

# Stoma, Transanal Irrigation and Catheter Care Engagement Report *NHS Lincolnshire Integrated Care Board*

**Engagement Period:** 3 December 2025 – 11 February 2026  
**Author:** Claire Hornsby, Primary Care Engagement Manager



# Executive Summary

Between **3 December 2025 and 11 February 2026**, NHS Lincolnshire Integrated Care Board (LICB) carried out a countywide survey to gather feedback from people with lived experience of Stoma care, Transanal irrigation (TAI), and Catheter services. This report presents the survey findings and the next steps for how this information will be considered to help shape services.

## Definitions

- **Stoma care:** A Stoma is an opening created on the surface of the skin during surgery to allow waste to exit the body into a bag, and individuals rely on these bags and related products daily.
- **Transanal irrigation (TAI):** is a prescribed medical procedure used to flush the lower bowel with water, supporting people with chronic constipation or faecal incontinence.
- **Catheter care:** A Catheter is a thin, flexible tube inserted into the body to drain urine from the bladder. People who use Catheters may rely on different types of Catheters and accessories depending on their medical condition, comfort and lifestyle needs.

## Who we heard from / numbers engaged

**176 survey responses were received.** Responses were received from:

- ✓ **Patients** – 69% (122/176)
- ✓ **Carers** – 11% (20/176)
- ✓ **Family members** – 13% (23/176)
- ✓ **Other**– 6% (11/176) (including healthcare professionals (n=3, including GP practice staff), prospective patients (n=2, including one expecting catheter use in 2026), and others such as friends of a patient and an observer.

Responses were received from across all Lincolnshire districts, with the majority of responses coming from North Kesteven (38% 65/176) with a broad age range represented.

## The survey had three sections (respondents could select more than one):

Responses per section were as follows:

1. Stoma care: 90 respondents
2. Catheter care: 60 respondents
3. Transanal irrigation (TAI): 9 respondents

*Respondents did not answer every question; the number of responses per question is clearly shown within the report*

# Executive Summary

The survey was promoted through targeted email communications, ICB webpages, social media channels, and partner networks. The feedback helped identify where care was working well and where improvements were needed, particularly around reviews, access to specialist support and post discharge care. This report highlights what people told us, including what is working well and where improvements are needed. The findings will be used to help improve services, strengthen care pathways, and make sure people receive the right support at the right time.

## **Stoma care** (90 respondents)

- Most respondents were satisfied with their stoma service, with 84% (57/68) reporting they were very satisfied (49%,33/68) or satisfied (35% 24/68)
- Most respondents said they were always treated with dignity and respect in relation to their stoma care (82%, 54/66)
- Around one quarter of respondents (24%, 20/82) said they had never had a stoma review since their surgery.
- The majority of respondents used a home delivery service (Direct Appliance Contractor) for their stoma supplies (86%, 68/79)

## **Catheter care** (60 respondents)

- Most respondents were satisfied with the catheter service, with 72% (37/52) reporting they were very satisfied (35%,18/52) or satisfied (37%,19/52)
- Most respondents said they were always treated with dignity and respect in relation to their catheter care (69%, 35/51).
- Almost half of respondents (49%, 26/53) said they had never had a catheter review
- The majority of respondents used a home delivery service (Direct Appliance Contractor) for catheter supplies (85%, 46/54).

## **Transanal irrigation (TAI) care** (9 respondents)

- A small number of responses were received (n=9). Feedback was considered indicative only and highlighted largely positive experiences where specialist support was available, alongside a need for clearer pathways and reviews.
- Most respondents were satisfied with the TAI service, with 67% (6/9) reporting they were very satisfied (56%, 5/9) or satisfied (11%, 1/9).
- Most respondents said they were always treated with dignity and respect in relation to their TAI care (78%, 7/9).
- 67% (6/9) said that they had never had a review of their TAI.
- Over half of respondents used a home delivery service (Direct Appliance Contractor) for their TAI supplies (56%, 5/9).

# Executive Summary

Across stoma, catheter and TAI care similar feedback was received for:

## What worked well:

People said services worked best when they could manage independently, had access to knowledgeable support, and experienced simple and reliable ordering and supply arrangements.

## What could be improved:

People consistently highlighted the need for more regular and planned reviews and quicker access to support when problems arose.

## What was missing:

Across all three services, people reported unclear care pathways and not always knowing who to contact for advice, with stoma respondents particularly highlighting the need for clearer advice and support after surgery.

## The difference it's made:

The feedback helped identify where care was working well and where improvements were needed, particularly around reviews, access to specialist support and post-discharge care.

Findings have been shared internally with the Medicines Optimisation team to inform service improvement discussions and support future work to strengthen pathways and patient experience.

## What's next?

The findings will be used to inform future service improvement work, with a focus on strengthening pathways, access to reviews and specialist support. Updates will be shared as this work progresses.

# How the survey was promoted

## Stoma, Transanal Irrigation and Catheter Care Survey

- Continuously promoted through the ICB Engagement Bulletin (public facing newsletter)
- Shared with GP practices, stakeholders, and provider partners
- Posters displayed in hospital clinics and GP practices
- Digital poster with QR codes developed and circulated to support engagement
- Promoted via Healthwatch, voluntary sector organisations, and key stakeholder networks and local support groups
- Advertised on the ICB website, social media channels, and Nextdoor
- Shared through Patient Participation Groups (PPGs) across Lincolnshire
- Distributed widely through community networks and local contacts to maximise reach



**NHS**  
Lincolnshire  
Integrated Care Board

**Help us to improve stoma care, bowel care and Transanal Irrigation (TAI) services, and catheter products**

NHS Lincolnshire Integrated Care Board (ICB) is inviting people with a stoma, those using Transanal Irrigation (TAI) or catheter products, and their carers, to share their views on stoma, bowel, and catheter care products and services across Lincolnshire.

### How to take part

Patients, carers, and anyone who uses these services are encouraged to complete the survey, available online at: [www.lincolnshire.icb.nhs.uk/stoma-tai-catheter-care-survey](http://www.lincolnshire.icb.nhs.uk/stoma-tai-catheter-care-survey).

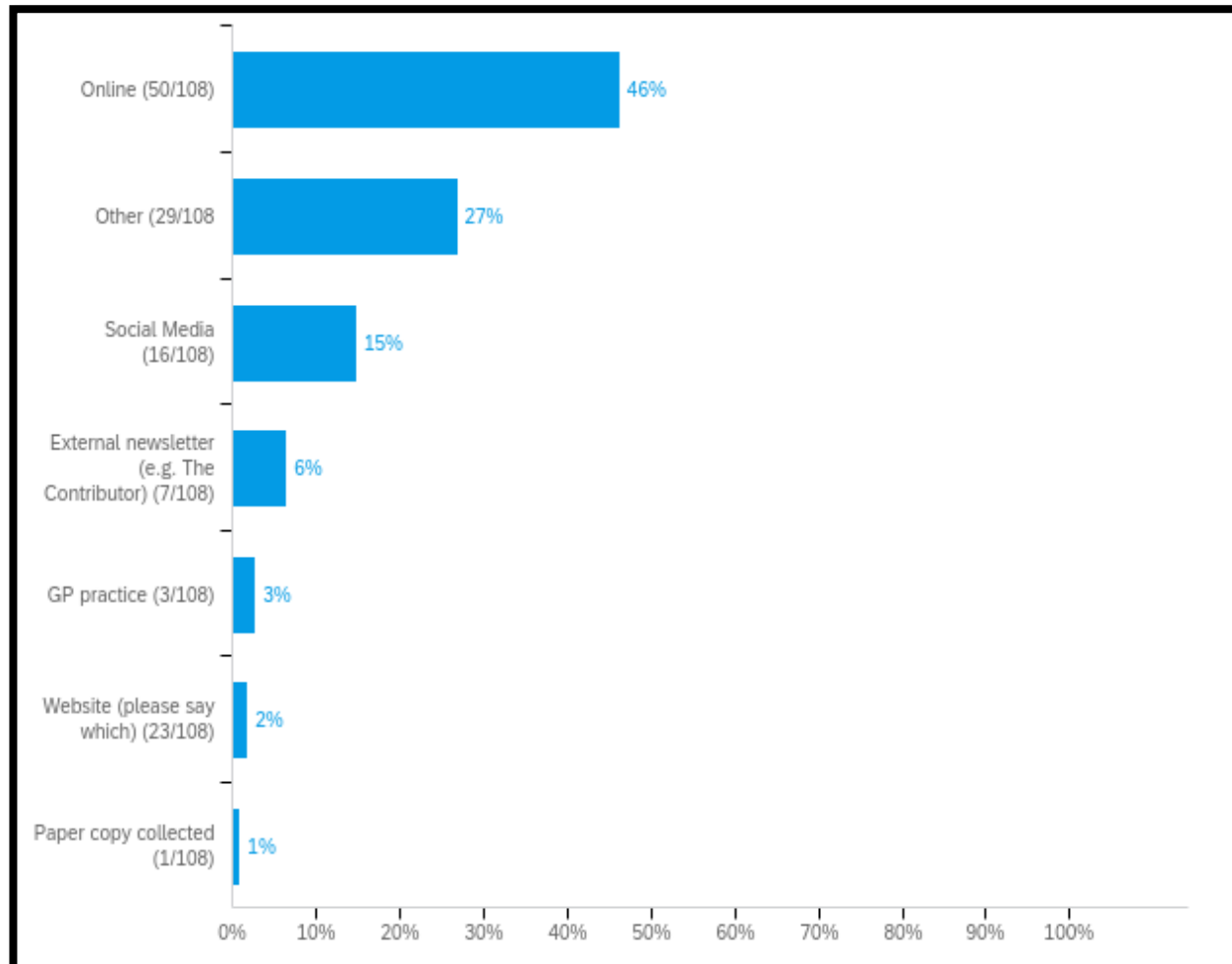
Those who would prefer to speak to someone, need assistance completing the survey, require it in an alternative format or language, or need an interpreter can contact the Engagement Team:

- Email: [licb.involveus@nhs.net](mailto:licb.involveus@nhs.net)
- Phone: 07814 939396



# Survey promotion and opportunities for further involvement

Respondents were asked how they heard about the survey to help understand which communication channels are the most effective in reaching communities. Most reported hearing about the survey online (46%), primarily via email links and text messages. This was followed by other methods, including posters in clinics, word of mouth, and emails from support groups, and partner websites. Social media was also a key channel, with Facebook being the most commonly mentioned platform – mainly from their GP practice facebook pages

