

Waiting times from Referral to First Appointment 2026

#LoveStHelens



Background

One of the recurring themes that we have identified from our patient feedback is the time it takes for people to see a consultant/specialist, after they have been referred for investigation or treatment.

We have also heard from colleagues and our Advisory Forum members that depending on the nature of the investigation/treatment, there is a huge variation in the time it takes to be seen.

Why we feel this area of work is important

We are aware that there is still a backlog with some services, due to the pandemic, however we would like to identify for which services patients are still waiting an unacceptable amount of time for an appointment.

Waiting an unacceptable amount of time for an appointment can cause unnecessary anguish and distress, which could potentially lead to poor mental health and wellbeing. In some cases, the patient's condition could worsen than if investigated sooner.

Our aim:

- To design a survey that will capture people's experiences, identifying which service they were referred for and how long they had to wait for their first appointment.
 - To identify whether waiting times are having an adverse effect on other areas of people's lives.
 - To produce a report of our findings which we will share with key partners and commissioners.
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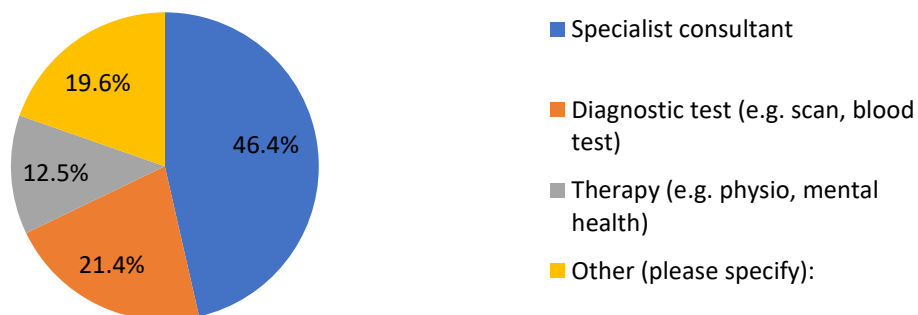
In May 2025, we held a Lunch and Learn session at the Totally Wicked Stadium, where we talked about our three priorities for the coming year, with waiting times being one of them.

The Survey

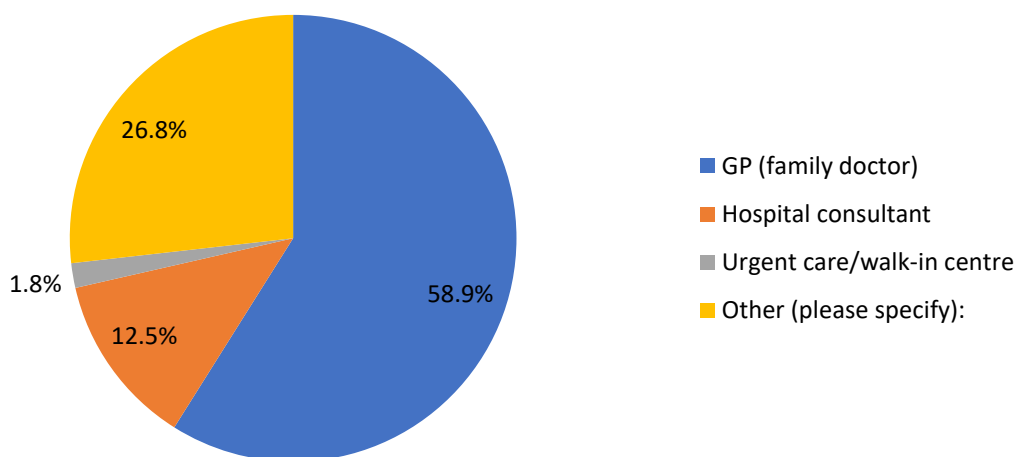
The survey was launched in September 2025 and ran until November 2025. We received 55 responses.

Results from the survey

What type of appointment were you referred for?

