

GP Referrals

Part Two

The referral journey.

2023

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Executive Summary

- Healthwatch England launched a national survey to gain insight into the process and peoples' experiences of getting a referral from their GP practice over the past 12 months.
- In Lincolnshire 56 respondents were referred for tests, diagnosis or treatment.
- 30% (17/56) of respondents had been referred previously for their symptoms/condition. There were two reasons why these respondents went back to their GP practice: their symptoms/condition had worsened/returned or they did not hear anything about the original referral.
- Whilst 52% (29/56) of respondents got their referral on their first appointment, 43% (24/56) were 'repeat visitors' meaning they had two or more appointments about their symptoms/condition.
- 36% (13/36) of respondents were referred in less than a month after first going to their GP practice about their symptoms/condition. However, for others it took months or even years.
- 60% (22/37) of respondents received confirmation that their referral had been accepted in less than a month. Though, others never received any confirmation that their referral had been accepted.
- Delays in the process resulted in 38% (21/56) seeking help from elsewhere:
 - 7 searched online,
 - 3 tried to get another appointment at their GP practice,
 - 3 called NHS 111,
 - 2 Went to a pharmacy, A&E or tried to contact the clinic directly.
- 89% (50/56) of respondents experienced consequences as a result of delays in the referral process:
 - 1 in 5 respondents (20% (11/56)) reported that their condition/symptoms got worse,
 - 13% (7/56) of respondents reported a decline in their wellbeing,
 - 11% (6/56) of respondents suffered ongoing pain,
 - 7% (4/56) reported increased costs or loss of income as a consequence of delays.
- 38% (21/56) of respondents were given information on why they were being referred.
- 1 in 5 (11/56) respondents were given information on how to manage their condition/symptom while waiting.
- Almost a third (16/56) of respondents were given no:

- Information on how to manage their condition, why they were being referred, the referrals process, their rights and choices and what to expect at the referral appointment
- Choice of appointment times, location and consultants
- Copy of the referral letter
- Estimate of when they would hear back about their referral or when they would be seen by the hospital/community clinic.
- 13% (7/56) of respondents had not heard anything further about their latest referral.
- When asked to rate their overall satisfaction with the referrals process, respondents answered as follows:
 - 82% (46/56) agreed that they were 'referred by the GP practice when necessary'.
 - 70% (39/56) agreed that they were 'referred by the GP practice without avoidable delay'.
 - 64% (36/56) agreed that they were 'referred to the most appropriate hospital/community clinic'.
 - 43% (24/56) agreed that they 'felt supported by the GP practice through the referrals process'.
 - 45% (25/56) agreed that they were 'given all the information I needed by the GP practice'.

Background

When people need help with symptoms or a health condition, their first point of contact is their general practice team. A range of skilled healthcare professionals such as GPs, nurse practitioners and paramedics work in general practice to diagnose and treat a wide range of conditions. They can also order tests and interpret results and refer people for more specialist or urgent care.

Some people visit their general practice with new symptoms and have no idea what is wrong with them nor have any expectations of what might happen next. Others may have an idea before contacting their general practice that they need a referral. It could be that this is a long-standing condition or recurring symptoms which they have been to their general practice about before, that a clinician at another medical setting told them to ask for a referral, they are experts in their own long-term condition or simply that they have some prior knowledge and clear expectations.

The patient journey from the initial appointment(s) about the symptoms/condition at their GP practice, to getting a referral, to attending the referral appointment can be a long one. The waiting times between many stages of this journey are not currently measured by national statistics. The only waiting time that is measured is the time waiting for the referral appointment (stage 4 outlined in figure 1). This suggests that behind the official statistics there are many 'hidden' waiting lists, that are not currently captured.

