

# **COVID-19**

## **How are we coping?**

**Part II**

**Hospital Appointments**  
**Week ending 12 July 2020**

# Background and Rationale for the Research

As Healthwatch continues to deliver its core function of gathering the current public views and experiences of Lincolnshire residents, it shares in this document the feedback from a short campaign, asking how Lincolnshire people who were either in the middle of treatment, awaiting treatment, or had been referred for diagnostics in hospital during the coronavirus pandemic experienced that service.

The short campaign ran from 25<sup>th</sup> June to 12<sup>th</sup> July and sought to enquire further into the comments seen in the general COVID-19 patient experience work that was carried out.

The experiences we looked to explore further related to feedback from national and local concerns raised by NHS England and our local NHS system with regards to why the public were not attending NHS hospital services during COVID19 pandemic, similarly during the COVID-19 Barometer Survey we saw large numbers of people frustrated at the lack of communication and information regarding their own or their loved ones care and treatment in a hospital setting.

We have already shared the generic findings within this report with the health and care system, this document only formalises the findings to be shared with a wider audience.

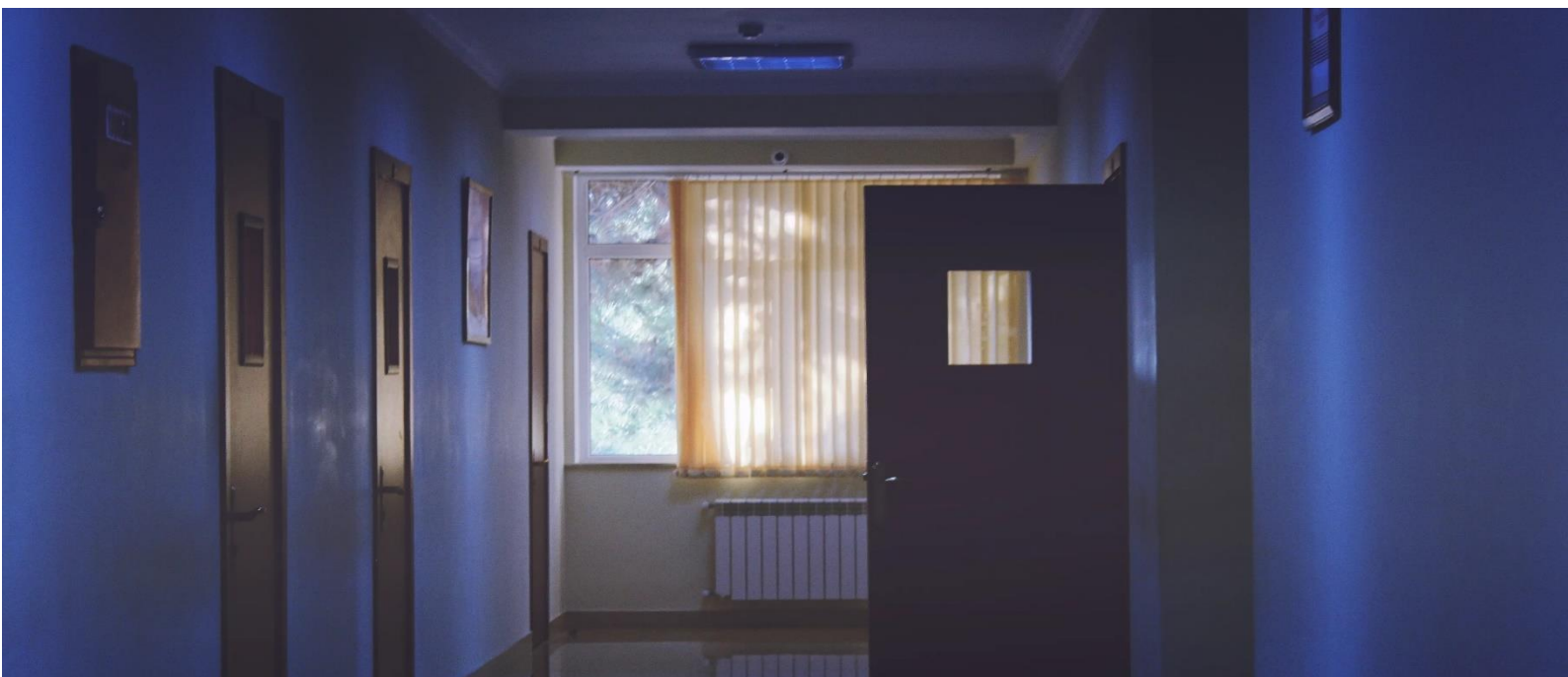
## People at risk of losing sight due to fear of hospital during coronavirus pandemic

*Wednesday, 3 June 2020 by Royal National Institute of Blind People (RNIB)*

We're calling for people to continue attending scheduled eye appointments, after evidence shows that people are missing vital treatment due to fear of coronavirus.

