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Prostate Cancer Patient Experience Review 2025
Survey Feedback Report

13 January – 03 March 2025

Introduction

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The purpose of this report is to:

1. To provide an overview of our engagement activities undertaken between January –March 2025 to gather feedback from patients regarding their experiences of Prostate Cancer Pathway in Lincolnshire.
2. To present findings from our survey to that will be reported into the Cancer Board and Prostate Cancer Stakeholder Group for consideration

Following feedback received through patient experience and the Living with Cancer Strategy 2023-28 engagement, the prostate cancer pathway was identified as an area of focus that required review.

This project sought to investigate and identify current/recent patient experience and to work closely with patients, carers, clinicians and others involved in the delivery of this service to improve the care, treatment and advice that patients receive.

The feedback received has been analysed across all population groups and equality categories. Where they exist, differences are highlighted within the report.

868
responses the survey

209
Volunteers wishing to be more involved in the project

Executive summary

Some differences were identified for those with a disability and by geographical area, these have been highlighted throughout the report.

Based on the demographic data provided, the highest level of response came from people living **in East Lindsey** and **North Kesteven,** and those **aged 70-79.**

22% (186) of the total respondents were referred for tests but **received a clear/negative result**. 89% (519) of the 586 respondents diagnosed with prostate cancer are **coping very well/well.**

Signs and symptoms

- **Needing to pee more often, often during the night** was the most common symptom experienced by just under **one half (47%)** of respondents that made them visit their GP. **32% (212)** of respondents had **no symptoms.**

Information and advice

- Most information was received on physical aftereffects with 73**% (340)** of **468 respondents** stating they had received this. Respondents told us they would **have liked more information around physiological and emotional aspects of living with cancer.** Better access to information and **advice for family/friends/carers** is key as well as more information and advice on **diet and lifestyle**.

Impact of treatment and long-term side effects

- Out of 305 respondents who have received treatment, **86% (265)** said they were **fully aware/ aware** of the possible side effects prior to treatment. **12% (38)** were **not very aware/aware at all.**
- **52%** of 301 respondents said they were **fully** able to discuss options for managing the impact of long-term side effects with a member of the care team. **21%** would have **liked more support** and **17%** said they **were not able** to discuss options
- Knowing the side effects now, **85% (246)** would have **still gone forward with the same treatment option. 7% (20)** would have **liked more advice** on other treatment options and **3% (9) would not** have gone forward with the **same treatment option** and 5% don't know.

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Section 1

Overview of engagement and promotion

Survey promotion

The survey was available in different formats on request as well as being available on the NHS Lincolnshire ICB and other partner websites. The NHS Lincolnshire ICB Engagement Team produces a fortnightly bulletin which is distributed to a variety of community and voluntary groups, Patient Participation Groups, support groups, stakeholders and people who have subscribed via the NHS Lincolnshire ICB website.

Information and the link to the survey was promoted in the ’This week's hot topic’ section of the engagement bulletin and was distributed to around 10,000 contacts on the ICB engagement team's stakeholder database.

The survey was regularly promoted through various channels including:

- 4733 mailshots posted directly to patients who have been referred for a prostate cancer diagnosis in the last 5 years.
- Posters with QR codes shared with Lincolnshire’s PPGs/GP Practices and pharmacies in Lincolnshire.
- Posters with QR codes and links handed out during other activities by the Cancer Team.
- Targeted social media posts to males aged 60+. Shared with Trusts’ accounts, as well as requests sent to Lincolnshire partners to share and extend the reach.
- Featured in **3** fortnightly NHS Lincolnshire ICB engagement bulletins and **2** Primary care bulletins and **1** Team Talk News.
- Nextdoor online forum - the total reach of the NHS Lincolnshire ICB Nextdoor account is 110,269 members spanning across 471 ‘neighbourhoods’ enabling us to reach a variety of communities, villages and towns across Lincolnshire.
- Providers’ member databases and staff networks.

Promotion of engagement

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Did you know?

Prostate cancer affects 1 in 8 men, but if we catch it early then it's more likely to be cured.

If you, your partner, family member or someone you care for has ever been diagnosed with **prostate cancer**, please spare a few minutes to complete our survey. We also want to hear from you if you have been referred for tests and had a negative result.

To complete the survey, scan the **QR code** or visit: **bit.ly/ProstateCancerSurvey**

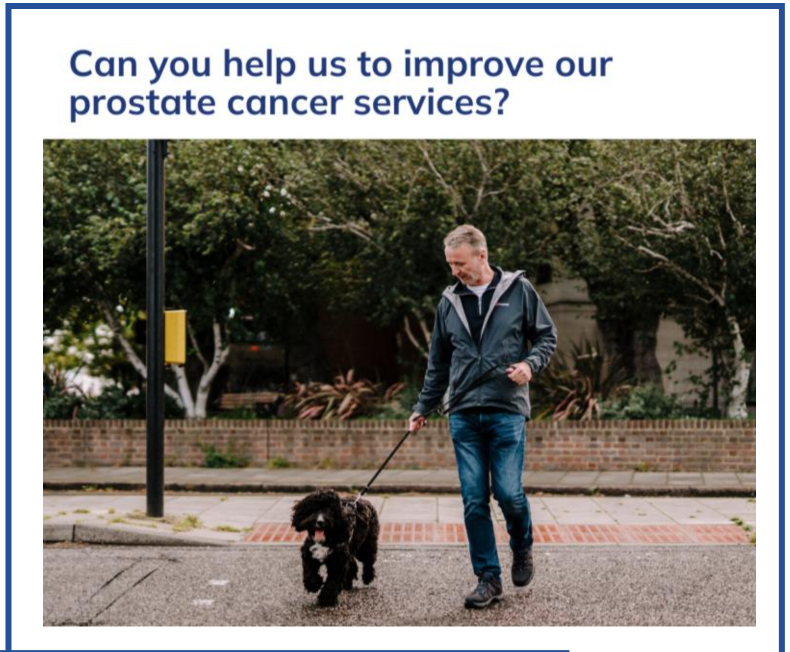
SCAN ME

If you need help completing the survey, require a different format or need the survey in another language please contact the Engagement Team at the NHS Lincolnshire Integrated Care Board via email at **licb.involveus@nhs.net** or call **07814 939396**

Posters

The NHS Lincolnshire ICB Communications team created a leaflet to provide a versatile and tangible means to:

- Build awareness of the survey
- Signpost/link people to the survey
- Leaflets were also left at several venues across Lincolnshire



Can you help us to improve our prostate cancer services?

Social media and website activity

NHS Lincolnshire ICB Communications team's used Facebook to push traffic towards the survey on the website. The team posted:

5 Facebook posts, reaching 13,396 people and generating **157 engagements**

339 people visited the webpage - Review of patient experiences on the Prostate Cancer Pathway - Lincolnshire ICB

They also drafted posts in the system Hootsuite to enable providers to duplicate and share across their channels and tagged in providers to some of the posts which were shared across provider organisations.

Promotion of engagement

The below groups received the distribution via NHS comms cascade or the engagement bulletin:

Audience	Distribution
Group identified by the co-production group	Men’s sheds/men groups Sports groups Veterans Prostate cancer support group CERG
Community stakeholders including volunteer groups, support groups etc. via the engagement bulletin	LPFT involvement database— 430 (service uses, carers, staff, voluntary sector reps & public supporters) Cancer groups Community, voluntary and support groups BAME communities LGBT Communities Carers Older people groups Young people groups Eastern European communities Disability groups (mental and physical)

Audience	Distribution
Health Partners	NHS Providers Lincolnshire Resilience Forum Community Connectors Neighbourhood leads
District Councils inc. elected members and staff	City of Lincoln Council Boston Borough Council East Lindsey Council West Lindsey Council North Kesteven Council South Kesteven Council South Holland Council
Local Employers	University of Lincoln Anglian Water The Environment Agency
Public sector providers	Lincolnshire Police and Crime Commissioners Lincolnshire Police Lincolnshire Fire and Rescue

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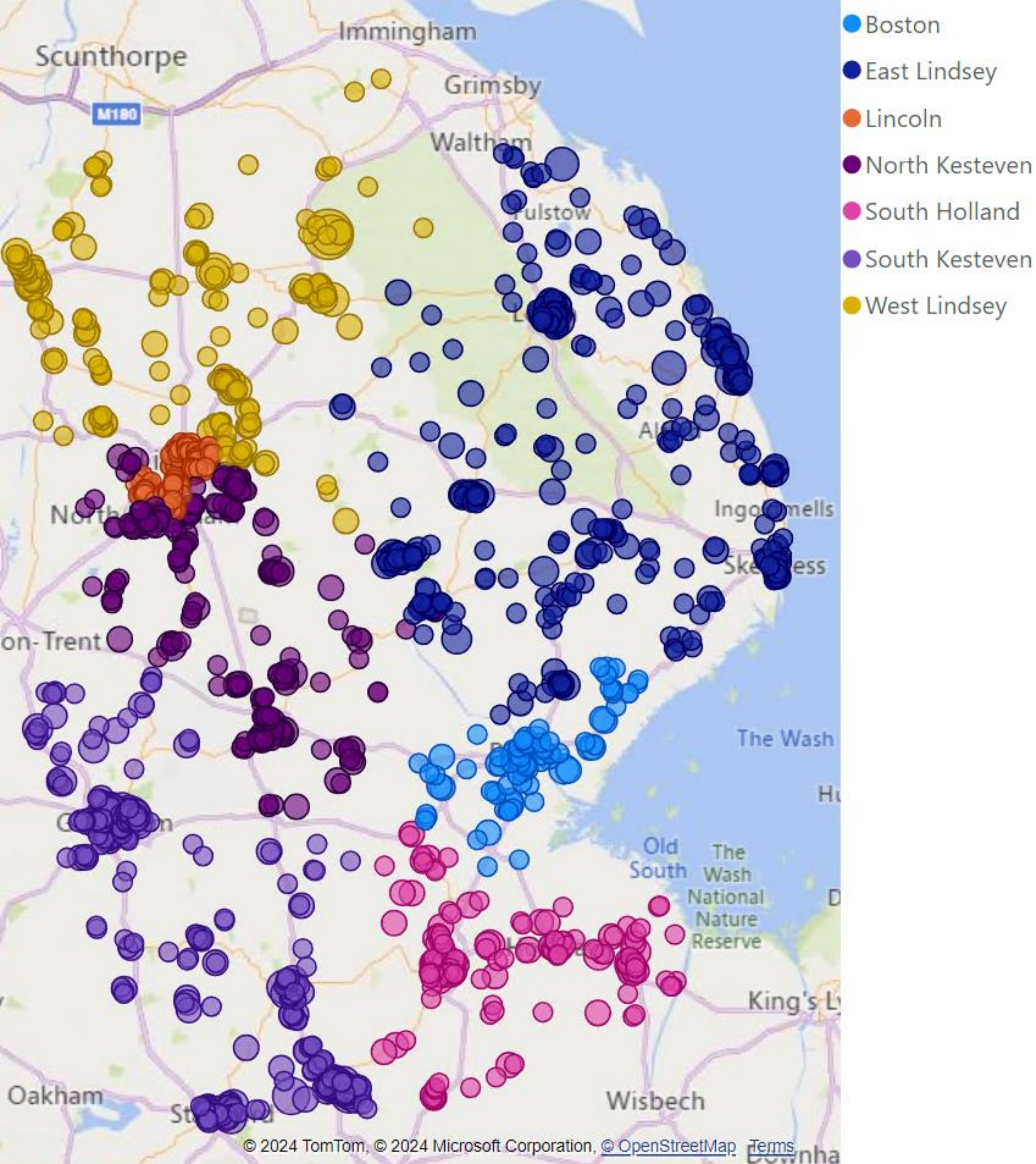
Section 2

