

Written evidence submitted by Healthwatch Suffolk

Healthwatch Suffolk: Who we are

As the independent “health and social care champion” for people in Suffolk, Healthwatch Suffolk has a core function to find out what local people think about their health and social care services, and to ensure those experiences are used to influence, shape, and improve services now and for the future. We are skilled and widely recognised in public engagement, co-production, evaluation, analysis, and communication.

Reason for submitting evidence

Whilst recognising the extensive efforts of the NHS to address the backlog of care, our own research shows that the support offered to people waiting for elective care does not adequately meet their needs, nor does it take into account the wider and long-term impacts that delays in treatment can have for people.

Our findings highlight why health AND care leaders must seriously consider how people’s needs can be addressed in a holistic way, and how communication can be improved to make sure people do not feel forgotten or isolated.

New NHS structures under Integrated Care Systems bring, in principle, opportunities to achieve this through effective system relationships between the NHS, social care and voluntary, community and social enterprise organisations and networks. We firmly believe that improvements can only come from brave decision-making, and integrated care systems working effectively, across all partners and sectors.

Taking action will help people to live well whilst they wait, and help with the avoidance of rapid deconditioning. We would like to see outcomes in local strategies centred around these wider determinants of people’s health and wellbeing, including (not an exhaustive list):

- Mental health and well-being
- Caring responsibilities
- Work and finances
- Social isolation and relationships.

This will require lasting, meaningful, and well-resourced connections with voluntary, community and social enterprise organisations that are well-placed to help the NHS and Adult Social Care to meet these needs.

Not taking action to address the wider impacts of people's extensive waits for care, and to improve communication with people whilst they are waiting across the NHS, will only serve to add pressure to other parts of our health and care systems. In essence, a status quo will have a significantly detrimental impact on the wellbeing of our population, both in the short and longer-term.

Summary of our findings

Our full report can be found on: <https://healthwatchesuffolk.co.uk/ourresearch/electivecare/>

What is the impact on people's lives?

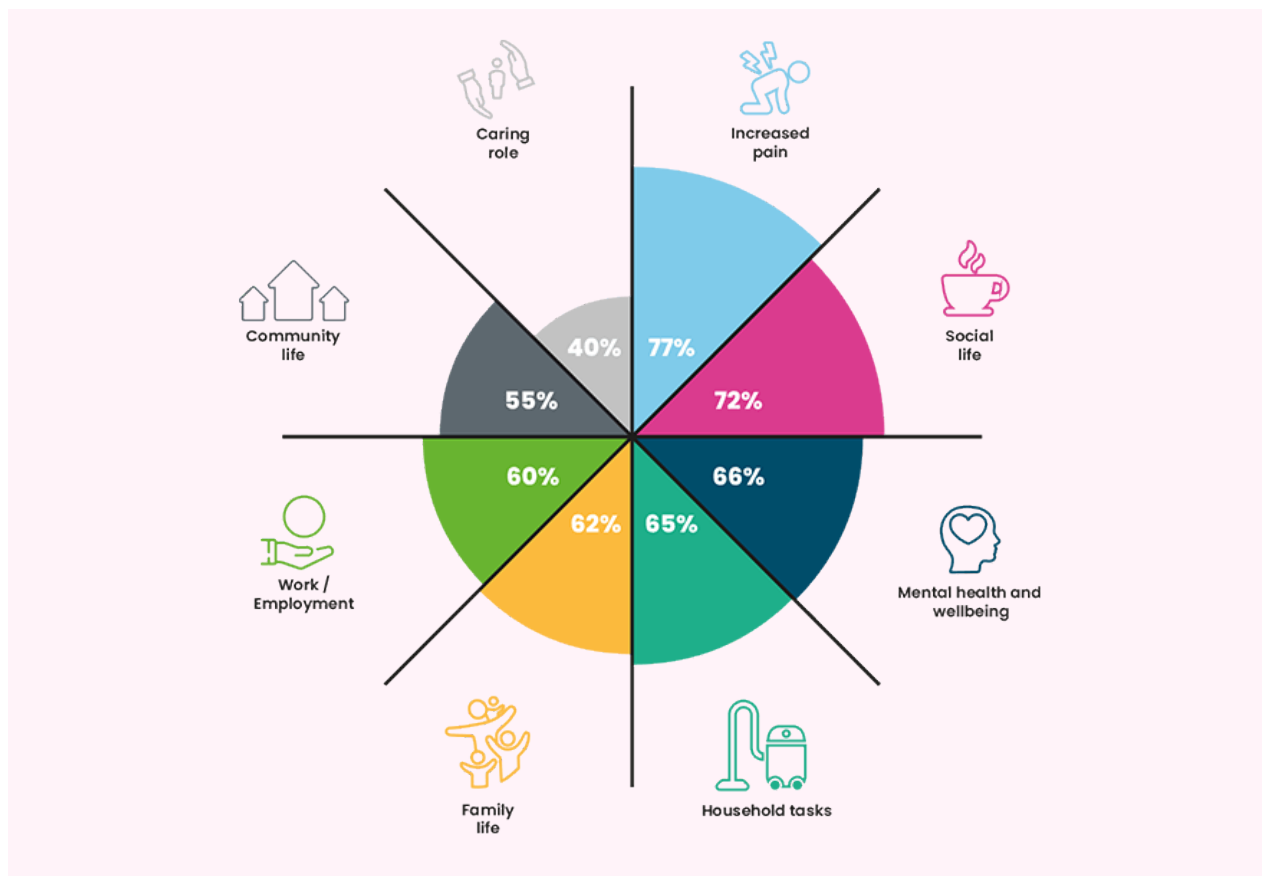
Overall, 62% (911) of the 1,462 people who responded to our survey felt their condition had become worse whilst waiting for treatment.

