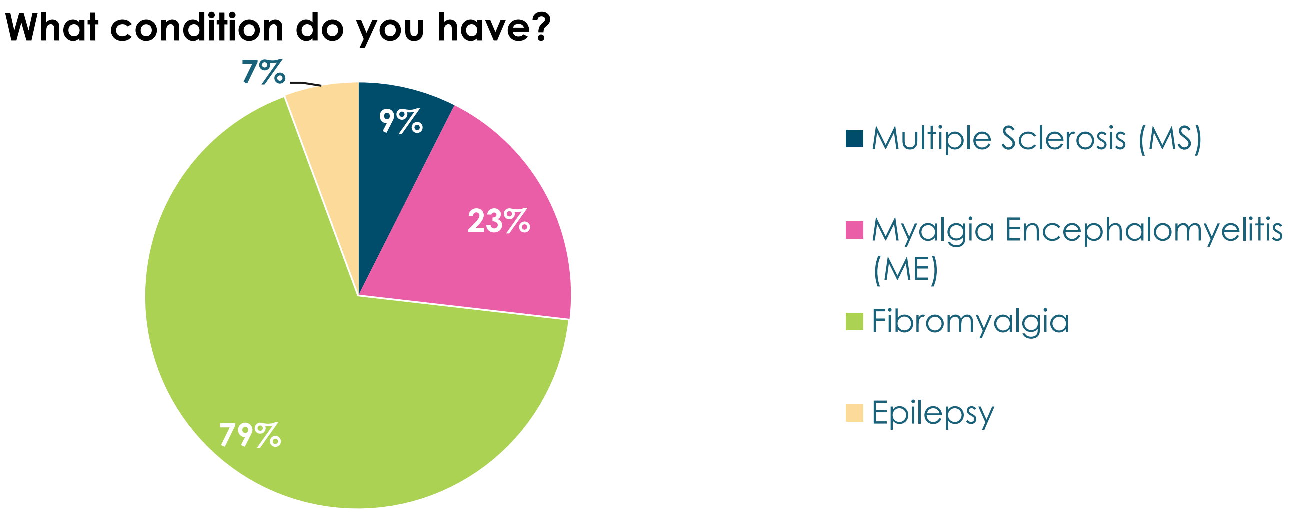
“There is no advertising of local changes that take place within my area. Only a few of the “supporters “ are made aware, those who control budgets and recommend change do not want to hear what the everyday person has to say.”

“This is the first opportunity we have had to comment - when I wrote to NHS England about my experience with GP I was told that the Practice concerned was free to exclude patients 200 yards away as “outside their area” even although they already HAD patients within one mile if their premises as a retired Lincolnshire singlehanded dispensing GP as I’ve already stated I am well aware of the real reason for their refusal - and as already commented we are NOT awkward, difficult or demanding patients.”

Seldom Heard Groups Survey

We heard from 521 individuals (no responses were removed) from the following four groups:

- Fibromyalgia
- Multiple Sclerosis (MS)
- Myalgia Encephalomyelitis (ME)
- Epilepsy



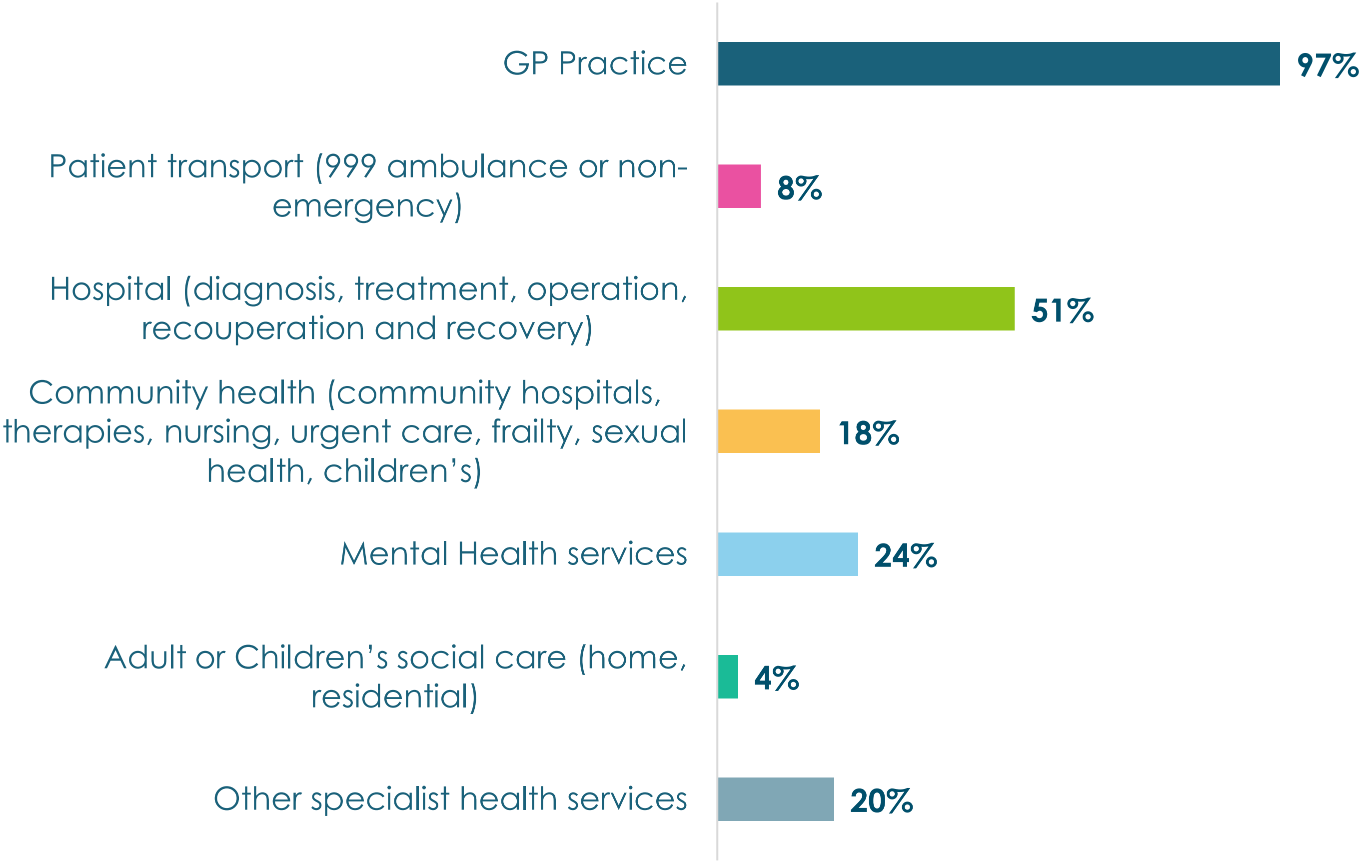
- 95% (488) of individuals shared their own views,
- 5% (27) of people were completing this survey on behalf of someone else in the role of a friend/relative/carer.

From analysis of responses to the survey, it became clear that there were no specific issues relating to the individual conditions. Instead, the issues raised were broader and present regardless of the condition.

All four groups were unanimous in calling for:

- Practitioners to have a better knowledge of their condition,
- Practitioners to be more understanding and supportive
- Services to communicate with each other and share information
- More support
- Better awareness, advertisement and signposting to existing support

Please tell us which services have you needed to access over the past year (tick all that apply)



How well as a Lincolnshire resident are you supported by health and care services?

- Just **12%** of respondents agreed that they were supported by health and social care services in Lincolnshire.
- Only **11%** of respondents felt they had health and care support that enables them to live as they want to.
- **23%** of respondents felt in control of planning their care and support if they need it.

What currently works well about how health and social care services are supporting you?

Some individuals praised GPs for listening, being understanding and providing support. Digital primary care services such as askmyGP were also praised for their convenience and allowing quick access to support. MS teams were highlighted to be effective as individuals appreciated having an accessible single point of contact.

Additionally, community mental health teams were recognised for the support they offer. For people with epilepsy, the support they receive from specialists out of the county, usually in Sheffield, was highlighted to be 'second to none'. These patients appreciated having access to high quality care and a clinician with expert knowledge of their condition.

"I have a direct contact with my MS Nurse. Having one person who knows me and my medical history and is my main point of contact with any questions really helps.

I was given all the options for treatment and then given time to ask all the questions I needed. I have updates on how my treatment is working and the Neuro Team check up with me after every session."

"Neighbourhood Team Mental Health Practitioner is of immense help & support. Our local chemist is very supportive."

"Support of nurse practitioners has been fantastic. Some of the GPs I have seen have been incredibly compassionate and understanding.

The online booking system that my practice has works fantastically for me. It is so much better than having to ring up repeatedly first thing in the morning in the hope that you'll manage to get through and get an appointment."

"Currently I feel that I am getting access to any support I need. I have access to my MS team and other community based clinics I need to access."

"I am supported by services outside of the county because there is a lack of the specialist care I need in Lincolnshire. This means travelling to Sheffield - currently monthly. The care I receive at the Royal Hallamshire is second to none."

However, most individuals responded to this question with ‘nothing’ or ‘what support?’. The most common concern raised was the **lack of understanding about their condition(s),** with individuals feeling dismissed by clinicians who knew little about their condition and were unsympathetic. A **lack of consistency, support and poor communication and coordination between services** left patients frustrated and waiting for support. Others aired their concerns about long waiting lists, with individuals waiting for years to receive support, even prior to the COVID pandemic. Access to services and support was noted to be poor throughout the county but especially for those who lived on the borders of Lincolnshire. Indeed, individuals noted that the support they received in different counties, either prior to moving to the area or due to the lack of specialists’ services in Lincolnshire, was vastly better than that they receive in Lincolnshire.

“Nothing! I've needed help since 2013, and it is a continual battle due to incompetence! No one deals with the same issues, so you have to spend hours every week calling everyone because they can't talk to each other! I still don't have everything I need in place.”

“Nothing - such a lack of consistency, a lack of availability to professionals and also lack of general understanding.”

“Nothing. None of the services talk to the other. Test results are not shared so unnecessarily repeated. Hard to see GP. Having 2 chronic conditions I have to choose, which is currently ruining my life the most at that moment.”

“I get no care in Lincs. Social services refuse to come out to assess needs. Even though I was under Norfolk cc social care team. Moved two years ago and Lincs ss repeatedly say I don't fit their criteria for a needs assessment.”

What could be done for health and social care services to better support you?

The most prevalent sentiment raised in response to this question included the following:

- **Clinicians to listen, acknowledge that these conditions exist and the impact they have on daily life**
- **Better awareness and understanding of these conditions**

In addition to the above, several other recurring themes appeared. These themes included:

- Use a holistic approach
- Communication between services and to patients
- Continuity and consistency (at the service level)
- Proactive support instead of the current reactive support
- Quicker access to support
- Signpost individuals to available support
- More support being available and this being in the county
- Access to an individual who has an in depth understanding of the condition

"A greater understanding of how it affects me and coupled with other things how it impacts my work."

"It took 18 months for me to get an appointment when my epilepsy get worse!"

"Provide access to same services that are offered in other counties, and offer services to local residents locally and not have to travel miles to access facilities or services that are offered at larger hospitals in different counties, also offer more alternative lines of treatments like acupuncture etc."

"Listen, support, compassion."

"To know where and how to get, had diagnosis then just forgotten."

Communication Quotes:

“Services need to communicate with one another. There needs to be access to integrated services for these conditions. Clinicians need more training in these conditions, and services need to be set up to support these conditions rather than create additional difficulties.”

“Each department sharing information between them. GP and hospitals having different systems and one doesn’t connect with another. Which is ridiculous how can you give continuity of care between several services that someone may need.”

“Communication needs to be better and making patients aware of what help is out there. I've been told absolutely nothing regarding what help is available I've had to Google but even then I don't necessarily know what I am supposed to be googling.”

“To have someone overseeing what's needed. I'm passed around like a hot potato that no-one wants to catch. Currently under Reablement Team and had a joint meeting with a covering social worker who appears not to have made notes. I somehow have to advocate for myself when I have severe ME plus multiple other conditions. I have to repeat the same information to multitude of people who first off say they will help […] I always have to do the research to know what to ask for and then it's to no avail.”