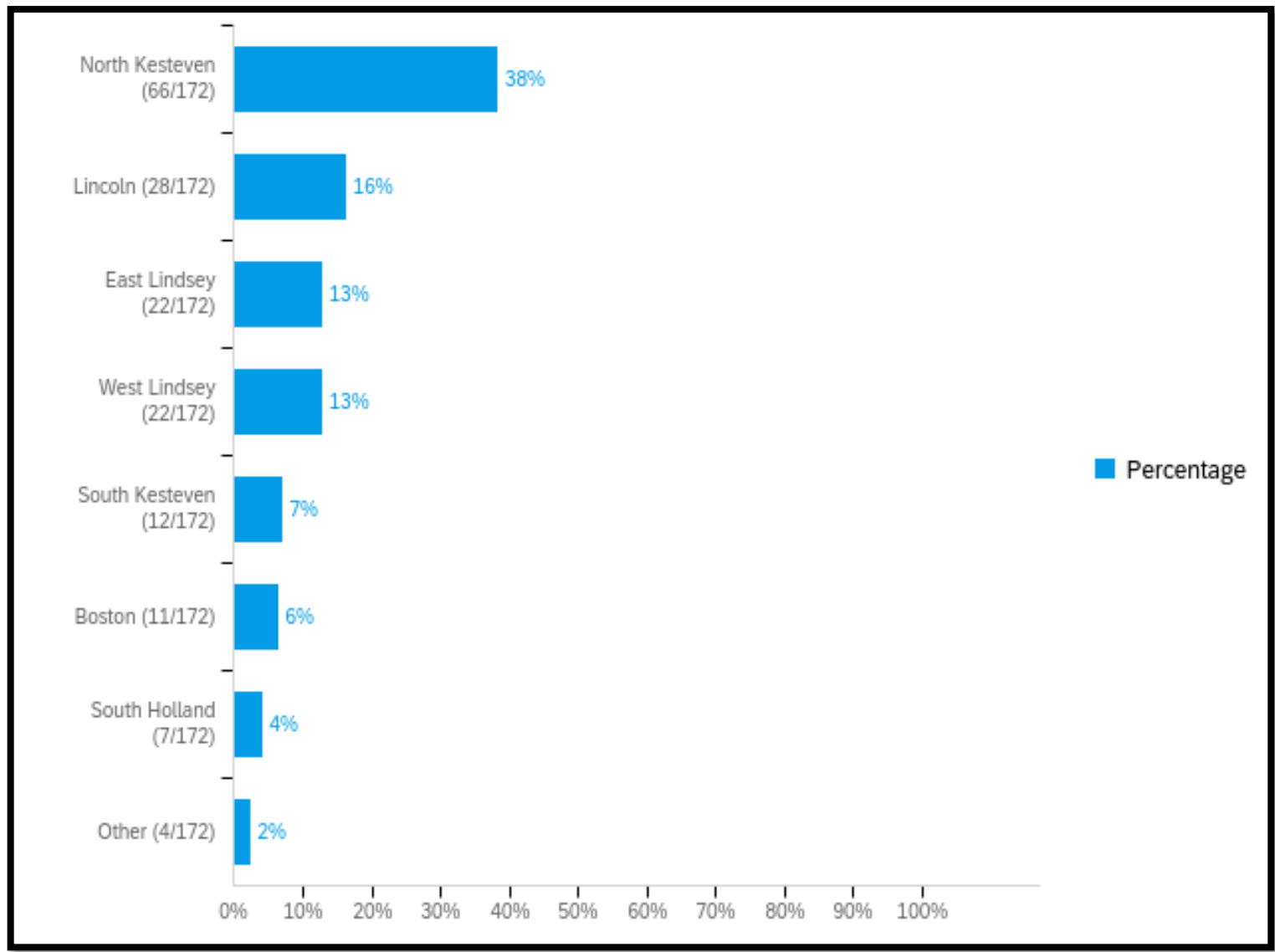


**Opportunities for further involvement** A total of 78 respondents also provided their contact details to express interest in taking part in future engagement activities to help shape the service.

# Geographic distribution of responses

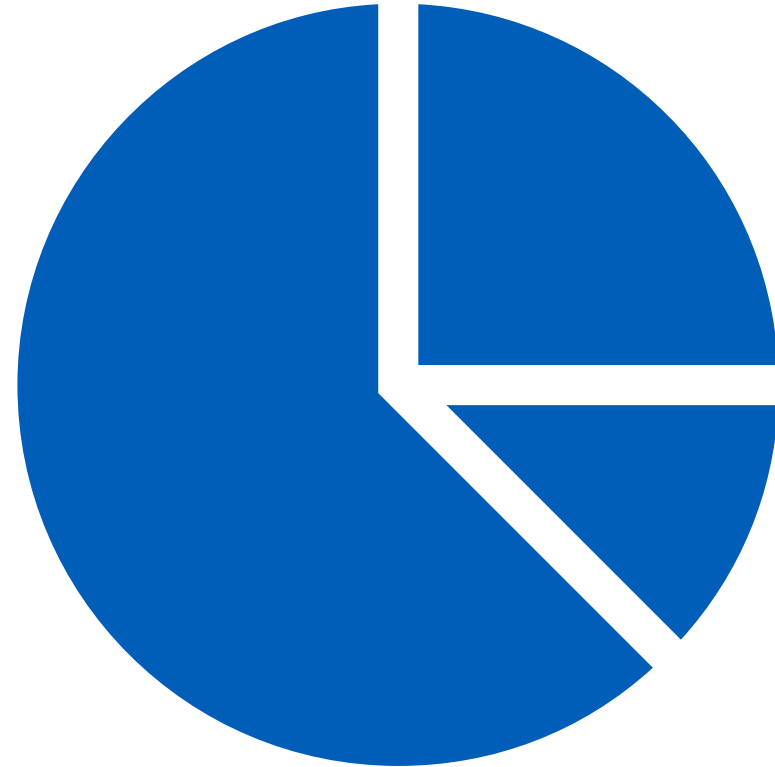


Lincolnshire  
Integrated Care Board



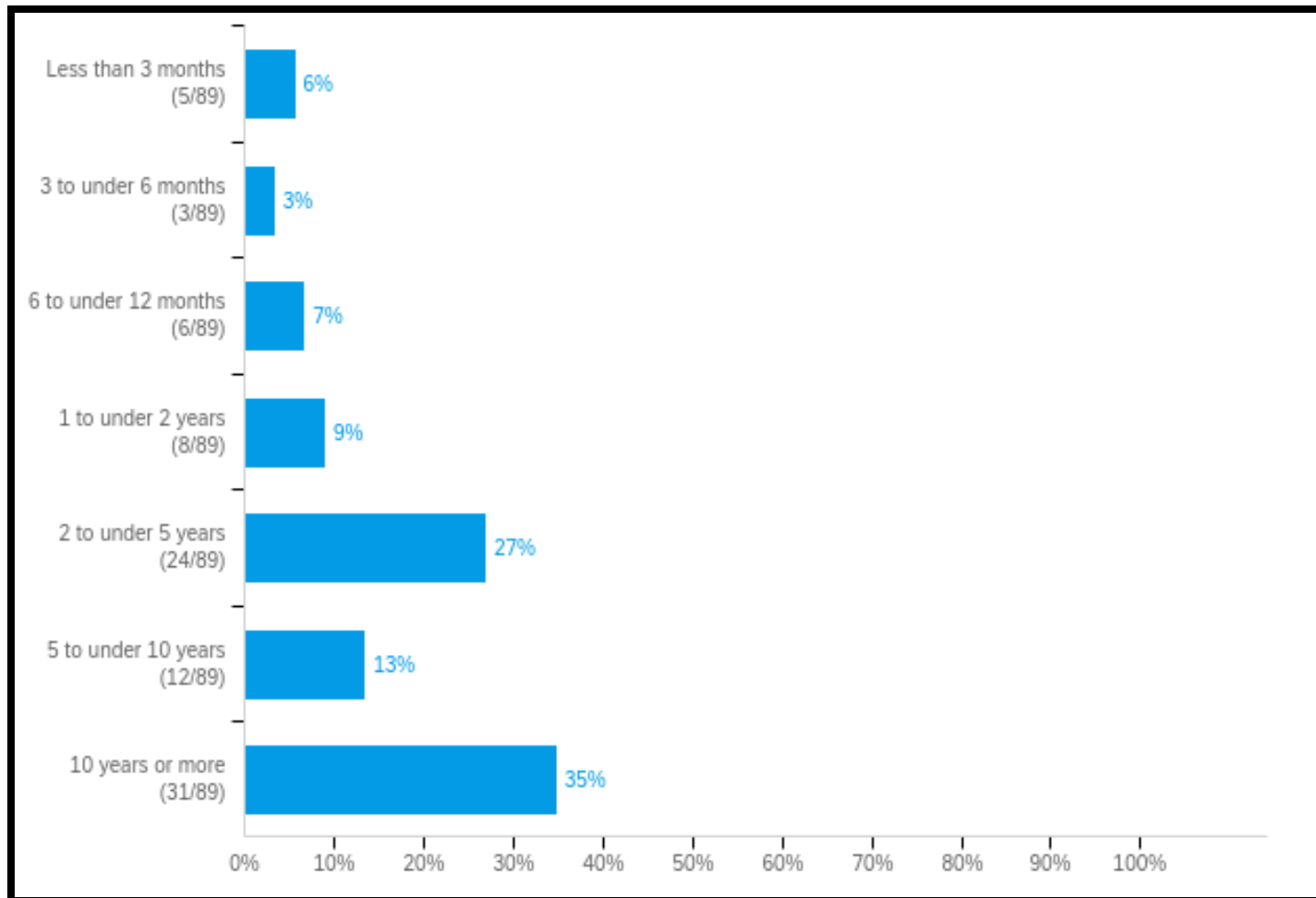
- ✓ **172 responses** were received from **all Lincolnshire districts**
- ✓ **North Kesteven** had the highest number of responses (38%, n=66)

# Section 1: Survey results- Stoma Care



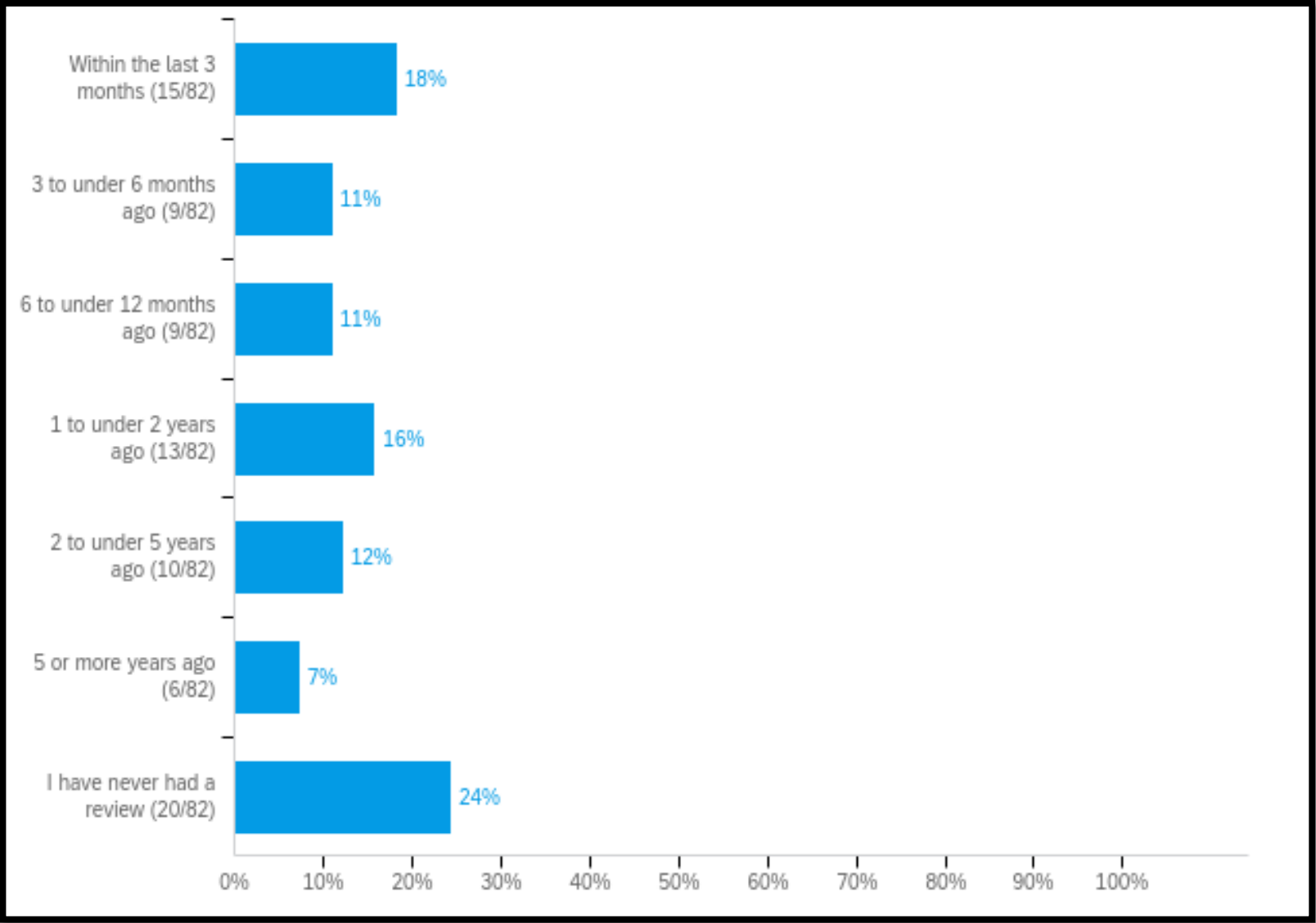
**Length of time living with a stoma:** Respondents mainly have long term experience. Over a third (35%) reported living with a stoma for 10 years or more, followed by 27% who had lived with a stoma for 2 to under 5 years.