Important appointments missed

Eye healthcare professionals across the UK have found that up to 50 per cent of people with urgent or acute eye conditions have not been attending appointments due to concern around coronavirus.



# Summary

We believe the results of this hospital survey work is particularly important in helping inform our NHS acute services, not only in Lincolnshire but across the region, as to what the possible patient barriers are. This we hope will help direct what the current and future patient communication messages need to be and more importantly give our health and care services a real time sense check from the patient perspective of what impact health and care service delivery has on the patient and their family, carers and loved ones.

We aim to share this work and these findings as widely as possible and as part of our collaborative approach with providers and NHS Lincolnshire Clinical Commissioning Group, we liaised with the United Lincolnshire Hospital Trust (ULHT) to inform them we were conducting this hospital survey. ULHT were keen for us to share the results with them to help improve understanding of real or perceived patient barriers to accessing care currently.

## **The following areas were identified as key findings:**

- Patients were not attending appointments, as we heard the hospitals had previously cancelled and not rearranged appointments or they had received no information regarding a new referral.
- Patients were frustrated at the lack of information about the status of their health and care treatment (where were they on the waiting list).
- Patients were also receiving the message that it was not appropriate for non-COVID patients to attend hospital due to the risk of infection and burden on NHS resources.
- For those patients that had attended hospital they had mixed views on their experiences, although overwhelming it must be stated, very good experiences. However we cannot ignore the patients who were scared, those who observed inconsistent practical application with regard to PPE being utilised both by staff and patients and those patients receiving care, treatment and or difficult news under impossible or isolated situations where the critical support of loved ones in these situations was not considered.

The messages and learning from this piece of work seem to revolve around the need for transparent and frequent communication, a need to keep in touch with patients and provide some assurance that they are not going to suffer harm, nor had they been forgotten, it is not enough for the system to say that they “didn’t want to raise patient expectations by sharing messages which could be misinterpreted”.

In addition, there is a need to apply consistent policies and protocols for patients and staff giving a greater sense of cohesive effective delivery and more assurance that care in Lincolnshire is safe. Finally, and perhaps the most concerning is where ‘putting the patient at the centre’ seems to have gone out of the window in some cases, where an individual’s needs and general wellbeing just weren’t considered on an individual care plan basis.

*Illustrative Example: It was very difficult for my family member who is 90% deaf. They were there to hear about their upcoming chemotherapy and initially they would not let their spouse come in with them, even masked. The spouse is their "ears" in situations like that, but it was made doubly difficult because they could not read the consultant's lips due to them being masked. The patient was about to walk out in tears when they decided to let the spouse come in. Doubly distressing for both of them.*

## Methodology & Demographics

Our hospital survey was open to the public via our Facebook page during the first two weeks of July, and resulted in 162 responses, this feedback was made up of both numerical and rich free text commentary which gave us an insight in their personal experiences, challenges and beliefs around access to hospital services.

The survey was open to a self-selected group and as such we saw usual demographic of higher levels (76%) of female respondents to males, and the general responses were seen in the 55+ age bracket (79%), however what was noted was despite the skew in demographic the respondents reported on other demographic groupings, such as males; children and varying types of medical condition.

In terms of locality split, we notice a similar pattern as we saw in the main COVID-19 work, with even representation from East Lindsey, North Kesteven, South Holland and South Kesteven districts at around 13-18% of respondents with lower representation from Lincoln, West Lindsey and Boston at between 8-10%.

90% of the respondents were personally awaiting care and treatment from a hospital setting.

What should also be noted at this juncture is that the experiences of Lincolnshire residents in hospital settings goes far beyond the United Lincolnshire Hospital Trust and demonstrates some of the challenges patients experience particularly when around 28% of respondents are receiving their health and care outside of Lincolnshire. Out of

county patient destinations included Hull, Scunthorpe, Sheffield, Nottingham, London, Wisbech, Addenbrookes, Doncaster, Scunthorpe, Peterborough, Grimsby and Kings Lynn.