Respondent profiling



Geographical locations of respondents

	Count	%
East Lindsey	190	23%
North Kesteven	182	22%
West Lindsey	131	16%
South Kesteven	101	12%
City of Lincoln	74	9%
South Holland	64	8%
Boston	59	7%
Other	40	5%

Respondent Profiling

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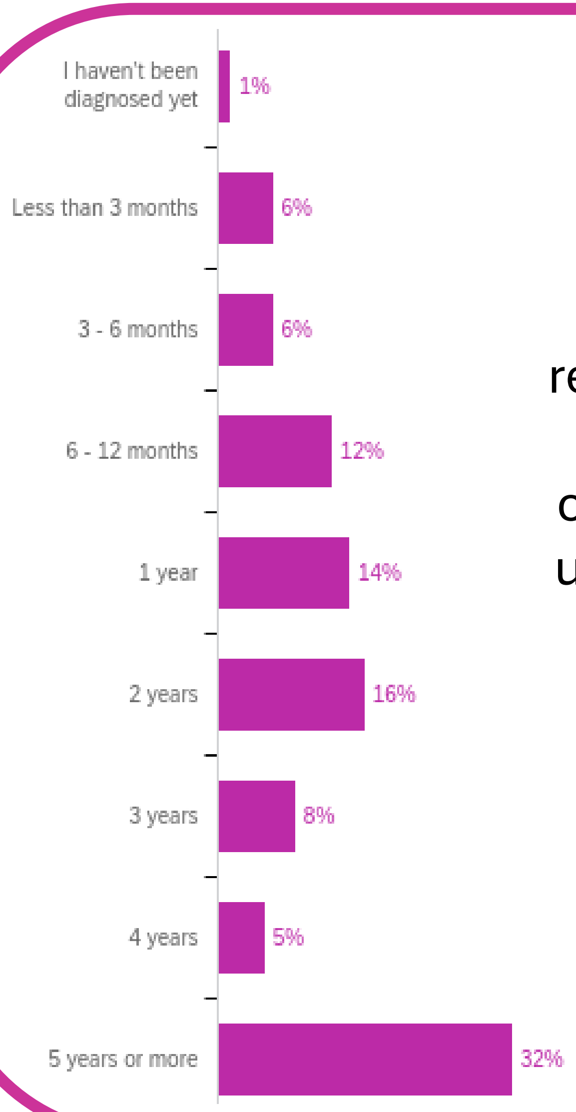
About you	%	Count
A person with suspected or confirmed prostate cancer	64%	544
A person with suspected or confirmed other cancer	1%	7
Family member/friend/carer of someone affected by prostate cancer	6%	54
A person referred for tests but results with clear/negative	22%	186
Other	7%	64
Answered		855

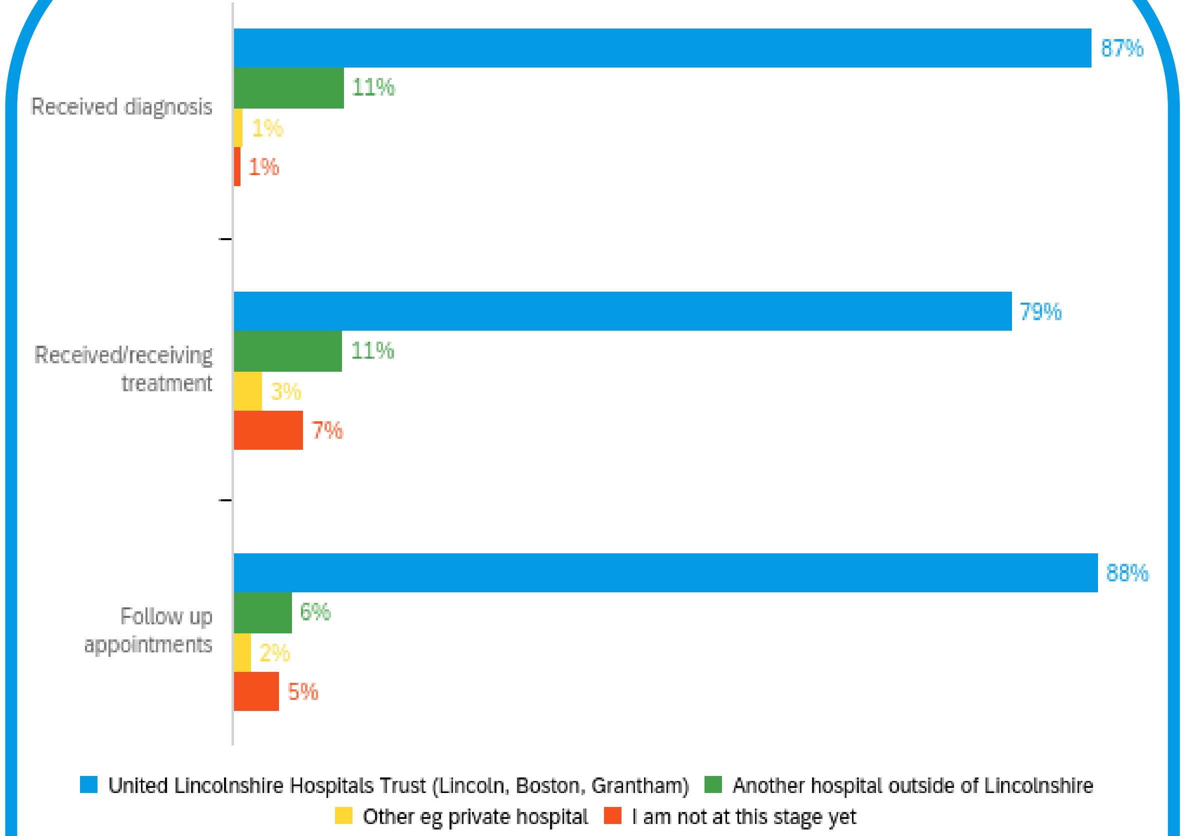
Current health needs	%	Count
Under active surveillance/ PSA monitoring	26%	166
Recently diagnosed with cancer	4%	27
Undergoing active cancer treatment	13%	83
Finished initial cancer treatment	10%	65
Under clinical follow up and monitoring	39%	242
Under watch and wait/ PSA monitoring	7%	45
Answered		628

Management of conditions	%	Count
Coping very well	49%	287
Coping well	40%	232
Not coping well	7%	43
Not coping well at all	1%	7
Don't know	3%	17
Answered		586

Respondent Profiling



Of the 580 respondents who have received a prostate cancer diagnosis, just under **one third** (32%, 183) received it **5 or more years ago.**



The majority of respondents either received their diagnosis (87%), received treatment (79%) or had follow up appointments (88%) at ULTH.

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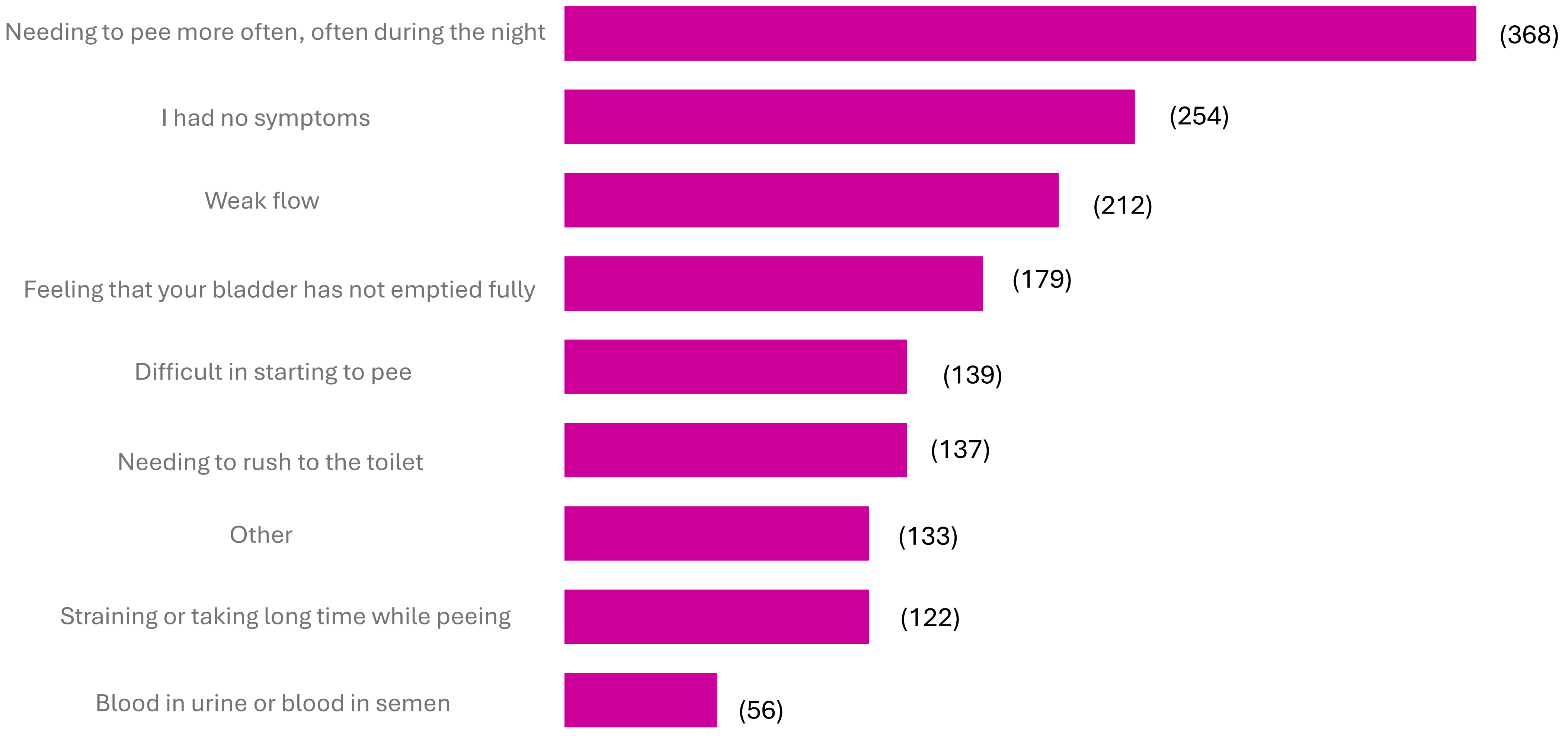
Section 3

Signs and symptoms

Respondents were asked to tell us all the signs and symptoms they noticed. **Needing to pee more often, often during the night** was the most common symptom experienced by just under **one half (47%, 368)** of the 789 respondents who answered this question. **32% (254)** of respondents had **no symptoms.**