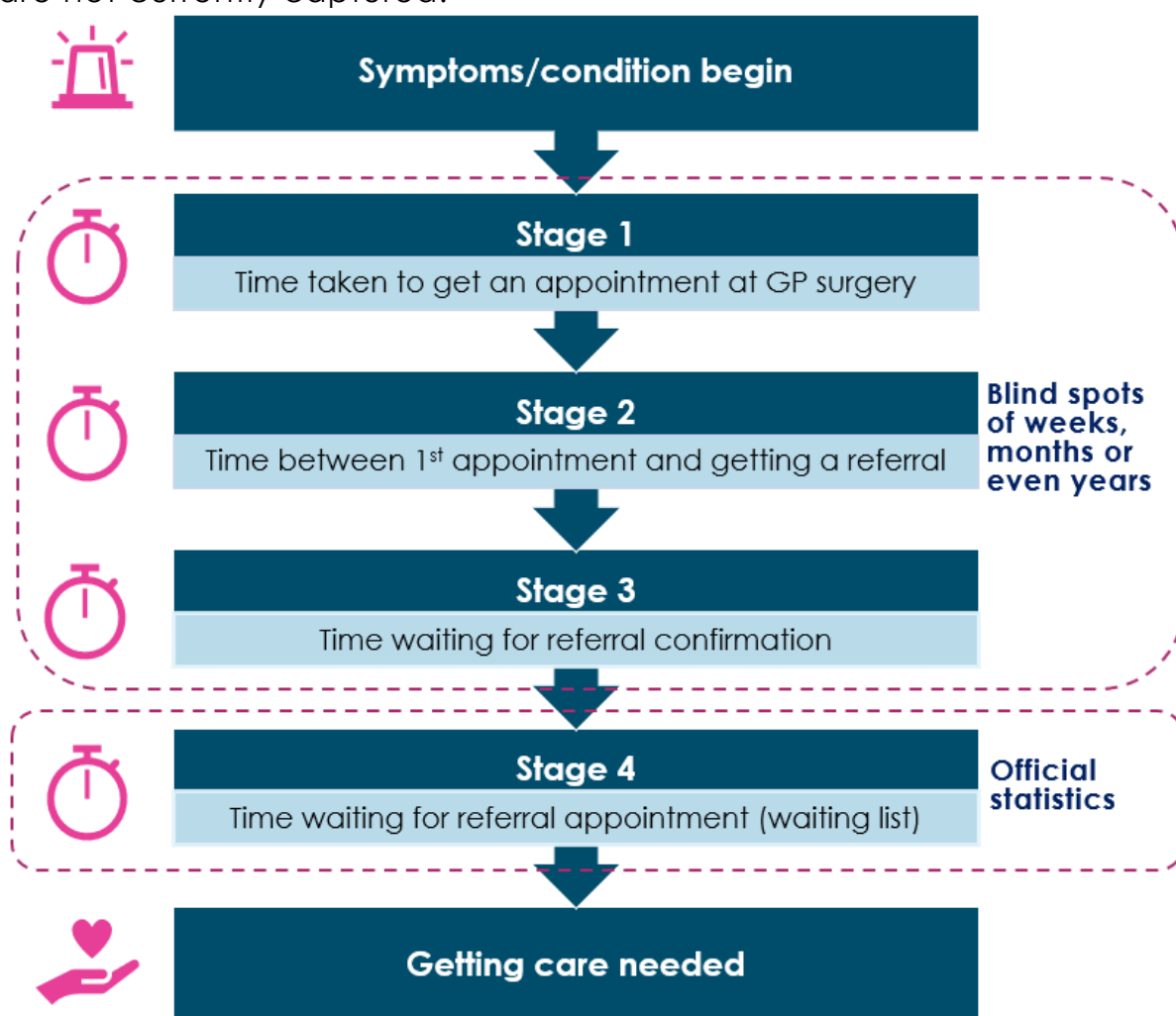


Figure 1: The journey to getting a referral appointment and the hidden waiting times

Indeed, existing [evidence and official statistics](#) from Healthwatch England, shows that even the journey to stage 1 can be a difficult and long one. Once referred, many patients spend long spells on a waiting list. However, the part of the referrals journey that is not currently measured is the time it takes to get that referral, or for the referral to be confirmed by the hospital or community clinic.

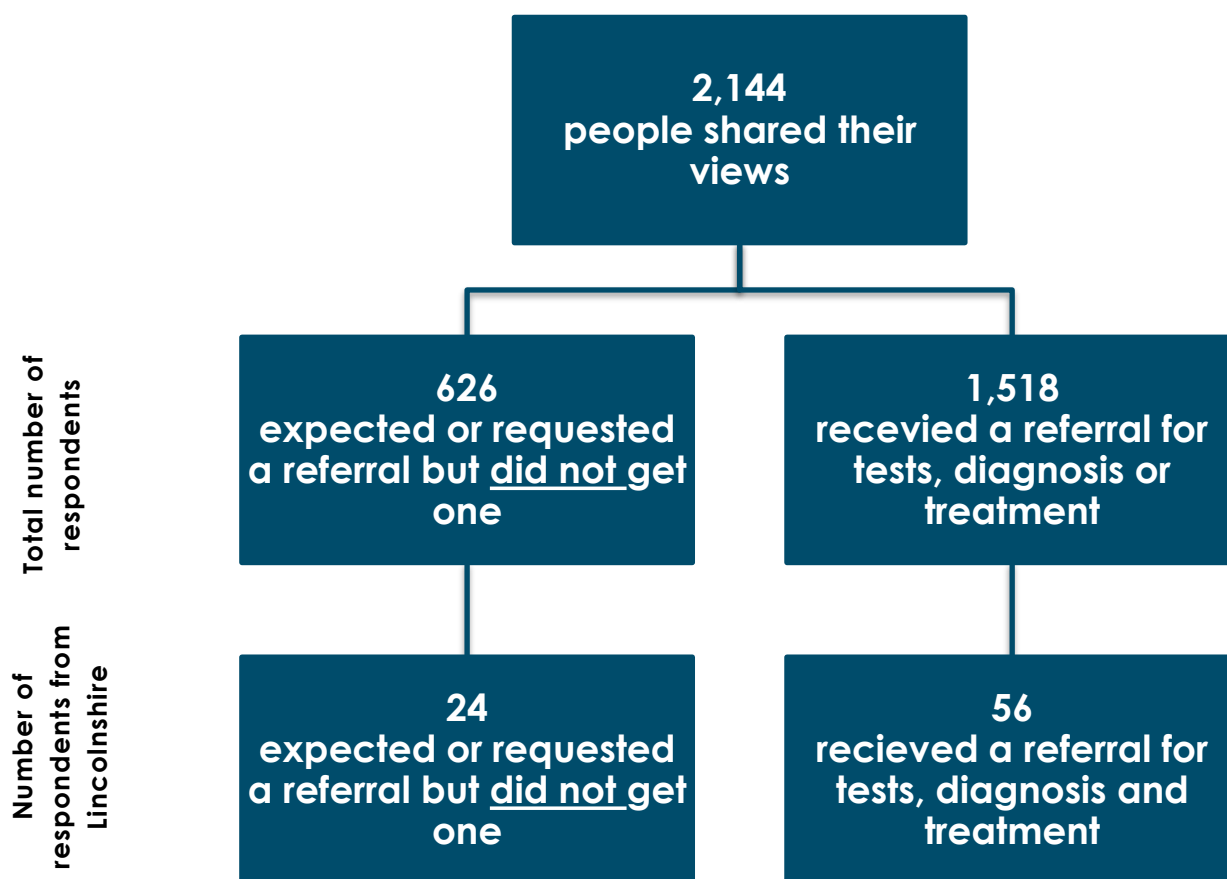
This report explores these 'hidden waiting lists'.

Overview

Healthwatch England commissioned [Panelbase](#) to conduct an online survey of two distinct groups who had an appointment with their GP practice in the past 12 months. The two groups were:

1. Those who either expected or requested a referral for tests, diagnosis or treatment, but did not get one
2. Those who were referred for tests, diagnosis or treatment

The survey was conducted during October 2022 and Healthwatch England also sent it out via their networks. In total **2,144** people shared their views. **80 of those respondents were from Lincolnshire.**



- Part one focused on those who expected or requested a referral but did not get one.
- This part two report focuses on those who received a referral.