How well do health and social care services in Lincolnshire work together?

- 11% of people agreed that they could access health and services when they needed them.
- Only, 8% of people agreed that they could move between services easily e.g. GP, hospital and community nursing.
- 16% of people understood what was happening with their health and care.
- 32% of people felt they are treated with dignity and respect.
- 19% of people manage and deal with the health needs in a way that makes sense to them.

What currently works well about health and social care services work together in Lincolnshire?

A minority of individuals commended their GP for listening, being supportive and referring them to specialist support. Digital primary care services were again praised by some for their quickness and convenience – especially for those who need to travel long distances and for who were struggling to leave the house due to a flare up in their symptoms. Community services were too acknowledged for providing quick local support and pain clinics were useful 'when I can get an appointment'. **However, no individuals shared examples of where services worked well together, positive experiences were of services in isolation.**

Again, despite this question focusing on the positive aspects of how services work together, many responses said, 'They don't' and 'Nothing.' Individuals felt that services did not appear to work together at all and again raised concerns around services not communicating and sharing information with each other.

"Partnerships with GP practices seem to work well."

"My GP is excellent and listens. If she feels I need referring for an issue she will do so."

"Being able to talk to people over the phone is a real help and saves me having to travel etc. Sometimes the physical and mental exertion from attending appointments intensifies my symptoms."

"The Rehab session is good in acknowledging the multi-dimensional nature of the condition and the way it impacts your whole life."

"When I can get an appointment with The Pain Clinic they do try to help, but they are so busy & seem to cover a large area in Lincolnshire."

"They don't seem work together at all."

"Don't appear to know what is actually available and each passes to each other."

"Services do not communicate; I have to repeat myself constantly."

How do you think health and social care services could work better together to support you or others in Lincolnshire?

Services communicating, sharing information and working together was repeatedly raised yet again in response to this question. **Respondents wanted all their medical records in one place which could be accessed by all the relevant services**. Many felt they were being pushed from service to service, with no one taking responsibility/accountability for their care, and at each service they had to **repeat their story**. Respondents called for **services to be 'on the same page', more coordinated and aware** of the support services can offer. Calls for a better understanding of the conditions by practitioners and a holistic approach in treating these conditions was also a common suggestion, as was a better pathway for people with chronic or long-term conditions.

"Have computer systems that work together or more teams using the same systems. Better shared access to information."

"Educate all healthcare providers and psychiatrists etc that these conditions are real and terrible to live with."

"Listen to the patient - they know their body better than anyone. Treat the patient holistically - challenges with the body affect the mind and vice versa. Please try to understand the needs of unpaid carers who devote their lives to the wellbeing of others, often to the detriment of their own health, welfare and emotional state. They need as much support to stay well as possible. Thank you."

"Publicise what help is available and signpost patients to which health care providers/settings might be the better option for certain scenarios ie unable to get a drs appointment during normal gp hours. Make it known how to obtain occupational therapy reports/assessments."

How well are you supported by health and social care staff in your area, if you need them?

- 61% of people did not feel supported by people who listen carefully, so they know what matters to me and how to support me.

This sentiment was repeatedly shared in the free text responses to questions throughout the survey and was highlighted as an area that needs to be improved.

- 15% of people felt supported to make decisions
- Just 14% of people felt they had considerate support delivered by skilled. The lack of the latter was again repeatedly raised as a concern in the free text responses to questions throughout the survey.

Can you give one or two examples of how well health and social care staff support you?

Again, in response to this question the majority, 60% (98 out of 164) replied along the lines of 'nothing, 'no' and 'I don't get any support'. However, for those who were being supported, the support was being provided by GPs. Like the responses to previous questions, these GPs were commended for listening, being understanding and explaining the different treatment and support available. There were other one-off cases where individuals mentioned other services being supportive such as the Long COVID Fatigue service, Lincs Wellbeing Service, Pain Clinics and Consultant, Occupational Therapist. These services were praised for their ease of access, quick responses and support offered.

Positive comments:

"My GP surgery is amazing both Doctors and nurses in their support. They listen and discuss options and will refer me to the right and agreed places for further help. They will always listen. I feel like they really care."

"My new GP has listened and explained his thoughts clearly. I have been given the time and been prescribed correct medication that helps me. Occupational therapy has been very good giving advice and support with my hands in particular. I really miss my appts with them and the support that they gave."

"Lincs well-being excellent."

“Pharmacy assistant assessed self harm, and supported me face-to-face which was much-needed at that time. She prevented worse outcome.”

“Long covid chronic fatigue service - available to contact easily and have said they won't quickly discharge me.”

Negative comments:

“No. I hardly ever see the same health care professionals. No consistency. No interest. No support.”

“They don't support me because I have not been told how to access their help despite needing it.”

“They don’t support me! They believe Fibromyalgia doesn’t exist and it’s all in my head! I get zero sympathy support or help from any services I have to self help.”

“I was very lucky in my early days of fibro and my Sjogren’s syndrome i was offered counselling which at that time was very helpful as gave me someone to talk to without upsetting anyone close to me. This was over 10 years ago now and from what i can gather not many people even get offered this now and if they do the waiting list is crazy. I was also lucky in my early days i got sent to the pain clinic but at that time the pain clinics were more suited for people with isolated pain and not chronic widespread pain there is a big difference the sessions were 4 hours long which was just to long for someone who live with chronic pain i was in so much pain at this time i just didn't know what to do with myself and because of my pain i found it very hard to take on board what was being said as i all i wanted to do was go home and rest. The pain clinics have got a lot better since then but for fibro there still needs to be a better understanding of this condition.”

What could health and social care staff do to better support you and others in Lincolnshire?

The responses to this question echoed those shared in previous questions. With the following be highlighted again:

- For support to be available/ provide a service
- Better understanding and recognition of these conditions and the impact they have on daily life
- For support to be proactive instead of reactive
- Better communication between services
- Listen to patients
- Do not 'pump patients full of medication' or 'fob them off'
- Local support groups
- Highlight what support is available

"Access to treatments and support that will actually help me."

"Communication needs to be better and making patients aware of what help is out there. I've been told absolutely nothing regarding what help is available I've had to Google but even then I don't necessarily know what I am supposed to be googling."

"To have better communication between different hospitals. For eg I am looked after by [local] MS Team locally but am under Hull for bloods and neurology. I cannot see any medical information in my GP notes relating to any Hull based stuff. I can only see what they send to my GP but feel that reporting of scans needs to be vastly improved as I was waiting a year for results of one I had in March 2021. I am very proactive in my care and like to keep track of everything which I am. It able to do. Patient knows best service provides no information either."

"ANYTHING ITS NON EXISTENT"

"Listen to me as a person. It's like my GP doesn't believe me"

"More understanding of the condition and more coverage in Lincolnshire."

"Multi agency approach. Transparency through the system."

"A system where all your medical diagnosis are in one place. I have a few things & having to explain over & over again is exhausting."

Do you get information and advice about health and social care services in Lincolnshire?

- Just 7% of respondents felt they could get health and care information and advice that helps me think about and plan my life.
- 10% of respondents felt they could get information and advice that is accurate, up to date and provided in a way they could understand.

What currently works well about how you get information and advice about health and social care services in Lincolnshire?

Despite, this question again focusing on what works well, most respondents stated 'nothing' or 'do not get any'. **Using the internet was by far the most common way respondents sought information and advice** about health and social care services in the county. For a minority, they were provided with information via GPs (through noticeboards and leaflets – this source has been removed due to COVID), Physiotherapists, a Pharmacy or specialised teams.

"I can contact my dedicated MS nurse either text or call and she is very quick to get back to me."

"GP keeps in touch re blood tests. OT give great advice and great service."

"Because of what i do with running my fibro groups i have found some services that can help people with fibro like the Lincolnshire wellbeing service and social prescribing but i have found those out for myself know one told me about these services. Its is helpful to me to know about these services as i then can recommend them to people in my group as most people don't know these things are around or even know where to start to get any help and support."

"I find out my own information on-line. I have never been offered any."

"My doctor basically said I had to use the internet and find my own resources."

How getting health and social care information and advice in Lincolnshire could be improved?

The following suggestions were made:

- Greater awareness of what to do after someone has been diagnosed
- Better communication
- Signposting to support services and information
- Information should be accessible, up to date and consistent
- Information should be all in one place, such as either a centralised database on a website or at an information hub (physical and virtual)
- A hybrid approach to sharing/publicising information was called for, as some individuals were worried that not everyone can access information online
- Information pack
- Dedicated contact or a case manager, who understands the conditions and the support available
- Flexible clinics i.e., do not discharge people because at the moment they do not need support, as it is challenging and lengthy process to get referred back to a service
- Flexible appointment times and more support to be available out of traditional working hours
- Localised clinics and support groups

People told us they wanted:

“Access to localised drop-in clinics at times suitable for those who are in a caring role and might find it challenging to visit during 'normal' hours. Peer-to-peer contact and support so we have a point of contact, should we need one, during a time of ill-health etc …. or someone we can go to for advice etc.”

“Information packs for patients, links to support services.”

“By having all multidisciplinary teams working from the same hymn sheet and improving their communication between each other.”

“Communication between teams.”

"Centralised database. Keeping resources up to date."

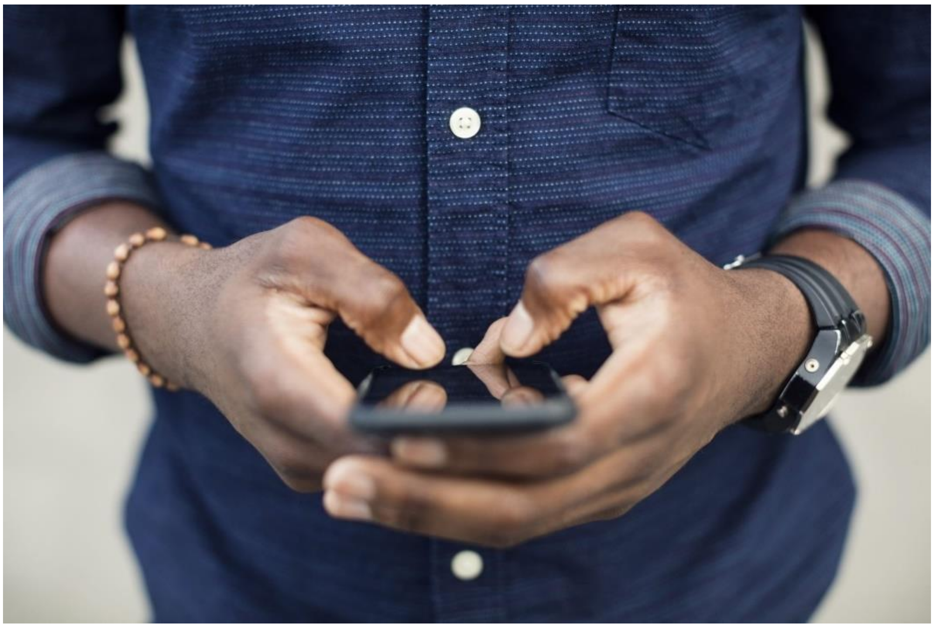
"Flexible clinic for things especially mental health so you not always having to be refereed and they don't keep discharging you."

"There is not much and so it requires lots of searching and reading. It would be helpful to have like a SharePoint/portal or website with it all in one place. This also needs to be advertised so that we know it's there."