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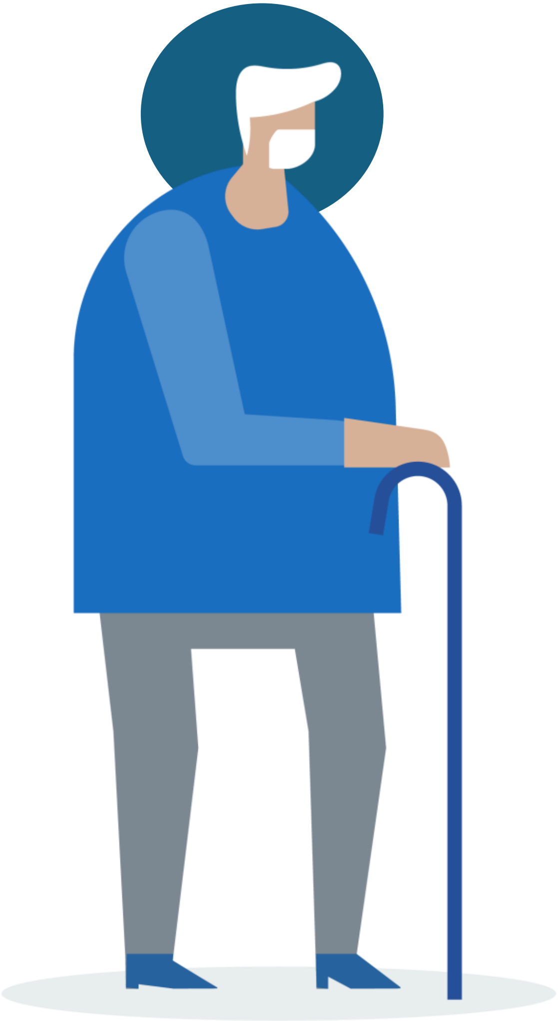
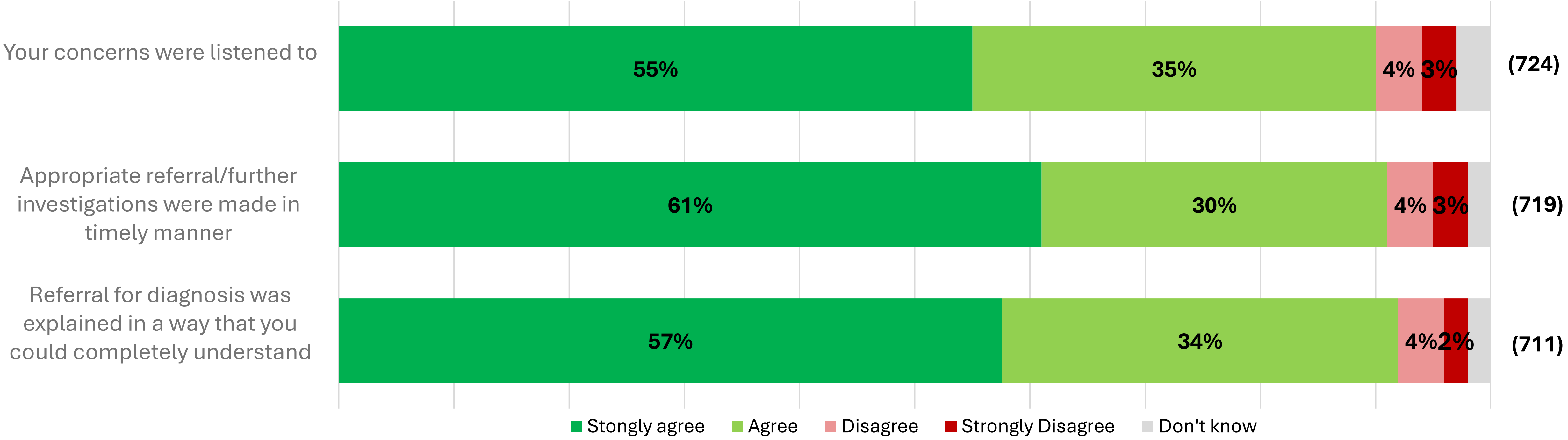
Section 4

Experiences of care and treatment



Respondents were asked about their experiences at different stages of their care and treatment from prostate cancer. The below graph details to what extent respondents agreed with various statements relating to their journey.

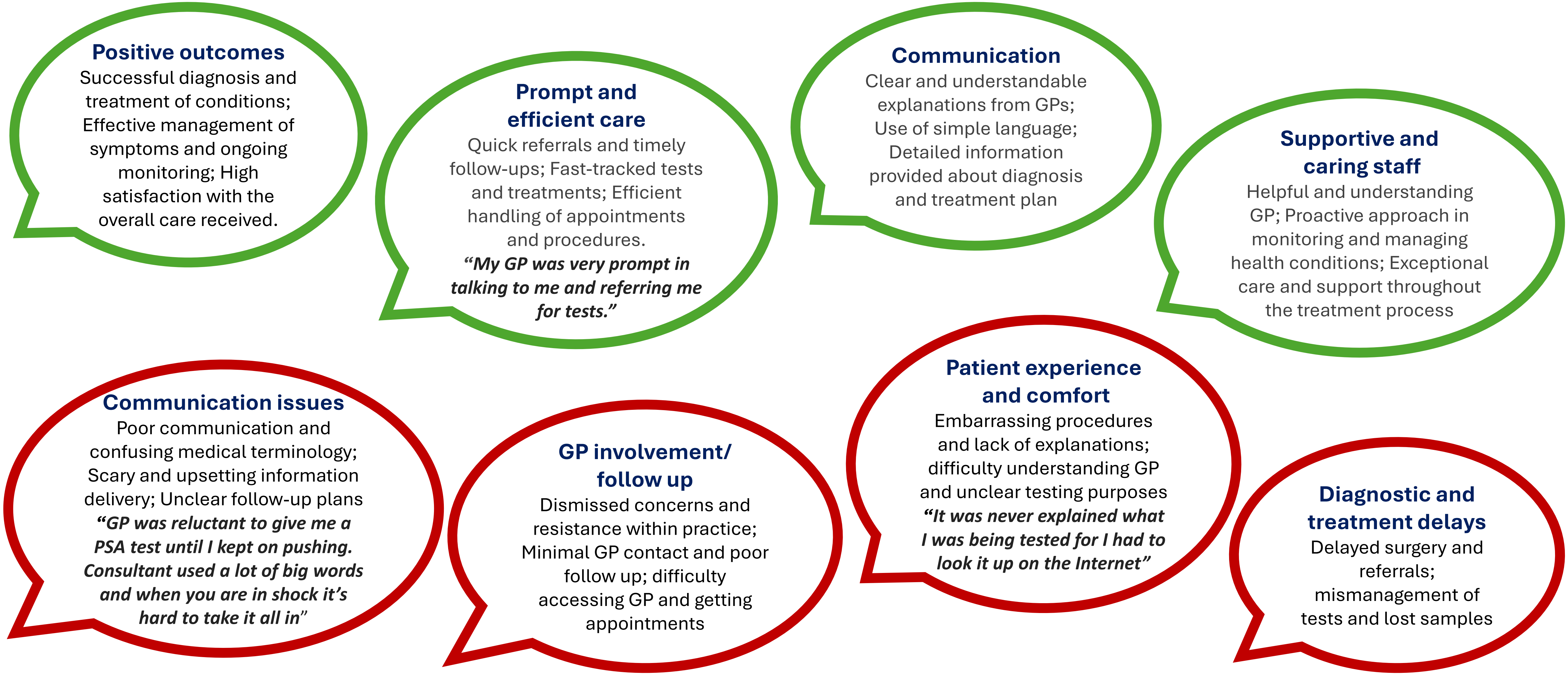
Support from your GP Practice



A **higher** percentage of respondents with a **disability disagreed** that **referrals were made in a timely manner.**

Similarly**, more respondents with a disability** felt that **referrals** were **<u>not</u>** explained in a way they could **completely understand.**

Below are the reasons for why people had positive or negative experiences when receiving **support from their GP practice**



Positive outcomes

Successful diagnosis and treatment of conditions; Effective management of symptoms and ongoing monitoring; High satisfaction with the overall care received.

Prompt and efficient care

Quick referrals and timely follow-ups; Fast-tracked tests and treatments; Efficient handling of appointments and procedures.

"My GP was very prompt in talking to me and referring me for tests."

Communication

Clear and understandable explanations from GPs; Use of simple language; Detailed information provided about diagnosis and treatment plan

Supportive and caring staff

Helpful and understanding GP; Proactive approach in monitoring and managing health conditions; Exceptional care and support throughout the treatment process

Communication issues

Poor communication and confusing medical terminology; Scary and upsetting information delivery; Unclear follow-up plans

"GP was reluctant to give me a PSA test until I kept on pushing. Consultant used a lot of big words and when you are in shock it's hard to take it all in"

GP involvement/ follow up

Dismissed concerns and resistance within practice; Minimal GP contact and poor follow up; difficulty accessing GP and getting appointments

Patient experience and comfort

Embarrassing procedures and lack of explanations; difficulty understanding GP and unclear testing purposes

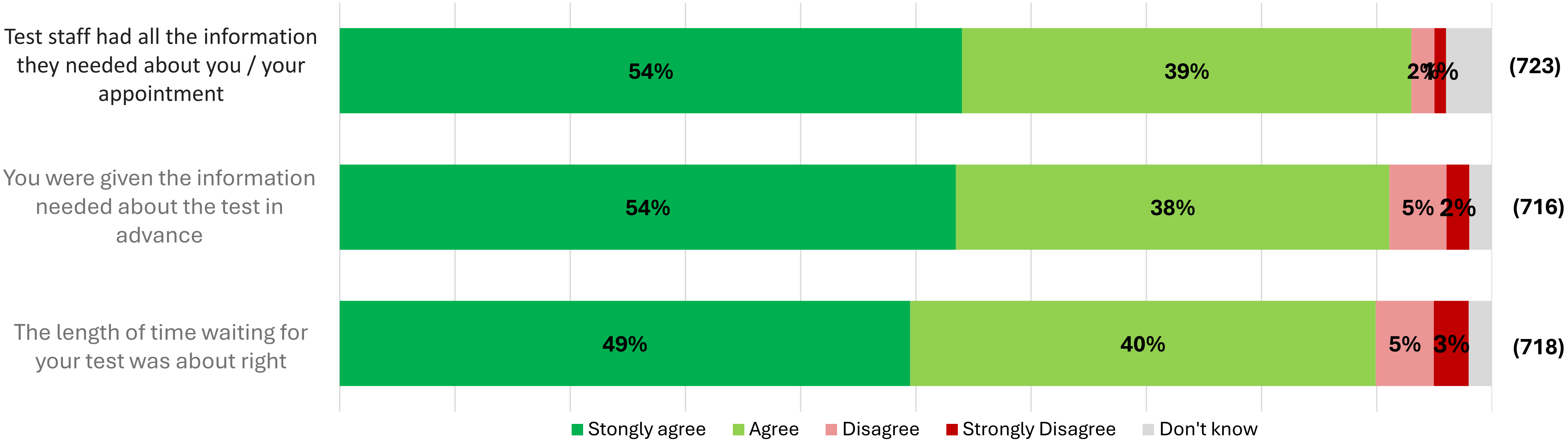
"It was never explained what I was being tested for I had to look it up on the Internet"

Diagnostic and treatment delays

Delayed surgery and referrals; mismanagement of tests and lost samples

Respondents were asked about their experiences at different stages of their care and treatment from prostate cancer. The below graph details to what extent respondents agreed with various statements relating to their journey.

Tests for cancer



A **higher proportion** of respondents who **received treatment at Boston Hospital**, **disagreed** that the length of time they had to wait for tests was about right.

Below are the reasons for why people had positive or negative experiences when receiving **their tests for cancer**

Prompt and efficient testing
Tests were carried out quickly and efficiently; Minimal waiting times for appointments and procedures; Fast-tracked MRI scans, biopsies, and other diagnostic tests.
"Being able to get prompt scan and biopsy made it easier to cope with, not having to wait."