Disclaimer

Owing to the small number of responses, both percentages and numbers are used throughout the following sections. However, numbers are given in brackets as a reminder of the relatively small sample size. The completion rate for this survey (i.e. the number of people who answered all the questions) was low meaning that whilst 56 people responded to the survey, not all 56 completed every question. All analysis is purely descriptive, no statistical analysis has been undertaken. We also acknowledge that due to the small sample size these findings are not likely to be representative of all those in Lincolnshire who have been referred for tests, diagnosis and urgent treatment. However, these experiences are still valuable and provide insight into referral journey and patient satisfaction with the process.

Findings

Out of the **80** individuals from Lincolnshire who completed the survey, **56 had been referred for tests, diagnosis or treatment in the last 12 months.**

Stage 1 – Initial appointment(s) at the GP practice

64% (36/56) of respondents had an appointment(s) at their GP practice about new/unexplained symptoms. The remaining 36% (24/36) had an appointment(s) about a pre-existing or known condition.

30% (17/56) of respondents had been referred previously for these symptoms/this condition.

There were two reasons why these individuals went back to their GP practice about their symptoms/condition. The first of which was that their symptoms/condition returned/worsened. This highlights the importance of timely care that meets the patient's needs.

The second reason was that they didn't hear anything further about the original referral. This highlights the need for effective communication between patients and services. When this communication breaks down it can place additional pressure on the system. This is because, as this data supports, these patients who do not hear anything about their referral, seek further appointment(s) at their GP practice which could be avoided with improved communication.

"It would be good to know the referral has actually been done. Because I'm just waiting, with no idea of when I'll be seen, despite it being a cardiac issue, which I would have thought would have been a more urgent issue than being told the waiting time was around a year!"

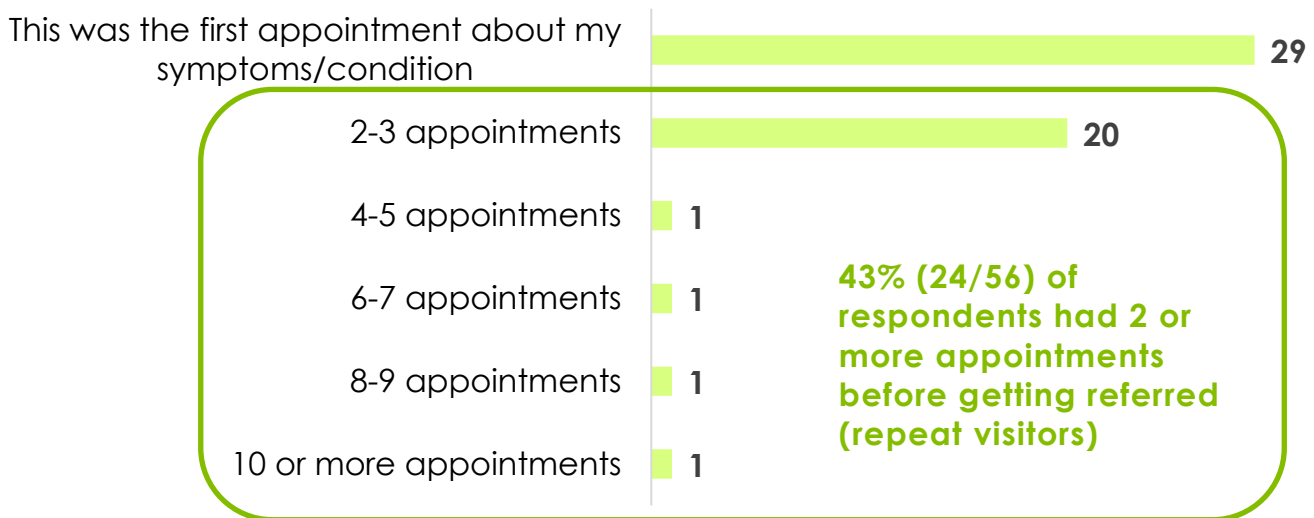
Stage 2 – Getting the referral from the GP practice

13% (7/56) of respondents were advised by a healthcare professional outside of their GP practice to ask for a referral.

52% (29/56) got their referral on their first appointment.

Most frequently respondents had only one appointment about their symptoms/condition before being referred. However, 43% (24/56) were 'repeat visitors' meaning they had two or more appointments about their symptoms/condition.

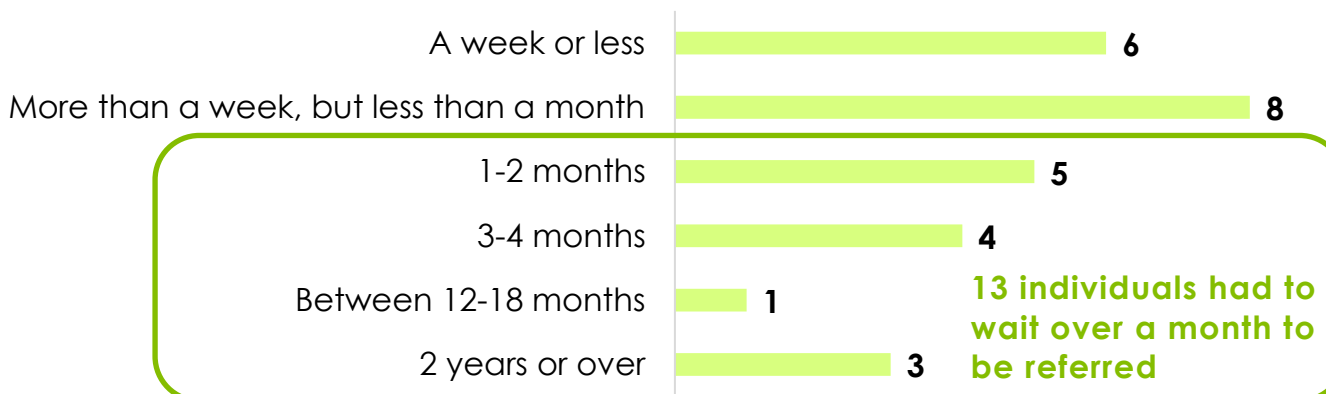
How many appointments (including this appointment) did you have with your GP surgery about these symptoms or condition?*



**3 individuals selected 'don't know/can't remember'*

36% (13/36) of respondents were referred within less than a month after first going to their GP about their symptoms/condition.