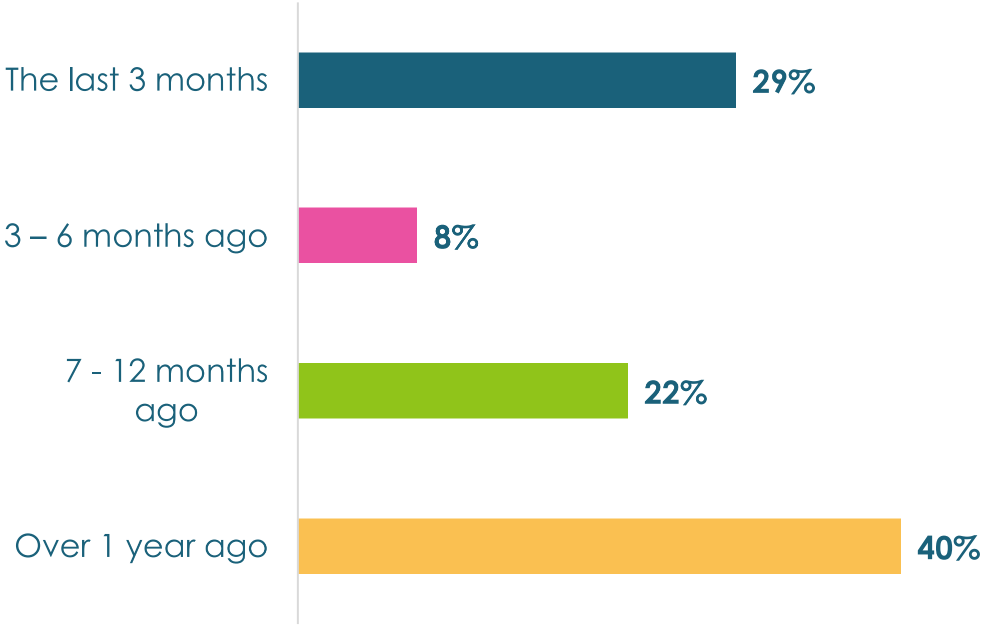
"More links of what is available to local charities who support us. Consideration for those that can't rely on technology to communicate. Consider those in rural locations."

"By actually having information and advice available and accessible."

"Perhaps by realising that there are towns in the south of the county who seem to be missing out. We all use our nearest hospitals, but if treatment I'd required (such as the preferred injection treatments advised by 3 separate consultants in Cambridgeshire) was blocked by Lincs CCG, doesn't it seem obvious to work together instead of arguing over payments. It seems like a constant battle where all the meetings and questionnaires mean nothing if the patient is left suffering. If there are even a few more like myself who answer these questions negatively, surely something needs improvement. Or is it just a pat on the back for the person that came up with this survey and nobody really wants to know the truth."

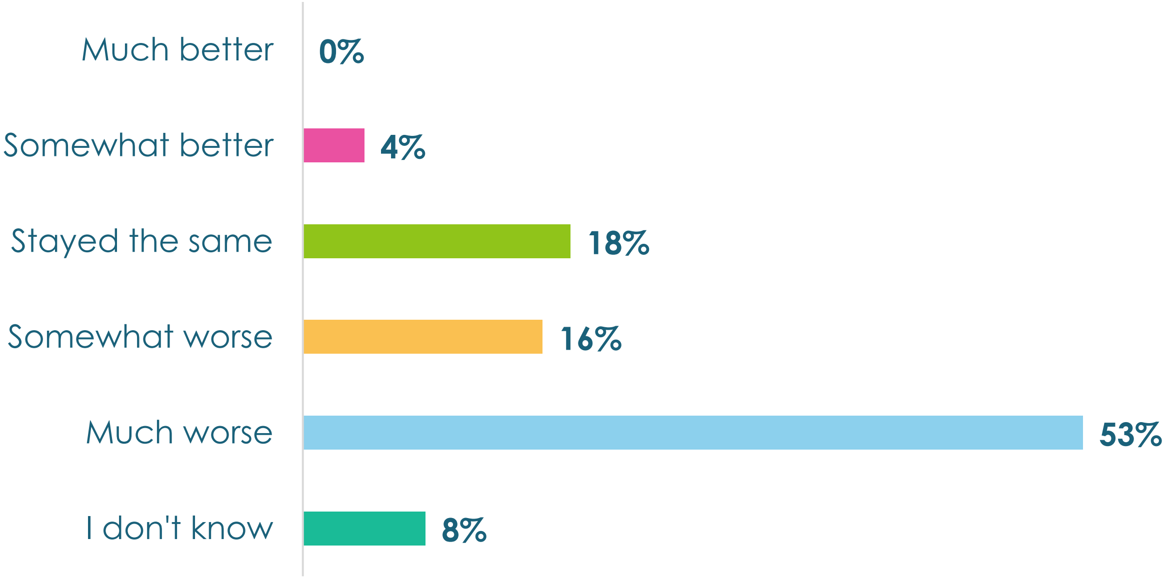


With the experiences you have shared, what time frame do your answers above relate to:



Interestingly, there was no difference between the responses from individuals whose experience was in the last 3 months and over 1 year ago. Indeed, many commented that services were already non-existent and poor prior to the COVID pandemic.

How do you feel that the COVID-19 pandemic has affected your experience of health and social care in the past 12 months?



Not surprisingly, 69% of people felt their experience of health and care services had worsened during the past 12 months. In the free text responses this was attributed to a decline in appointments, especially face to face appointments, longer waiting times for referrals and treatment and the increase in digital services. Many also noted that it was now harder to get appointments especially GP appointments. However, others praised digital services for being more convenient and saving time. In contrast, others felt that services and support were already poor prior to the pandemic.

"Phone appointments are much better than having to travel for a face-to-face meeting that is not always needed. Due to some appointments being done over the phone and less people being in one building at once, when I do have to attend there is parking, waiting room space, less of a wait.

"Everything is cleaner and when there are touch screens to sign in, that hundreds of people touch, there is cleaning wipes or hand gel available to use".

"The is a long wait on new referrals of appointments due to the large backlog but this is expected and understandable."

"Housebound and so things that were impossible previously miraculously became available."

"I do not consider my health care was affected in any way by covid. I still had access to my GP and specialists albeit some of the appointments were carried out remotely. I still received the care and treatment I required."

"Not fibro related but diagnosed with breast cancer in 1st lockdown. Care was excellent during covid but has been appalling since lockdown/ shielding has finished."

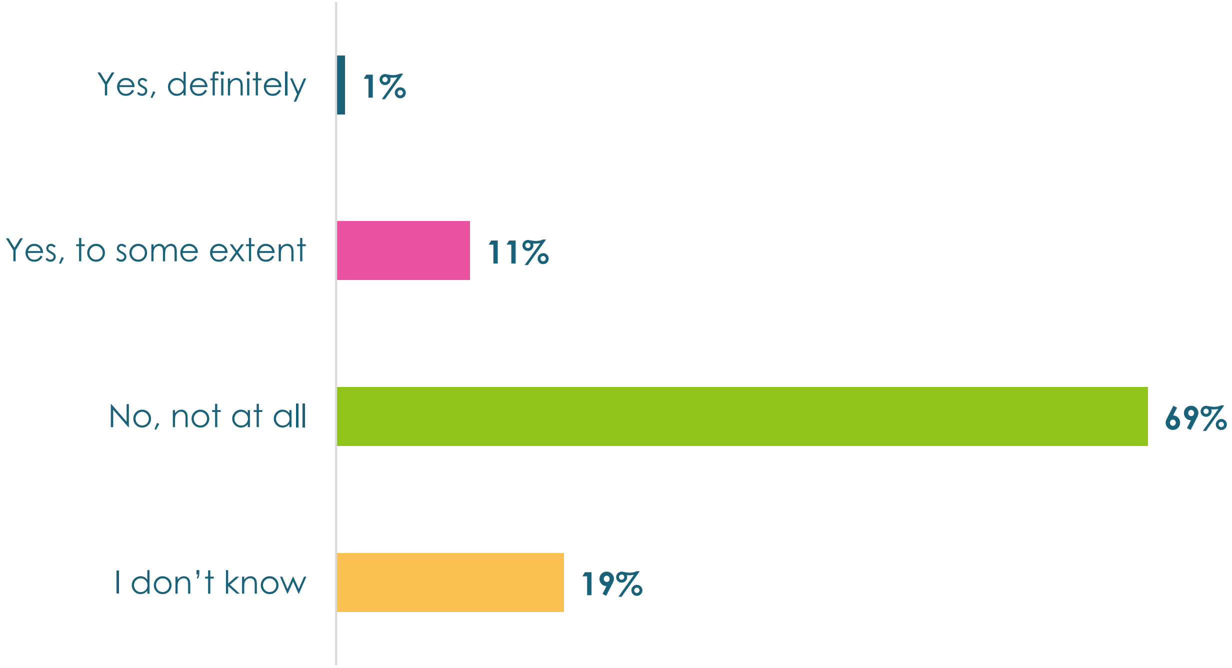
"It just meant it was harder than usual to actually speak to someone and was dismissed much easier than normal."

"Harder to get an appointment."

"Covid hadn't affected it, as it has always been awful!"

"I have never been supported pre COVID or now.

Do you feel as a Lincolnshire resident your experiences of health and social care are actively taken into consideration in helping to share future health and social care services?



When examining the free-text responses to this question, many stated they had never been asked for their opinion on services before and this survey was the first time. Others were despondent and felt that when or if they shared their experiences they were ignored.

"I feel that as I have lived in rural Lincolnshire I have been ignored and forgotten."

"Do not listen and act on what people need."

"Houses being built all over, and population increase is vast but no increase in funding or services to cope with this."

"Even though there have been consultations regarding hospitals etc locally - I have no faith that the public will be listened to - decisions appear to be made regardless of public opinion."

Closing remarks

In closing this report, we would firstly like to thank the people of Lincolnshire for their time and commitment completing the survey, meeting and talking with us. Most importantly we would like to thank them for their openness and at times no doubt personal and difficult stories.

Thanks also go to our health and care leaders and to the Care Quality Commission Engagement Public Engagement and Insight Team for contracting with us to complete this work.

From the information shared with us, more work needs to be done to ensure people's experiences are really at the heart of service redesign and decision making. This is an area that we know CQC will want to focus on when regulating how well our Integrated Care Systems are meeting the needs of local communities, and most importantly ensuring positive health and care outcomes are achieved for patients, service users and their carers.

We believe it would be a useful recommendation to repeat this work in 12 to 18 months' time, when our health and care systems have had time to recover post Covid-19.

Appendix one

The following is a list of engagement group activities we completed between April and May 2022

Date	Time	Format	Name of Group	Additional Information
5 April 2022	10 am to 12 noon	Face to Face	Lincolnshire Sensory Group Boston	Informal Presentation about Healthwatch including Promotion of Project and survey
5 April 2022	1pm to 3 pm	Face to Face	Fibromyalgia Support Group, Stamford	Survey link given (sent once available) Shared experiences recorded
11 April 2022	1 pm to 3 pm	Face to Face	Fibromyalgia Support Group, Spalding	Survey link shared Shared experiences recorded
12 April 2022	9 am to 12 noon	Virtual	Service Quality Review Meeting (LCC)	Survey link shared
13 April 2022	2 pm to 4 pm	Face to Face	LCVS Community Information Points Launch	Networking Event and Contact made with ALFORD HUB who requested hard copies of surveys to give out to service users
19 April 2022	10 am to 12 noon	virtual	ULHT Panel	Promotion of the Survey and Project
20 April 2022	10 am to 12 noon	Face to Face	Community Group, Pinchbeck	Promotion of the Survey and Project

26 April 2022	6pm to 9pm	Face to Face	Louth Town Council AGM	Presentation of project and survey
27 April 2022	111 am to 12 noon	Face to Face Interview	1:1 Interview (fibromyalgia respondent)	Case Study
27 April 2022	2 pm to 4 pm	Face to Face	Stamford Methodist Community Group	Promotion of project and Survey
28 April	10am to 2pm	Face to Face	Sutterton Church Flower Festival	Talking to visitors and promoting the survey
3 May 2022	10 am to 12 noon	Face to Face	Bishop Grosseteste University, Lincoln 3rd Year Health and Care Students	Informal Presentation about Healthwatch, overview of Projects and promotion of ICS and survey
3 May 2022	9.30am to 1pm	Face to Face	Crowland Community Pharmacy	Talking to customers and promoting the survey
4 May 2022	During practice opening hours	Face to Face	Beechfield Medical Practice	Talking to patients and promoting the survey
5 May 2022	1 pm to 2 pm	Telephone Interview	1:1 Interview (parent carer of child with epilepsy)	Case Study
6 May 2022	During practice opening hours	Face to Face	Beechfield Medical Practice	Talking to patients and promoting the survey
9 May 2022	2 pm to 4 pm	virtual	Lincolnshire Veteran Network	Promotion of project and Survey
11 May 2022	3.30 pm to 4.30 pm	Telephone Interview	1:1 interview (ME and Chronic Fatigue Syndrome)	Case Study
12 May 2022	10 am to 12 noon	Face to Face	Social Eyes Social Group run by Lincs Blind Society	Informal Presentation about Healthwatch including Promotion of Project and survey