Flexibility and accommodation
Appointment dates adjusted to accommodate personal schedules; Efficient handling of holiday dates and other personal needs

Communication
Detailed explanations of test results and procedures; Clear and precise information provided by consultants; Patients felt well-informed at all stages.

Supportive and caring staff
Medical staff were helpful, supportive, and efficient; Friendly and sympathetic hospital staff; Personalized care and attention to individual needs.

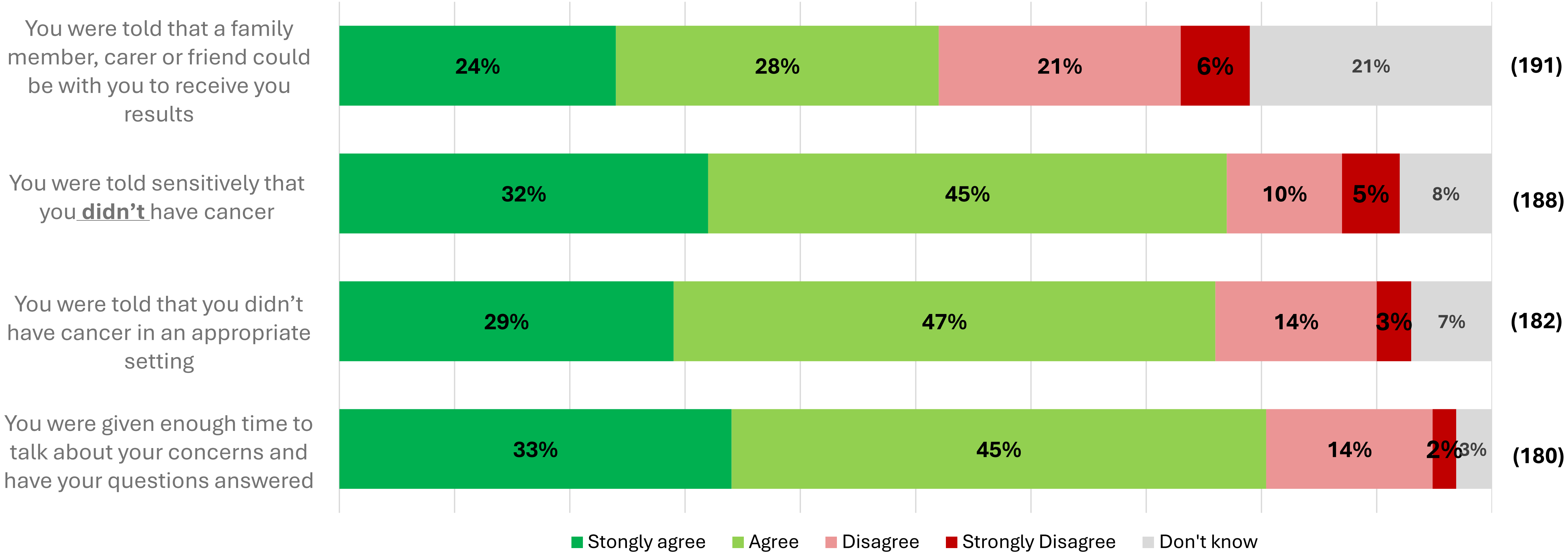
Consultant availability
Consultant was not available for 3-4 months due to illness and there was no replacement during this time.

Lack of trust in the NHS
Patients are scared at the state the NHS is in- They feel it is broken.

Diagnostic and treatment delays
Patient waited 12 months for appointment before giving up and going private
"It took 5 months to see a urologist then a week later for the tests"

Respondents were asked about their experiences at different stages of their care and treatment from prostate cancer. The below graph details to what extent respondents agreed with various statements relating to their journey.

Receiving your results (respondents who didn't have cancer)



Below are the reasons for why people had positive or negative experiences when receiving **their results (patients who didn't have cancer)**

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Communication of results
Many patients received their results over the phone, which was generally appreciated for its convenience and efficiency.

Efficiency and timeliness
Several patients reported receiving their results quickly, which helped in reducing anxiety and facilitating timely follow-up actions

Emotional support
Patients appreciated when healthcare providers communicated results with empathy and provided reassurance, especially when delivering negative results.

Clarity and understanding
Positive feedback was given when consultants and nurses provided clear and understandable explanations of the results and next steps.

Communication of results
Some patients received results via letters or the NHS app, which sometimes led to delays or lack of clarity.
"No follow up appointment - Negative result discovered on NHS app"

Clarity and understanding
Issues arose when results were not explained properly, leading to confusion and the need for further clarification.

Follow up and next steps
Negative feedback was given when there was no follow-up or when patients had to chase up their results and next steps themselves.
"It was a quick call at home for both post biopsy results. Just told me I was off cancer pathway. No further advise for enlarged prostrate."

Finding out you had cancer

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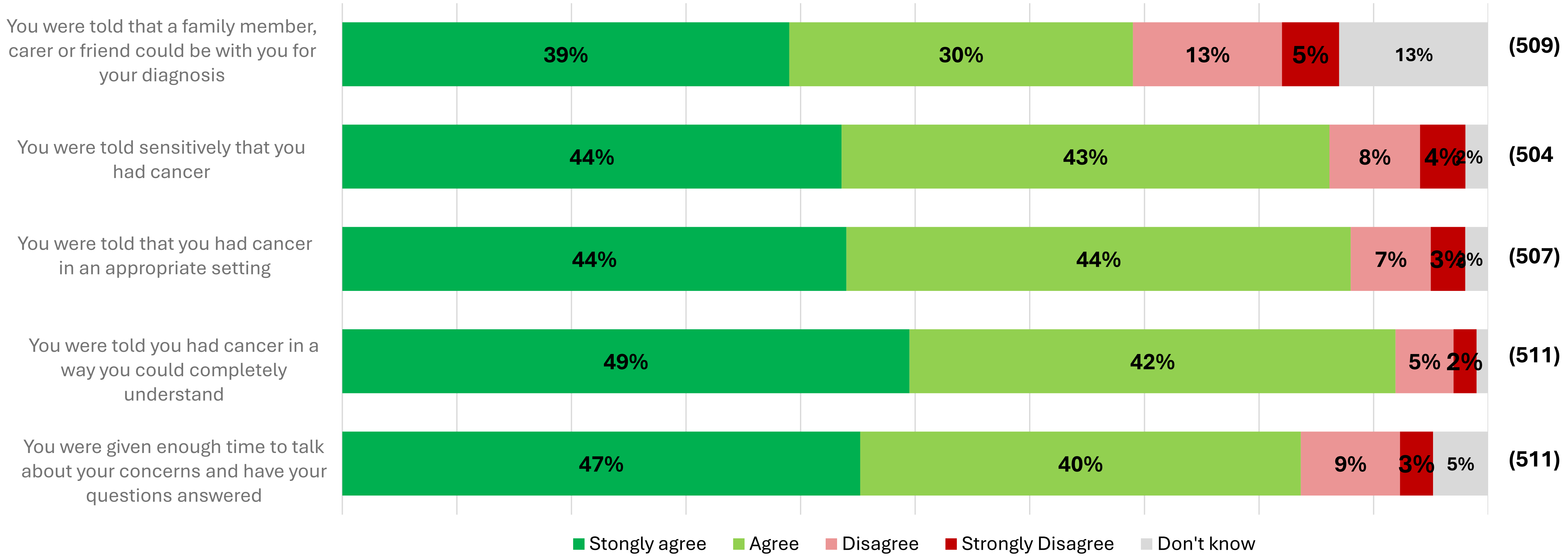

A **higher proportion** of respondents from **City of Lincoln**, said they **were not told a family member/carer could be with them for their diagnosis** compared to other districts.

A **higher proportion** of respondents from **South Holland** as well as those with a **disability, disagreed** that they were **given enough time to talk about their concerns** following their diagnosis

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Below are the reasons for why people had positive or negative experiences when **finding out they had cancer**

Communication

Clear and thorough explanations of diagnoses, treatment options, and prognoses, Information was delivered with care and sensitivity, ensuring patients felt supported.

"The consultant at Lincoln Hospital was very good and informative from giving results of biopsy and bone scan etc"

Support and care

Family able to be present during consultations, which helped in understanding and asking relevant questions, Consultants provided reassurance and positive outlooks, which helped patients cope with their diagnosis

"My wife was with me at all appointments giving us both the time to absorb the information"

Treatment options

Detailed discussions about treatment options, Patients felt informed and confident in decision-making.

Efficiency and professionalism

Patients experienced prompt and efficient consultations with specialists, The medical team were praised for their professionalism and thoroughness.

Communication of results

Several patients received their diagnosis or test results over the phone, which was perceived as blunt and impersonal, Cancer diagnosis was delivered in a blunt manner, which patients found hard to process emotionally.

"Didn't even have to pay the car park it was quick and blunt"

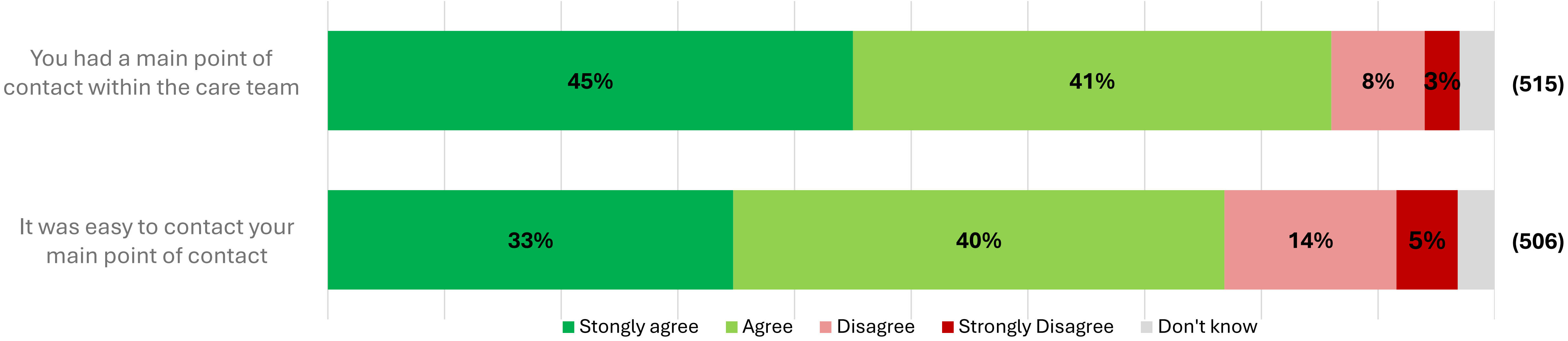
Clarity and understanding

Some patients did not receive a clear diagnosis and had to seek further information themselves, Difficulty understanding the diagnosis due to poor communication skills or language barriers of GP.

Follow up and next steps

Patients experienced delays in follow-up communication, leading to frustration and the need to chase up results, Minimal contact from the GP surgery regarding diagnosis and follow-up

Support from a main contact person



A **slightly higher** proportion of respondents from **Boston,** and patients who **received treatment at Boston Hospital**, **disagreed** that they had **a main point of contact** within the care team.

A **greater** percentage of respondents from **City of Lincoln**, as well as those with a **disability**, **disagreed** that it was **easy to contact their main point of contact.**

Below are the reasons for why people had positive or negative experiences when receiving **support from a main contact person**:

Dedicated support and care

Named contacts and specialist nurses provided personalized care; Patients felt confident in their care due to the consistent support from their assigned nurses and oncologists.

"All the cancer nurses have been very good, but I have spoken with several rather than one specific contact."