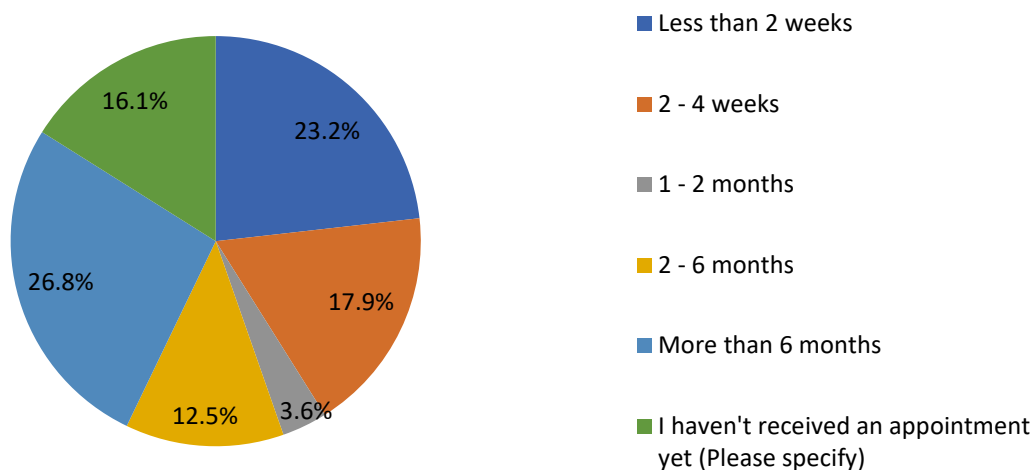


Who referred you?

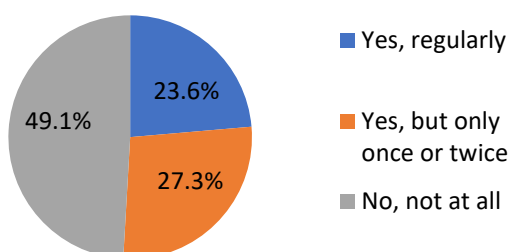


Where people answered 'Other', they were Talking Therapies Counsellors, other mental health professionals and one was a self-referral.

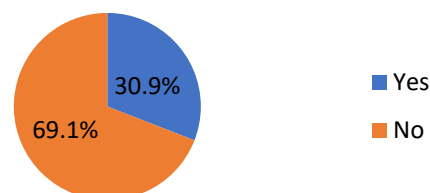
How long did you wait from referral to receiving your first appointment date?



Were you kept informed about your referral and waiting times?



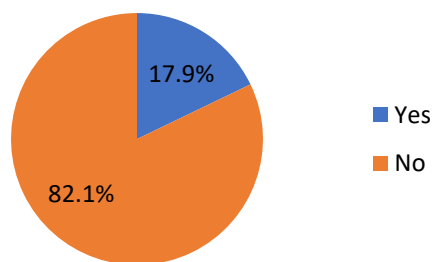
Have you been asked to contact the service if you don't receive an appointment within a certain timeframe?



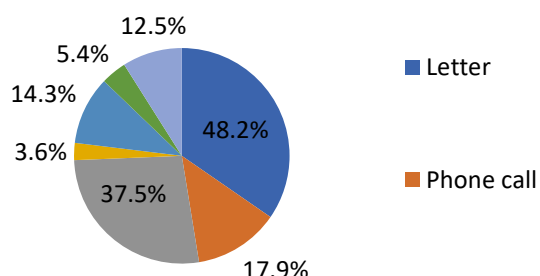
82% of the people who answered our survey were not signposted to any other service that might offer them support, while they waited for an appointment with a specialist.

Only 23.6% of people were kept informed about their waiting time and 69.1% of people were not advised to make contact within a certain timeframe if they had not received an appointment.

Were you signposted to any services in the interim?