13 May 2022	10 am to 12 noon	Face to Face	Social Eyes Social Group run by Lincs Blind Society	Informal Presentation about Healthwatch including Promotion of Project and survey
13 May 2022	1.30 pm to 3 pm	Face to Face	AGM for the Spalding Good Neighbour Scheme	An Agenda Item: Informal Presentation about Healthwatch including Promotion of Project and survey
16 May 2022	12 noon to 2 pm	Face to Face	Fibromyalgia Support Group, Bourne	Informal Presentation about Healthwatch including Promotion of Project and survey
18 May 2022	4 pm to 6 pm	Face to Face	Focus Group, Spalding	Key Questions relating to ICS: discussion

Appendix two

Appendix two provides feedback from group activities including focus group

CQC ICS project: Integrated Care Systems FOCUS GROUP
Date: Wed 18 May 2022
Venue: Johnson Community Hospital, Room ADM 124, Spalding
Signed Up: 6
Attendees: 3 (all were living with Fibromyalgia)

Feedback from the Group:

When CQC is gathering evidence about health and care services, what should it be looking at? What key questions should they be asking? (For example, did you have to tell your story more than once?)

- Patients do have to repeat their story with each new health and care professional especially as there is little understanding of conditions such as Fibromyalgia amongst health and care professionals.
- Less use of figs and stats. Patients are more interested in the health outcomes of the community rather than the number crunching.

What would good joint up health and care look like for you?

- A holistic approach to supporting a patient living with a life changing condition such as Fibromyalgia. To be seen as a whole person and not just the condition or symptoms in isolation.
- Improved knowledge from the professionals.
- Improvements in an understanding of the condition.
- Improvements in Staff attitudes – lack of empathy or support due to lack of knowledge or understanding of the condition.
- Specialised Clinics and Nurses or other professionals who understand the condition. There are Specialised Diabetic / Parkinson’s/ Wound Care Nurses.
- Seeing you as an individual and not just a “condition”.
- Regular wellbeing checks and medication reviews.

- Improved communication and use of language. Examples given included: the term “exercise” for people living with chronic fatigue, this can be very challenging. Substitute words offered were “activity” or movement”. Better sharing of information between services so that the patient does not feel left alone to “get on with it”.
- Ask the person “what is important to you?” “What are your own goals?” Examples given were around weight gain due to combination of weight gain and medication. Too many professionals expect patients to do “more exercise” without having a discussion with them about what they are already doing. K the question “How active are you?”
- Once a patient has been given a life changing diagnosis an opportunity to talk through with an appropriate professional about the condition or how this will affect their mental wellbeing.
- Having a Single Point of access SPA to get information, advice or signposting to appropriate support when ready to do so.
- Improved signposting from Primary Care professionals such as counselling following diagnosis or referral to the Pain Management Service.
- Regular medication reviews.
- Better communication between services. Patients expressed that they do not feel that the professionals are connected and work in silos.
- Mental wellbeing to be part of the physical wellbeing from day one. Not to be seen in isolation.
- Basic information such as Fact Sheets / FAQ sheets / local support groups to be offered as a starting point including how to access some psychological support when appropriate.
- Recognition of the condition that it does exist!

How should Lincolnshire Health and Care Systems involve patients / carers / service users?

- Through a variety of formats. Not an exclusive list but these were offered: online forums, information and signposting opportunities, feedback though all media channels including in person, via social media and through regular updates such as newsletters /

bulletins, hosting events. “you said…. we did” 360-degree feedback. Ensuring that what has been said is really being listened to.

As patients, service users how do you want patient experience and feedback to be part of the CQC Inspection of the whole Lincolnshire System?

- Some of the feedback formats in place such as Friends and Family are very “system orientated”.
- There should be a variety of options for people to choose from including both digital and non-digital formats (online / websites / forums both in person and virtual, feedback forms, by mobile or phone and text messaging, social media)
- Through an independent organisation such as Healthwatch as many patients feel that if their feedback is not what the provider wants to hear that it will affect their treatment in the future (e.g., staff attitudes to them).
- Patients want to know that they have really been listened to and that it isn’t just a tick box exercise. What difference will it really make?
- Consult with patients when designing or redesigning services from the start not as an afterthought. Patients need to be at the heart of the process.
- Managing patient and service users’ expectations.

How well do health and care providers currently work in your area?

- All participants felt that the services do not currently work well, are very disjointed especially where communication and access is concerned. They expressed that they ‘get on with it themselves’ due to lack of understanding and support from professionals.
- All expressed that they had to do their own research as they were given no help. When newly diagnosed, where do you go for help and support?

What would you like to see in a CQC report about the services in your area?

- Less figs and stats and more information about people and health outputs, quality of life and the impact this has on the individual and then the whole community.
- More thought put into how people process information. i.e., language used and some information on how these impacts on the demographics and socio- economic aspects of the community. Taking into account the external factors that affect people's health and wellbeing.

When the CQC is gathering evidence about health and care services, what should it be looking at?

- Socio-economic aspects of the community and putting health and care into the "whole picture". (e.g., individual Medical Centres in context with Primary Care across the whole of the county).
- Individual services at local level in context to the whole community.
- How joined up with other services is the one they are inspecting.
- Listening to the patient and service user from the start and not as an afterthought.
- What will be done with the information about the service and how will this be communicated to the community?

CQC ICS project: April / May 2022 Feedback from Fibromyalgia Groups
Stamford Group: 10 members

- **GP Surgery** – patient expressed their lack of trust in the surgery. Medications are on a monthly prescription for a number of conditions associated with their fibromyalgia (including asthma, arthritis, osteoarthritis, COPD and migraine). When patient tried to order their meds in March which were due was not able to do so online as the meds needed to be reviewed and was instructed to make an appointment for this to be carried out. Took nearly 3 days to get an appointment for the meds to be reviewed which resulted in another week delay for the prescription to be sent to the pharmacist in Stamford. Patient was on the last day of their meds even though they had tried to order them in advance and then only some of the meds were made available to them. This resulted in a number of phone calls to the Surgery and Pharmacy to sort it out.

- GP surgery –patient called the surgery about issues with their breathing due to a change in medication. Surgery receptionist informed the patient that their "breathing issues" were due to a panic attack even though the receptionist is not medically trained. Patient did eventually get a call back appointment and it was established that the breathing issues were a side effect of the medication and not due to a panic attack.
- **Medication Reviews:** all reviews were scheduled to take place last year at the same time which caused a number of issues for patients who could not order repeat prescriptions and were not able to get an appointment with a clinician. In the end, many had they medication "reviewed" over the phone, but patients felt that it was not very satisfactory.
- Patients expressed that they had decided to "get with the times" and try the online system rather than trying to get through on the phone. Lots of frustration with the system with over 90 minutes completing the online forms, submitting photos, uploading medical history and listing medications. Finally, when they got through found that the system would only then allow them to ask about one condition/symptom. Patients were frustrated by the system as they had to go through the whole process again when asking about another condition or symptom. Patients had very mixed feeling about the new system that was being used at the surgery.

Spalding Group: 8 members

- **GP Surgery, Spalding** Patient living with fibromyalgia was given their diagnosis within the last 2 years having lived in chronic pain for several years with a number of conditions. Very little understanding of the condition and very little support given by the surgery. Once diagnosis was given no follow up and no information was passed across to the patient. Patient was advised to "go onto the internet" and do their own research. Patient felt dismissed by the GP and the medical team at the surgery. Found the Fibromyalgia Support

Network themselves and spoke directly with the Lead Volunteer. Once restrictions had lifted because of COVID, was able to attend a face-to-face support group and gained so much more understanding form the members who are willing to support each other. Patient understands that everyone is different but just feels that the understanding of the condition is not clear to the doctors and staff at the surgery.

- **GP Surgery, Spalding** Patient has fibromyalgia and was diagnosed about 5 years ago. It has been a real struggle to access help and support from the medical professionals. There is no coordination of help and care. Each contributing condition for fibromyalgia is dealt with in isolation. **This patient has a number of symptoms (neurological, mental health, osteoarthritis, rheumatoid arthritis, IBS, urology, diabetes). Each specialism looks at their own area and does not approach the patient in a holistic way.**
- Patients getting frustrated with having to go through their medical history again and again. There is no holistic approach and not being seen as an individual. Many patients feel that they are left to get on with it. There is no consistency to care from the professionals and lack of understanding of the condition.
- Patients are not being referred to the Pain Management Service. Contact details for self-referral were given to the group to follow up themselves.

Bourne Group: 8 members

- Patients expressed frustrations with the lack of understanding from health and care professionals about the fibromyalgia diagnosis. Lack of support and information. Being dismissed by the professionals and lack of communication between professionals. Most patients expressed that they felt that they were “left to get on with it”.
- Primary Care: no information or signposting offered to people that have been newly diagnosed. Many felt that there is a reluctance on the side of the primary care professionals to refer to a Rheumatologist or to confirm a diagnosis. No psychological support is offered to people to help them come to terms with a life changing

condition. Quite a few mentioned that when a cancer patient is given this diagnosis the system automatically offers them access to counselling or a Specialist Service such as Macmillan Nurse Team. Why is there no Fibromyalgia Specialist Nurse Team commissioned for the residents of Lincolnshire?

- **Mental Health support:** not all patients need this service, but it is extremely difficult to access when you need it.
- **Signposting** was given to a number of people around Advocacy Services, update on Dental Services and how to make complaints through PALS, NHS England and CCG depending on nature of issues raised.
- Patients raised concerns around the fact that many Primary Care professionals look at individual symptoms rather than considering the whole picture. E.g., patients being treated for IBS / migraine/ chronic pain/ diabetes / arthritis, rheumatoid arthritis (to name but a few) in isolation rather than as part of their overlying diagnosis of fibromyalgia.
- **Care Home concern:** one member had serious concerns about the way that they felt their relative was not being looked after in a care home. The relative is living with Downs Syndrome and the Social Worker assigned to them is being very “controlling” and insisting that the relative has “capacity” to make important decisions. However, the relative has concerns that the person has limited capacity (such as yes, I want to go out / stay in/ watch TV, I am hungry etc) but does not fully understand their financial situation. Relative had concerns around how they felt that the Care Staff were mis using / guiding their relative and their Mobility Allowance to run other residents around. They also expressed concerns about the other resident that the person is sharing a home with. They also felt that their relative looks unkept. When this has been questioned, the relative has been told “they have capacity”. Relative disagrees and wants to find out who assessed them for capacity and why as their named next of kin they are not being kept informed of decisions being made on behalf of the relative. Advocacy Services Information was given to the person to follow up to get advice and support.

Appendix three

The following pages provide a summary of the conversation from each of the four one to one interviews:

CQC ICS Project: **Case Studies**
Case Study One: **Parent Carer, South Holland area, Lincolnshire**
Diagnosis: **Epilepsy**

Tell us Your Story

"As a parent carer of a young child, you have to be strong both for the sake of your child and yourself. Your maternal instincts kick in and you know when something is not right. You then start what seems like the biggest challenge… getting answers about what is going on with your child. My child was diagnosed with epilepsy (December 2021) when they were about 9 months old following a period of not being well and what was recognised by myself as a seizure.