Time between 1st appointment at GP surgery about the symptoms/condition and being told that you were going to be referred.* (Stage 2)



**Please note that 36 respondents did not answer this question and an additional 3 selected 'Don't know/Can't remember'.*

The time between first visiting the GP practice about the symptoms/condition to being told that they are going to be referred (stage 2) is a 'hidden waiting time' and is not currently monitored or measured by official statistics.

Respondents were referred to a range of services, 5 respondents were referred to cancer specialists and surgical specialists and 1 respondent was referred to mental health services. The remaining respondents were referred to non-surgical services such as cardiology, neurology and gynaecology.

Stage 3 – Waiting for confirmation of the referral

Whilst patients are often relieved that they have been referred for tests, diagnosis or treatment, they have to wait again to receive confirmation that their referral to the hospital/community clinic has been accepted (stage 3). This waiting period is again another 'hidden waiting list' not currently measured by official statistics.

60% (22/37) of respondents received confirmation that their referral had been accepted in less than a month.

However, 5 respondents were waiting for over 3 months. Whilst waiting for the referral appointment respondents continued to experience their symptoms.

Delays in the journey to a referral appointment resulted in 38% (21/56) seeking help from elsewhere in the meantime.

The varying ways the individuals tried to seek help had differing impacts on the NHS.



Most commonly, (7) respondents sought help from the internet, which arguably does not directly affect the NHS as much as some of the other ways respondents tried to seek help. Others sought help from A&E, 111 and tried to get another appointment with the GP. All of which have a direct impact on NHS services. A full breakdown of the alternative ways respondents tried to seek help can be seen in Appendix 2.

**Please note that 19 respondents did not answer this question*

89% (50/56) of respondents experienced consequences as a result of delays in the referral process.

The consequences can be categorised as medical and non-medical.

1 in 5 respondents (20% (11/56)) reported that their condition/symptoms got worse.



13% (7/56) of respondents reported a decline in their wellbeing.



11% (6/56) of respondents suffered ongoing pain.

"I was in extreme pain but carried on at work. Didn't always feel really listened to by GP's"

The most frequently reported non-medical consequences of delays in the referral process, with each of the following being reported by 7% (4/56) respondents were losing income or increased cost, negatively impacted their ability to work and put pressure on relationships.

A full list of the consequences experienced by respondents due to delays in the referral process can be seen in Appendix 2.

As a result of not receiving timely care that met their needs, respondents faced real and varied consequences. It is therefore understandable why so many respondents tried to seek alternative help (as outlined above).

Few people are getting comprehensive advice, choices and information

38% (21/56) were given information on why they were being referred.

1 in 5 (11/56) were given information on how to manage their condition/symptom while waiting.

Almost a third (16/56) of respondents were given no:

- Information on how to manage their condition, why they were being referred, the referrals process, their rights and choices and what to expect at the referral appointment
- Choice of appointment times, location and consultants
- Copy of the referral letter
- Estimate of when they would hear back about their referral or when they would be seen by the hospital/community clinic



“Would appreciate some form of contact to know where I am on list that is If a referral has been made - on contacting surgery been told there is 12 month wait for echo cardio gram been waiting 8 months already.”

“Hospital sends a letter with a date to ring and all you get is a voice mail saying if you were ringing for an appointment they will get back to you. No timescale given.”

“After the initial telephone call asking which hospital I would prefer in June I have since heard absolutely nothing.”

Providing patients with information such as how to manage their symptom/condition whilst waiting and setting their expectations for timelines could reduce confusion, some of the consequences respondents faced (as outlined above) and the number of those who try to seek help from elsewhere.

13% (7/56) of respondents had not heard anything further about their latest referral.

“The letter to me came from a referral hub but never heard any more or received an appointment.”

Furthermore, 1 respondent disclosed they were referred to the wrong clinic and another, contacted the clinic only to be told they had no record of their referral. This poor communication could potentially result in some respondents going back to their GP practice and having to start this long journey all over again. In the meantime, this is likely to put additional stress on the system and the patients.

Overall Satisfaction of the referrals process

82% (46/56) agreed that they were 'referred by the GP practice when necessary'.

39/56 (70%) agreed that they were 'referred by the GP practice without avoidable delay'.

36/56 (64%) agreed that they were 'referred to the most appropriate hospital/community clinic'.



Whilst respondents agreed that the above three areas worked well, the process appears to breakdown and the areas respondents were least satisfied with were as follows:

Only 43% (24/56) agreed that they 'felt supported by the GP practice through the referrals process'.

Only 45% (25/56) agreed that they were 'given all the information I needed by the GP practice'.



The above again highlights the importance of ensuring patients are provided with sufficient information on 'how to wait well' as it could avoid many of the unnecessary negative consequences outlined above and patients trying to seek help from elsewhere. Both of which, to varying degrees, impact the NHS.

Please see Appendix 2 for a full breakdown.

When respondents were asked for their final comments, they highlighted the importance of services working together and good communication between services and to patients as being key to a smooth referral journey.

"The hospital and GP practice are consistently disagreeing on how the process works and telling me contradictory things. This shows there is a severe and dangerous lack of communication between the two branches of the NHS."

"Horrendous lack of communication & a 6 month wait for an URGENT referral from the hospital."

"All seems to be such a muddle previously couldn't fault NHS but there now seems to be extra layers of telephone calls emails texts and just go round in circles no urgency and maybe not urgent to them but the person in pain is feeling it urgent, blame game GPs blaming hospital and no sense of any urgency and thin the patient is often last in line of priority needs far better management the caring is there but the management is shockingly poor."