Fewer respondents reported more recent experience, with 7% having had a stoma for 6 to under 12 months and 6% for less than 3 months.



Question: How long have you had a stoma? (89 respondents answered this question)

**Stoma reviews:** Review frequency is inconsistent. Nearly one in four respondents (24%, 20/82) reported never having had a stoma review, with over a third reviewed one year or more ago.



Question: When did you last have a Stoma review? (82 respondents answered this question)

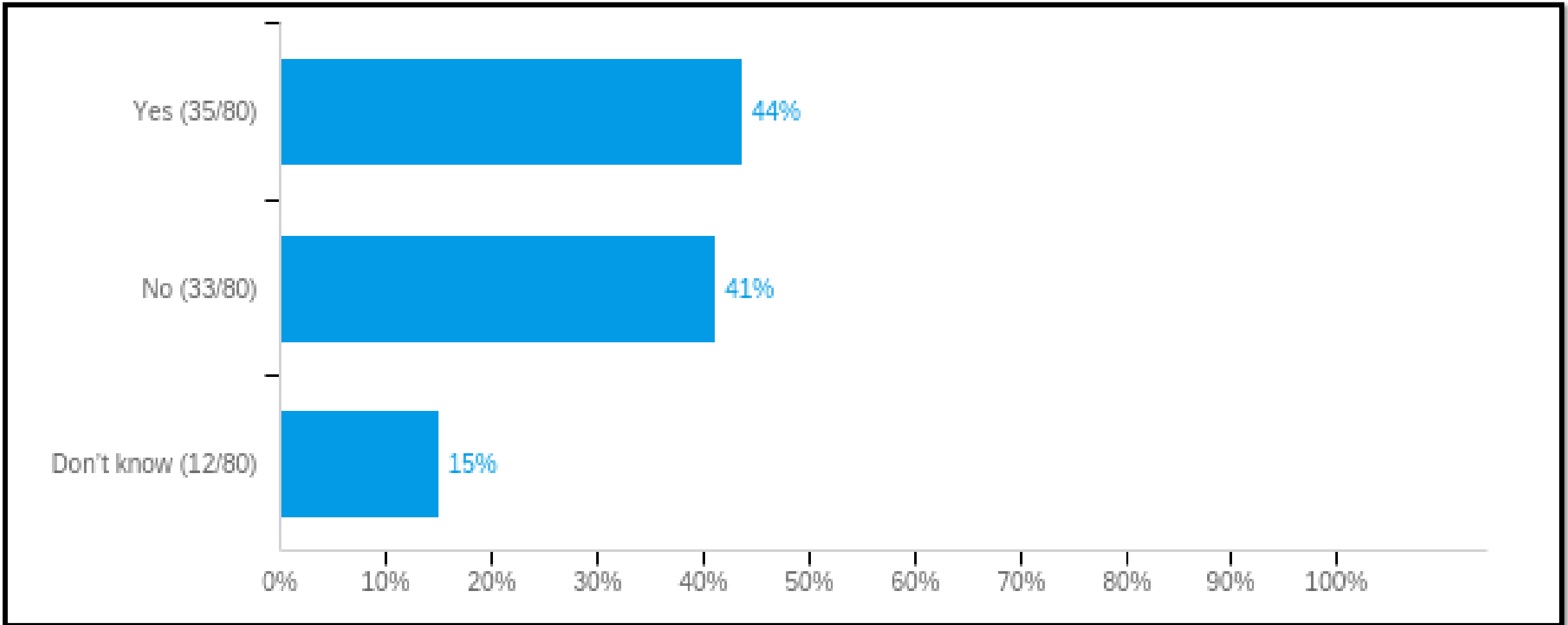
**Location of Stoma reviews:** Most respondents reported attending acute hospital sites. Some reviews took place in GP practices care homes, or at home, including telephone reviews and support from specialist stoma nurses.

Responses highlight variation in review location and pathways, with some patients needing to actively request specialist support.

<b>Hospital care mentions</b>	<b>34</b>
Lincoln County	14
Grantham	8
Pilgrim	6
Scunthorpe	1
John Coupland Hospital, Gainsborough	1
Queen's Medical Centre	1
Hospital site not specified	3

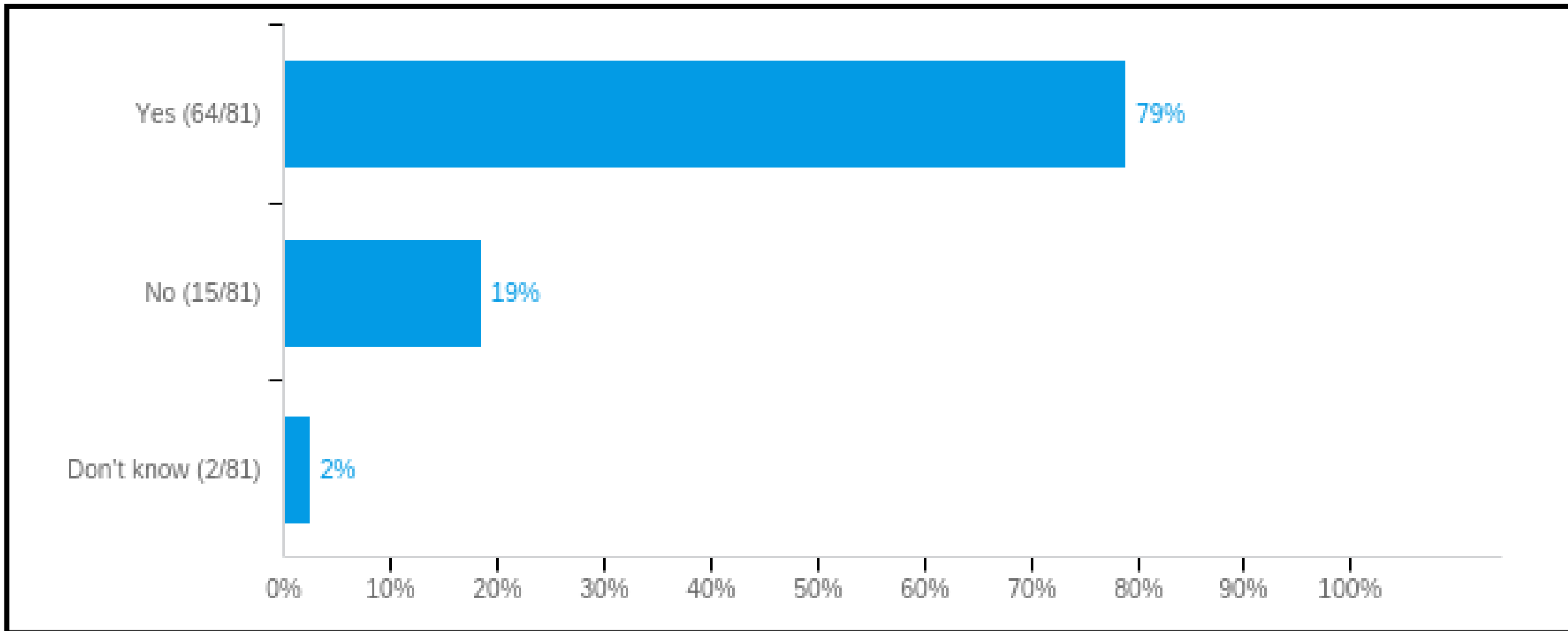
<b>Primary care and community mentions</b>	<b>19</b>
GP practices	6
Portland Street Practice, Lincoln	1
Nettleham	1
Sleaford Medical Group	1
– Hawthorn Medical Practice, Skegness	1
GP practice not specified	2
DAC nurse support	2
Home	3
Telephone	1
Care home	1
Don't know	1

**Current hospital care for stoma management:** Just under half of respondents reported being under the care of a hospital for their stoma, while a similar proportion reported they were not, with a further group unsure.



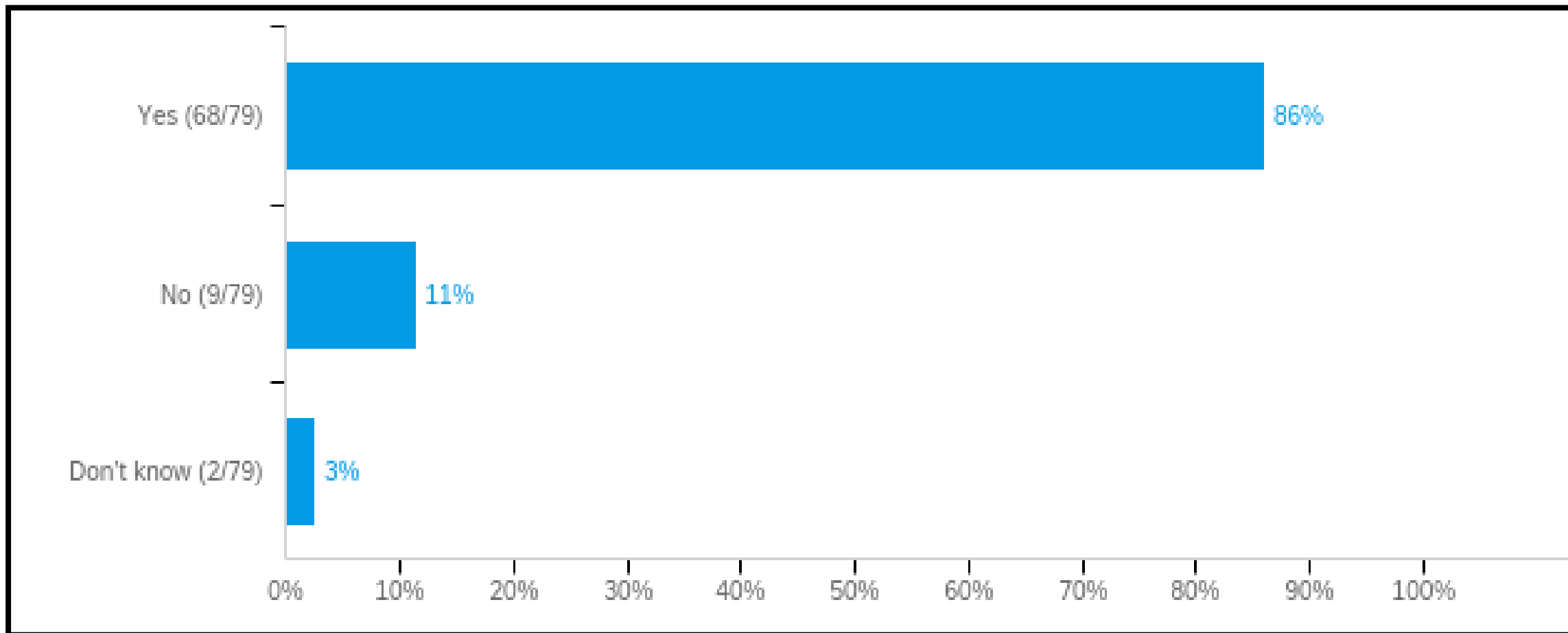
Question: Are you currently under the care of a hospital for your Stoma? (80 respondents answered this question)

**Awareness of patient choice for stoma appliance supply:** Most respondents reported awareness of patient choice for stoma item dispensing, though a smaller proportion were unaware or unsure, indicating some variation in understanding.