Lack of consistent contact

Always a different person, no specific point of contact; Contact person constantly changing over the years

Communication issues

Slow responses, unanswered emails, and phone calls; Reliance on answerphone messages, often not followed up.

"The team are fantastic but getting through to them by phone is not so good"

Communication and accessibility

Calls and emails were usually returned promptly; When direct contact was not possible, messages left on answering machines were typically responded to within 24 hours.

Availability and accessibility

Consultants and contact persons often unavailable; Limited availability of secretaries for appointment cancellations

Deciding on the best treatment

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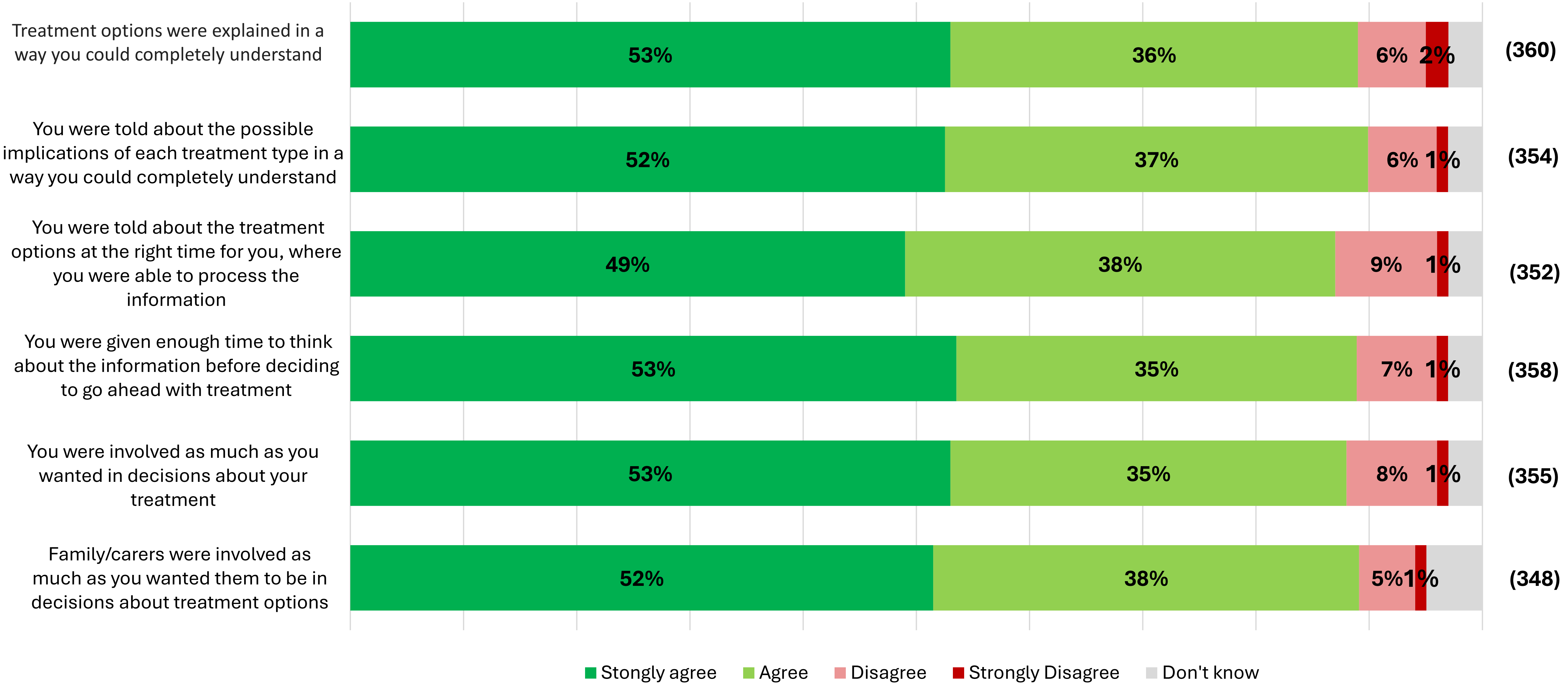

Below are the reasons for why people had positive or negative experiences when **deciding on treatment**

Communication

Detailed explanations of treatment options, risks, benefits, and outcomes.

Decision making and options

Patients were given choices between surgery, radiotherapy, hormone therapy, and other treatments; They appreciated being able to make informed decisions, sometimes with the help of family members or mentors

Support and involvement

Staff were described as sensitive, kind, and reassuring; Detailed and personalized support provided by healthcare teams.

Timeliness and efficiency

Generally, the process was seamless and timely, though some experienced delays, COVID-19 affected treatment plans and led to changes in the usual procedures.

Communication and explanations

Large amounts of information provided in a short period, sometimes overwhelming; Preference for face-to-face meetings with specialists for better understanding

Decision making and options

Some patients felt they needed more guidance in choosing the best treatment option; Not enough time was allocated to explain treatment options thoroughly

"whilst the oncologist & surgeon provided detail about their treatments, I felt a bit alone in deciding which of all the options (including active surveillance) were best for me. ie no-one seemed to want to provide an expert opinion embracing all my circumstances."

Involvement of family

Patients wished their partners or family members were more involved from the start of the process

Limited treatment options

Several patients were told that radiotherapy was the only treatment option, limiting their choices; Some patients sought alternative treatments privately, such as brachytherapy, which was not initially offered

Care planning

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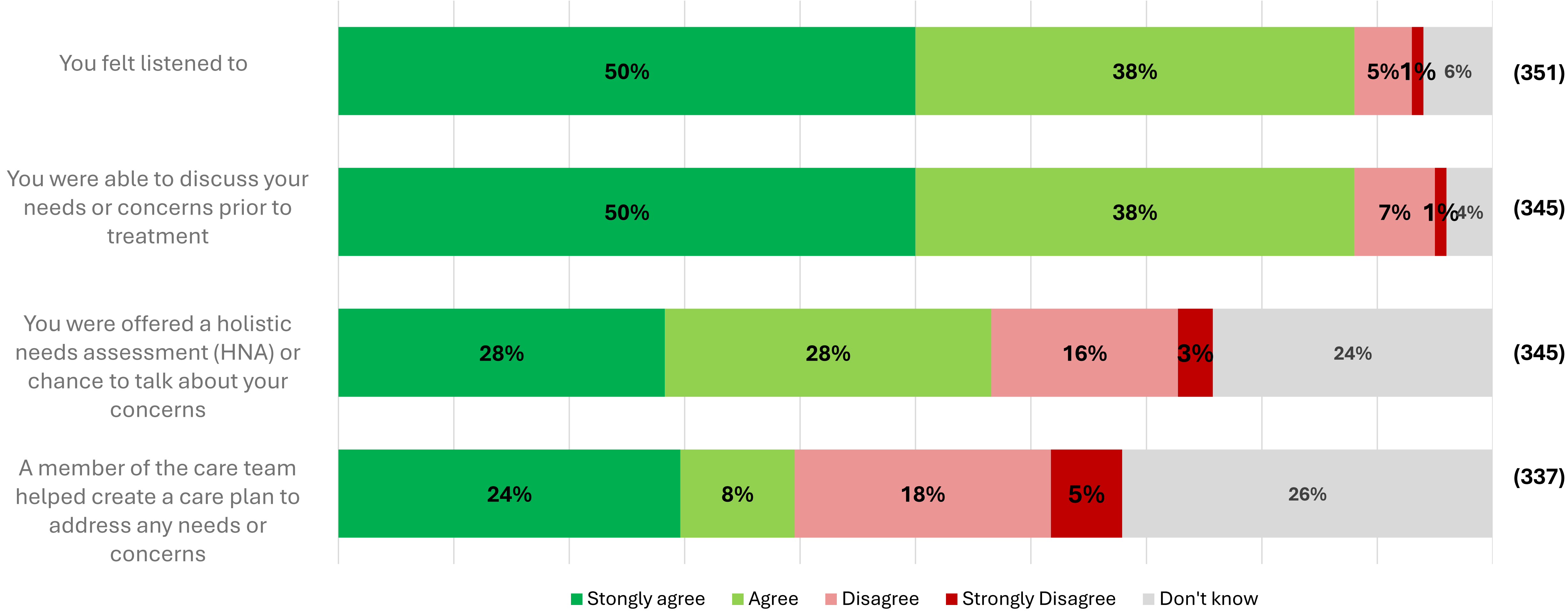

A **higher** proportion of respondents from **West Lindsey,** and patients who received **treatment at Lincoln County Hospital, disagreed** that they were **offered a holistic needs assessment (HNA)** or chance to talk about their concerns

Below are the reasons for why people had **positive** or **negative** experiences with **care planning**

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Care planning

Care plans were created and covered all necessary details;
For some, the only plan was annual monitoring of PSA levels

Support and follow up

Patients received support through various departments and phone calls;
There was always someone available to assist and answer questions.

Communication and explanation

Treatment options and plans were well explained, ensuring patients felt informed;
Both oncologists and surgeons provided detailed options and care beyond expectation

No/Limited care plans

Only basic treatment plans involving regular tablets and injections were provided, with no wider support for patients or families; Some patients were not aware of any care plans or did not receive one

"No idea whether a care plan existed or not"

Insufficient support

No additional support groups, literature, or resources were offered to patients and their families;
Follow-up was limited, with some exceptions where support was excellent.

Communication and coordination issues

Follow-up correspondence was often slow in reaching patients and GPs; Promised assessments, such as the HNAs, did not take place.

"Spoke to a key worker regarding the HNA but nothing really came of it"

Self-directed patient research

Patients had to conduct their own research and reach out for treatments, such as for erectile dysfunction

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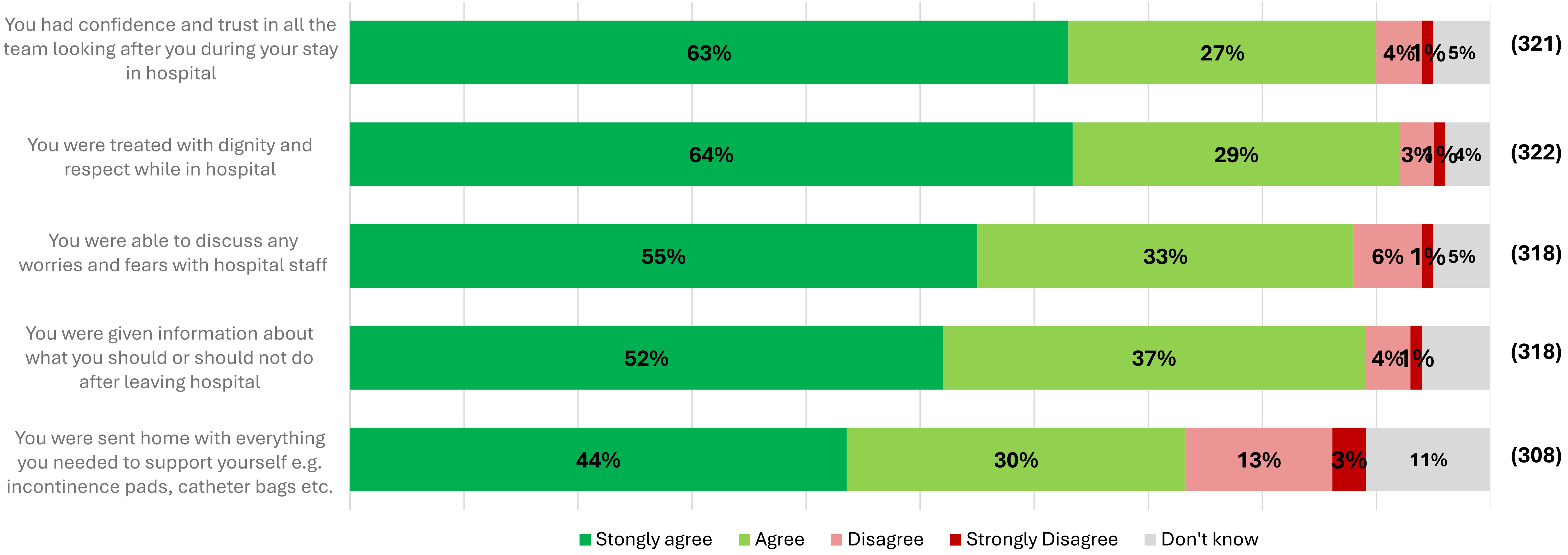
Treatment and hospital care



A **slightly higher** proportion of respondents from **East Lindsey,** and respondents with a **disability, disagreed** that they were sent home with everything they needed to support themselves e.g. incontinence pads.