Recommendations

Millions of people are referred by their GP practice every year but current data does not allow for us to fully understand the experiences of patients while they go through the referral process. As outlined above the journey to a referral can be a long and complicated one, often with many 'hidden waiting times' which are not currently measured.

These 'hidden waiting lists' can lead to a range of problems. Some respondents faced long waits for their referral appointment and in the meantime they experienced a range of negative consequences which drove them to seek help from elsewhere. Both of which have varying impacts on the NHS.

Respondents were also rarely given information, timescales, or choices about their referral. This leads to referrals not always progressing as quickly as possible, and patients bouncing back to extremely busy general practices. Healthwatch England has suggested the following policy recommendations which aim to support staff and bring about changes to the referrals process to improve people's experience of moving from general practice to the care of a team in a hospital or community clinic.

Recommendation	Why is this change needed?	Who is responsible for implementation?
Add questions on the referral process to the GP Patient Survey.	There is currently no published national data collection covering people's experiences of referrals, or the time people wait for a referral. Additionally, data isn't collected on where referrals fail and bounce back to general practice for a new referral. NHS England should work with Healthwatch England to add questions on the referral process to the annual GP Patient Survey. This would ensure a greater understanding of the current patient referral journey and also support the development of baselines and KPIs for satisfaction over the longer-term	NHS England
Ensure all practices are using the e-referral services and improve the online	The GP contract ¹ states that GP teams must use the NHS e-referral service. However, the HSJ ² has recently found that 27 Trusts still do not have an electronic patient record system. Trusts and GP practices should prioritise full transition to electronic systems, supported by appropriate resource from NHS England. This will ensure that all referrals and	NHS England NHS Trusts General Practice Teams

¹ [General Medical Services \(GP\) Contract](#)

² [HSJ – Use of the electronic patient record system](#)

<p>referrals tracker for patients.</p>	<p>appointment data is stored centrally, and is accessible to the relevant services, minimising risk of referrals being lost or different professionals having contradictory understanding of where someone is on the referral pathway. It will also support improvements to online tracking and booking systems.</p> <p>Some of the respondents shared they received no information along with their referral. Some of these people have gone on to discover that the referral was never actually sent or received by specialist teams.</p> <p>Currently, patients can book their appointments through the online 'Manage My Referral' system, but only after they have already received their booking number, which most receive via letter. This system should be improved to ensure that patients and teams in general practice, referral management centres, and hospital admissions teams should all have access to the same centralised information about which stage of the referral process the patient has progressed to. This should start from the moment a GP agrees to make a referral, not after the referral is accepted by specialist teams. Information should also be available and shared with patients via other preferred communication methods where relevant, as noted in their care records.</p>	
<p>Offer flexible appointment slots in general practice to give people more time with clinicians.</p>	<p>Many of the respondents were 'repeat visitors'. Some of these patients will have required multiple appointments, but for others there may have been opportunities to refer more quickly.</p> <p>Additionally, the majority of respondents were given no information, timescales, or choice along with their referral. In some instances, this reduced the likelihood of referrals progressing directly to appointments or joining a waiting list. Both issues could be helped by the allocation of additional GP appointment time. This would give staff more time to provide patients with information about their referral, as well as more time to assess patients, potentially reducing the frequency of visits to general practice before onward referral.</p>	<p>NHS England</p> <p>Integrated Care Systems</p> <p>General Practice Teams</p>
<p>Improve processes for patients to contact NHS teams about their</p>	<p>More support should be given to help GP and hospital teams to reduce the numbers of people returning to general practice due to communication failures following a referral. As well as improving channels for the NHS to update patients about their referral, patients must also have access to care navigators in general practice and a single point of contact at their hospital (or another referral setting). This is so patients</p>	<p>NHS England</p> <p>Integrated Care Systems</p>

<p>condition following a referral.</p>	<p>can give feedback about their condition while waiting for care, without needing to book a new GP appointment. This includes whether they need to cancel or reschedule appointments or quickly chase up a referral if they have not received information about its progress.</p>	<p>General Practice Teams</p>
<p>Review NHS guidance related to the referrals process</p>	<p>Guidance on referral optimisation should be updated. Approaches such as 'advice and guidance' are currently being used across the country, but without shared decision making, patients can remain unaware that the process is underway and that they will either be contacted soon about a hospital referral, or treatment from the GP team. This leads to frustration, and their demand for healthcare moving elsewhere in the system. Consultant-to-Consultant referral guidance should also be updated. Over one in five people we spoke with had been told by another healthcare professional to ask their GP for a referral. This will include consultants in secondary care settings.</p> <p>The latest guidance relating to consultant-to-consultant referrals was published in 2018. This guide suggests scenarios where hospital consultants should recommend patients return to their GP for a referral, to ensure a holistic approach to care. However, since this guidance was published, median waits have more than doubled, and the people waiting the longest for treatment are being affected disproportionately. Patients such as those we spoke with could wait weeks for a GP appointment, months to join a waiting list, and now almost a year for their hospital care. Where once a holistic approach may have been advised for some referrals, more timely access may now be preferred by patients.</p>	<p>NHS England</p>
<p>Review pathways for which additional roles in primary care can refer</p>	<p>With the expansion of primary care teams to include more nursing staff, pharmacists, and physiotherapists, the NHS should review the roles and responsibilities of these staff. This includes which team members may be able to support integration of NHS services by referring patients for some conditions. We know that patients in some instances are happy to see the most appropriate health professional, and where possible, these teams (under the supervision of the GP) could support increasing demand for care by referring on.</p>	<p>NHS England</p> <p>Integrated Care Systems</p>

Conclusion

The patient journey from the initial appointment(s) about the symptoms/condition at their GP practice, to getting a referral, to attending the referral appointment can be a long one. The waiting times between many stages of this journey are not currently measured by national statistics. The only waiting time that is measured is the time waiting for the referral appointment. This suggests that behind the official statistics there are many 'hidden' waiting lists, that are not currently captured.