# Findings

The following presents the findings from the respondents and focuses on the general consensus of the feedback, but where it adds value, it identifies anomalies and some of the free text commentary which adds depth and richness to the data sets.

The focus of the survey was simple focussing on the 3 following questions:

1. To what extent are patients fearful about going to hospital for necessary care not related to COVID-19 symptoms?
2. Why have patients, who need to access health and care services, not been attending hospital?
3. If you/they have attended a hospital appointment since the COVID-19 outbreak what was the experience like?

## 1. To what extent are patients fearful about going to hospital for necessary care not related to COVID-19 symptoms?

We asked this question as from the 'health and care system' it could not be fully ascertained how people were feeling about accessing hospital care for non-COVID related treatment and care. We know from the 10-week Barometer survey that some people were concerned about risk of infection, but more over their concerns lay with not knowing how or when to access services or not wanting to overburden the NHS.

The findings shared above from the 10 week Barometer survey related to 'all' health settings, whereas this question was specific to the feelings and beliefs related to 'hospitals'. The respondents told us:

Only 3% of respondents were so **worried** about going to hospital because of the fear of catching COVID19 that they would avoid seeking the care they need.

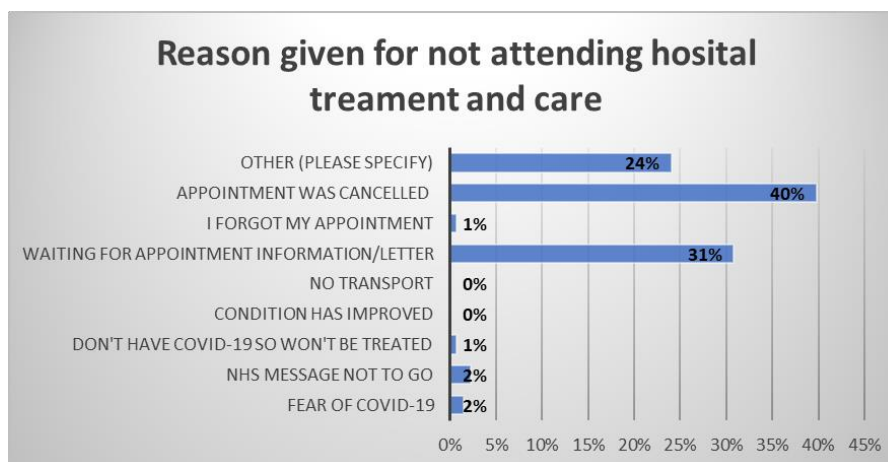
Although, worth noting 77% of people did indicate some concerns about fear of catching COVID19 as a reason but not enough to prevent them seeking and attending health and care services.



## 2. Why have patients, who need to access health and care services, not been attending hospital?

We asked why people who were due to receive health and care from a hospital setting, if they had not yet attended, what the reason. The findings were as follows:

- 31% of people were waiting to receive appointment information
- 40% of patients had their appointment cancelled with no further information given
- 2% of people felt the message from the NHS is that we should not be going into hospital at present
- Less than 2% of people had not attended due to fear of contracting COVID-19
- 24% were for other reasons - many of the comments mention patients had received a telephone consultation in place of a face to face appointment. Other issues within this category included treatment that had been transferred to primary care from a hospital consultant but refused, patients being told they didn't fall into the category of urgent and patients attending and on arrival being told the appointment had been cancelled.



### *Correlation with Part I of the COVID-19 survey:*

In the first 10-week COVID-19 survey many comments revealed patients feeling left in the dark with regards to their non COVID-19 related treatment and appointments. We feel that much better communication needs to be sent to patients in order for them to understand the process, timescales, how their treatment/appointments will be effected during this pandemic and what to expect moving forward, without risk to patients health.

*The following provides some of the free text comments provided by patients.*

“Phone appointment offered sent instead”

“THEY DIED BEFORE GETTING SEEN CANCER”

“Appointments have turned to teleconference or videocalls”

“Had to have phone appointment, other appointment cancelled not rebooked”

“My GP says it’s very very risky for me as I’m extremely clinically vulnerable”

“Waiting to receive appointment for MRI scan. Been waiting since lockdown started”

“Telephone appointment but I needed Xrays so new appointment in August”

“GP surgery asked to carry out treatment following online consultation with consultant. GP’s surgery refused to do treatment due to being closed because of covid 19. I contacted hospital to have appointment with them but now have to wait for an appointment. Therefore, prolonging preventative treatment”

“I have a new referral from the start of lockdown. I have yet to even be contacted regarding this. When I called them, they stated hadn’t even been graded yet as ‘routine’ or ‘urgent.’ I don’t honestly understand why clinics can’t be held remotely”

### 3. If you or a loved one has attended a hospital appointment since the COVID-19 outbreak what was the experience like?

