



# Experience of Elective Care Waiting Times in North East Essex

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**healthwatch**  
Essex



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## Contents

<b>1.0 Introduction</b> .....	3
<b>1.1 Healthwatch Essex</b> .....	3
<b>1.2 Topic Background</b> .....	3
<b>1.3 Acknowledgements</b> .....	3
<b>1.4 Disclaimer</b> .....	4
<b>2.0 Purpose</b> .....	5
<b>2.1 Engagement methods</b> .....	5
<b>3.0 Key Findings and Recommendations</b> .....	19
<b>4.0 Conclusion</b> .....	22
<b>5.0 Terminology</b> .....	24

## 1.0 Introduction

### 1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences people in Essex are encountering daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share difficult experiences such as the one's shared in this report.

### 1.2 Topic Background

The recent Covid-19 pandemic saw the delay and cancellation of many elective care operations due to the redeployment of staff and equipment, and the additional burden placed on already stretched parts of the service in North East Essex, increasing both the numbers of people on waiting lists, and the average waiting time.

At the end of August 2022, ESNEFT and WSFT had a combined 106,702 patients with incomplete pathways, with 4,741 waiting longer than a year (NHS RTT Waiting Times Data).

This is mirrored across the country, with NHS England data showing there was a record number of 7.00 million people on the waiting list at the end of August 2022, compared to 4.41 million waiting for treatment at the end of August 2019. This includes 387,257 waiting more than a year (NHS RTT Waiting Times Data).

### 1.3 Acknowledgements

Healthwatch Essex would like to thank the members of the public who participated in this project through completing the survey. Our thanks are also made to those individuals who took the time to speak with us and share their personal and emotive stories.

## 1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

## 2.0 Purpose

As we move away from the Covid-19 restrictions, and work towards reducing the backlog, it's vitally important that we also assess the impact that waiting times have physically and emotionally, not just for the patient, but for family and friends as well.

Listening to the lived experiences of those directly affected can help us shape how we manage the care and support received by patients during their waiting period. Dovetailing this in with the practical and logistical steps being implemented to make full use of operating theatres and treatment centres, alongside efficient admissions and discharge policies, will combine to help improve this vitally important area of NHS healthcare.

SNEE ICS has stated:

The best planned treatment and care, when and where people need it, is essential if everyone in Suffolk and North East Essex is to live well.

As an Integrated Care System, we will ensure that:

- People have the right treatment and support to prevent, treat and manage conditions
- People have planned and non-emergency treatment and surgery when they need it, and in the place of their choice
- People have the best experience of planned and non-emergency care

The learnings will help the service keep aligned with the NHS Constitution which makes a number of pledges in relation to patient care including to:

- Provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution.
- Make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered.
- Make the transition as smooth as possible when you are referred between services, and to put you, your family and carer at the centre of decisions that affect you or them.

## 2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website and newsletters, partners, other organisations in North East Essex, relevant online communities and through word of mouth. They were engaged in two ways:



### **Survey**

A survey was created to gain perspective and insight from residents who have had experience of waiting for elective care.



### **Interviews**

Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during September and October 2022 and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

## **2.2 The Survey**

The survey consisted of eight core questions combined with three additional ‘free text’ information boxes enabling the participants to expand on their answers to preceding questions.

It was devised to encompass:

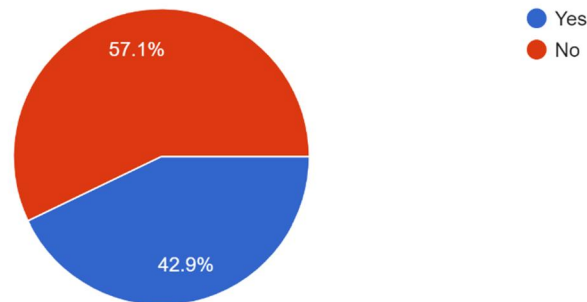
- Knowledge levels of elective care options
- Information and communication
- Average waiting times
- The impact and repercussions of having to wait

The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses received, were as follows:

In our first question, we asked whether patients were aware they had a choice of where they were referred:

1. Did you know that you can ask to be referred to a hospital of your choice, including private hospitals contracted to do NHS work?