To gain insight into the referral process/journey Healthwatch England commissioned Panelbase to conduct a survey during October 2022. 2,144 people shared their views with 80 respondents being from Lincolnshire. 56 of these individuals had been referred for tests, diagnosis or treatment in the last 12 months.

Just over half (52% (29/56)) of respondents got their referral on their first appointment. However, the remaining respondents were 'repeat visitors' meaning they had two or more appointments about their symptoms/condition. Over half of the respondents then had to wait over a month to be referred with 3 respondents having to wait for over 2 years.

This is just the beginning of the journey for most patients, with respondents having to wait again to hear if their referral had been accepted by the hospital/community clinic. Whilst the majority of respondents received this confirmation within less than a month, others were waiting for over 3 months.

These delays resulted in respondents seeking help from elsewhere, all of which had a varying impact on the NHS. Most commonly respondents searched online whereas others tried to get another appointment at their GP practice, called 111 or even visited A&E. It is easy to understand why some respondents tried to seek help from elsewhere, when delays in the referral process resulted in 89% (50/56) of respondents facing a range of medical and non-medical consequences. These consequences included suffering ongoing pain, seeing their symptoms/condition worsen, increasing costs or loss of income and straining relationships with loved ones.

Some of the above consequences could have been potentially avoided if all respondents had been provided with information on how to manage their symptoms/condition and given estimates of waiting times and timescales. It was also these areas that scored lowest amongst respondents when asked to rate their overall satisfaction of the referral process. With just 43% (24/56) agreeing that they 'felt supported by their GP practice through the referral process' and 45% (25/56) agreeing that they were 'given all the information I needed by the GP practice.'

It was positive to see that 82% (46/56) agreed that they were 'referred by the GP practice when necessary' and 70% (39/56) agreed they were 'referred by their GP practice without avoidable delay'. However, as discussed, this is just the beginning of a long journey for many patients. A journey with many 'hidden waiting times' which can, if patients do not receive timely care or support to manage their symptoms/condition whilst waiting, lead to a range of negative consequences.

These findings have also allowed Healthwatch England to make several recommendations to improve patient's experiences. These recommendations include adding questions on the referral process to the GP Patient Survey, improving processes for patients to contact NHS teams about their referral and reviewing NHS guidance relating to the referrals process.

Demographics – Who shared their views?

Due to the small numbers, only numbers not percentages are listed in the tables below.

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)	Expected or requested a referral for tests, diagnosis or treatment but <u>didn't get it</u> (NOT REFERRED)
	56	24
Age		
18-24	0	2
25-49	3	9
50-64	11	4
65-79	36	9
80+	6	0
Prefer not to say	0	0
Gender Identity		
Male	17	8
Female	36	16
Non-binary	0	0
Prefer not to say	3	0
Gender identity the same as sex recorded at birth		
Yes	53	24
No	0	0
Prefer not to say	3	0

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)	Expected or requested a referral for tests, diagnosis or treatment but <u>didn't get it</u> (NOT REFERRED)
Sexual orientation		
Heterosexual / Straight	45	18
Bisexual	1	1
Asexual	6	2
Lesbian / Gay woman	1	0
Prefer not to say	2	1
Which of the following statements apply to you?		
I am a carer	6	3
I have a disability	16	6
I have a long-term condition	33	13
I am neurodivergent (Autistic, ADHD/ADD, Dyslexic, Tourette's etc.)	0	4
None of the above	15	8
Prefer not to say	0	0
Ethnicity		
White: British / English / Northern Irish / Scottish / Welsh	49	23
White: Any other White background	2	0
Another ethnic background	1	1
Prefer not to say	3	0

Over the last 12 months, which of the following has applied to you?	Referred for tests, diagnosis or treatment (REFERRED)	Expected or requested a referral for tests, diagnosis or treatment but <u>didn't get it</u> (NOT REFERRED)
Current financial situation		
Very comfortable (I have more than enough money for living expenses, and a lot spare to save or spend on extras or leisure)	1	1
Quite comfortable (I have enough money for living expenses, and a little spare to save or spend on extras or leisure)	28	11
Just getting by (I have just enough money for living expenses and little else)	22	9
Really struggling (I don't have enough money for living expenses and sometimes run out of money)	0	2
Prefer not to say	5	1
Not known	0	0
Highest level of education completed		
None	1	0
Primary (left school before/ at 11)	0	0
Secondary (left school before/at 16)	16	3
A-levels, high school or equivalent	8	6
Post-secondary vocational/ technical	12	3
University (1st degree)	5	5