Below are the reasons for why people had positive or negative experiences when **receiving treatment and care in hospital**

Communication
The good humour and friendliness of staff helped make the treatment experience more positive; Nursing staff provided the best communication, ensuring patients were well-informed.

Support and care
Patients felt well-supported by their designated cancer nurses and the hospital team.

“The whole hospital team were very caring”

Smooth discharge
Some patients reported a smooth discharge process with all necessary supplies and follow-up appointments.

Mixed quality of care
Different staff members provided varying levels of care, leading to a need for patients to chase answers and outcomes;
Patient records were not always accurate or up-to-date.

“Agency staff on the ward. Don’t think they understood aftercare”

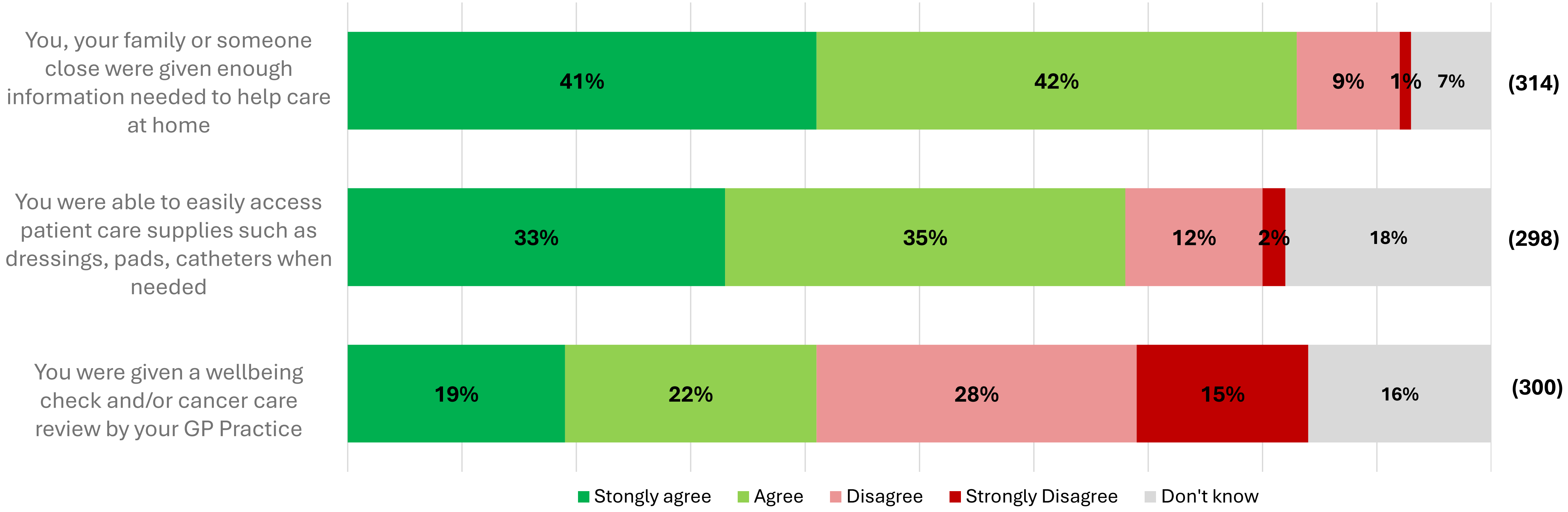
Discharge issues
Long waiting time for discharge prescriptions; Patients were often discharged with insufficient medical supplies, such as catheter bags and incontinence pads;
Important information about medications and care post-discharge was not always communicated effectively.

“I wasn't given any incontinence pads & had to buy my own until my NHS ones came 2weeks later”

Insufficient information and support
More information was needed about specific treatments, such as penile rehabilitation;
Patients and families felt there was insufficient support for general concerns, incontinence, and aftereffects.

Respondents were asked about their experiences at different stages of their care and treatment from prostate cancer. The below graph details to what extent respondents agreed with various statements relating to their journey.

After treatment



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Below are the reasons for why people had **positive** or **negative** experiences **after treatment**

Communication
Patients appreciated follow-up calls from GP surgeries and oncology departments.

Supplies
Some patients received all necessary supplies, while others faced issues with catheter bags and incontinence pads;
Difficulty in sourcing appliances from the NHS led some patients to buy their own supplies privately.

Information
Patients were given all necessary information and explanations.

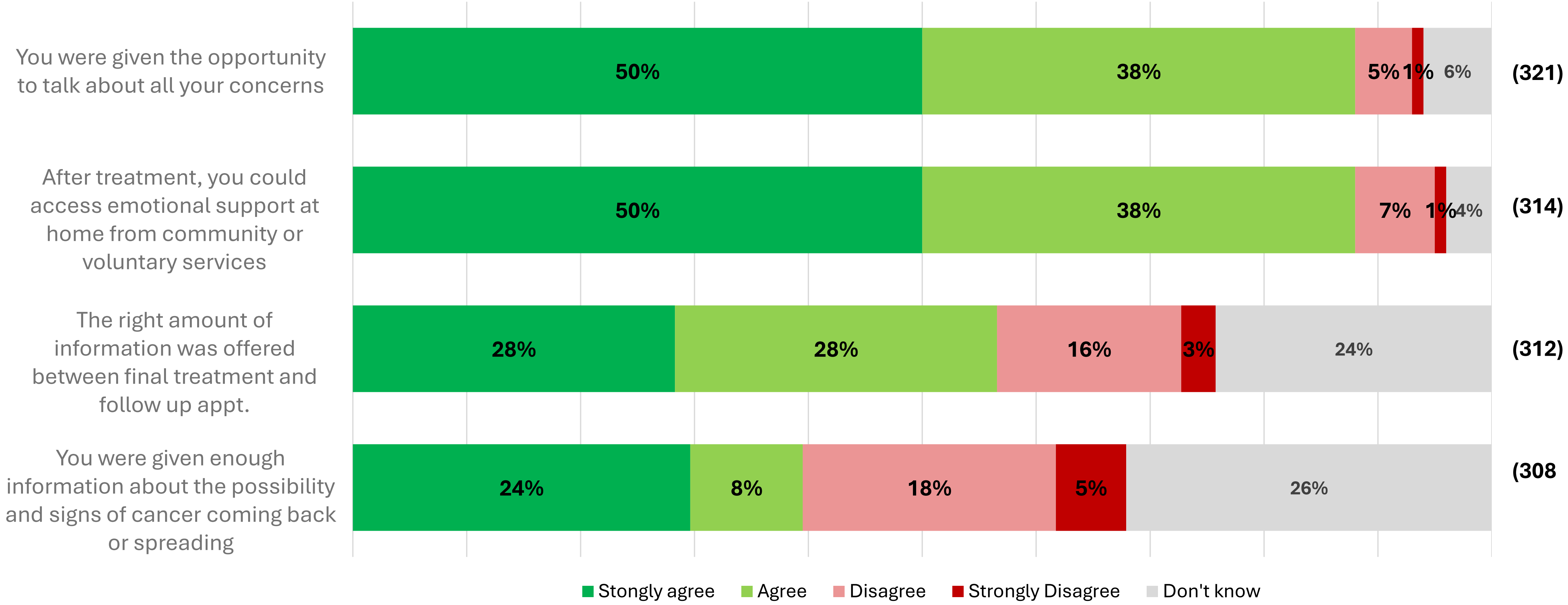
Inconsistent/limited GP involvement
Limited involvement from GP practices, often restricted to specific tasks like Prostap 3 injections or PSA tests;
Many patients reported no follow-up or contact from their GP after initial diagnosis or treatment.
"I was disappointed with their interest which was very limited"

Impact of Covid-19
COVID-19 affected follow-up care and communication, leading to reliance on phone consultations and limited in-person support

Difficulty accessing supplies
Challenges in obtaining necessary medical supplies, such as incontinence pads, due to poor coordination between hospital and GP services

Conflicting information and communication
Different timescales and information provided by various practitioners, causing confusion;
Lack of clear communication and support led to emotional distress and confusion for patients and their families.

Living with and beyond cancer



Below are the reasons for why people had positive or negative experiences of **living with and beyond cancer**

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Quality of care
Overall, patients described their treatment journey as positive and well-managed; Patients felt listened to and had confidence in their treatment and follow-up care.

Follow up and monitoring
Ongoing monitoring through regular PSA tests, with some patients having tests every 6 months or annually; Effective follow-up by specialist nurses through phone appointments.

Clear explanations
Patients received thorough explanations and plenty of information about their treatment and follow-up care.

Emotional and practical support
Participation in support meetings and clinical trials provided some ongoing contact and reassurance; Patients felt that support was available if needed, though some did not require emotional support.

Self-management
Patients often had to source information themselves, including signs of cancer returning and side effects;
Aftercare follow-up was confusing, with patients feeling unsupported and having to rely on external sources for information.

Communication Issues
Initial diagnosis did not mention cancer spreading, later changed to end-of-life prognosis.
Patients were not informed about the possibility of cancer returning or spreading.

Support and monitoring
Good access to nursing staff but difficult to access physicians; PSA levels were regularly checked, but other side effects of treatment were not adequately addressed.

Section 5

Information and advice received by patients

Information and advice received by patients

Most information was received on physical aftereffects with 73**% (340)** of **468 respondents** stating they had received this. Respondents told us they would **have liked more information around physiological and emotional aspects of living with cancer.** Better access to information and **advice for family/friends/carers** is key as well as more information and advice on **diet and lifestyle**. **Fewer patients** received information on financial help and benefits and advice for young people in the family.

	Yes (received info/advice)	No / Would have liked more on this topic	COUNT
How to access support groups	67%	33% (147)	445
Psychological and emotional aspects of living with cancer	55%	45% (196)	434
Physical aspects of living with cancer	62%	38% (170)	444
Physical aftereffects of treatment	73%	27% (128)	468
Information/advice for family/friends/carers	54%	46% (192)	417
Information and advice for young people in family (under age of 23)	47%	53% (50)	94
Returning to or staying in work	54%	36% (91)	197
Prescriptions	73%	27% (99)	369
Financial help and benefits	38%	62% (161)	261
Physical activity and exercise	61%	39% (163)	423
Diet and lifestyle	57%	43% (186)	434
Car parking at hospital	63%	37% (156)	420

The results from the survey show that accessing information and advice has **improved** in **recent years** with more patients diagnosed in the last two-yeasr stating they received information on the various topics detailed in the table opposed to patients diagnosed 5 or more years ago.