21 responses

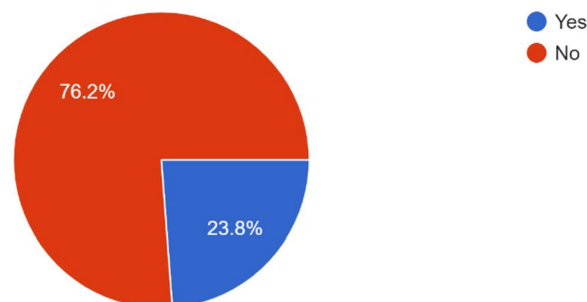


57.1 percent of the respondents were not aware that they could request a referral to a preferred hospital of their choice.

The second question asked whether they knew they could search to see if certain hospitals had shorter waiting times:

2. Did you know you can search by hospital for waiting times?

21 responses



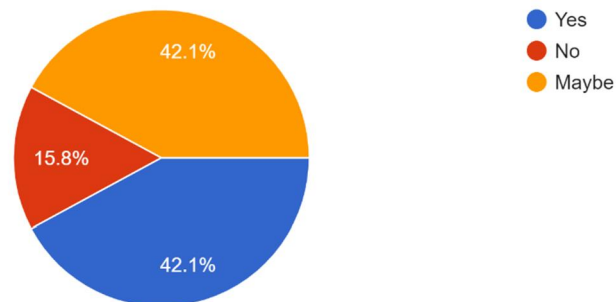
An overwhelming 76.2% were unaware they could see individual hospital waiting times.



Question 3 asked those that were unaware they could choose where to be referred or check waiting times, whether knowledge of these options and information might have led them to requesting treatment at a different location:

3. If you answered no to either of the above, would you have chosen to be treated at a different location if you had known?

19 responses



In response to this question, 84.2% said they would, or might have chosen to be treated at a different location to the one they were.

Following on from this, they were asked to expand on why they answered as they did. These were the comments:

*'Happy with where I'm being treated.'*

*'Nobody ever tells you that you have any kind of choice, it's all so directive.'*

*'My choice was Colchester; my nearest hospital and I know it.'*

*'Shorter waiting list.'*

*'Information not provided.'*

*'I would have looked into other hospitals, especially surgeons.'*

*'I have previously been treated at a Nuffield hospital and also my local Oaks hospital. These would be my preferred options.'*

*'I would have considered any option which meant I could have had my operation sooner; I was not made aware of these options.'*

*'Happy with where I was referred to but didn't know waiting time compared to elsewhere.'*

*'To be treated locally rather than get FOUR buses each way.'*

*'If I knew for certain how long I would have to wait, then I might have changed, but they tell you it will be three or four months and then it gets delayed and delayed.'*

*'If I had known maybe I could have had my surgery sooner.'*

*'My clinician indicated that I was not suitable for treatment in a private clinic.'*

*'I may have asked to go to a private hospital doing NHS work.'*

*'I was vulnerable. I would have gone elsewhere if I could have had it done more quickly.'*

The response to these first 3 questions highlights the gap to achieving the SNEE ICS policy aiming to ensure that:

*'People have planned and non-emergency treatment and surgery when they need it, and in the place of their choice'*

The next question asked how long they waited (if they have now had their procedure) or have been waiting (if yet to have their procedure).

For those who have had their treatment, responses varied from two people who had to wait just one month, to three people who had to wait for 12 months.

Of those still waiting, three people have been waiting for a year or more.

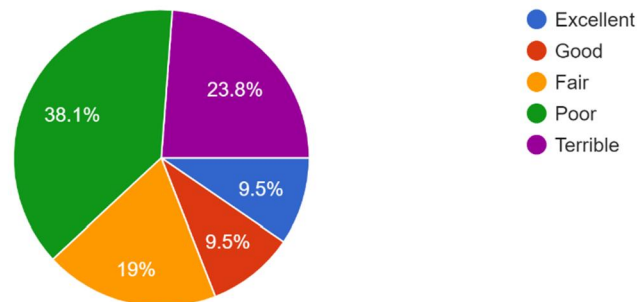
The average wait for those who have now had their procedure was approximately seven months (circa 30 weeks).