Respondents were asked what impact the delay in treatment had on eight key aspects of their lives:

- My ability to work
- My ability to carry out daily household tasks
- My ability to care for someone else or children
- Increased level of pain experienced
- Affected my mental health and wellbeing
- Affected my family life
- Affected my social life
- Affected my ability to be part of my community

On average, people reported at least **3.7** different aspects of their life had been impacted, and almost a third of respondents said six or more aspects of their life had been affected. Those waiting longest, those who said their condition had got worse, and people with 'vulnerabilities', were the most impacted groups.

Graph A shows the areas most affected.



Graph A

Comments left by respondents highlight the many ways in which their lives had been affected, often deeply, and with serious consequences for their mental health and wellbeing.

*“The pain that I experience causes me to **wish that when I go to bed I don’t wake up** to another day to face.”*

*“The pain has increased the longer I have waited, which has resulted in me having to **leave work** and made it difficult for me to continue with **socialising**.”*

*“I am in so much pain I can barely walk and get around even using a stick, I don’t go out anywhere not even to the shop to pick up a few groceries, I stay in my room all day, **I have no life, I have chronic depression**.”*

*“I am aware of how much the problem is visible through my clothing. I feel unhappy & worried about it. I am careful about the exercise I do because it gets in the way. **It has impacted my self-esteem & my relationship**. “*

*“I was stuck in bed in pain constantly. It took such a **toll on my marriage we ended up separating**.”*

*“The pain can be so unbearable that I am in danger of passing out or throwing up and so **cannot leave the house.**”*

*“It has made everyday tasks much harder and I’ve had to **rely on my teenage children to care for me.**”*

*“I am now frightened of eating. I look at a plate of food and filled with fear. The pain experienced and not being far from a toilet after eating significantly impacts my social life that I **no longer wish to socialise with friends.**”*

*“I am unable to do anything physical for more than about half an hour, and sometimes even visiting the local supermarket can be agony. This also **affects my ability to do gardening, decorating, housework, and car cleaning.**”*

*“My hands are constantly swollen and painful all the time. **Which prevents me taking part in anything in my local community.** I just want to stay in and not head out anywhere.” “I am an active retired man who is part of a few organisations and the pain.”*

*“I have an elderly parent who’s **care has suffered because of my pain.**”*

*“My social life now is non-existent. My friends and even now my family have **stopped including me in plans** because they assume I can’t take part because of my pain. I feel really isolated.”*

*“It’s hard for me to work but I have to go through the pain barrier as **I can’t afford not to work.**”*

Access to support

More than 80% had been offered some form of support whilst they were waiting, but only 39% felt they had access to the right help, and information (see Graph B).

There is a gap between the types of help offered to people, and the ways in which people’s lives have been impacted by their wait. For example:

- **16% (125)** of people who said their mental health had been affected were offered mental health support;
- **53% (489)** of people who said they had experienced increased levels of pain said they were offered support with pain relief;
- **8% (65)** of people experiencing difficulty with household chores were offered additional help from social care services, and only **6% (48)** said they had been offered help from a community or charity group.



Graph B

Inequality

Inequality was evident within some of our data. However, whilst our findings have synergy with other research, we are limited as to the conclusions we can draw from them because of low sample size.

Some key findings included:

- People waiting the longest were also the most likely to say they could not afford to pay for private treatment to be seen more quickly;
- 59% of people from multi-ethnic communities said they had been waiting more than a year, compared to 40% of those who were white;
- Respondents from multi-ethnic communities were more likely to say all aspects of life included in the survey (except community life) had been detrimentally impacted by their wait for treatment;
- A higher proportion of respondents with learning disabilities or autism were waiting for a first appointment (26%) compared to respondents with any of the other listed vulnerabilities, or those who had no vulnerability (16%).