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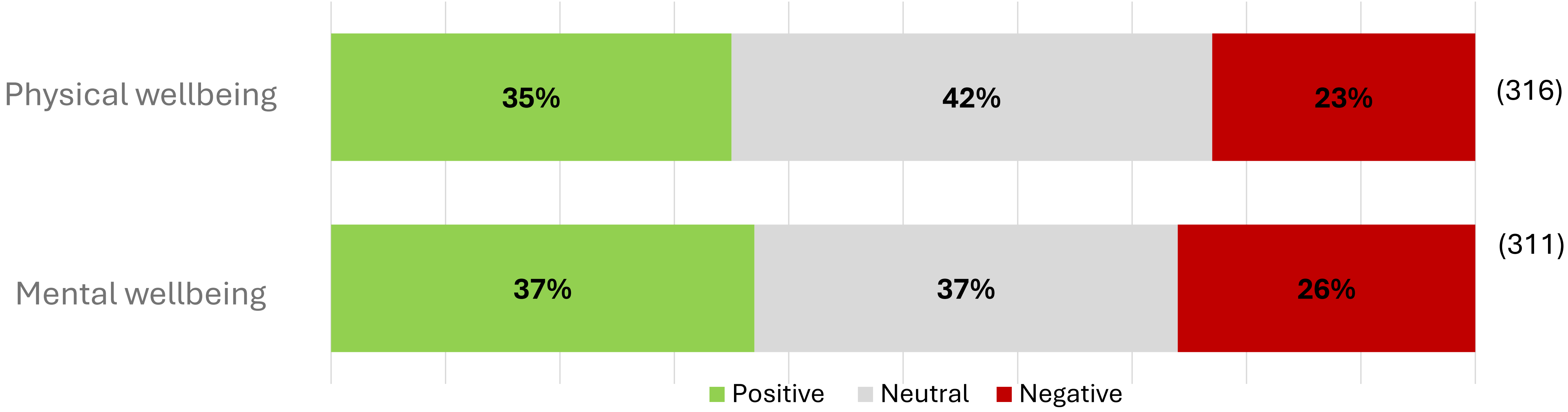
Section 6

Impact of treatment and long-term side effects

Out of 305 respondents who have received treatment, **86% (265)** said they were **fully aware/ aware** of the possible side effects prior to treatment. **12% (38)** were **not very aware/aware at all.**

The results from the survey show a **positive** trend in **recent years** with more patients stating they were **fully aware/ aware** of the possible side effects of treatment in comparison to patients diagnosed 5 or more years ago.

The below table details what impact treatment had on respondents physical and mental wellbeing:



The below table details the reasons why respondents felt the treatment had a positive, negative or neutral effect on their wellbeing.

Positive	Neutral	Negative
Relief and Positivity • Feeling relieved and positive after the cancer removal, maintaining a positive outlook on life and future. **Treatment and Recovery** • Successful treatment and recovery, including radiotherapy and surgery, leading to improved prognosis and minimal side effects. **Support and Information** • Being well-informed and supported throughout the diagnosis, treatment, and aftercare process, with strong support from medical professionals and family. **Coping and Resilience** • Adopting a resilient and stoic attitude, accepting the situation, and carrying on with life while maintaining a positive mindset and gratitude.	**Minimal Effects** • Experiencing little to no physical or mental effects from treatment. **Treatment and Recovery** • Starting treatment and maintaining normal routines, with some side effects but overall better than expected recovery. **Mental and Emotional Impact** • Facing mental challenges like disorientation and difficulty concentrating but not experiencing depression. **Coping and Resilience** • Adopting a resilient attitude, accepting the situation, and carrying on with life positively. **Support and Information** • Encountering mixed levels of support and needing to insist on certain tests, with some gaps in follow-up care. **Positive Outlook** • Maintaining a positive outlook, confident in treatment success, and balancing constraints with the knowledge of successful treatment.	**Physical Side Effects** • Experiencing various physical issues such as muscle weakness, bowel and bladder complications, incontinence, and erectile dysfunction due to treatments. **Mental and Emotional Impact** • Facing depression, mental exhaustion, and stress related to the side effects and the fear of cancer spreading. **Treatment Challenges** • Undergoing extensive treatments like surgery, radiotherapy, chemotherapy, and hormone therapy, which have significant tolls and sometimes limited success. **Lifestyle Changes** • Adapting to new lifestyle challenges, including constant concern about toilet access, physical disabilities, and changes in fitness and sexual health. **Support and Coping** • Receiving mixed levels of support from medical professionals and using counselling to cope with the emotional and physical impacts of the treatments.

Respondents were asked if they were able to discuss managing the impacts of long-term side effects

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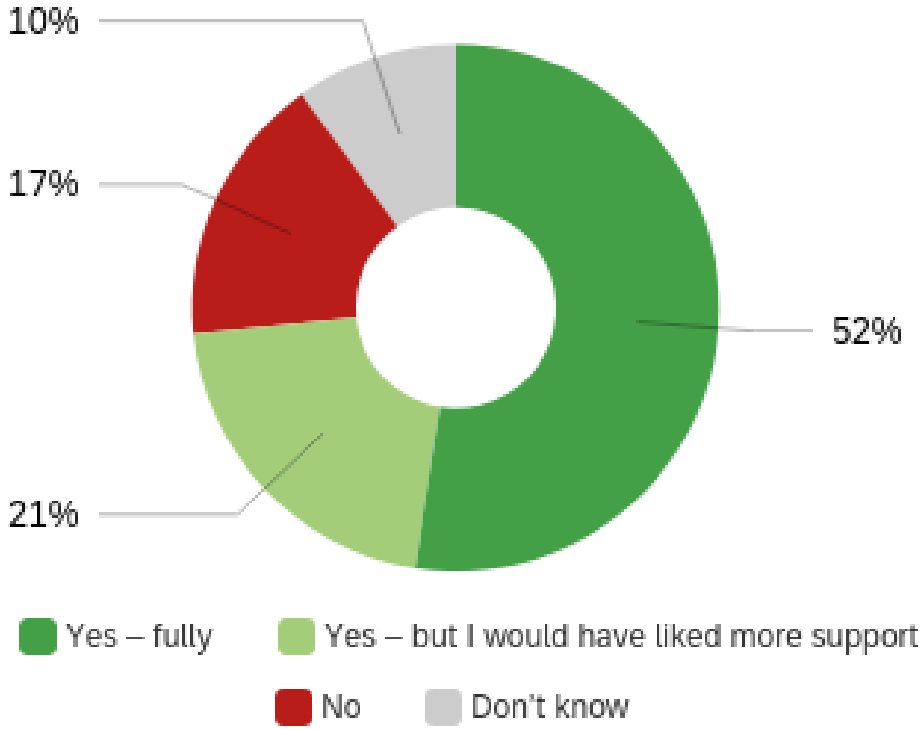

52% of 301 respondents said they were **fully** able to discuss options for managing the impact of long-term side effects with a member of the care team.

21% would have **liked more support** and **17%** said they **were not able** to discuss options.

A **higher** proportion of respondents from **West Lindsey,** said they were **not** able to **discuss options for managing the impacts of long-term side effects**

"The number of leaflets given at the start was overwhelming it would have been better to have a few then a follow up consultation"

"We got excellent advice, help and support from the oncology nurse and without her the experience would have been extremely challenging as no one else seemed interested."

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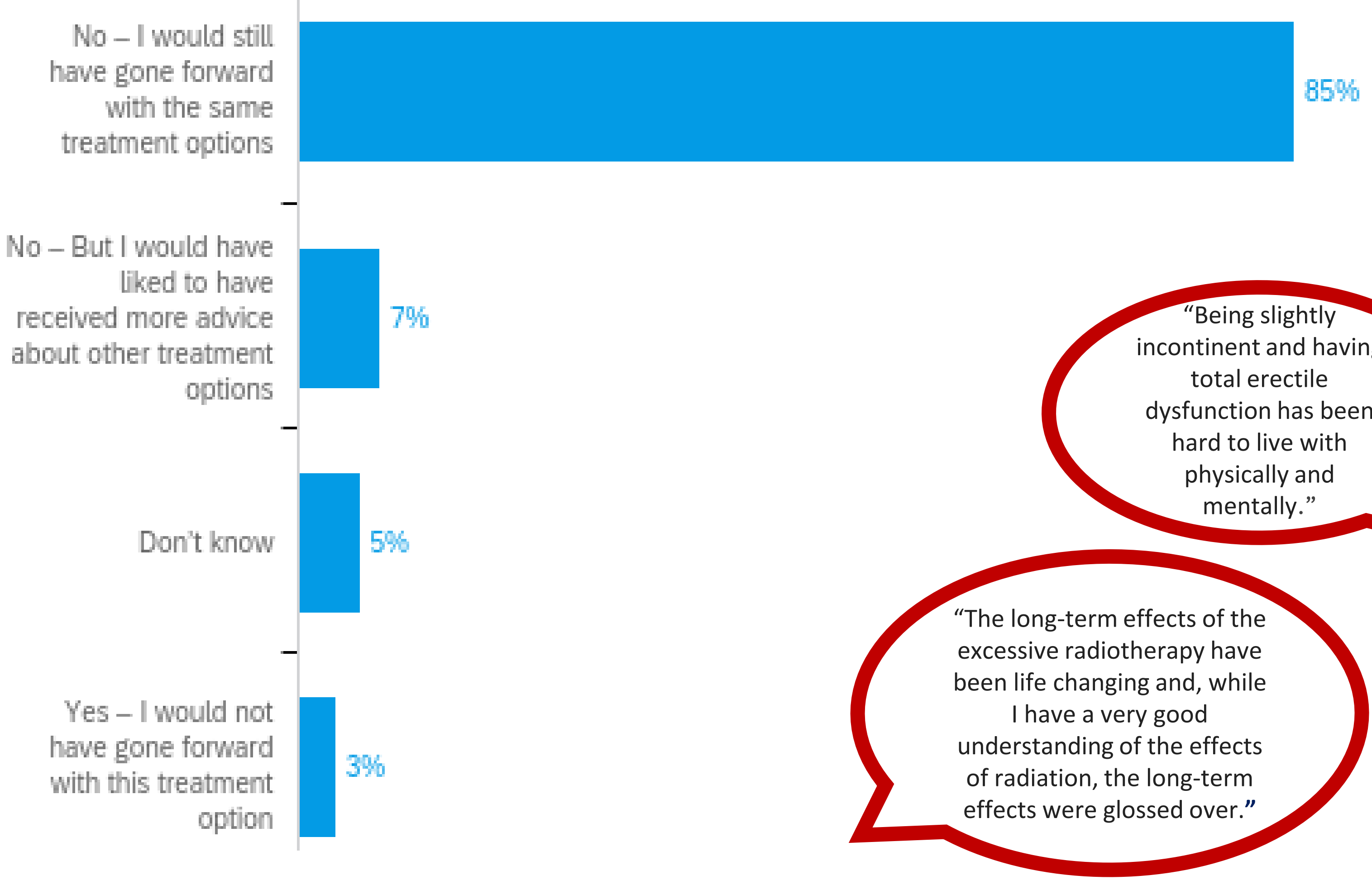
Respondents were asked about their side effects and whether this would have affected their treatment choice.

Knowing the side effects now, **85% (246)** would have **still gone forward with the same treatment option.**

7% (20) would have **liked more advice** on other treatment options and **3% (9) would not** have gone forward with the **same treatment option** and 5% don't know.



"Being slightly incontinent and having total erectile dysfunction has been hard to live with physically and mentally."

"The long-term effects of the excessive radiotherapy have been life changing and, while I have a very good understanding of the effects of radiation, the long-term effects were glossed over."