Postgraduate (2nd or further degree)	5	6
Prefer not to say	7	1

Appendix

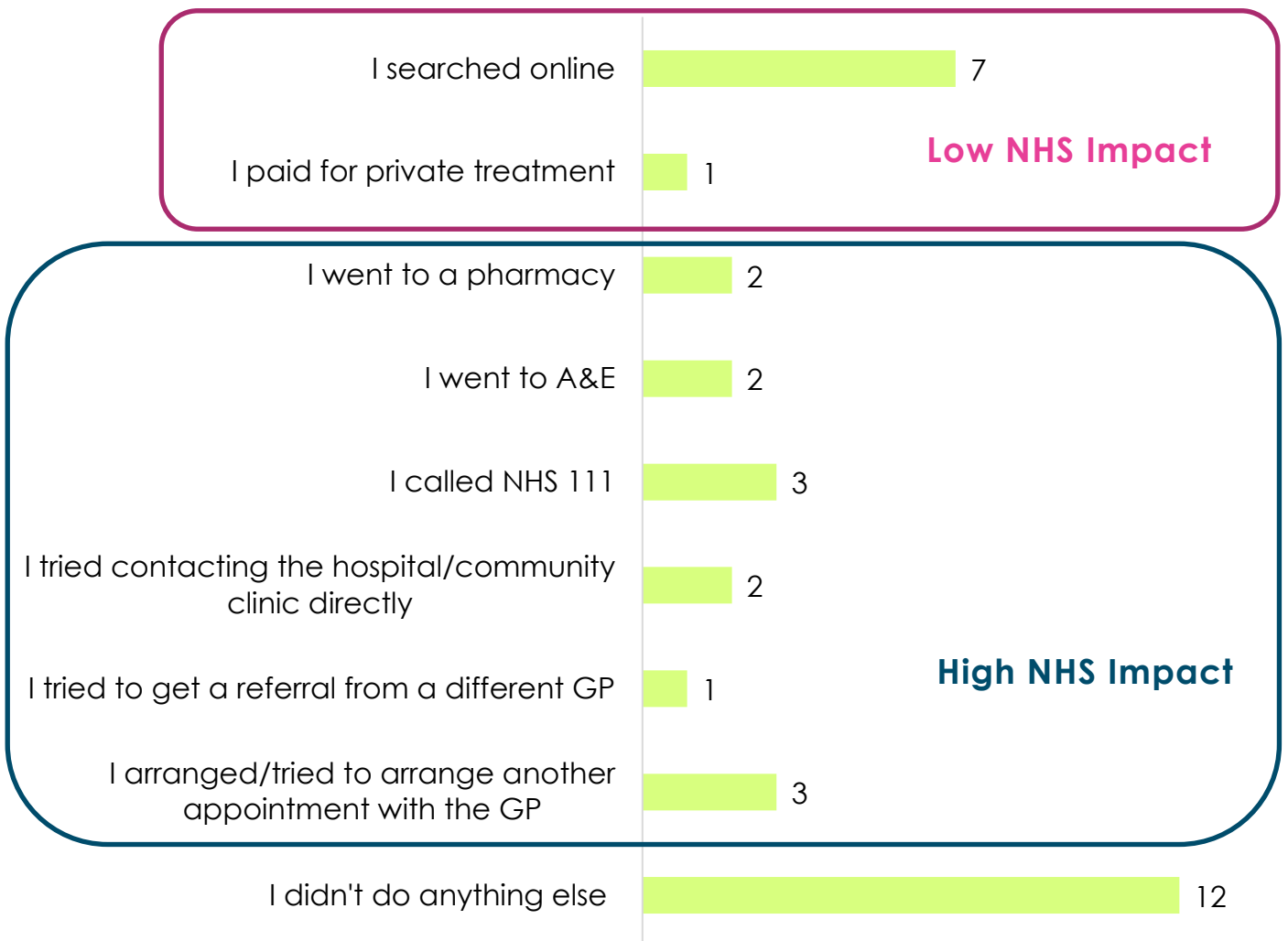
Appendix 1 – Methodology

Information from Healthwatch England

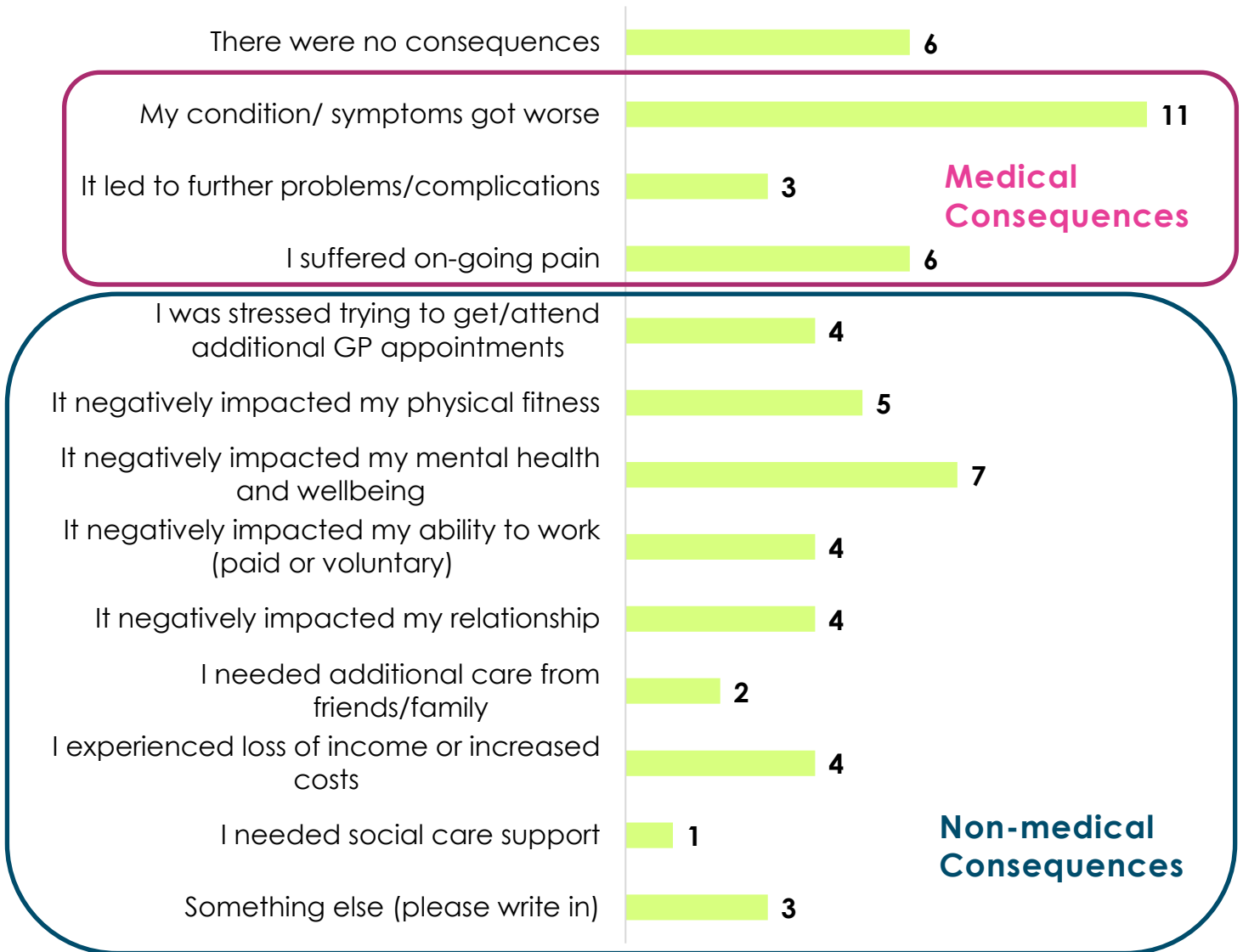
Survey 1	
Fieldwork	29 September to 20 October 2022
Supplier	Panelbase DRG
Methodology	Online survey
Sample	The sample size for the whole survey was 2,144, but the base for group covered in this briefing is 626 people who did not get a referral. We set minimum quotas for ethnic minority and financial status. The figures quoted in this briefing come from this survey.
Questionnaire design	The survey covered numbers of visits to the GP, including whether they were return visits for an existing condition and reason for the return visit. It explored why patients think they may have not got, or been refused a referral, the impact it had on them and what alternative actions they took to get the desired medical attention. The survey also explores the experience of getting a referral for those that got one, including what information they were given, wait times, impact of any wait, what alternative actions they might have taken for past failed referrals and what the outcomes were.
Survey 2	
Fieldwork	22 August to 11 October 2022
Source	Healthwatch England
Methodology	Online survey
Sample	The sample size for the whole survey was 1,825, but the base for group covered in this briefing is 367 people who did not get a referral. The comments quoted in this briefing come from this survey. The survey was distributed online by our local Healthwatch network, and respondents are self-selecting.
Questionnaire design	Identical to the Panelbase survey, except that the demographic questions are at the start of the survey to facilitate quota checks.