On average, those still waiting have been doing so for seven months (circa 30 weeks).

For the next question, we moved on to information and communication:

6. During the wait, how would you rate the information and updates you received regarding the treatment plan and timescales?

21 responses



38.1% said that information and updates were poor and a further 23.8% saying it was terrible against 9.5% saying good and 9.5% saying excellent.

When combined, 61.9% of the survey participants felt that the information and updates they received regarding their treatment and timescales was either poor or terrible, with 19% saying good or excellent.

They were then asked to elaborate on their reasons for rating as they did:

*'I have had to telephone twice now for information.'*

*'Kept completely in the loop throughout.'*

*'I'm under a consultant who has always discussed timings and agreed when I should try and have the operation - she will organise it and book me in.'*

*'Not very good Communication.'*

*'I have received no updates and when I ask for an appointment due to changes in symptoms, I was told my priority for my op was increased. But that was six months ago and nothing. When I chase for updates, I am told different things every time.'*

*'I was just left waiting, there were no letters or phone calls, and nobody ever picked up the phone when I rang to query.'*

*'No updates received at all.'*

*'Directed from GP to a physio who confirmed the diagnosis of consultant surgeon that I consulted privately. SILENCE SINCE.'*

*'Depending what surgeon I was under really.'*

*'After six months of waiting I called my consultants secretary to ask for an update. My GP has asked for my surgery to be expedited on more than one occasion. Regular updates and where I was on the list would have helped.'*

*'No information at all and no one answered calls.'*

*'Got last minute cancellation and nothing else, no phone call, no updates, no guidance no communication and would like some / more communication.'*

*'My GP referred me, so a call from them to keep me updated, inform me of delays, check on my wellbeing and so on would have been great, but I got nothing, just a cold letter that op had been cancelled and booked for another date.'*

*'Lack of information It's always you that has to do the chasing - more information please.'*

*'I do not recall receiving any updates regarding timescales, but details I received about treatment were helpful and adequate.'*

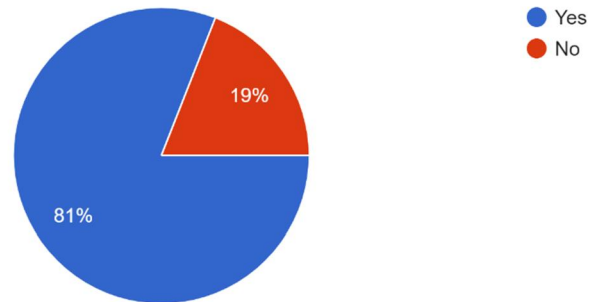
*'Received no contact at all and a regular update would have been useful.'*

*'I didn't receive any contact while waiting.'*

We then asked questions concerning physical and mental wellbeing whilst waiting:

8. Did your physical condition significantly worsen during the wait for treatment?

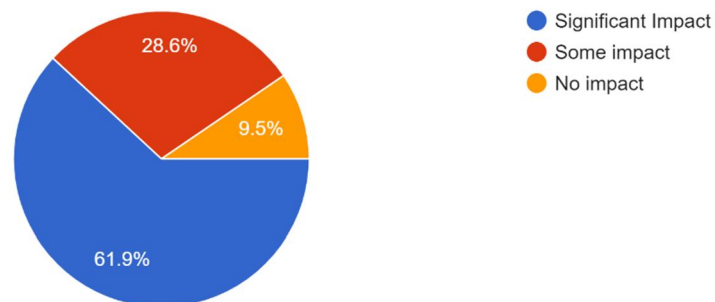
21 responses



Unsurprisingly, 81% said their physical condition worsened while having to wait for their operation.

9. What effect did the wait have on your general wellbeing, relationships and mental health?

21 responses



A worryingly high 90.5% of our respondents had their mental health, relationships and general wellbeing impacted by being on a waiting list.