Section 7

Patient experiences

Patient experience of getting **advice** and **support** when needed

Themes are presented in order of mention so those at the top of this table were mentioned the greatest number of times and those at the end, the least.

Impact	Feedback
Long wait times	• Many respondents experienced long wait times for tests and consultations, which added to their anxiety and frustration. For example, one person mentioned, "Very difficult waiting so long to get tests and see my consultant."
Difficulty in communication	• Communication with hospitals was often challenging. Some respondents found it hard to get in touch with medical staff or leave messages. One person noted, "Getting hold of anyone at Lincoln Hospital is a complete challenge."
Lack of consistent Support	• While initial support during treatment was often good, post-treatment support was lacking for some. One respondent said, "Pre and during treatment was good, but after treatment left to fend for myself.
Confusing information	• Some respondents felt confused about their treatment options and the information provided. One person described their experience as "Confusing - not knowing which path to take."
Variable quality of support	• The quality of support varied between different consultants and medical staff. One respondent mentioned, "One consultant was very good, the other poor.“ • The overall experience of getting advice and support was described as "hit and miss" by some respondents, indicating variability in the quality and availability of support

Patient experience of getting **advice** and **support** when needed contd.

Theme	Feedback
Inconsistent follow-up	- Follow-up appointments were sometimes inconsistent, with cancellations and delays. One person shared, "Follow-up meeting cancelled and has still not taken place 5 months later."
Impact of covid-19 pandemic	- The COVID-19 pandemic affected the availability and quality of support, with many consultations conducted via telephone, which made it difficult for patients to feel fully supported. One person noted, "Being told you have cancer during the constraints of the pandemic was difficult."
Lack of support for family members	- Some respondents felt that their family members did not receive adequate support or advice. One person mentioned, "Advice to myself was ok but there was a total lack of support/advice for my wife."

Patients feel that **support from friends and family**, **help and care from healthcare staff** and having a **positive attitude and continuing with normal routine** has helped most since their cancer diagnosis.

Friends and family support
Family and spouse support were crucial for many

Caring and helpful healthcare staff
Consistent care from medical professionals and counselling sessions were highly valued.

Positive attitude and outlook
Maintaining a positive attitude, continuing with normal routines and staying active helped many cope

Information and communication
Clear explanations and access to information were important

Monitoring and follow-ups
Regular PSA tests and follow-up care provided reassurance

Community and peer support
Support groups and conversations with peers were beneficial.

Timely and effective treatment
Early detection and swift treatment were crucial

Resources and tools
Access to helpful resources and tools, like booklets and parking badges, was appreciated.

What has stopped patients leading the life they want since being diagnosed with prostate cancer

Themes are presented in order of mention so those at the top of this table were mentioned the greatest number of times and those at the end, the least.

Theme	Feedback
Physical and Health Issues	• **Erectile Dysfunction (ED):** Many respondents mentioned ED as a significant issue affecting their quality of life. • **Incontinence:** Frequent urination, urinary urgency, and incontinence were common problems. • **Fatigue and Lack of Energy:** Tiredness and lack of energy were frequently cited, impacting daily activities and overall well-being. • **Pain and Discomfort:** Issues like muscle weakness, bladder and bowel problems, and pain from treatments were highlighted. • **Other Health Issues:** Some mentioned additional health problems like peripheral neuropathy, rectal bleeding, and general body weakness.
Mental and Emotional Impact	• **Depression and Anxiety:** Depression, anxiety, and mental stress were common, often related to physical symptoms and the fear of cancer recurrence. • **Loss of Confidence:** Some respondents experienced a loss of confidence and self-worth, particularly related to ED and incontinence. • **Emotional Strain:** The emotional toll of dealing with cancer and its treatments was significant for many.
Lifestyle Changes	• **Impact on Daily Activities:** The need to be near a toilet, fatigue, and other physical limitations affected daily routines and activities. • **Travel and Social Activities:** Many respondents mentioned difficulties with travel and social activities due to the need for frequent toilet access and physical limitations. • **Sexual Activity:** Changes in sexual activity and relationships were commonly reported, often due to ED and lack of libido.

What has **stopped** patients leading the life they want since being diagnosed with prostate cancer contd.

Theme	**Feedback**
Treatment and recovery	• **Side Effects of Treatment:** Side effects from treatments like radiotherapy, chemotherapy, and hormone therapy were frequently mentioned. • **Ongoing Medical Appointments:** Regular medical appointments and the uncertainty of waiting for results impacted planning and daily life. • **Recovery Process:** The recovery process from surgeries and treatments was challenging for many, with long-term effects still being managed.
Lack of support and information	• **Lack of Support:** Some respondents felt they did not receive adequate support or information from healthcare providers.

Despite challenges, many respondents emphasized the importance of maintaining a positive outlook, respondents also highlighted their efforts to adapt and cope with the changes, often focusing on the positives and continuing with life as normally as possible.

What respondents feel could have been improved

Themes are presented in order of mention so those at the top of this table were mentioned the greatest number of times and those at the end, the least.

Challenge	Feedback
Communication and Information	• **Clearer Communication:** Ensure clear and consistent communication about diagnosis and treatment impacts. • **Better Information:** Provide more detailed information before surgery and regular updates on test results. • **Face-to-Face Meetings:** Increase the number of face-to-face appointments instead of relying solely on phone calls. • **Better Post-Op Advice:** Provide better post-operative advice and assurance about recovery processes.
Timely and Accessible Support	• **Quicker Access to Tests and Treatment:** Reduce wait times for consultations and tests. • **Speedier Reporting:** Improve the speed of reporting test results. • **Easier Access to Antibiotics:** Make it easier to obtain antibiotics for related health issues. • **Early Diagnosis:** Emphasize the importance of early diagnosis and regular PSA testing.
Follow-Up and Monitoring	• **Regular Follow-Up Contact:** Increase the frequency of follow-up contact to monitor well-being. • **Routine Testing:** Implement more routine testing and annual MRI scans.
Support Services	• **Pain and Incontinence Nurses:** Provide access to specialized nurses for pain and incontinence management. • **MacMillan Nurse:** Offer earlier contact with MacMillan nurses or similar support services

What respondents feel could have been improved contd.

Challenge	Feedback
Administrative Efficiency	**Better Coordination:** Improve communication between patients, GPs, and surgeons. **Single Point of Contact:** Establish a single point of contact for patients to streamline communication. **Improved Discharge Process:** Overhaul the discharge process to ensure smoother transitions.
Emotional and Psychological Support	**Emotional Support:** Provide more emotional support for patients and their families. **Psychological Effects of HT:** Address the psychological impacts of hormone therapy more effectively.
Accessibility and Convenience	**Parking and Facilities:** Offer practical support like blue badges for parking and access to disabled facilities. **Closer Hospital Locations:** Ensure tests and treatments are available at hospitals closer to patients' homes.
Patient Involvement	**Discussion Groups:** Create discussion groups for patients to share experiences and support each other. **Involvement in Decision Making:** Involve patients more in decision-making processes regarding their treatment.

Other comments and suggestions about patients' experiences

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Theme	Feedback
Awareness and Education	• Increase public awareness and education about prostate cancer, like breast cancer. - "This disease needs to be spoken about in schools alongside Breast Cancer."
Communication and Information	• Improve verbal discussions and provide timely, clear information about diagnosis and treatment options. - "Not enough verbal discussion on the potential ways forward and consistency."
Emotional and Psychological Impact	• Address anxiety, fear, and feelings of isolation experienced by patient - "I have felt very isolated as a result of the lack of support following increasing problems."
Support and Care	• Highlight positive experiences with care and identify areas where support was lacking. - "Glad it is over but so thankful for the care I received."
Treatment and Recovery	• Ensure effective treatment and address challenges such as cancelled appointments. "Cancelled/delayed appointments limited options on treatment which did not allow me the choice I would have preferred."

Other comments and suggestions about patients' experiences contd.

Theme	Feedback
Administrative Efficiency	• Improve appointment management and coordination between different health trusts. - "Leicestershire health trust were brilliant but lack of communication between other trusts caused most of my problems."
Accessibility and Convenience	• Provide better access to parking permits and address travel challenges for treatment. - "Apart from travelling from Skegness to Lincoln for the treatment, credit to the staff at Lincoln Hospital unit for their care and help."
Suggestions for Improvement	• Emphasize the importance of testing, early diagnosis and better support systems during treatment. - "Not enough contact from professionals during treatment to check on patient progress."

Section 8

Equalities Monitoring

Survey respondent demographics

Sexual orientation	%	Count
Heterosexual	65%	563
Gay	1%	6
Lesbian	0%	0
Bisexual	2%	17
Prefer to self-identify	1%	10
Prefer not to say/ don't know	29%	252

Physical disability or mental illness expected to last more than 12 months	%	Count
Yes	17%	145
No	30%	260
Prefer not to say/ don't know	53%	463

Caring responsibilities	%	Count
Yes	12%	104
No	24%	212
Prefer not to say/ don't know	64%	551

Gender	%	Count
Male	73%	636
Female	1%	9
Intersex	0%	0
Non-binary	0%	0
Prefer not to say/ don't know	26%	223

Gender reassignment	%	Count
Yes	0%	0
No	64%	559
Prefer not to say/ don't know	36%	309

Survey respondent demographics

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Age	%	Count
16-24	0%	0
25-29	0%	1
30-39	0%	1
40-49	0%	4
50-59	6%	48
60-69	25%	213
70-79	35%	301
80-89	8%	72
90+	1%	6
Prefer not to say	0%	0
Prefer not to say/ don't know	26%	222

Ethnicity	Responses	
Bangladeshi	0%	0
Indian	0%	4
Pakistani	0%	0
Any Other Asian Background	0%	1
African	0%	1
Caribbean	0%	1
Any Other Black Background	0%	0
White and Asian	0%	0
White and Black African	0%	0
White and Black Caribbean	0%	0
Any Other Mixed Background	1%	6
White British	71%	615
White Irish	0%	2
Any Other White Background	1%	10
Chinese	0%	0
Gypsies/Travellers/Roma	0%	1
Any Other Ethnic Group	0%	1
Prefer not to say/ don't know	27%	228

Religion	%	Count
Christianity	45%	394
No Religion	14%	118
Atheist	9%	75
Buddhist	0%	1
Jewish	0%	1
Muslim	0%	1
Hindu	0%	1
Any other religion	1%	12
Prefer not to say/ don't know	3%	27
Prefer not to say/ don't know	27%	238

Survey respondent demographics

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Health inequality information	%	Count
Have served in the UK's regular or reserved armed force	**12%**	**106**
Currently working in the Farming/ agricultural industry	**2%**	**18**
Have worked in the Farming/ agricultural industry	**4%**	**32**
Currently homeless	**0%**	**1**
Have experience of being homeless	**1%**	**5**
Currently serving in UK's armed forces	**1%**	**9**
Refugee, immigrant or asylum seeker	**0%**	**1**
Previous experience of being a refugee, immigrant or asylum seeker	**0%**	**2**
Prefer not to say/ don't know	**80%**	**694**

Employment status	%	Count
Employed full time	**8%**	**73**
Employed part time	**5%**	**35**
Homemaker	**0%**	**0**
Not employed and looking for work	**0%**	**4**
Not employed and not looking for work	**0%**	**4**
Retired	**55%**	**480**
Self employed	**5%**	**34**
Student	**0%**	**0**
Prefer not to say	**0%**	**4**
Other	**1%**	**8**
Prefer not to say/ don't know	**26%**	**226**