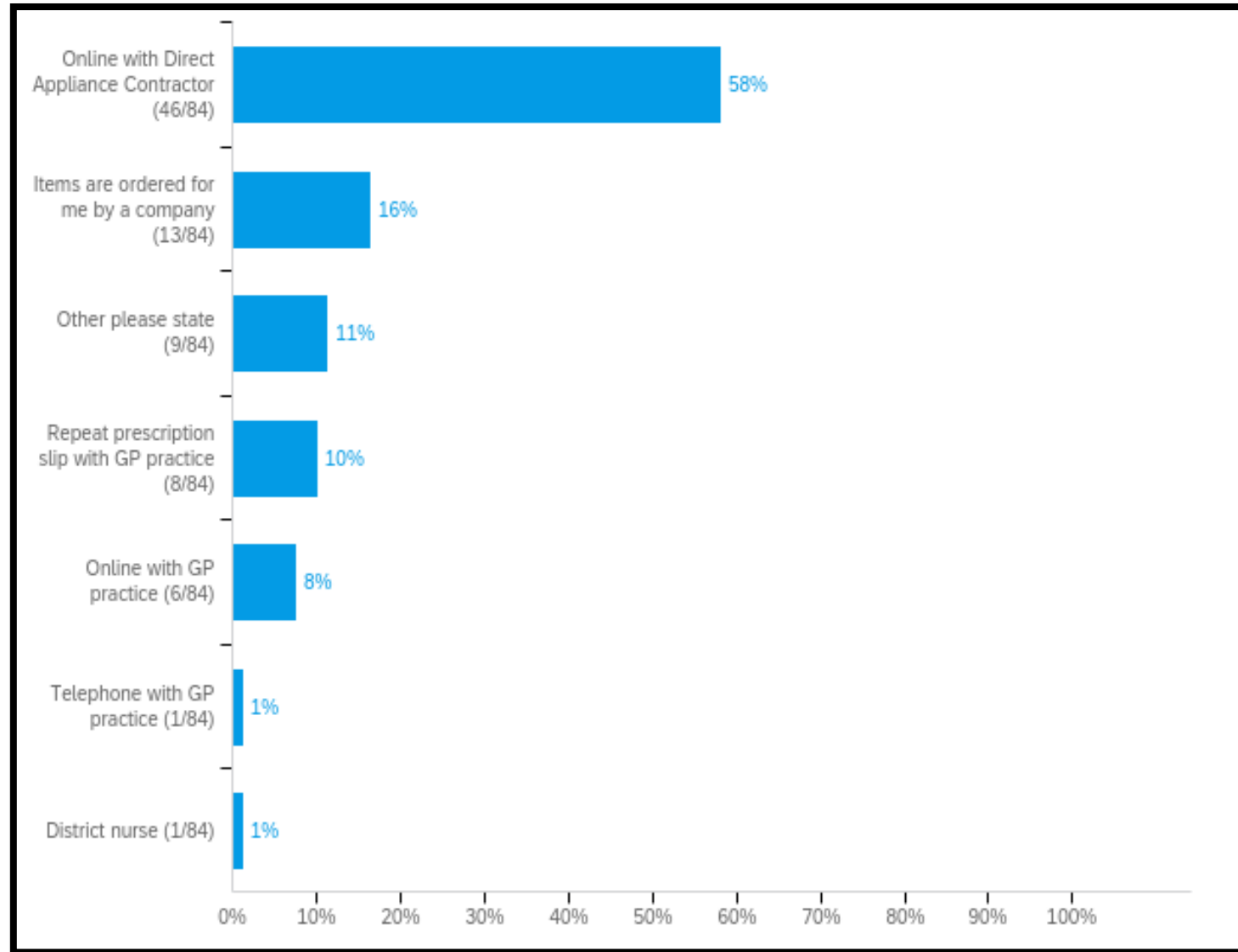
Question: Do you know that you have patient choice to have your Stoma items dispensed by a pharmacy or contractor of your choice? (81 responses)

**Use of home delivery services for stoma supplies:** The majority of respondents reported using a home delivery service for stoma supplies, with some respondents using alternative arrangements or unsure of their current supply route.



Question: Do you use a home delivery service for your Stoma (known as a Direct Appliance Contractor or DAC)? (79 responses)

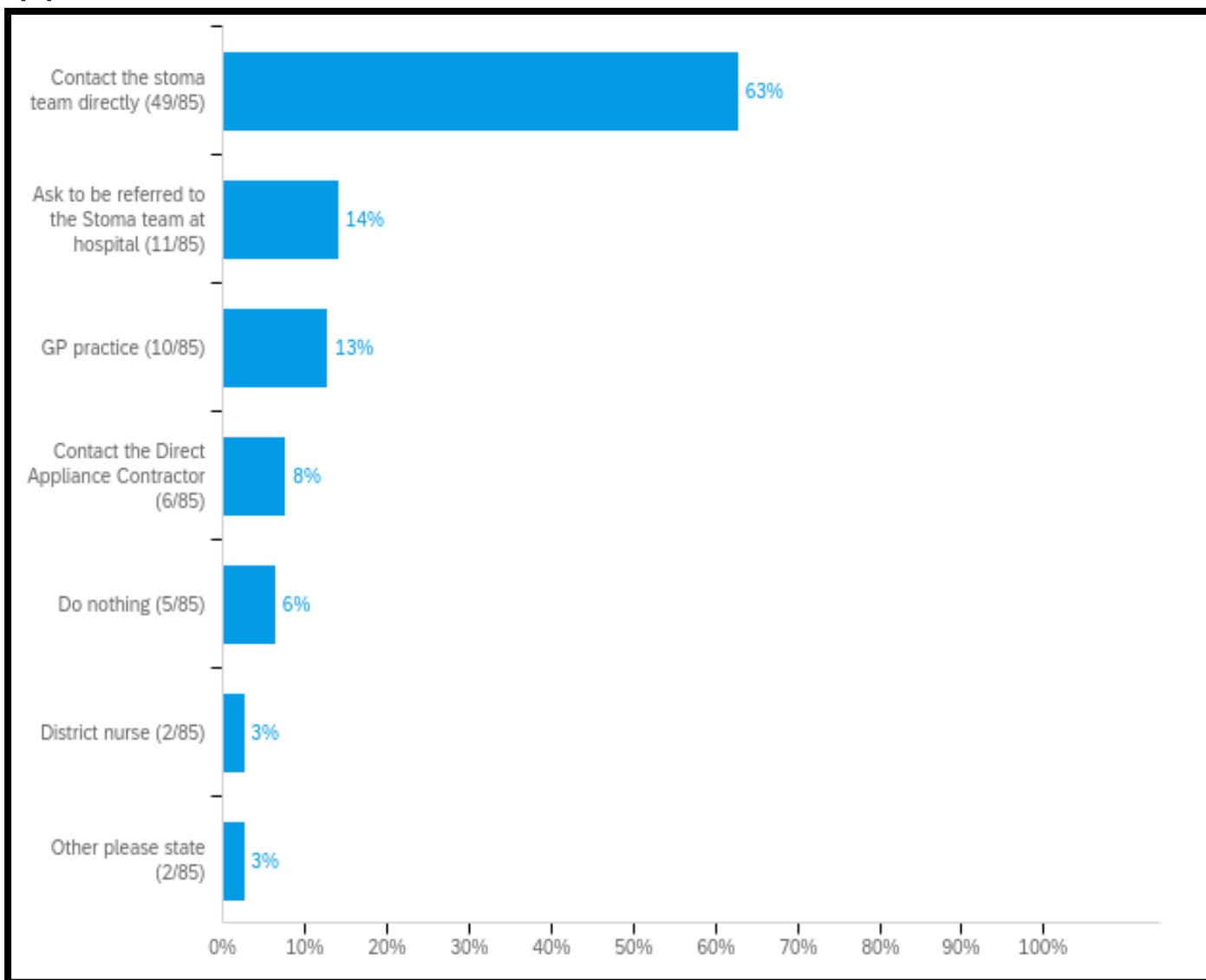
**Current ordering:** Most respondents order their stoma items online via a direct appliance contractor, with smaller proportions using GP practices, pharmacies, or other routes.



**Other please state:**  
telephone with direct  
appliance contractors.

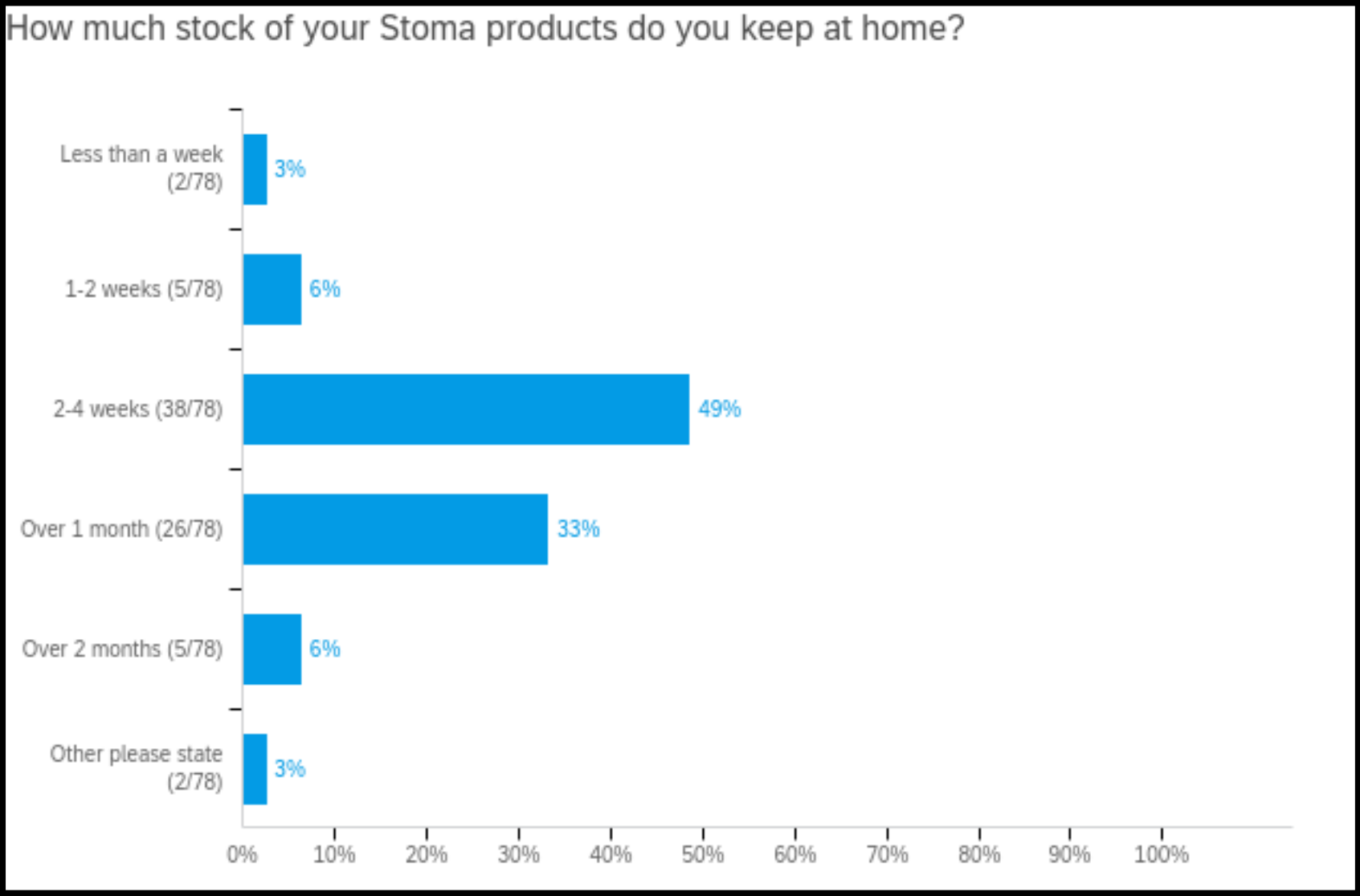
Question: How do you currently order your Stoma items? (84 responses)

**Stoma Support:** When experiencing a problem with their stoma, most respondents reported contacting the stoma team directly. Smaller proportions sought support via GP practices, Direct Appliance Contractors, or other routes



Question: If you have a problem with your Stoma where would you go? (85 responses)

**Stoma stock at home:** Most respondents reported keeping between two to four weeks supply of stoma products at home. Around one third held more than one month's supply. Relatively few respondents had less than two weeks supply available.