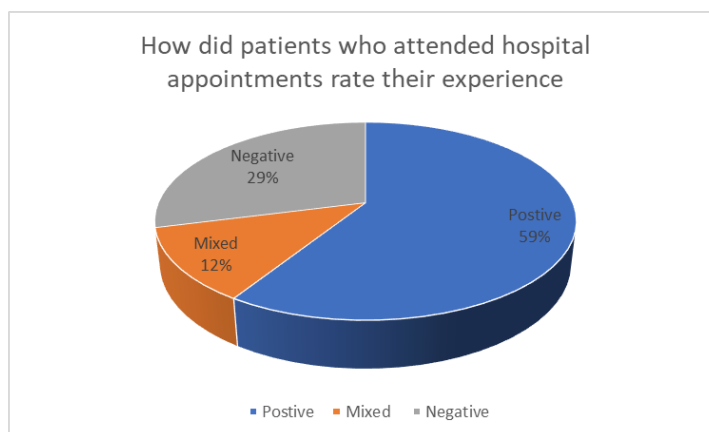
Equally we wanted to know what the experience had been like for those that had attended a hospital appointment, these messages are important not only to share where patients, family and carer experiences are positive, but also where there is learning which can be applied to future situations.

Where respondents left free text comments, there were significantly more positive comments than negative or neutral.

The main sentiments were good, with patients and families feeling the care was good, precautions were being taken and their treatment was continuing irrespective

of the COVID-19 pandemic. For others the whole experience was scary, with poor communication, inconsistent approaches and compassion for how people get a individualised care plans which meet their needs lacking in places.

Overall whilst the messages were positive, the Trusts need to consider for the future, the value and importance of patients holistic wellbeing needs, delivering on consistent messages and actions across hospital sites (for example use of PPE);



and the implementation of a 'always event' where the need for individualised care needs to be completed sensitively and with the whole person in mind.

### Press release

Face masks and coverings to be worn by all NHS hospital staff and visitors

All staff in hospitals in England will be provided with surgical masks which they will be expected to wear from 15 June. **All visitors and outpatients must wear face coverings at all times.**

*Published 5 June 2020 from, Department of Health and Social Care*

Below highlight patient comments from those who had experienced patient access to hospital services during the COVID-19 pandemic.



#### Positive:

*OK. Social distancing where could. Treatment prompt*

*Had CT scan, no problem whatsoever*

*Very good. Self-distanced and hand gel, I wore my own mask before it was mandatory*

*I attended an appointment and it was ok staff very helpful and cautious.*

*Excellent care from Breast Unit, Haem/Onc clinic, Haem/onc ward, diagnostic imaging, DTU and theatres*

*The clinical staff in the hospital were excellent*

*Positive and excellent safeguards were in place*

*Very good dealt with very quickly and underwent many tests*

*Very good ,very caring, and very helpful, and everything was in place with ppe, they put all chairs at a distance hand sanitizer was there to use they wiped everything down ready for the next patient and they took very good care of me*

*Attended A&E treatment was rapid and superb from all the staff in the unit. Wearing a mask was a minor inconvenience, but necessary. Nothing but positive praise for all staff, including porters, healthcare workers and cleaners.*

*Very safe environment.*

*Had a MRI scan, no problem. Felt at ease*



#### Negative:

*My spouse who I care for was sent to a&e several times and onto the ward where they were welcomed by numerous staff. They had to keep asking for drinks and not given any food.*



Waiting room was quiet. However, it was busy elsewhere with lots of staff wandering the corridors up to the ward not wearing masks, which did worry me a little as it was quite busy mainly with staff.