As a family we have had experience of the Primary Care Service (not very successful), Peterborough Hospital including the A+E Department, Specialist Paediatric Consultant and Team at Stamford Hospital and the Specialist Epilepsy Nurse (through Peterborough Hospital). There was no consistency of care from Primary Care to Hospital Care. It was important to have the input from the Specialist Epilepsy Nurse who we know that we can contact at any time for support and advice. My child's epilepsy is now under control through medication which has made a huge difference to the number of seizures that he may experience. We were also offered First Aid Training as parents, but this was also expanded to the extended network to support my child to include: grandparents, aunts and uncles and childminder. As a family we have not taken this offer up yet as everything is going well at the moment. We have been discussing that we should maybe look into this while all is well so that we know what to do if it is needed in the future when something happens.

"We are at the very start of this journey with our child and things are working well with the Specialist Team at Peterborough Hospital at the moment. We know that there is someone that we can contact who will

support us, answer our queries and address our concerns. However, going forward as our child growing, we do not know what challenges we may face with their condition. What we would like to see is that we have contact with the Specialist Team ongoing, their medication is being monitored and being tracked, good support in place for the extended family as well as the parents and regular reviews of the child's wellbeing and medication. e.g., dosage against weight / age etc.
"One of the biggest issues for us has been the communication between services. There needs to be access for all concerned in my child's care to have open access to their medical history. As a parent I need to feel confident that everyone involved knows about my child's medical condition, treatment and care plan. We have a follow up in August 2022 but unless I get in touch then we have no communication from the professionals.

"Access to services can be difficult at times. Waiting times to be seen by the professionals is critical! My child had what we now know was a seizure in November 2021 but was discharged from hospital and we were left not knowing what was going on. As their parent I had to fight to get answers from the clinicians including suggesting that further diagnostics be undertaken in order to find out what was going on. Following this, a diagnosis was made, and we knew what was behind it all. It was very frustrating.

"Parents need to be given more information about the condition and how they can support the child working with the Professionals. Don't feel that we were really involved in the care planning-decisions made by the clinicians and then we were informed. As parents we have asked questions and expected responses from the Team, but it feels at times like you have to fight in order to get the right care for your child.

"We do not know what we might need in the future as we are ensuring that our child is being looked after to the best of our ability on a day-to-day basis. Looking forward, though, there will be challenges up ahead such as milestones that they will need to reach. However, having access to online support ongoing would be really useful and sharing information with other parents dealing with a similar situation is comforting and informative. As our child getting older things may well change and need to be adapted accordingly. Coordination of this is vital.

"I think it is important for the child and their carers to have continuity in health and care. For children in particular, for the service to be delivered in familiar surrounding be that at the hospital or within the community. Parents to have access to the child's medical notes so that they have a full picture of what's going on that is also shared amongst all involved (Health and Care Professionals) and the potential to be able to communicate via a secure email address to all involved in their child's health care. Sharing of medical information is also really important and makes life so much easier for all concerned – as a carer I would not have to repeat my story more than once, but it does rely on all professionals involved to also read the patients' notes."

CQC ICS Project: Case Studies
Case Study Two: Female (early 30's), Market Rasen area, Lincolnshire
Diagnosis: Multiple Sclerosis (MS)

Tell us Your Story

"I had been experiencing some issues with my health over a number of months. My body didn't seem to be mine anymore with extreme fatigue and pain and sensations. It was causing me a lot of concern and anxiety. This started about 12 months ago but in the last 6 months has been getting increasing worse. I got to the point that in early February 2022, I was taken to A+E at Lincoln County Hospital following a GP appointment as my GP was very concerned by what I was displaying. I was initially referred to the Neurology Consultant who basically told me that it "was all in my head" and that I would need to be seen by the Mental Health Team.

"In April 2022, following another serious episode of acute illness, I was sent for several diagnostic tests including a lumbar puncture, brain scans, full body scan and a number of blood tests. When all the results were in, I was not allowed to bring anyone in with me (my parents had to

wait in the car park), and I was given my diagnosis of Multiple Sclerosis (MS). I was in shock!"

"I have a contact for the Specialist MS Nurse and was informed that I would be referred to the physiotherapist at Louth Hospital but by mid May 2022 when I hadn't heard anything, I called the hospital myself to be informed that I had not been referred. However, I have since been told that I am number 23 on the list and I have no idea when that appointment will come through.
"I have experienced a very supportive GP at the Practice in Market Rasen and have had mixed feelings about Lincoln Hospital. The Specialist Nurse is great, and I feel that I can call at any time to get advice or information. However, the rest of it is very disjointed!

"Looking to the future, I am trying to stay positive. I am a young woman with a life changing condition, and I do not know how this will affect me as I get older. The future is very scary at the moment. I was not offered any psychological support to come to terms with this news from my recent diagnosis. I am taking one day at a time and feel that I have been "left to get on with it".

"My main concerns are how I am going to support myself going forward. I am a self-employed artist, so the financial stress is quite daunting. My parents have been great, and we made the decision that I would move back home so that I had some moral support on a day-to-day basis. I have been caring for my dad who is disabled, and I worry what will happen to him when I am no longer able to look after him full time. Other things are how to adapt the house to what I will need as I don't know how this condition will affect me and my ability to stay independent.
"Currently, I am not on any medication and there is no care plan in place. I have a follow up appointment in a few months with the Consultant and hopefully there will be a better indication of what I do next etc. The Specialist Team have been great so far and my GP is fab! Though getting appointments can be challenging at times especially if you need to get a face to face but once you are seen they are great at the surgery.

“What I would like to see going forward is better communication with the patient once a diagnosis has been given. The patient needs to be part of the decision making, after all this is about me. No-one has asked me “what is important to you?” Also, I would have found it very useful if the news had not been broken to me on my own – give the patient the choice to have someone with them especially when receiving life changing information. As a new patient with this diagnosis, I feel a little bit overwhelmed some days and I feel that my mental health is not as good as it could be. The Outreach Team via the Occupational Therapist said that I could be referred for some counselling, but I am still waiting to hear about that. No information has been offered to me about the condition – I have had to do my own research and then I will ask questions of the Professional when I am in contact with them.

“What has worked well for me so far is that there has been consistency in my GP and the Consultant. There also needs to be the accountability for the professionals to follow up when they say they are going to do something, e.g., referral to the physiotherapist. When a diagnosis such as MS is given, it would be useful to have some sort of Fact Sheet, list of support groups or where to go for further information that the patient can digest in their own time and then can access when they are ready to. Each person is different and will deal with the news in a different way. I am learning to live each day as it comes as I never know how I might feel when I wait up in the mornings now.”

CQC ICS Project: Case Studies
Case Study Three: Woman (in late 50s), Louth, Lincolnshire
Diagnosis: Myalgia Encephalomyelitis (ME)/
Chronic Fatigue Syndrome (CRF)

Tell us Your Story

“Until about 3 years ago I was a very fit and active person, competing in triathlons at national level and coaching up and coming athletes. About 3 years ago, I started to experience being “cold to the core” and extremely tired/exhausted so much so that by Wednesday evening each week just simple tasks such as raising my head off the pillow was so

exhausting and took me so long to get motivated. This would result in me over a period of months not being able to go into work, letting my clients down and had an impact on my financial situation.

"I had experienced a very personal trauma in September 2018 which resulted in me collapsing and my brain shutting down. English is not my first language, so I lost the ability to speak and understanding language when spoken to me."

"As a result of the collapse I was taken to the Hospital and a series of diagnostic tests were done on me to find out what had happened. Slowly as I was recovering, my ability to speak and to understand came back to me. I was being investigated for stroke and brain tumour.

"I have a great GP at James Steet Surgery, Louth who after my discharge from hospital went through a process of elimination to get to the bottom of what had happened and to try and get me some answers. I was given the diagnosis by the GP. Unfortunately, once this GP left that surgery, I have had no follow up at all. I feel that I have been "left to get on with it" with little professional help or support.

"I reduced my work commitments and took part in a number of seminars run by the ME Society. The course was helpful in that it helped me to understand the condition but was exhausting as it was being held in Lincoln and used up all of my energy in travelling to and from Lincoln to be part of it.

"Currently, nothing is going very well. I have no follow from GP Practice or a Specialist in any shape or form. There is no Specialist Nurse that you can make contact with and although I can do research myself and have made contact with the ME Society there does not appear to be anything. I feel very let down by the system. No one has asked me what is important to me. With the medication and lack of activity due to the chronic fatigue I have put a lot of weight on and have mobility issues. This in turn is affecting my mental health and overall wellbeing. I have always been such a positive active and independent person and now I am very scared about being unwell, always feeling so low and tired and being a burden to my partner.

“What would work for someone like me and maybe others with similar diagnosis is access to some counselling so that we can come to terms with the new person that we are now. I look in the mirror and I do not recognise the person that is staring at me. My weight gain has really impacted on me both mentally and physically. I have tried the OneYouLincolonshire programme but found that too low level and patronising. I was an athlete so know a lot about nutrition and exercise. I need someone to recognise that I am so chronically fatigued that I do have the energy to do exercise. Why not ask me what’s important to me and how active I am currently. Don’t make assumptions about what you think I am doing or not doing!

“The system is not working very well at the moment in my opinion. Bad communication, lack of empathy with patients, lack of understanding of the condition such as ME / chronic fatigue syndrome to name but a few. “What I would find very useful is knowing that there is a professional that understands my condition and can support me to self-manage. Understand the impact that it has on the individual when you get life changing diagnosis. I have a fear of “what if…..” – how am I going to be able to support myself financially, getting infections such as COVID-19 and I am exhausted with having to fight the system with no one listening to me.

“What would a good health and care system look like to me? I would like to see better communication and sharing of information, seeing the whole of the person not just the condition, the offer of counselling for those that have been given a life changing diagnosis (this works extremely well for those people living with cancer why is the NHS not learning from good practice? Consistency of health and care (whoever is delivering it) at the moment it’s a lottery! Getting the diagnosis as quickly as possible and having a dedicated ME Specialist Nurse. Give people time to come to terms with the diagnosis.

The impact on wellbeing and mental health is huge! Produce a series of Fact Sheets and information booklets by lived experience of ME for ME people! Have a single point of access for signposting and information sharing that everyone can access when they are ready in a variety of formats and not just digital.”

CQC ICS Project: Case Studies
Case Study Four: Female late 50s, Stamford area, Lincolnshire
Diagnosis: Fibromyalgia

Tell us Your Story

"I have been living with fibromyalgia for about 12 years now. My initial diagnosis, prior to fibromyalgia was Sjogren's Syndrome basically a condition that affects parts of the body that produce fluids, like tears and spit (saliva) caused by the immune system mistakenly attacking the body. I am supported by a wonderful GP at Lakeside, Stamford. I was referred to the Rheumatologist at Grantham Hospital and put on a medication for 6 months.

"However, things did not improve and following many more tests I was finally referred to another Rheumatologist at Peterborough Hospital who did the pressure points and gave me the diagnosis that it was fibromyalgia.

"Nothing is in place for the long-term impact that a long changing condition has on a person. You almost feel like that you are given a diagnosis and then "left to get on with it". The second Rheumatologist and my GP have been amazing and are very supportive but nothing else is joined up. No offer of any counselling is given to a newly diagnosed person to help them understand the condition and its impact on you and your long-term wellbeing. You have to do so much for yourself.

"There is a Pain Management Service in Lincolnshire, but people are not being referred into it. For some people they need to understand the long-term effects on a person living in constant pain on a day-to-day basis and how it wears you down both mentally and physically. The last thing that you want someone saying is "do more exercise" when your body is in chronic pain. The language needs to change – such as activity or movement. What about asking the person what is important to you and how active are you currently? Don't make assumptions about people – we are not all the same!

“For me, improvements to health and care systems need to start at the basics: awareness and understanding of the condition, recognise it a as “real” condition, use of language, see the whole person and not the condition and use a holistic approach. Better communication between all professionals would make such a difference and then better communication with the patient and carer. Look at the whole picture not just in silos!