Question: How much stock of your Stoma products do you keep at home? (78 responses)

# What **worked well** about the Stoma ordering process

What worked well	Summary of 70 comments (in order of mention)
<b>Quick and easy ordering</b>	Respondents frequently described the process as quick, simple, easy, and straightforward, particularly when ordering online or directly with suppliers.
<b>Reliable and timely delivery</b>	Many valued prompt, reliable home delivery, often highlighting items arriving within a few days, on time, and direct to the door.
<b>Direct ordering via DAC / supplier</b>	Respondents appreciated being able to order directly from DACs or suppliers, who then handled prescriptions.
<b>Convenience and flexibility</b>	The ability to order when needed, vary quantities, order only what is required, and fit ordering around daily life was strongly valued.
<b>Online portals and digital options</b>	Online ordering systems, portals, email ordering, and confirmations were frequently praised for convenience and ease of use.
<b>Reduced GP involvement</b>	Many comments highlighted benefits of avoiding GP delays, queues, or errors, with suppliers managing prescriptions efficiently.
<b>Helpful knowledgeable staff</b>	Praised DAC and supplier staff for being friendly, supportive, responsive, knowledgeable.
<b>Good proactive communication</b>	Positive feedback included reminder calls/emails, updates on orders, tracking information, and named contacts.
<b>Efficiency when routine / no problems experienced</b>	Several respondents stated the system “works well” when routine and reported no issues over long periods.
<b>Home delivery and automation</b>	Monthly deliveries, automatic ordering processes, and minimal effort required
<b>Control and independence</b>	Respondents valued being trusted to manage their own ordering, having control
<b>Stock management support</b>	Keeping appropriate stock levels, ordering ahead, and avoiding waste or expired products
<b>GP surgery or dispensary support</b>	A smaller number reported positive experiences when GP dispensaries or surgeries were efficient and supportive.

Question: What works well about your ordering process for your Stoma products? (70 comments)

# What **improvements** to the Stoma ordering process could be made

Improvements for ordering	Summary of 66 comments in order of mention
<b>No improvements needed</b>	Around half of respondents stated they were happy, satisfied, or felt the service was excellent and did not require any changes.
<b>Faster GP prescription approval</b>	Delays caused by GP approval were frequently highlighted, with respondents reporting slow, variable, or inconsistent approval times that sometimes left them short of supplies.
<b>Reduced or removed GP involvement</b>	Many respondents felt GP involvement adds unnecessary delay and stress, suggesting direct NHS or DAC funding, or removal from GP prescribing where possible would be preferred
<b>Improved ability to change products</b>	Respondents reported difficulties adding new products, changing sizes, or implementing stoma nurse recommendations in a timely way.
<b>Improved stock availability</b>	Product shortages were raised, including regular out of stock items, difficulty finding suitable alternatives, and reliance on larger buffer stocks.
<b>More consistent and reliable delivery</b>	Issues included late deliveries, missed delivery dates, courier wrong delivery, and poor coordination with new drivers.
<b>Simpler and more streamlined ordering</b>	Respondents wanted fewer steps, less duplication, and clearer responsibility between DACs, GPs, pharmacies, and delivery companies.
<b>More online ordering functionality</b>	Requests included easier online ordering, ability to amend orders online, order pre-cut sizes, and avoid phone calls or multiple contacts.
<b>Ability to order larger quantities</b>	Some respondents wanted to order more supplies at once to reduce the frequency of ordering and avoid delays.
<b>Improved communication</b>	Respondents highlighted stress caused by changes to delivery or products without sufficient notice or explanation.
<b>Improved order accuracy</b>	Repeated errors in monthly orders, missing items, or incorrect products were noted by a small number of respondents.
<b>Automatic monthly ordering option</b>	Some respondents suggested automatic or repeat monthly ordering to avoid delays and repeated GP approvals.

Question: What improvements to your ordering process could be made? (66 comments)

# Stoma Management: what worked well

What worked well	Summary of 61 comments (in order of mention)
<b>Effective self-management, confidence and experience</b>	Many respondents described managing their stoma independently, often over many years, with established routines, confidence, and knowing when to seek help.
<b>Access to stoma nurses and specialist support</b>	Respondents valued being able to contact stoma nurses directly by phone, access timely appointments, and receive specialist advice when needed.
<b>Supportive and knowledgeable stoma nurse teams</b>	Stoma nurses were frequently described as excellent, helpful, reassuring, and knowledgeable.
<b>Appropriate products and equipment</b>	Respondents highlighted access to suitable appliances, correct fitting bags, skincare products, irrigation systems, and product choice.
<b>Independence and control</b>	Many valued being treated as “expert patients”, having control over their care, and not being required to attend unnecessary reviews.
<b>Routine and consistency</b>	Established routines, consistent products, and predictable processes supported effective long term management.
<b>Ease of ordering and reliable supply</b>	Easy access to supplies, straightforward ordering, and reliable delivery were seen as supporting good stoma management.
<b>Reduced reliance on GP services</b>	Respondents often preferred specialist stoma services over GP involvement due to faster access and greater expertise.
<b>Feeling supported and reassured</b>	Emotional reassurance, discretion, and feeling supported contributed to confidence and adjustment to living with a stoma.
<b>No problems / everything works well</b>	Some respondents explicitly stated they had no issues and that their stoma management was working well overall.

Question: What works well about the management of your Stoma? (61 comments)

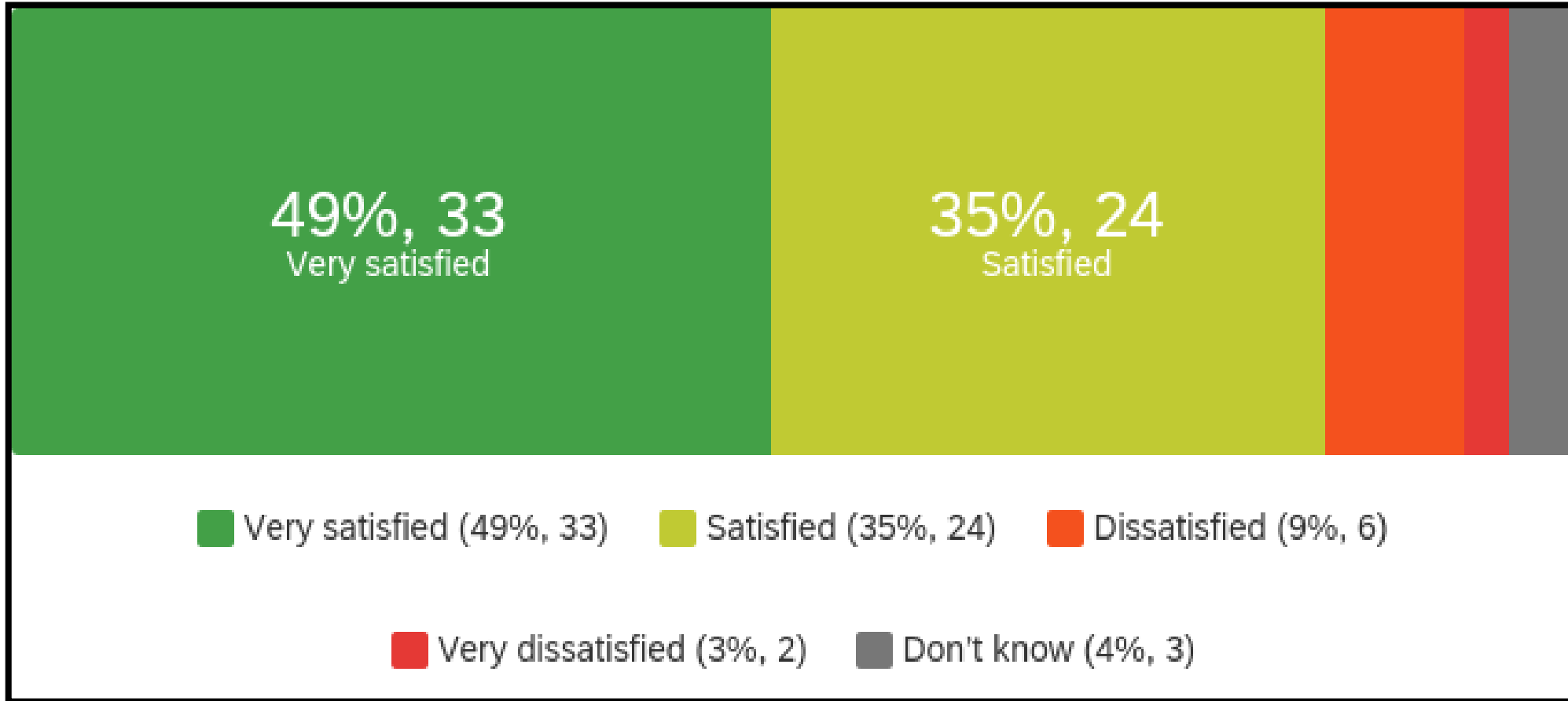
# Stoma Management: what could be improved

What could be improved	Summary of 58 comments (in order of mention)
<b>No improvements needed / satisfied</b>	A third of respondents were happy with their current management
<b>Access to stoma nurses</b>	Difficulty reaching nurses, response times
<b>Regular planned reviews</b>	Requests for annual or scheduled reviews - some wanted these automated
<b>Community based and home support</b>	Home visits and care closer to home
<b>Communication and consistency</b>	Clearer, less conflicting advice, some wanted more training and for this to be face to face.
<b>Holistic and person centred care</b>	Emotional, psychological and lifestyle support
<b>Post hospital discharge support</b>	Improved followup after hospital discharge
<b>Recognition of the expert patient</b>	Respect for patient knowledge and autonomy
<b>Wider specialist access</b>	Dietetic, mental health, cancer and hernia services
<b>Information and education</b>	Better NHS led guidance and updates and more support for children (paediatrics).
<b>GP engagement</b>	Improved GP understanding of stoma care
<b>Service resilience and continuity</b>	Cover during emergencies and busy periods

Question: What improvements to the management of your Stoma could be made? (58 comments)

**Overall satisfaction:** Most respondents were satisfied with the service, with 84% (57/68) reporting they were very satisfied (49%,33/68) or satisfied (35% 24/68).

- Respondents who reported being **satisfied** most commonly cited reliable access to supplies, responsive knowledgeable stoma nurses, and confidence that support was available when needed.
- Those expressing **dissatisfaction** described difficulties accessing specialist support, poor coordination between services, and feeling unsupported after discharge, particularly following emergency surgery and