*Absolutely Disgusting* - at the beginning of April my relative was taken into Pilgrim with a chest infection; they tested on arrival and it WAS NOT COVID-19. Pilgrims communication with my family was appalling! After three weeks they were sent home WITHOUT BEING COVID TESTED PRIOR TO DISCHARGE - THIS WAS CONFIRMED BY THE NURSE WHO THEN PROVIDED THEIR END OF LIFE CARE TO ME!!!!!! Early May they were rushed back into Pilgrim, a few days later we were told they were COVID-19 positive, and then they passed away. THE COMMUNICATION WAS AGAIN APPALLING

*Worrying*

*Alright but my had to walk a long distance to get to a scanner*

*Little frightening, hit and miss attitude (to PPE), was told to wash my hands before sitting in the waiting room, but wasn't offered a mask, when I was collected for my scan I was told I should be wearing a mask, wasn't filled with confidence .*

*I was sent to A&E with a query chest infection from covid. I was assessed in the car park and told that they were just sending patients home. I had to explain my symptoms several times before I was allowed in for investigations. I felt like a leper at a time when I was very unwell and anxious.*

*Queuing outside in the warm, 2m apart when you are seriously ill already dehydrated, was not good.*

*Poor*

*It's very hard knowing your loved one is going in to get bad news on their own.*

*It was very difficult for my family member who is 90% deaf. They were there to hear about their upcoming chemotherapy and initially they would not let their spouse come in with them, even masked. The spouse is their "ears" in situations like that, but it was made doubly difficult because they could not read the consultant's lips due to them being masked. The patient was about to walk out in tears when they decided to let the spouse come in. Doubly distressing for both of them.*

*Nerve racking. Masks were not in operation for patients and toilets did not seem to be cleaned very often*

*Alien felt very vulnerable and lonely as only one in waiting room, couldn't have anyone there with me.*

We noted no correlation, themes or trends between the presenting medical condition and the patients experience. The reasons given for attending hospital and were categorised as follows:

<i>Condition Type</i>	<i>% of Responses Given</i>
<i>Other - included Bloods, A&amp;E, Bowel, Urology Orthopaedics and Eye Clinics</i>	70%
<i>Cancer</i>	13%
<i>Heart</i>	10%
<i>Diabetes</i>	3%
<i>Respiratory</i>	3%
<i>Stroke</i>	1%

## Finally

Overwhelmingly from this short piece of patient engagement work, respondents told us they felt communication was poor, and that they were left in limbo not knowing what was happening with the status of their health and care treatment. We also heard that patients received mixed or limited messages nationally and locally in terms of what was available, how patients should gain access and more importantly what should they expect, most patients just sat and waited for a letter or contact from the hospital, not ever sure if this would come.

Worryingly we heard experiences that showed individualised care for those most vulnerable wasn't always considered a priority over the practical aspects of COVID, this was particularly evident in situations where complex care or difficult conversations were needed.

We heard that patients were sometimes concerned about what they saw, heard, and were told in terms of consistency of applying PPE policies and protocols for staff *and* patients in hospital.

However, we also heard that for the vast majority they were not worried enough about COVID to prevent them from accessing hospital services if and when they were invited to. Furthermore we heard for a good number of people, the experience of visiting or being in hospital during the pandemic was one which demonstrated assurance that safety was a priority.

This information is provided to the health and care system, and others as an informative sharing of public insight, in the hope it will be acknowledged as a public barometer for learning and improving the systems for all in the future.

## **Additional Information:**

### **Background to previous COVID19 barometer campaign**

Under the Health and Social Care Act 2012, the Healthwatch network is required to involve and engage with the general public as to their experiences of health and care services. In Lincolnshire HWLinCs holds the contract to deliver the Healthwatch service on behalf of Lincolnshire County Council. Until mid-March 2020 we did this through a mix of predominantly face to face but also a smaller number of digital engagement activities.

At the very start of the COVID19 pandemic outbreak we quickly re-evaluated our process of engaging with the public to ensure we continued to meet our statutory requirements and LCC contractual performance. This change focused on our need to deliver digital engagement and resulted in an initial planned 13-week survey campaign.

Over the first 10 weeks of survey work, we received over 3,000 responses and reached over 250,000 people via social media and website activities.

Our overall summary of the barometer survey responses told us the key priority areas were:

- A concern above all else for those who were vulnerable and weak.
- A concern for people's own wellbeing and that of their families and loved ones.
- Frustration at mixed and negative messages being given through fake news, media and local and government sources.
- Frustration and concern about the impact on new or existing health and care issues outside of COVID-19.
- Frustration and concern for the lack of support systems within primary care, secondary care and mental health.
- Mixed tolerance levels for how the community is reacting to lock down restrictions and how they are being enforced

We have also linked into the Lincolnshire Resilience Forum and along with them are sharing our summary reports with CQC, Healthwatch England as well as key local system contacts.

# hw | lincs

*Proud to deliver .....*

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