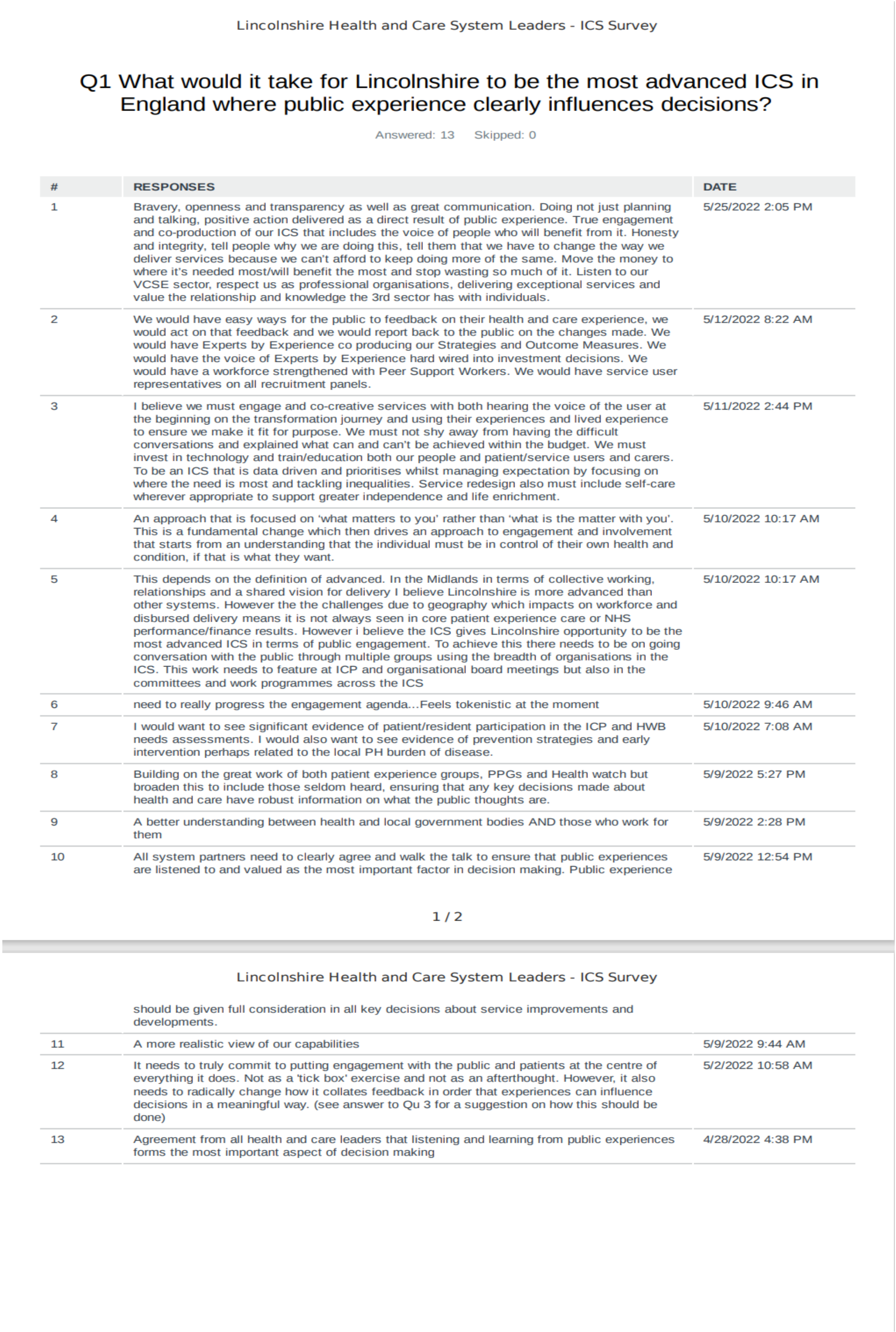
“A good health and care system for me would be where I feel confident that everyone is working together with the patient at the heart of everything. Being involved and being part of the decision making in your own wellbeing and condition management is critical. After a life changing diagnosis, have the offer of counselling available for those that need it so that they can come to terms with their diagnosis. Recognise that everyone might need this at different stages in their journey with their condition. Make the person feel that you really are “person centred” by actions not just “talking and using the words”. Have information in straight forward, jargon free language in a variety of formats (ask how I want my information!) about the condition and basic information on support services that I can go to if I need them or when I am ready to engage with them. Patients go through a series of “bereavement” for the old “me” and need time to adjust to what this new person is capable of. It would also be important to have Specialist Nurses in Fibromyalgia who have a better awareness and understanding of the condition – this might highlight to many health and care professionals that it is a “real” condition and in the “heads” of the people who are living with this every day of their lives.

“A good health and care system should have the patient at the centre of all designs or redesign of services and not just as an afterthought. Patients need to be included from the start and be able to make contributions to the how process and not made to feel like a tick box. Good feedback through a variety of means so that the patient feels that they have really been listened to and that they can help services to improve. Having an independent organisation such as Healthwatch to go to who the patient can trust that does not have a vested interest in the service, organisation other than to ensure that the patient voice is central and is being heard. This will also mean that people will not feel that they will be treated differently if they voice their opinions etc.

“What do I need in the future, at this moment in time I do not know what I might need but I would like to think that trainees of the future would be better equipped to understand conditions such as fibromyalgia and not be so dismissive of people who seem to not to fit the system. Shouldn’t the service be designed to meet the needs of the people and not the other way round?”

Appendix four

Appendix four provides individual comments from health and care leaders

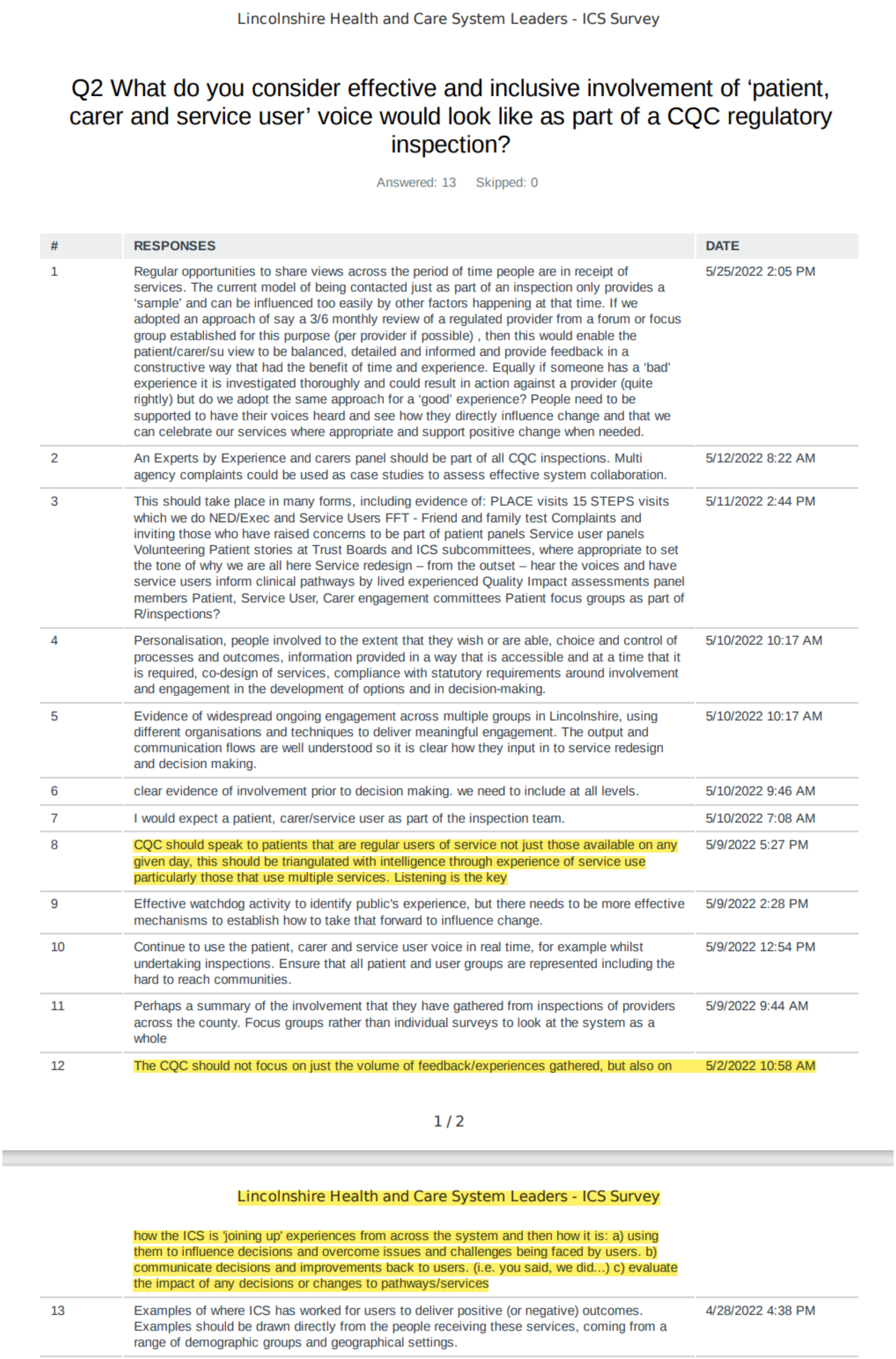


Lincolnshire Health and Care System Leaders - ICS Survey

Q1 What would it take for Lincolnshire to be the most advanced ICS in England where public experience clearly influences decisions?