Asked for more information relating to the answers above, we were told:

*'I can tell that my mobility is deteriorating, and I am now MORE at risk of falling than when the first application was made. The condition is obviously getting worse.'*



*'The ongoing pain had a significant impact in my day-to-day life, and on my mental state. However, knowing there was a light at the end of the tunnel did help compared to how I felt before being put on the waiting list.'*

*'Discussed with consultant and agreed on the best timings.'*

*'Felt very alone and depressed.'*

*'I feel I am unable to live my life. I can't plan things in case a date for surgery comes along and my symptoms mean I struggle to do normal things.'*

*'Luckily it didn't deteriorate too much but that was more by luck than clinical judgment.'*

*'Less mobility and more pain of course but I could still walk and knew the operation was in the pipeline.'*

*'Husband still waiting for 1st hip replacement which will be followed by a second one. The first hip has worsened resulting in more pressure etc being placed on the second hip which is now as bad as the first hip when first seen by a consultant. Quality of life severely impaired.'*

*'Pain prevents proper sleep.'*

*'It's just the awful dread of waiting for something that you hate and loath to happen i.e., surgery.'*

*'My mobility is greatly affected, and my pain continues to worsen. This resulted in me slipping into depression and anxiety with suicidal thoughts. I had to be treated by a mental health team and I still take antidepressants.'*

*'Mental health suffered greatly.'*

*'I experienced prolonged physical discomfort. Anxiety associated with fear of bouts of pain and discomfort as well as the changes I had to make to my lifestyle to accommodate my condition led to stress and poor mental health.'*

*'Had to sleep on my own on a sofa, couldn't go out, never knew if the op would go ahead, felt depressed and suicidal. Could only sit with my children when they came over. No life whatsoever, no support offered by NHS. Nobody cared - why couldn't somebody even phone when my op was cancelled to see how I was doing and to see if I needed some mental support and help at home?'*

*'Unable to walk / exercise.'*

*'I got really upset and depressed and felt that no-one cared. Put a real strain on my (30 year) marriage.'*

*'Mine was my mobility Having to use crutches and mobility Scooter before my surgery.'*

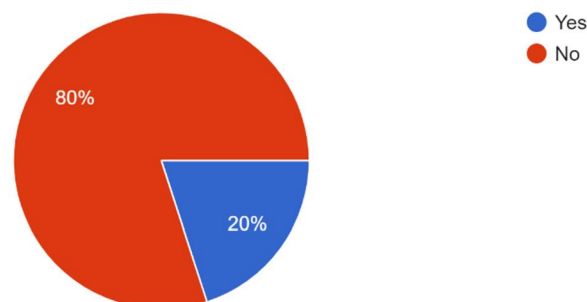
*'The pain I was experiencing grew worse and curtailed some of my physical activities.'*

*'Less able to get around.'*

Our final question was whether people know they can ask to be referred elsewhere if their wait goes beyond 18 weeks.

11. Did you know that you could be referred to a different hospital if you have waited 18 weeks or longer for treatment to start?

20 responses



A resounding 80% were unaware of this.

## 2.3 Interviews

Many people offered to talk to us directly and tell us about their stories in depth. We would like to thank everyone who took the time to talk to us and share their experiences. Names have been changed to protect identities.

### Case Study 1

‘Roger’ is 73 years old and has been told he needs a hip replacement. He was seen by a consultant 4 months ago.

His wife ‘Anne’ (who spoke with us) has failing eyesight and cannot drive until she can have a cataract operation. She has had one eye done but is waiting for the second one.

Roger initially had physio to try and heal his hip.

“He’s done all the physio. They stopped doing the physio because they said it was making it worse. He then had a course of hydrotherapy.”

“They stopped that after three visits and said that wasn’t making any improvements at all. He then got referred to a consultant who obviously did all the x-rays and said, yes, it’s wear and tear and they both need doing.”

“(His mobility) is not good. I mean, he’s managing to get around, but the problem is, it’s just compounding everything.”