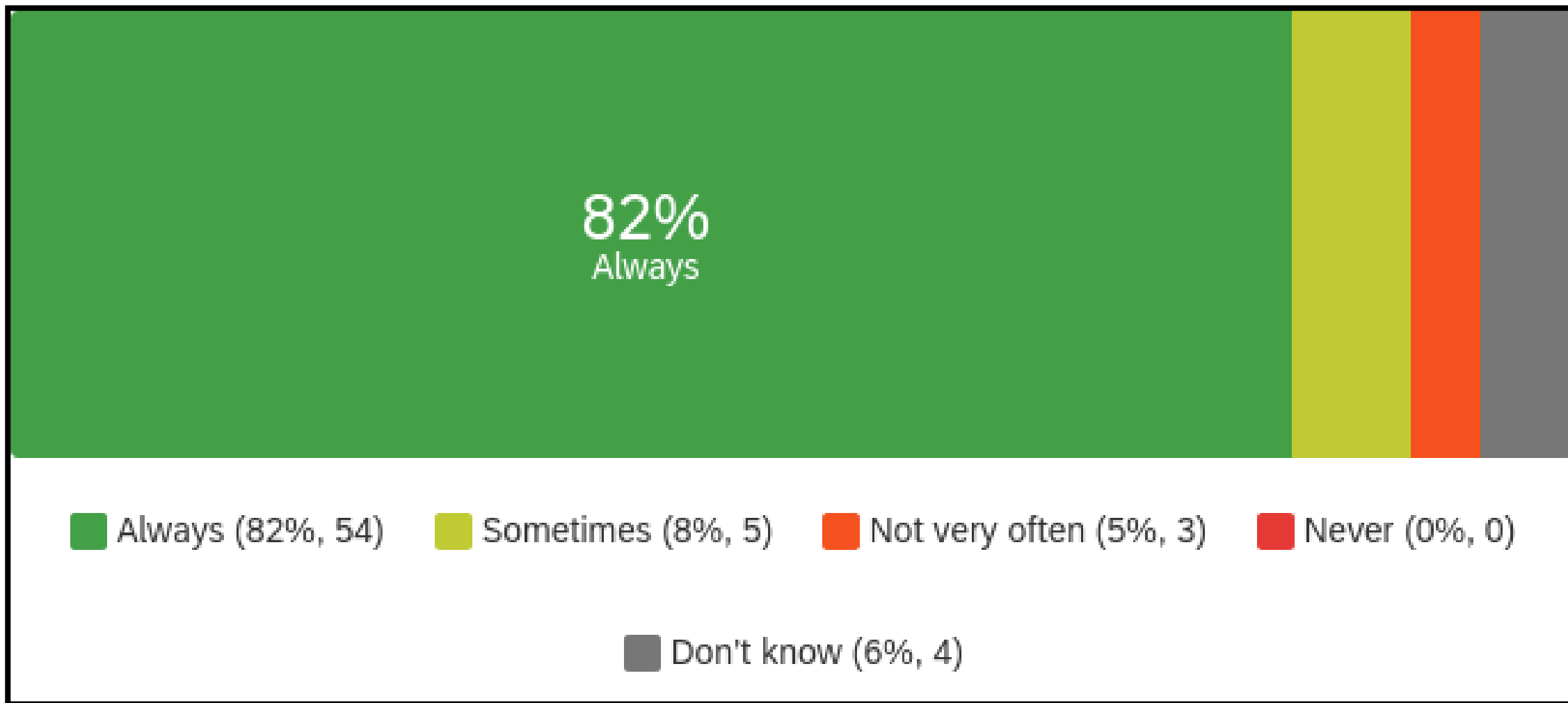


Questions: Overall, how satisfied are you with the service you receive in relation to your Stoma? (68 responses)  
Please give the reason for your answer

**Dignity and Respect:** Most respondents said they were always treated with dignity and respect in relation to their stoma care (82%, 54/66).

**Positive experiences** most commonly related to professional, kind, and supportive behaviour from stoma nurses, DAC staff, and specialist teams.

**Negative experiences** is was mainly associated with interactions with non-specialist staff, limited understanding of stoma care, and feelings of being judged or unsupported during inpatient care.



Questions: Are you treated with dignity and respect in relation to your Stoma care? (66 responses)

Please give the reason for your answer

# Additional suggestions

**Question: Are there any elements of the Stoma care pathway that you feel are missing at the moment?** (55 comments)

- 40% of respondents (23 comments) said there were no missing elements and that they were satisfied with the current stoma care pathway.
- Where gaps were identified, respondents raised the following points (in order of mention in their comments):
  - Lack of aftercare and support following discharge, particularly after emergency surgery
  - Limited routine follow ups or regular reviews e.g. annual check-ups
  - Need for improved community based and paediatric stoma support.
  - Gaps in training and awareness of non specialist staff
  - Inconsistent advice on templates, fitting, and skin care
  - Limited access to dietetic advice, including specialist diets
  - Need for clearer communication about available products, including what options are available or suitable to trial
  - Lack of clarity around the stoma care pathway, points of contact and roles
  - Need for earlier provision of hernia belts and practical supports
  - Need to reduce GP involvement in processes such as ordering supplies
  - Requests for better recognition of patient self management and experience
  - Suggestion of “Stoma Buddies” so people with lived experience can help others on a volunteer basis

# Additional suggestions

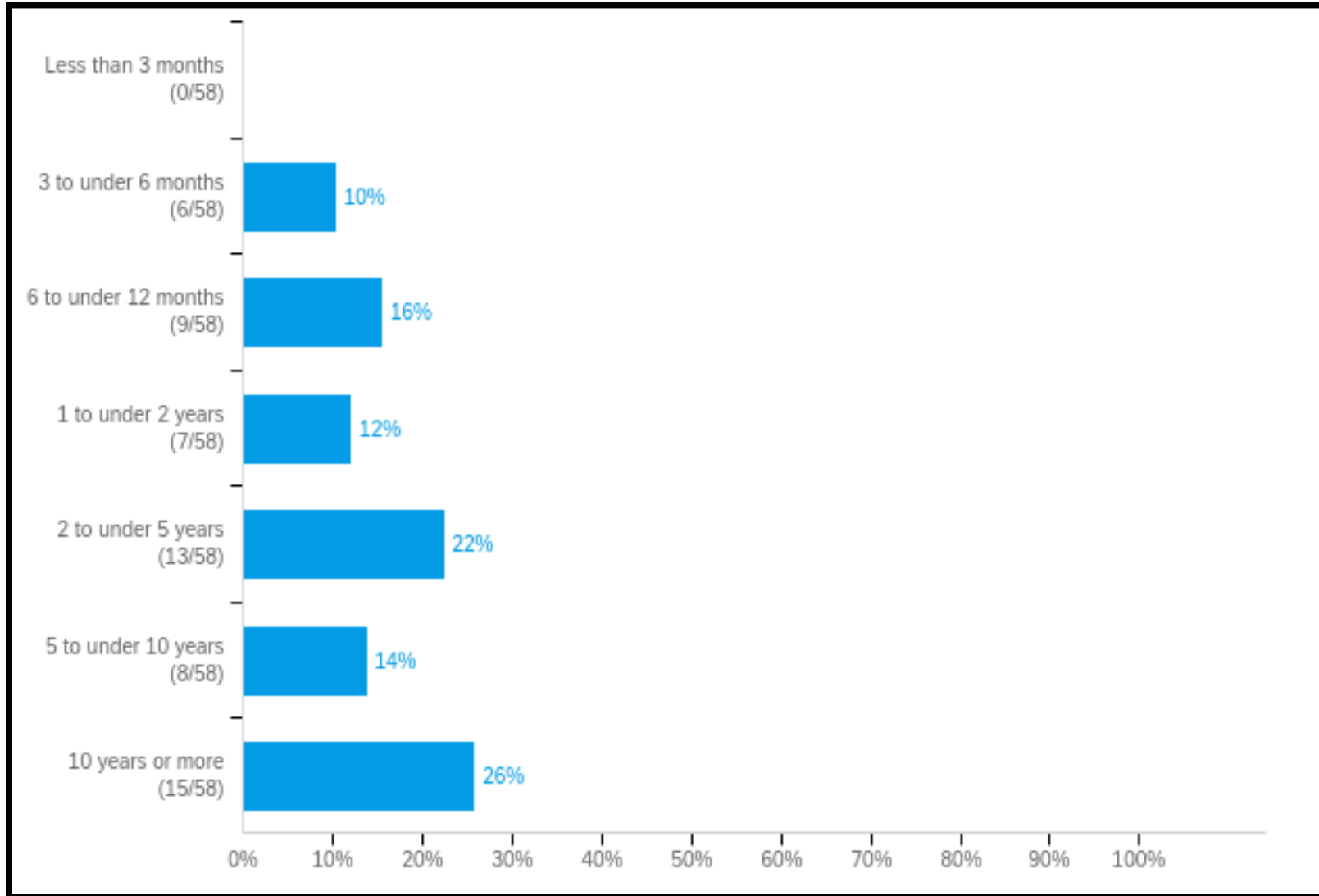
**Question: Is there anything else you'd like us to be aware of or take into account? (46 comments)**

- 61% of respondents (28 comments) said there was nothing else to be aware of or take into account
- In the remaining comments respondents raised the following points (in order of mention in the comments):
  - A need for greater sensitivity, training and consistency within stoma services
  - Importance of continuing access to specific skin care products to maintain skin health
  - Requests not to make ordering or prescribing processes more difficult, particularly for essential products, caution against unnecessary changes or additional bureaucracy
  - Significant emotional and psychological impact of living with a stoma and the challenges of a hidden disability
  - Feelings of being unsupported or alone, unless patients actively advocated for themselves
  - Lack of joined-up medical records in the NHS
  - Gaps in public facilities, particularly the lack of appropriate toilets to support stoma care outside the home
  - Limited availability of local peer support or stoma groups
  - Out of date information materials, with requests for more relevant and age-appropriate resources
  - Concerns about dietary provision in hospital, particularly for people with specialist dietary needs (e.g. gluten-free diets)

# Section 2: Survey results- Catheter care

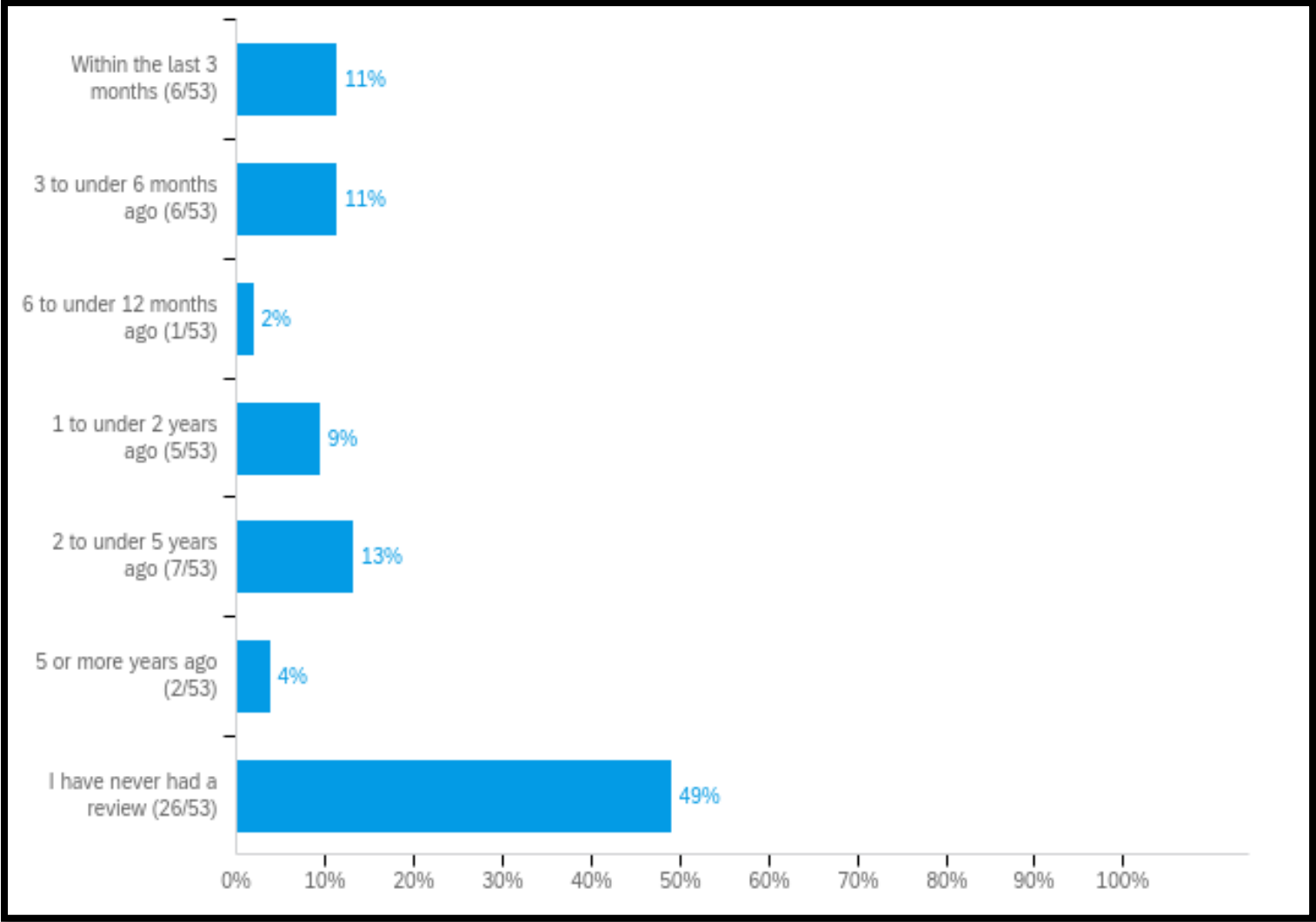


**Length of time using a Catheter:** Respondents predominantly reported longer term catheter use. Over a quarter (26%) indicated they had been using a catheter for 10 years or more, followed by 22% who reported use for 2 to under 5 years.