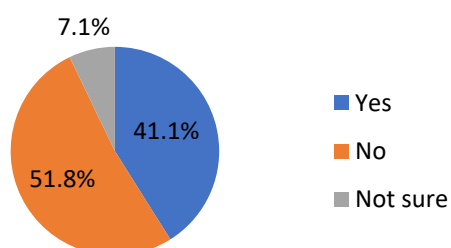


How did you receive your appointment information? (Tick all that apply)

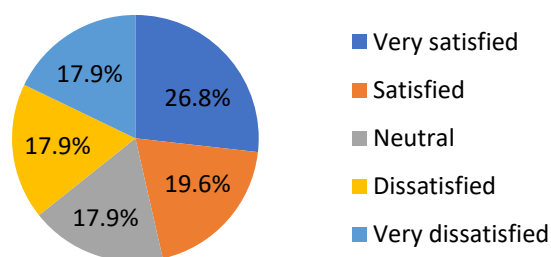


Only 17.9% of patients were signposted to another service that might be able to offer support during their wait.

Did you feel the time you waited was reasonable for your condition?



How satisfied were you with the referral process overall?



More than half of the people who answered our survey felt that the time they waited for their appointment was unreasonable.

Less than half expressed satisfaction with the referral process overall.

What you told us

We used artificial Intelligence to analyse the feedback from our survey.

Key Themes Identified

Theme	Examples from Responses	Frequency
Long waiting times and delays	Waiting 15 months, 4 years, 46 weeks; referral administration delays	Very common
Worsening physical symptoms	Increased pain, reduced mobility, bladder issues, infections, vision problems, deterioration of condition	Very common
Mental health impact	Anxiety, stress, frustration, worry, loss of confidence, deteriorating mental health	Very common
Increased medication use	More pain medication prescribed, reliance on co-codamol	Common
Impact on daily life and quality of life	Difficulty working, reduced mobility, self-esteem issues, effect on stoma management	Common
Poor communication and uncertainty	No acknowledgement of referral, having to repeatedly chase progress, uncertainty about waiting lists	Common
Perceived unfairness of the system	Others being seen sooner, concerns about referral pathways and prioritisation	Occasional
Seeking private treatment	Paying privately due to delays	Occasional
Positive management while waiting	GP support, diagnostic testing undertaken before specialist appointment	Rare

Most Common Impacts Reported

Deterioration in Physical Health

Many respondents reported that symptoms worsened while waiting, including:

- Increased pain
- Reduced mobility
- Ongoing infections
- Worsening vision
- Bladder problems
- Untreated symptoms

Mental Health and Emotional Wellbeing

The strongest recurring theme was anxiety and emotional distress:

- Anxiety
- Stress
- Frustration
- Worry about deterioration
- Loss of confidence
- Feeling unsupported

Several respondents specifically stated that lengthy waits made their mental health worse.

Lack of Communication

Respondents described:

- No acknowledgement of referrals
- Having to repeatedly contact services
- Uncertainty about where referrals were in the system
- Confusion caused by referrals being redirected between services

Impact on Everyday Life

Delays affected:

- Work and employment
- Quality of life
- Self-esteem and confidence
- Ability to carry out daily activities
- Family life and caring responsibilities

Example Quotes

"I waited over 4 years. I wasn't sure they even had my referral properly."

"My pain levels increased and it affected my mobility."

"Made me feel very anxious."

"It was stressful as my health was deteriorating."