“If they’re unable to get him to be seen quickly, then there’s some real problems and issues going on, because surely, he must be someone that should be at the front of the queue. It’s certainly getting him down, because he’s very active for his age. I mean, he normally plays golf once a week, but he can’t do that anymore. He likes his garden, et cetera. He’s getting quite down about it.”

“Also, I mean, we used to go for a walk every day around the village. We can’t do that now. As I said, really, he’s quite able bodied, I don’t know if it sounds silly, but he’s healthy, and we’ve never needed it (help) really.”

While all this is happening with her husband, Anne is trying to deal with her eyesight problems.

“I had my first one done on the 18th of June. But what particularly annoyed me was, when I went for my first test on March the 11th, I was asked specifically if I would mind going to

the Oaks Private Hospital, as they were trying to get everything done. It wasn't my choice. I didn't select it. They asked me if I would go, but I said yes of course."

"Then in June, got the appointment, had my cataract done, and it was at the general, not a problem. But I did say to them I had been asked to go to the Oaks. They then said, well, we were using the Oaks because we had such a waiting list. But we've now caught up and we're not using more outside resources. Fine. I had my eye done, brilliant."

"The consultant said to me after he did it that he would put me in straight away to have the other one done, but in the meantime I would struggle. I certainly struggled and I am struggling. I haven't heard anything. I've had my postop appointment at the opticians and everything's absolutely fine. I rang last week to see if there was any news on when I could expect an appointment, to be told that it wouldn't be done until next year now."

"I mean, the problem is, my husband obviously can't drive now. I wear spectacles obviously. I've got plain glass in the eye that was done, and a vary focal lens in the other one. I'm having real trouble. I've been back to the optician, and they said that it's, my brain is unable to cope with the fact that I've got one vary focal and one plain glass."

## Case Study 2

'Lorraine' had problems with her knees and over time they deteriorated, so she went to see her GP.

"I actually was referred to the hospital, I think, in November, and I actually didn't see my surgeon until the springtime."

"Yes, I suppose it was (a long wait). But at the time, I think, like most patients, you don't think anything of it. I think it was about five months."

"But the thing is, I never thought of it as being a long period. I don't know whether it is now, or whether I have no idea because you'll speak to patients who will say to you, 'you have no idea'. You just wait because there's nothing else you can do."

"I'll wait for my letters to come, so I couldn't tell you if it was good, bad, or indifferent. I just waited."

"The only other criticism I suppose that I've got, which is really... I don't think the system realises how it affects you as a patient. And that is when you get that far that you've got a letter to say that you're going in to have your surgery, and then you're told that you're not. Now, that happened to me a couple of times, and I don't think anybody behind the scenes realises what that causes."

"Because when you're in a situation like I was, where you're totally reliant on someone else taking you to the hospital, organising the fact that you're not going to be in your own home for a few days, and also, you've got to sort things out for when you come home.

And that really is infuriating, although I'm the sort of person who won't stress myself out over something I can't do anything about."

"I was lying next to somebody in the bed next to me on the day of my surgery, and she was in the hospital going to have her surgery that day and she was told to go home because it wasn't going to be done."

"And it wasn't me, but I just was lying next to a lady that it had happened to. And when the consultant left, she was so distressed because she went to tell me the fact that she's got a dog, that she had to organise that to be looked after, and she was just so stressed, bless her. And I just listened."

"I couldn't do anything. But I was fortunate. I was there and I had my surgery that day. But as I say, I don't think anybody behind the scenes realises how... It's not the fact that if you had two- or three-weeks' notice, but I think sometimes when you get that letter, or even that phone call because—don't forget you have to phone up at seven in the morning to see if that bed is available—you've made all the arrangements and to be told it's not... It's quite distressing."

"And I do wonder if anybody behind the scenes realises that."

### Case Study 3

'Valerie' is in her late 60's and had a fall outside her home. 'Nothing was broken', but she never felt quite right, and her hip gradually deteriorated. She visited her GP and was referred to hospital. She had to wait a month or two to be seen, but it was confirmed that she needed a replacement.