Question: How long have you been using a Catheter? (58 respondents answered this question)

**Catheter reviews:** Review frequency is inconsistent. Almost half of respondents (49%, 26/53) reported never having had a catheter review, with the remaining responses spread across varying timeframes, and only a small proportion (11%, 6/53) reporting a recent review within the last 3 months.



Question: When did you last have a review of your Catheter management? (53 respondents answered this question)

**Location of Catheter reviews:** Responses indicate that catheter reviews most commonly took place in hospital settings, particularly within specialist services such as spinal injury units and urology departments. Several respondents described attending hospitals both within Lincolnshire and outside, suggesting that catheter care is frequently delivered through regional or specialist pathways.

A smaller number of respondents reported catheter reviews occurring in out of hospital settings, including at home, in care homes, or via telephone contact.

Overall, the responses highlight variation in where catheter reviews take place.

**Where catheter reviews took place** (in order of mention)

**Hospital and specialist settings (most common):**

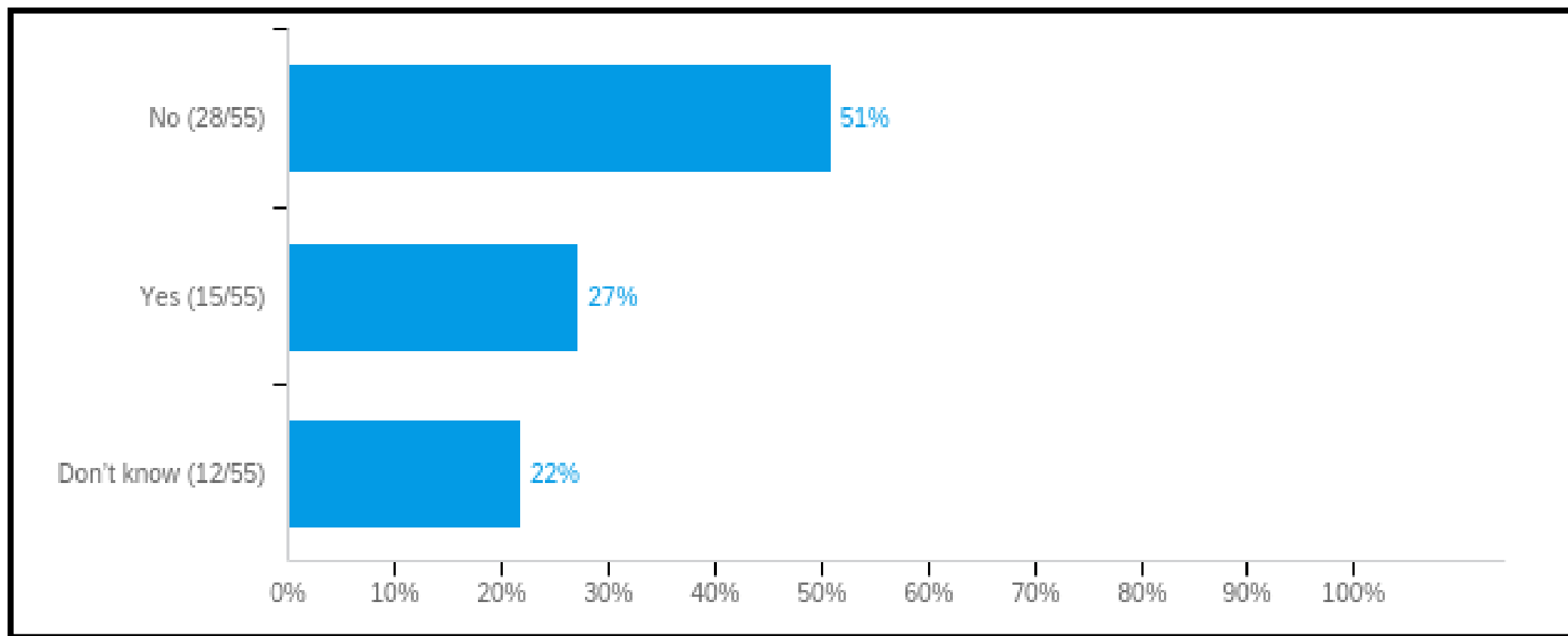
- Spinal injuries units (e.g. Princess Royal Spinal Unit, Sheffield)
- Acute hospitals (e.g. Lincoln County Hospital, Spalding, Grimsby Hospital)
- Specialist urology services (e.g. Nottingham City Hospital)
- Hospitals outside Lincolnshire (e.g. Sheffield, Grimsby)

**Community and alternative settings (less common):**

- At home
- Care home
- Via Telephone
- Continence clinic

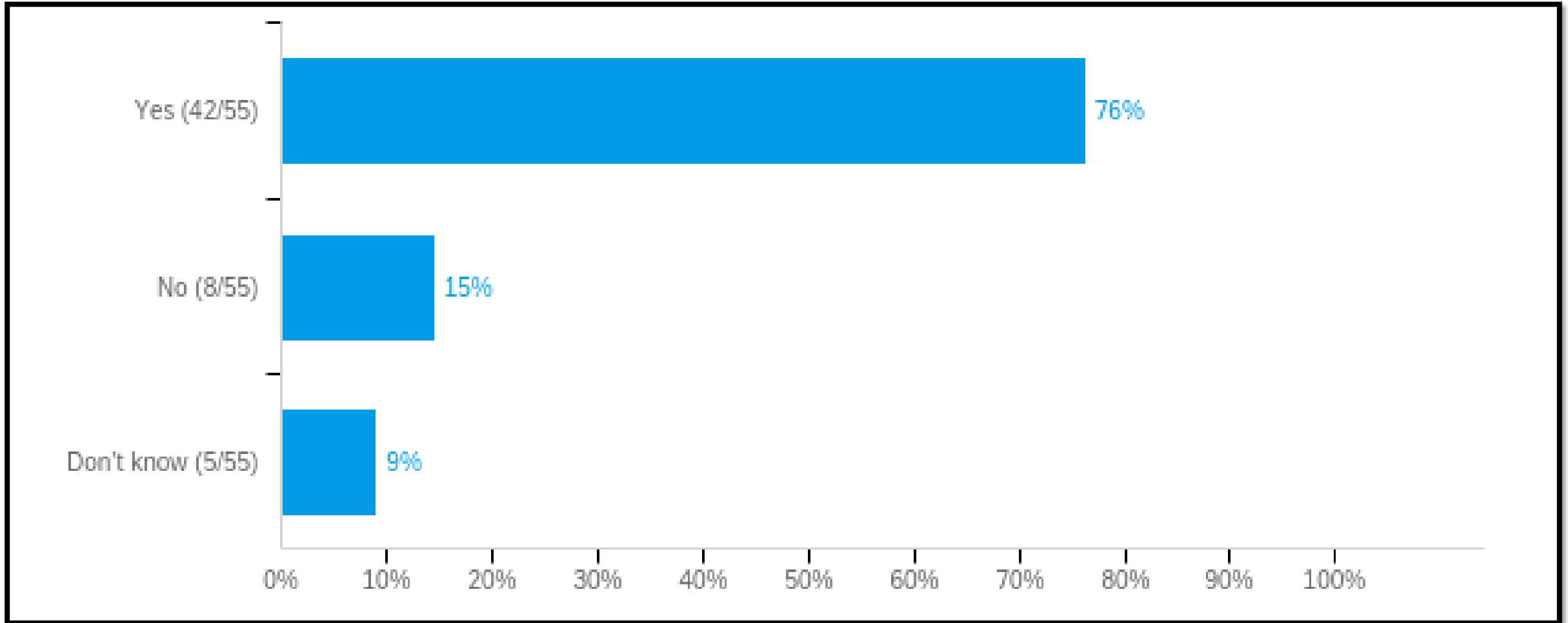
**Review not yet undertaken – 1 response.**

**Current hospital care for catheter management:** Just over half of respondents (51%) reported that they are not currently under the care of a hospital or specialist team for their catheter. Just over a quarter (27%) reported that they are under hospital or specialist care, while a further 22% were unsure. This highlights variation in ongoing catheter care arrangements and a lack of clarity for some respondents about who is overseeing their catheter management.



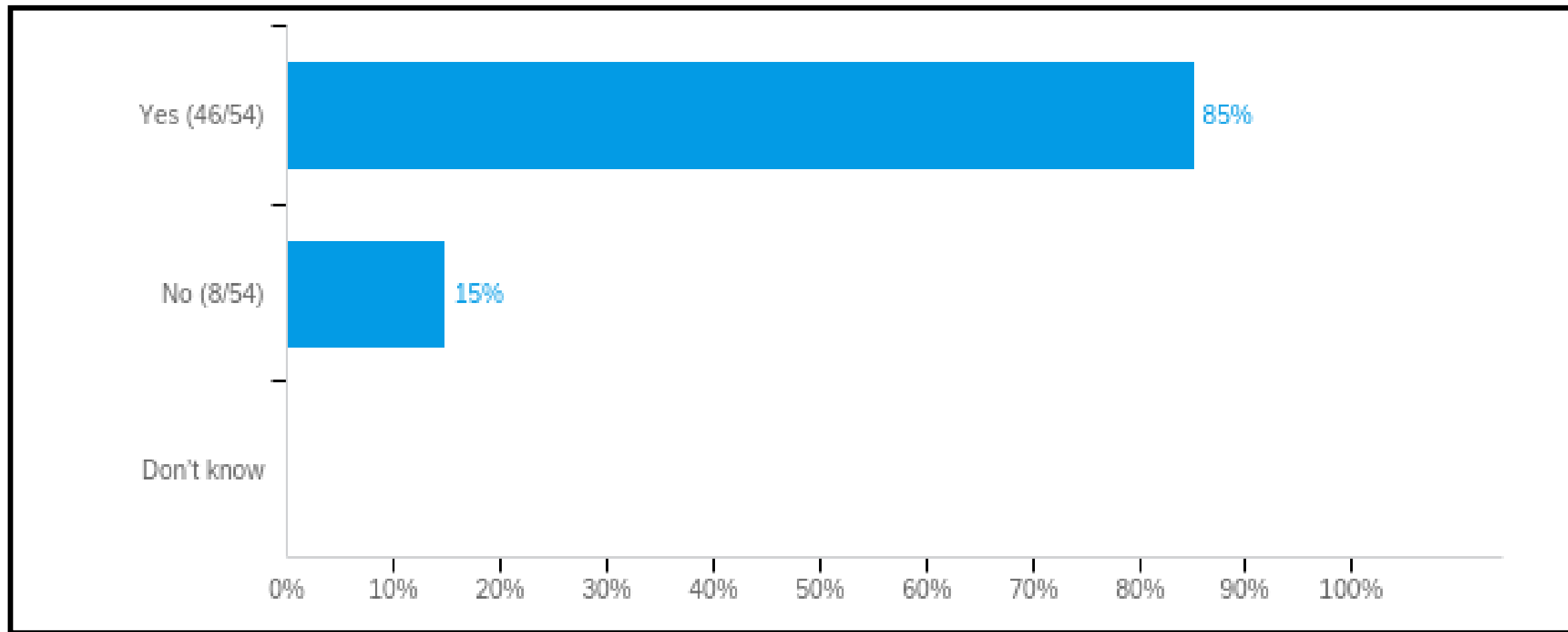
Question: Are you currently under the care of a hospital or specialist team for your catheter? (55 respondents answered this question)

**Awareness of patient choice for Catheter supply:** Most respondents reported awareness of patient choice for Catheter supply, though a smaller proportion were unaware or unsure, indicating some variation in understanding of patient choice