Answered: 13 Skipped: 0

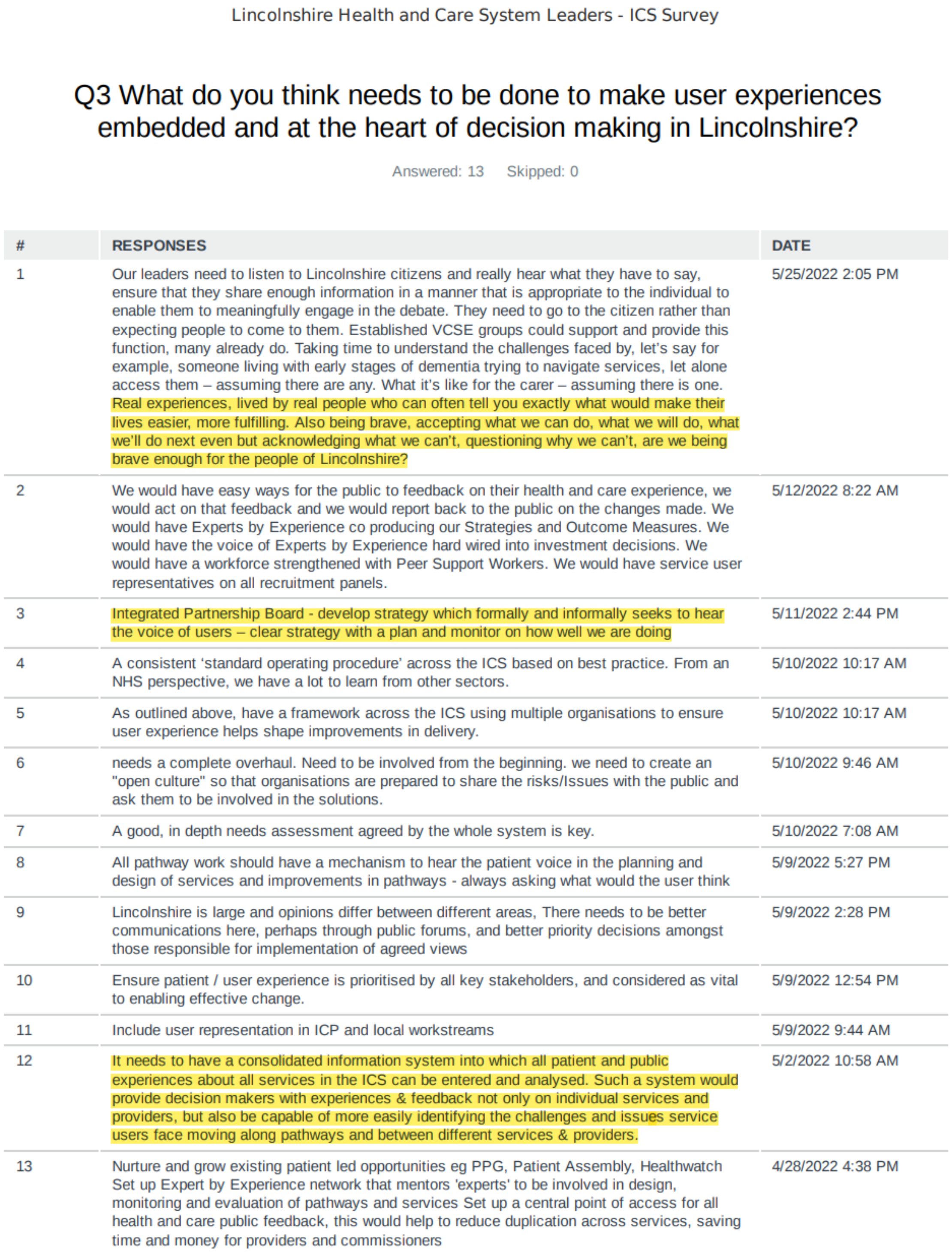
#	RESPONSES	DATE
1	Bravery, openness and transparency as well as great communication. Doing not just planning and talking, positive action delivered as a direct result of public experience. True engagement and co-production of our ICS that includes the voice of people who will benefit from it. Honesty and integrity, tell people why we are doing this, tell them that we have to change the way we deliver services because we can't afford to keep doing more of the same. Move the money to where it's needed most/will benefit the most and stop wasting so much of it. Listen to our VCSE sector, respect us as professional organisations, delivering exceptional services and value the relationship and knowledge the 3rd sector has with individuals.	5/25/2022 2:05 PM
2	We would have easy ways for the public to feedback on their health and care experience, we would act on that feedback and we would report back to the public on the changes made. We would have Experts by Experience co producing our Strategies and Outcome Measures. We would have the voice of Experts by Experience hard wired into investment decisions. We would have a workforce strengthened with Peer Support Workers. We would have service user representatives on all recruitment panels.	5/12/2022 8:22 AM
3	I believe we must engage and co-creative services with both hearing the voice of the user at the beginning on the transformation journey and using their experiences and lived experience to ensure we make it fit for purpose. We must not shy away from having the difficult conversations and explained what can and can't be achieved within the budget. We must invest in technology and train/education both our people and patient/service users and carers. To be an ICS that is data driven and prioritises whilst managing expectation by focusing on where the need is most and tackling inequalities. Service redesign also must include self-care wherever appropriate to support greater independence and life enrichment.	5/11/2022 2:44 PM
4	An approach that is focused on 'what matters to you' rather than 'what is the matter with you'. This is a fundamental change which then drives an approach to engagement and involvement that starts from an understanding that the individual must be in control of their own health and condition, if that is what they want.	5/10/2022 10:17 AM
5	This depends on the definition of advanced. In the Midlands in terms of collective working, relationships and a shared vision for delivery I believe Lincolnshire is more advanced than other systems. However the the challenges due to geography which impacts on workforce and disbursed delivery means it is not always seen in core patient experience care or NHS performance/finance results. However i believe the ICS gives Lincolnshire opportunity to be the most advanced ICS in terms of public engagement. To achieve this there needs to be on going conversation with the public through multiple groups using the breadth of organisations in the ICS. This work needs to feature at ICP and organisational board meetings but also in the committees and work programmes across the ICS	5/10/2022 10:17 AM
6	need to really progress the engagement agenda...Feels tokenistic at the moment	5/10/2022 9:46 AM
7	I would want to see significant evidence of patient/resident participation in the ICP and HWB needs assessments. I would also want to see evidence of prevention strategies and early intervention perhaps related to the local PH burden of disease.	5/10/2022 7:08 AM
8	Building on the great work of both patient experience groups, PPGs and Health watch but broaden this to include those seldom heard, ensuring that any key decisions made about health and care have robust information on what the public thoughts are.	5/9/2022 5:27 PM
9	A better understanding between health and local government bodies AND those who work for them	5/9/2022 2:28 PM
10	All system partners need to clearly agree and walk the talk to ensure that public experiences are listened to and valued as the most important factor in decision making. Public experience should be given full consideration in all key decisions about service improvements and developments.	5/9/2022 12:54 PM
11	A more realistic view of our capabilities	5/9/2022 9:44 AM
12	It needs to truly commit to putting engagement with the public and patients at the centre of everything it does. Not as a 'tick box' exercise and not as an afterthought. However, it also needs to radically change how it collates feedback in order that experiences can influence decisions in a meaningful way. (see answer to Qu 3 for a suggestion on how this should be done)	5/2/2022 10:58 AM
13	Agreement from all health and care leaders that listening and learning from public experiences forms the most important aspect of decision making	4/28/2022 4:38 PM



Q2 What do you consider effective and inclusive involvement of ‘patient, carer and service user’ voice would look like as part of a CQC regulatory inspection?

Answered: 13 Skipped: 0

#	RESPONSES	DATE
1	Regular opportunities to share views across the period of time people are in receipt of services. The current model of being contacted just as part of an inspection only provides a ‘sample’ and can be influenced too easily by other factors happening at that time. If we adopted an approach of say a 3/6 monthly review of a regulated provider from a forum or focus group established for this purpose (per provider if possible) , then this would enable the patient/carer/su view to be balanced, detailed and informed and provide feedback in a constructive way that had the benefit of time and experience. Equally if someone has a ‘bad’ experience it is investigated thoroughly and could result in action against a provider (quite rightly) but do we adopt the same approach for a ‘good’ experience? People need to be supported to have their voices heard and see how they directly influence change and that we can celebrate our services where appropriate and support positive change when needed.	5/25/2022 2:05 PM
2	An Experts by Experience and carers panel should be part of all CQC inspections. Multi agency complaints could be used as case studies to assess effective system collaboration.	5/12/2022 8:22 AM
3	This should take place in many forms, including evidence of: PLACE visits 15 STEPS visits which we do NED/Exec and Service Users FFT - Friend and family test Complaints and inviting those who have raised concerns to be part of patient panels Service user panels Volunteering Patient stories at Trust Boards and ICS subcommittees, where appropriate to set the tone of why we are all here Service redesign – from the outset – hear the voices and have service users inform clinical pathways by lived experienced Quality Impact assessments panel members Patient, Service User, Carer engagement committees Patient focus groups as part of R/inspections?	5/11/2022 2:44 PM
4	Personalisation, people involved to the extent that they wish or are able, choice and control of processes and outcomes, information provided in a way that is accessible and at a time that it is required, co-design of services, compliance with statutory requirements around involvement and engagement in the development of options and in decision-making.	5/10/2022 10:17 AM
5	Evidence of widespread ongoing engagement across multiple groups in Lincolnshire, using different organisations and techniques to deliver meaningful engagement. The output and communication flows are well understood so it is clear how they input in to service redesign and decision making.	5/10/2022 10:17 AM
6	clear evidence of involvement prior to decision making. we need to include at all levels.	5/10/2022 9:46 AM
7	I would expect a patient, carer/service user as part of the inspection team.	5/10/2022 7:08 AM
8	CQC should speak to patients that are regular users of service not just those available on any given day, this should be triangulated with intelligence through experience of service use particularly those that use multiple services. Listening is the key	5/9/2022 5:27 PM
9	Effective watchdog activity to identify public's experience, but there needs to be more effective mechanisms to establish how to take that forward to influence change.	5/9/2022 2:28 PM
10	Continue to use the patient, carer and service user voice in real time, for example whilst undertaking inspections. Ensure that all patient and user groups are represented including the hard to reach communities.	5/9/2022 12:54 PM
11	Perhaps a summary of the involvement that they have gathered from inspections of providers across the county. Focus groups rather than individual surveys to look at the system as a whole	5/9/2022 9:44 AM
12	The CQC should not focus on just the volume of feedback/experiences gathered, but also on how the ICS is 'joining up' experiences from across the system and then how it is: a) using them to influence decisions and overcome issues and challenges being faced by users. b) communicate decisions and improvements back to users. (i.e. you said, we did...) c) evaluate the impact of any decisions or changes to pathways/services	5/2/2022 10:58 AM
13	Examples of where ICS has worked for users to deliver positive (or negative) outcomes. Examples should be drawn directly from the people receiving these services, coming from a range of demographic groups and geographical settings.	4/28/2022 4:38 PM

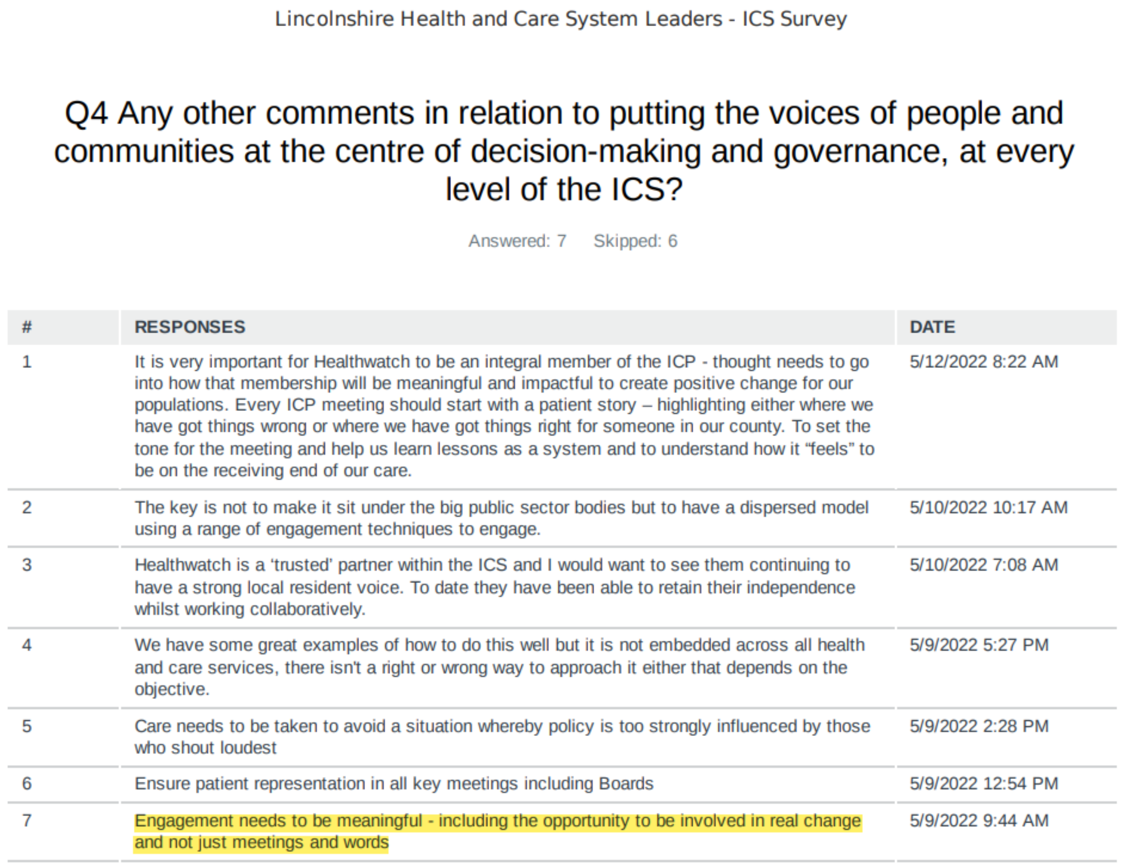


Lincolnshire Health and Care System Leaders - ICS Survey

Q3 What do you think needs to be done to make user experiences embedded and at the heart of decision making in Lincolnshire?