She was put on the waiting list, but they said they were unable to tell her when she would have the operation. She was just sent home and told to wait. She wasn't told what, if anything, she could do to help herself - physio or something similar.

After a while, she got a letter with a date for the operation, which immediately lifted her spirits - even though it was due to happen seven months after her initial hospital visit.

However, a few weeks before the operation was due, she got a letter telling her it was cancelled.

By this stage, Valerie was sleeping in her living room as she 'couldn't manage the stairs.' At first, she slept on the sofa, 'but that quickly proved impossible', so they took the sofa out and moved a single bed in.

The cancellation letter left her feeling depressed and she barely left the living room. Her overall physical health declined, and she argued with her husband as he wanted to get her up and about whenever possible. She felt unable to have anyone visit, even family.



She got another appointment through, 'but that was also cancelled'. The next date that was sent was again cancelled before she finally had the operation 18 months after her initial consultation.

Other than letters for the appointments and cancellations, she had 'no correspondence from anyone.' No calls from her GP, nothing from social care, no suggestions of physio or other wellbeing support. 'Nobody seemed to care', she 'felt invisible'. When she or her husband called the hospital, they 'got nowhere'.

Since the operation, her recuperation has been so much harder. Physically she had to start from scratch and mentally she has really struggled to rebuild friendships and socialise again.

## 3.0 Key Findings and Recommendations

### GP Surgeries and other referrers

- Information and guidance at first referral

Awareness of the options available to service users when they are first referred is very low and needs addressing. Over 57% of people in our survey were not aware they have a choice of where they are referred, and over 76% did not know they could find out about different waiting times at different hospitals.

With 84.2% saying they would or might have chosen to go elsewhere if they had known, this is a long way from the ICS pledge for “people to have planned and non-emergency treatment... in the place of their choice.”

GPs must work in close consultation with their patients to inform them of their choices right at the start of the process. Without knowing the options, patients cannot make informed decisions regarding their choice of treatment.

It's not just about waiting times. The ‘best’ choice for the patient can be strongly linked to convenience for their support network, public transport issues, anxiety from previous experience at a particular location and numerous other factors.

*‘Nobody ever tells you that you have any kind of choice, it's all so directive.’*

*‘I would have looked into other hospitals, especially surgeons.’*

- Ongoing support

Surgeries should liaise with their Care Advisors and maintain regular contact with patients while they are waiting, especially when planned procedures are cancelled or postponed. This will help ensure their wellbeing is always at the top of the agenda.

Visits to see and talk to patients or appointments for them to attend the surgery can be diarised, giving reassurance that they are still being cared for.

Support systems need to be put in place to ensure patients’ mental and physical wellbeing is managed as best as it can be while they are waiting. The right training to talk with them, and a good knowledge of local signposting services such as Healthwatch and others can help maintain their overall health.

*‘I would just say, to be honest, just very generally, I think my mental health and wellbeing was impacted. It was just on my mind all the time. It made it very difficult to*

*do anything. Even in terms of focusing at work and getting on with all sorts of things, yeah, just, it was very difficult.'*

*'I was really uncomfortable. I was in a lot of pain and discomfort. I couldn't eat properly at all, which just makes you miserable, to be honest. I'm not sure I'd really appreciated quite how unpleasant that would be.'*

*'My GP referred me, so a call from them to keep me updated, inform me of delays, check on my wellbeing and so on would have been great.'*

## Hospitals and treatment centres

- Cancellation letters

Departmental letters that cancel elective procedures should be written in an empathic way, including signposting patients to sources of help and support.

Ideally, letters should be backed up by a phone call to reassure people that they are not being discarded, they are still a priority, and everything is being done to get them in as soon as possible.

*'I got nothing, just a cold letter that op had been cancelled and booked for another date.'*

*'The ongoing pain had a significant impact in my day-to-day life, and on my mental state. However, knowing there was a light at the end of the tunnel did help.'*

## Holistic Approach

- Mind, body and spirit

The survey has highlighted that it is almost impossible to be on a waiting list, and at the same time carry on with life in a completely normal way.