Appendix 2 – Additional Data

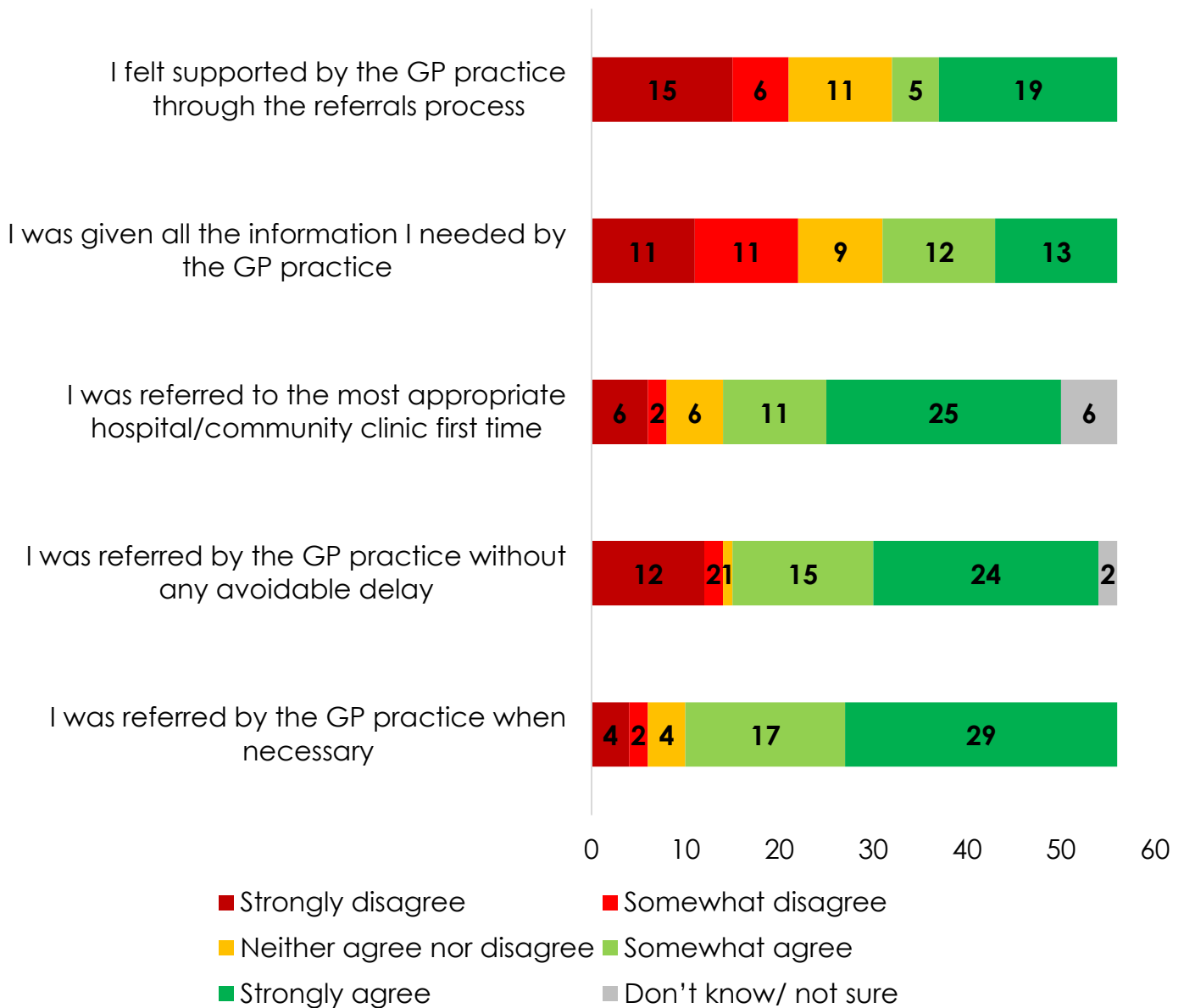
Graph 1 – The alternative ways respondents tried to seek help whilst waiting for their referral appointment



Graph 2 – The consequences as a result of delays in the referral process



Graph 3 – Overall respondent satisfaction with the referral process



Numbers rather than percentages have been plotted on this graph. The percentage of people who 'agreed' with a statement was calculated by adding the number of people who selected 'strongly agree' and 'somewhat agree' together, divided by 56 and multiplied by 100.



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