Answered: 13 Skipped: 0

#	RESPONSES	DATE
1	Our leaders need to listen to Lincolnshire citizens and really hear what they have to say, ensure that they share enough information in a manner that is appropriate to the individual to enable them to meaningfully engage in the debate. They need to go to the citizen rather than expecting people to come to them. Established VCSE groups could support and provide this function, many already do. Taking time to understand the challenges faced by, let's say for example, someone living with early stages of dementia trying to navigate services, let alone access them – assuming there are any. What it's like for the carer – assuming there is one. Real experiences, lived by real people who can often tell you exactly what would make their lives easier, more fulfilling. Also being brave, accepting what we can do, what we will do, what we'll do next even but acknowledging what we can't, questioning why we can't, are we being brave enough for the people of Lincolnshire?	5/25/2022 2:05 PM
2	We would have easy ways for the public to feedback on their health and care experience, we would act on that feedback and we would report back to the public on the changes made. We would have Experts by Experience co producing our Strategies and Outcome Measures. We would have the voice of Experts by Experience hard wired into investment decisions. We would have a workforce strengthened with Peer Support Workers. We would have service user representatives on all recruitment panels.	5/12/2022 8:22 AM
3	Integrated Partnership Board - develop strategy which formally and informally seeks to hear the voice of users – clear strategy with a plan and monitor on how well we are doing	5/11/2022 2:44 PM
4	A consistent 'standard operating procedure' across the ICS based on best practice. From an NHS perspective, we have a lot to learn from other sectors.	5/10/2022 10:17 AM
5	As outlined above, have a framework across the ICS using multiple organisations to ensure user experience helps shape improvements in delivery.	5/10/2022 10:17 AM
6	needs a complete overhaul. Need to be involved from the beginning. we need to create an "open culture" so that organisations are prepared to share the risks/Issues with the public and ask them to be involved in the solutions.	5/10/2022 9:46 AM
7	A good, in depth needs assessment agreed by the whole system is key.	5/10/2022 7:08 AM
8	All pathway work should have a mechanism to hear the patient voice in the planning and design of services and improvements in pathways - always asking what would the user think	5/9/2022 5:27 PM
9	Lincolnshire is large and opinions differ between different areas, There needs to be better communications here, perhaps through public forums, and better priority decisions amongst those responsible for implementation of agreed views	5/9/2022 2:28 PM
10	Ensure patient / user experience is prioritised by all key stakeholders, and considered as vital to enabling effective change.	5/9/2022 12:54 PM
11	Include user representation in ICP and local workstreams	5/9/2022 9:44 AM
12	It needs to have a consolidated information system into which all patient and public experiences about all services in the ICS can be entered and analysed. Such a system would provide decision makers with experiences & feedback not only on individual services and providers, but also be capable of more easily identifying the challenges and issues service users face moving along pathways and between different services & providers.	5/2/2022 10:58 AM
13	Nurture and grow existing patient led opportunities eg PPG, Patient Assembly, Healthwatch Set up Expert by Experience network that mentors 'experts' to be involved in design, monitoring and evaluation of pathways and services Set up a central point of access for all health and care public feedback, this would help to reduce duplication across services, saving time and money for providers and commissioners	4/28/2022 4:38 PM



Lincolnshire Health and Care System Leaders - ICS Survey

Q4 Any other comments in relation to putting the voices of people and communities at the centre of decision-making and governance, at every level of the ICS?

Answered: 7 Skipped: 6

#	RESPONSES	DATE
1	It is very important for Healthwatch to be an integral member of the ICP - thought needs to go into how that membership will be meaningful and impactful to create positive change for our populations. Every ICP meeting should start with a patient story – highlighting either where we have got things wrong or where we have got things right for someone in our county. To set the tone for the meeting and help us learn lessons as a system and to understand how it "feels" to be on the receiving end of our care.	5/12/2022 8:22 AM
2	The key is not to make it sit under the big public sector bodies but to have a dispersed model using a range of engagement techniques to engage.	5/10/2022 10:17 AM
3	Healthwatch is a 'trusted' partner within the ICS and I would want to see them continuing to have a strong local resident voice. To date they have been able to retain their independence whilst working collaboratively.	5/10/2022 7:08 AM
4	We have some great examples of how to do this well but it is not embedded across all health and care services, there isn't a right or wrong way to approach it either that depends on the objective.	5/9/2022 5:27 PM
5	Care needs to be taken to avoid a situation whereby policy is too strongly influenced by those who shout loudest	5/9/2022 2:28 PM
6	Ensure patient representation in all key meetings including Boards	5/9/2022 12:54 PM
7	Engagement needs to be meaningful - including the opportunity to be involved in real change and not just meetings and words	5/9/2022 9:44 AM

NHS Lincolnshire CCG Exec meeting 19 April Health and Care Leaders
Present
John Turner; Peter Burnett; Martin Fahy; Sarah-Jane Mills; Andy Rix; Dr David Baker
Dr Majid Akram; Matt Gaunt; Dr John Parkin
Guest – Sarah Fletcher, CEO, HWLincs

NHS Lincolnshire CCG Executive meeting invited Healthwatch to attend their meeting with the offer of an ICS agenda item to discuss leaders survey questions.
During the meeting Sarah Fletcher provided a very brief resume of results from ICS public survey but was clear any feedback should be treated with caution as the data has not yet been analysed.
This was followed by general discussion and comments surrounding the leaders survey questions, which can be summarised as follows:
Respondent one: query with regards to increase in wanting face to face appointments. Population segments, is there a factor between request for more face-to-face appointments influenced by people with LTC wanting reassurance?
Respondent two: Why wouldn't we want to be the best. Reflecting on two years of Covid the NHS [during this period] have not had enough chances for formal conversations with the public. If the CCG reflects on innovative approaches such as weekly radio slots on BBC Radio Lincolnshire, the Healthwatch Covid and vaccination webinars, there is evidence of engagement which can be built on. However, there is an importance for the CCG to refresh their Engagement Strategy and include multiple platforms to engagement. In their new ICS they have not yet identified a non-exec that will have responsibility for engagement which needs rectifying.
Respondent three: GP surgery has recently had a CQC Inspection, the discussions with CQC team were open and honest. One of their biggest problems was how the surgery staff had to guide/help the CQC to understand the challenges surgeries are facing on a daily basis. Respondent felt that too much change has happened and one area they would suggest is how is this change being communicated to patients? For example, during the week one of their surgery GPs now has one face to face clinic a week, should these appointments be prioritised for patients with chronic diseases and co-morbidities to ensure accessibility from these cohorts? At management level there is not the understanding that pre-bookable appointments must be online. They are also experiencing at this surgery patients coming in with a 2-year list of health issues.
Respondent four: Systems cannot always meet expectations because of constraints from NHS. Patient experience needs to be embedded. Leaders and other relevant people should know what an advanced ICS is, and that patient information flows into the ICP and ICB. This should include what are your local challenges as an ICS, how is the system working together to ensure best outcomes for people
Respondent five: Wants and needs – sometimes all providers and commissioners can do is address needs, how do they address wants. Contribution to change - would like to see patient stories at every board meeting, brings home why they are there.
Formality of feedback, lots of areas that can be drawn from, patient voices, PPG involvement etc but there is also a need to look at a more formal approach. Feels that service change needs to be constructed with patient involvement, moving away from

single style of change led approach with a strong voice in provider collaborative. Use existing examples of robust patient engagement such as in Lincolnshire the ASR as leverage, demonstrating what has been/can be done.

Respondent six: askmyGP is an increasing problem due to demand and the number of inappropriate messages left on the system. Better communication is required with patients, these systems are not designed to be used like social media e.g., *what do I do my kid has a snotty nose.* An example of online demand outstretching resources is where a GP surgery received 200 patient responses *by* 11am on Monday morning, practices are nearing the stage of crisis and as a result feel like abandoning the *online* service.

Respondent seven: How do we get patients to help with their care in the future? MDTs are in place, but these must have patients at the centre and include community-based specialist involved in supporting people with their LTC needs. How do MDTs expand their workforce in primary care e.g., add in health coach?

We should include the public in co-production with providers which would be a big change. Patient engagement platform would be a very good idea.

NHS day-to-day job impacts on new ways of working.

Respondent eight: Success of ICS depends on their relationship with three voices:

1. Influence through ICS people
2. Partners
3. People they serve

Getting the right mind-set of ICB Board is crucial and needs to go through every organisation

What does excellence look like? – start with what is being done well by organisations and its people and use this to build on e.g., mental health transformation, vaccination programme, better births

We have areas of excellence that need recognising, but challenges acknowledged. CCG is aware the system has been relentless with asking population 'what is working well'? Local is very important they need to support PCN at local footprints. Cannot always meet expectations because of constraints from NHS.

Appendix five

Below is a small sample of just some of the free text comments shared with us through the public and seldom heard surveys

“Integrate services. Look at the model of Community urgent care team in northeast Lincolnshire and use it all in other ways. GP surgeries. Hospitals and even school services. MDT teams work”

“Yes, think about the needs and services for Lincs patients who have secondary care outside if Lincs borders”

“It might work great for others in the north of the area, but I seem to have medical records at [four hospitals] which I thought would have been coordinated by my GP in Lincolnshire. I had an MRI [date removed] at Peterborough on my spine. As nobody there could interpret the results, it was sent to Addenbrooke’s. A neurosurgeon from Addenbrooke’s operated on my back (presumably using that MRI information) at Nuffield Cambridge on [date removed] which failed. A complaint was made but after three separate attempts to have sight of that MRI, I have had no response. Nothing to do with Lincolnshire? It should be because my GP should have a copy. A later MRI showed rotational scoliosis with a protruding part of my spine which is causing considerable pain. It seems that anyone with scoliosis should be seen by a scoliosis specialist. Having emailed the Scoliosis Association UK, they agreed but unfortunately there isn’t one in Lincolnshire! I’m appalled that that is the case when there are two at Addenbrooke’s. I had a second opinion on my spine at the Fitzwilliam Hospital Peterborough. The consultant said, as did the first, that I required spinal injections to get me moving but he never would have operated as I have no discs in my lumbar spine, just gas. He referred me to the Pain Consultant at the Fitzwilliam who was appalled at my treatment and booked me in straight away on the NHS. At the last minute these injections were blocked because an administrator noticed my PE6 postcode. During this nightmare of pain (which continues) I have had a further diagnosis of ME/CFS which the ‘recommended’ Pain Clinic (Connect Health) in Lincs knew nothing about. I had to point out that it had been proved that graded exercise therapy (GET) was proven to be harmful for people with this condition. I was offered a meeting with someone from the Pain Clinic at our local surgery which I declined due to the high Covid risk in this Market Deeping backwater. I think I would now change my mind and will ask my GP to set up this meeting again but if I cannot see a Specialist Pain Consultant there is little point.

I've gone through this all on numerous occasions but after crying in pain for a good chunk of last night (my birthday too) I feel I'm in desperate need of help."

"Confidentiality so not discussing cases for others to hear. Not leaving paperwork for others to see. I think more priority for older or those with disabilities to get appointments and be able to see someone."

"Health and social care do not work together outside of the hospital. The reality of the neighbourhood teams is not true partnership working as different agencies have their own agendas rather than working holistically with people."

"More joined up services and more planning for the future. Less poorly thought out reaction. More proaction. Integrated care systems are what we had 30 years ago when Lincolnshire Health Authority worked across the county with Lincolnshire County Council. All came apart by the disastrous Lansley review with useless 4 CCG."

"Do not work in SILOS! Better communication between all health professionals who are involved in the care of the patient. See the person and not the condition. Improve IT access so that all parts of the system work better together by sharing medical information / updates etc about the person. Treat the person holistically rather than on a condition by condition basis. Many conditions interact and will effect the patient on a day to day basis."

"The first element would be better communication between the NHS medical providers and support services. The second would be for the support service providers to be more educated and informed of the pain and it's effects of each condition people are suffering from, to enable them to relate to the persons needs and the mental anguish they may be experiencing A lot of this would help both the patient and the support/carers understand that quality of life is still a major factor in living with a debilitating condition Instead of being given meds on top of meds and told to deal with it"

"I dont feel treated as an individual person, I dont feel people have time to do this"
"Work together and put patients at the centre of care not focused on the professional."

"Access is needed at the onset of problems with trained personnel. Home conditions need to be brought into consideration also. Fewer phone call diagnosing minor troubles but rather knowledgeable personal contact provided."

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