To a greater or lesser degree, every element of daily life can be affected.

People are regularly left feeling lost, unable to get anyone to listen and unable to take back any control of the void they are suspended in.

Healthcare professionals must appreciate the ongoing back story of every patient and ensure their concerns are fully addressed and they get the right help and support, at the right time, and in the right way.

*'Felt very alone and depressed.'*

*'...slipping into depression and anxiety with suicidal thoughts.'*

*'Anxiety associated with fear of bouts of pain and discomfort as well as the changes I had to make to my lifestyle to accommodate my condition led to stress and poor mental health.'*

*'My mobility is greatly affected, and my pain continues to worsen.'*

## 4.0 Conclusion

By listening to the lived experience of people, family, carers, and friends, it is hoped that the findings in the report will help the Integrated Care System to identify areas of improvement to support their community and meet its future needs.

### Communication is key

Throughout this project, the need for information at the beginning of a person's journey, and communication between the healthcare providers and patients while they are on the waiting lists has come to the fore.

It is inherently distressing to have decisions taken out of your hands, to be waiting and waiting, feeling out of control while no one contacts you and to have no idea what's going on or if anyone really cares.

*'I was not made aware of these options.'*

*'I think to be honest, at that point I felt so awful that I just needed some reassurance that I was on a list, and maybe there was a little voice in the back of my head that was saying, you never know, you better check.'*

*'The staff that I interacted with initially there, were very rude and unhelpful, I have to say, through telephone. Trying to get through to somebody when you don't have a consultant's name was incredibly difficult, and, as I say, to the point of rudeness, really.'*

But it is clear this doesn't have to be the case:

*'I'm under a consultant who has always discussed timings and agreed when I should try and have the operation - she will organise it and book me in.'*

*'Kept completely in the loop throughout.'*

Implementing simple processes to ensure healthcare professionals keep in touch with patients through their journey, keeping them up to date and ensuring they have access to support and advice, will make them more comfortable physically and mentally and have positive outcomes.

It is evident from our engagement with participants that everyone hoped for a person centred, holistic approach from services during their wait for elective procedures, and that an integrated system across the North East Essex footprint is essential in ensuring this. Partnership working between health, social care, and the community and voluntary sectors is key, along with the assurance that the views and needs of the patient, and in turn their carers and loved ones, are sought, heard, and respected at every stage. Services working together will be fundamental to improving outcomes for all patients.



## Wellbeing

There is a clear correlation between time spent waiting for treatment, and the decline in a person's general wellbeing.

The acknowledgement of the importance of community wellbeing, and the investment made in programmes such as the Livewell Campaign and the Essex Wellbeing Service means that there are rich sources of holistic support available to all.

**The opportunity to embed a best practice regime of a person-centred approach, regular and appropriate communication, clearly defined options and qualified wellbeing support is there to be taken.**

## 5.0 Terminology

**Elective Care** - a term for routine, non-emergency care which can be planned or booked following a referral by a GP or an outpatient clinic.

**Health and Social Care Act 2012** - an act of the Parliament of the United Kingdom. It provided for an extensive reorganisation of the structure of the National Health Service in England.

**RTT** - Referral to treatment. Waiting times, which monitor the length of time from referral through to elective treatment. Monthly RTT waiting times data has been published since March 2007.

**ESNEFT** - East Suffolk and North Essex NHS Foundation Trust

**WSFT** - West Suffolk NHS Foundation Trust

**SNEE ICS** - Suffolk and North East Essex Integrated Care Services

**NHS Constitution** - is a document that sets out the objectives of the National Health Service, the rights and responsibilities of the various parties involved in health care, (patients, staff, trust boards) and the guiding principles which govern the service.

**Circa** - approximately

**Treatment Plan** - The road map that a patient will follow on his or her journey through treatment.

**Wellbeing** - 'Wellbeing' is a broad concept and is described as relating to the following areas in particular: personal dignity (including treatment of the individual with respect) physical and mental health and emotional wellbeing control by the individual over their day-to-day life (including over care and support provided and the way they are provided).