- Respondents with any of the listed ‘vulnerabilities’ (e.g. having a diagnosed mental health difficulty, being a carer, or having a disability) were more likely to say hospital delays had impacted their lives;

Information and communication

Almost 50% said they had not been told how long they might have to wait. This increased to 67% of those waiting for a diagnostic procedure.

Communication has been a key challenge, with some respondents highlighting that not knowing about their wait had affected their mental health. Here are some of the ways people felt information, and communication, could be improved.

- **Information about waiting times** – Many people wanted improved information about their wait. People were often uncertain about the length of their wait, or how they were being prioritised. Some were not sure whether or not they remained on the list for treatment.
- **Regular updates and reassurance** – People often commented about the need for regular ‘updates’ on waiting times. Many noted the current absence of information, and how the stress and anxiety of ‘not knowing’ was having a direct impact on their mental health.
- **Consistency** – Some reported a lack of consistency in the information they had received from professionals and services (e.g., that staff advice differed to information in letters). Comments also highlighted a lack of communication between primary and secondary health care, and between departments.
- **Misleading language** – People reported that the language used by professionals involved in their care had been unhelpful at times, leading to the wrong impression about how their treatment was being prioritised.
- **Information about treatment** – Some people felt they needed more information about their condition or procedure whilst they were waiting (e.g. how symptoms might change whilst they are waiting).

Our Recommendations

1. Holistic management of people waiting for care

Our findings suggest that, if waiting is inevitable, we can help people to cope by improving dialogue with patients about how their wait for treatment and care is affecting their daily lives – and improving the support available to them.

People's lives have been deeply impacted by their wait for treatment. This has included living with increasing levels of pain and poorer mental health. People have also found it harder to care for loved ones, faced increasing social isolation, endured damage to their relationships with family and friends, and felt unable to be a part of their local community. Yet most people felt they had not been offered support or information to help them to address these impacts.

That is why we want the leaders of integrated care systems to think about how we can more effectively, and holistically, support people whose lives have been impacted by their waits for elective care. Much greater collaboration between hospitals, commissioners, and voluntary, community and social enterprise organisations around elective care management will help to ensure people's needs are met – including better provision of communication about local support available to people now.

Importantly, integrated care systems must also look beyond the 'end goal' of the treatment or care people are waiting for. Whilst patients may be physically improved, the wider impacts of their wait may have a lasting influence on their life for many years to come. Our health and care systems must act compassionately, and account for this longer-term impact in their developing plans and strategies.

Improvements can only come from brave decision-making, and integrated care systems working effectively across all partners and sectors.

2. Information and communication

A much-improved process of communication across the span of time people are waiting is needed. This should include defined opportunities to update people transparently about their wait, to check in on their condition and to remind people about the fullest extent of support available to them. This includes timely pre-op preparation advice.

Many people have noted that there is a need for improved communications from services about their wait for care, and this includes that the absence of information has had a detrimental impact on their mental health and wellbeing.

3. Inequality and data transparency

Our findings suggest that inequality may be leading to poorer outcomes and experiences for some groups, including people from multi-ethnic communities, people with disabilities, people with mental health concerns, and Carers.

That is why we are asking integrated care systems to further consider how different groups may be impacted more by their wait for care, and to identify specific ways to prevent inequality. In general, we

feel the ‘conversation’ about elective care waiting requires much more transparency and openness, to encourage better debate about addressing inequalities amongst those waiting for care.

The response to our findings

The response to our report by health and care leaders has been positive, and we have observed how the findings have influenced leaders thinking in Suffolk. However, there is a need to continue to drive for change in local approaches and policy.

The insights have encouraged leaders to acknowledge the people behind the waiting lists, and the extent to which their lives have been deeply impacted by their waits for care. It has also caused systems to reflect on the lasting consequences for people’s health, care and wellbeing - an aspect that had not been widely considered previously, but that is likely to affect the long-term management of population health and wellbeing by integrated care systems.

The report has been an important opportunity for leaders to dedicate some time to understanding more about the real-life consequences of hospital delays for local people, and their families/carers. We feel this is key to health and care systems having a compassionate response to people’s experiences, and to bringing about a different approach to how people are supported whilst they are waiting for care.

But there are practical next steps too. For example, we are starting to explore how our findings can be used by specific services (e.g., hospitals), and health and care commissioning structures, to inform local policies around elective care, and to improve the transparency, and frequency, of communication with local people.

November 2022