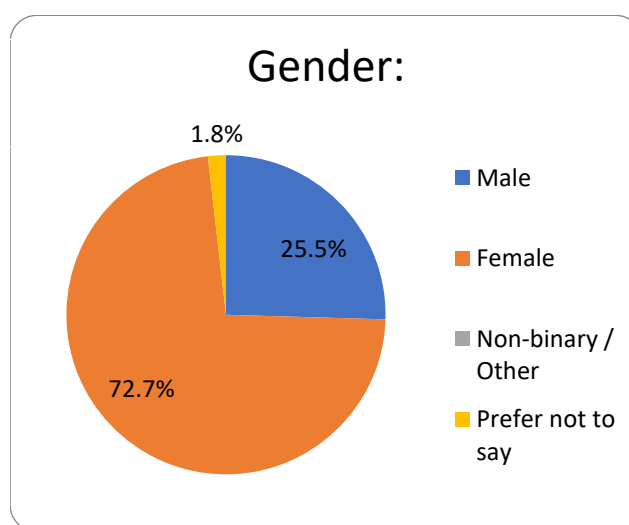
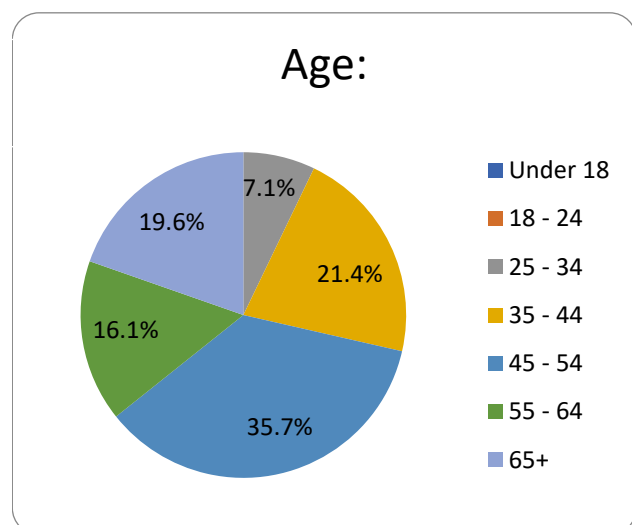
"The process seems a bit unfair."

Overall Summary

The overwhelming message from respondents is that long waiting times are not simply an inconvenience; they are contributing to worsening physical symptoms, increased anxiety and stress, greater reliance on medication, and reduced quality of life.

Many respondents also expressed frustration with communication and uncertainty around referral pathways, with some choosing private treatment due to NHS delays. A small number of respondents reported positive experiences where they received ongoing support from their GP while awaiting specialist care.

Who completed our survey?



Artificial intelligence made some suggestions.

Top priorities to fix

- Waiting times: Repeated calls to reduce delay from referral to first appointment, and between appointments. Some cite waits of 10+ months and 6 weeks for final letters.
- Communication and updates: People want acknowledgment of referral, estimated wait times, and periodic updates (even yearly) so they know they're still on the list.
- Signposting and referral routes:
 - Frustration with being sent to MSK first; preference for GP-led referrals when appropriate.
 - Allow intra-trust consultant-to-consultant referrals to avoid a GP “middle step” and losing place in the queue.
 - Enable appointment booking once a hospital/clinic is chosen.

Service experience

- Empathy and attitude: Some felt a lack of sympathy/empathy; one flagged the specialist's attitude. Others said “nothing to change, brilliant.”
- Access options: Online worked for some but may exclude those with limited IT/language/connectivity.
- Geography and admin: Confusion/concern when appointment communications came from another region (Midlands).

Specific suggestions from comments

- Provide information/advice while waiting (e.g., allergies), plus realistic wait-time ranges.
- Address DNAs by offering short-notice slots and better reminders.
- Maintain funding for specific services (e.g., long COVID).
- Ensure patients are seen in order added to the list (transparency on prioritization).
- Faster dispatch of diagnosis letters to GP and patient.

Quick wins

- Send an immediate referral acknowledgment with a wait-time range and how prioritization works.
- Monthly or quarterly “still on the list” updates via SMS/email; yearly at minimum.
- Publish typical wait times by specialty on the website and in letters.

We believe it's important that providers assess their own practices and evaluate whether waiting times are acceptable and if not, what can be done to improve the situation.

Local people tell us all the time, across the board, how important communication is and being kept informed so we would urge providers to develop systems that make patients feel as though they have some awareness of their potential waiting times.

Acknowledgements

We would like to thank:

- Everybody who completed the survey and shared their experiences.
- Everyone who helped to promote and distribute the survey.

The report will be sent to:

- Commissioners and providers
- Public Health St Helens
- The People's Board
- St Helens Place Partnership Board
- The Health & Social Care Scrutiny Committee
- Healthwatch England

Disclaimer

Please note that the information contained in this report does not reflect the opinions of staff or volunteers from Healthwatch St Helens. It relates entirely to the views and experiences provided by members of the public who completed our survey or told us their story.



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