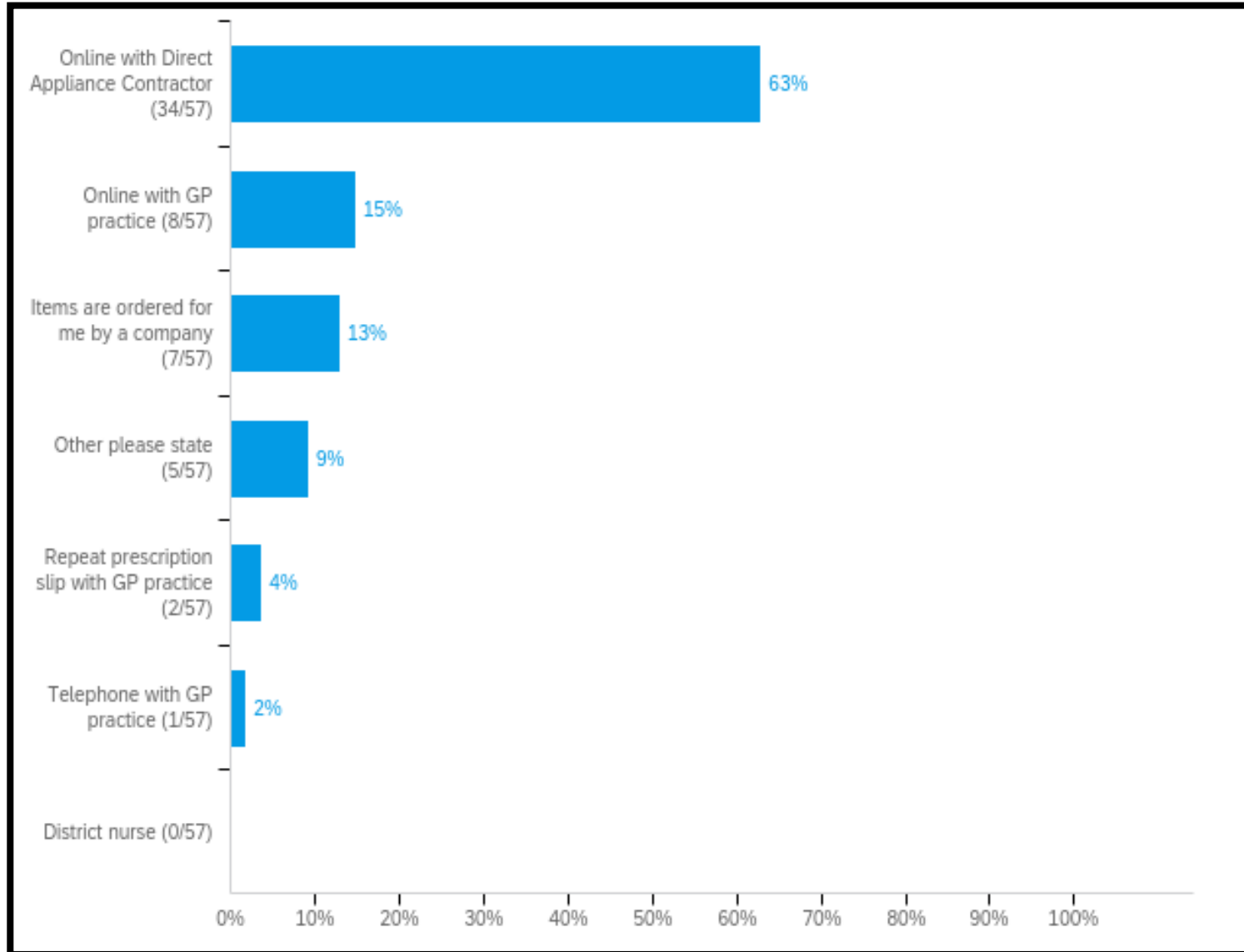
Question: Do you know that you have patient choice to have your Catheter supplies dispensed by a pharmacy or contractor of your choice?  
(55 responses)

**Use of home delivery services for Catheter supplies:** The majority of respondents reported using a home delivery service for Catheter supplies, with some respondents using alternative arrangements.



Question: Do you use a home delivery service for your Catheter supplies (known as a Direct Appliance Contractor or DAC)? (54 responses)

## Current ordering: Most respondents order their Catheter supplies online via a direct appliance contractor, with smaller proportions using other routes

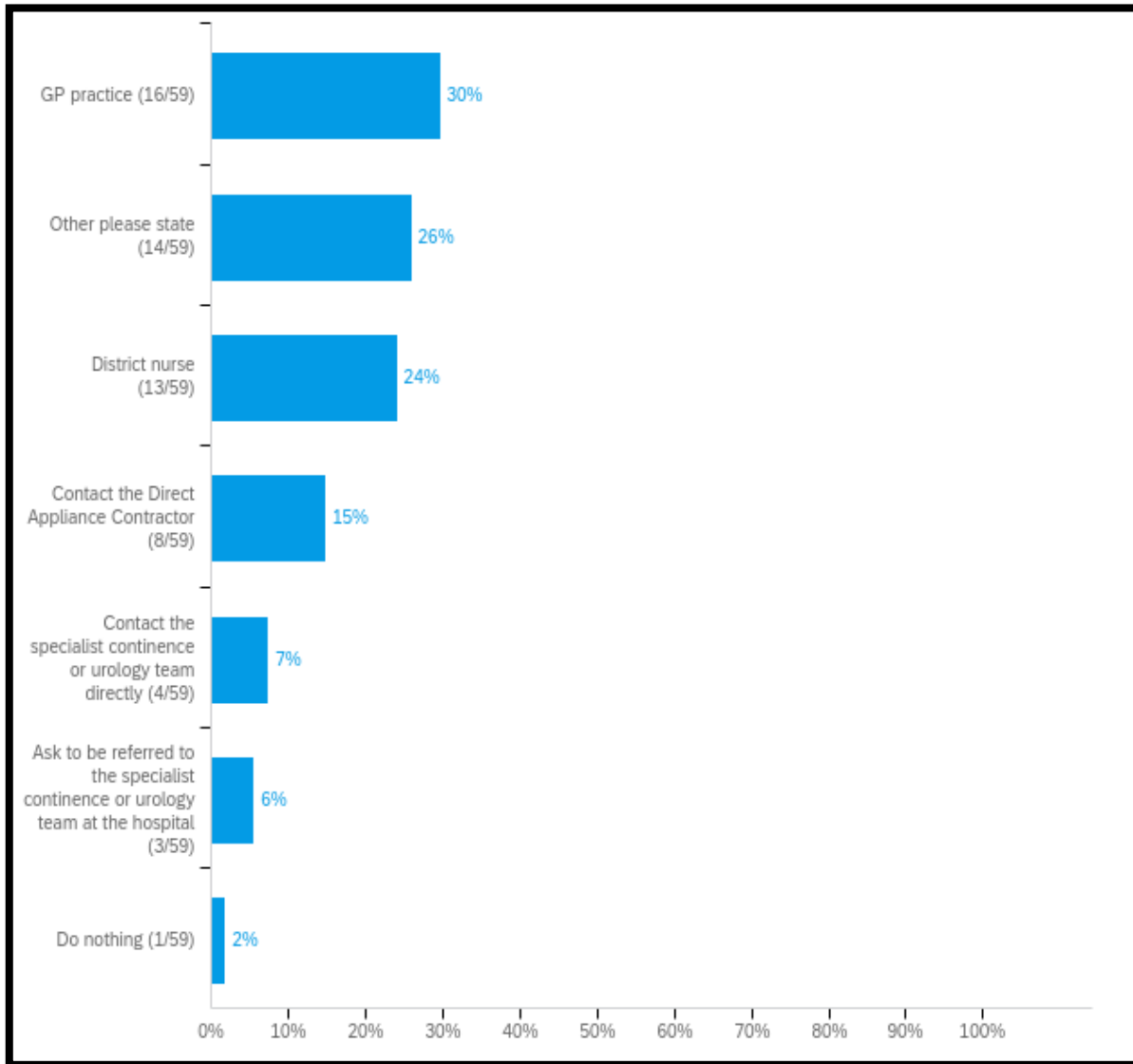


**Other please state:**

- DAC
- Hospital
- Short time use following prostate cancer last year and follow up treatment presently.
- DAC app.

Question: How do you currently order your Catheter supplies? (57 responses)

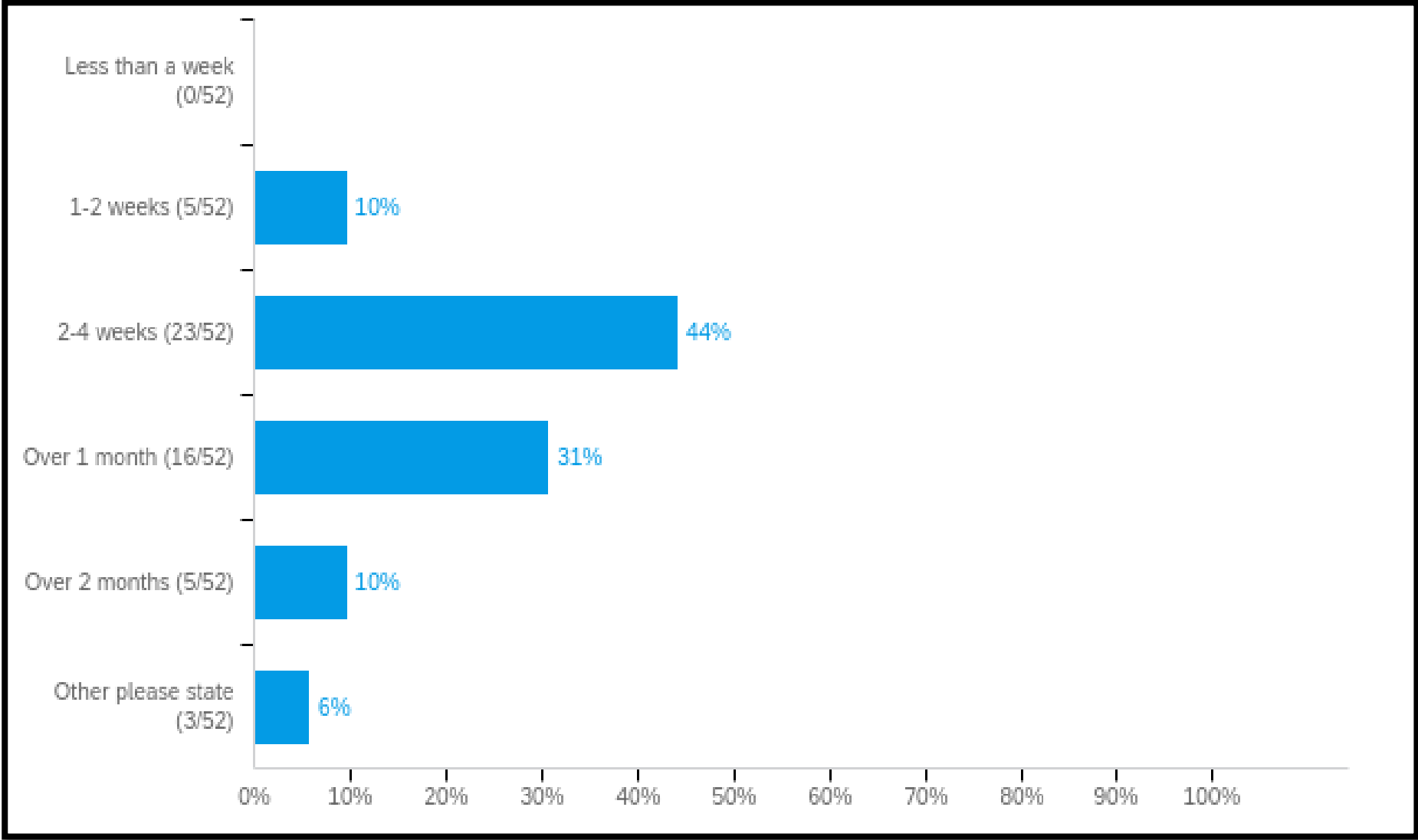
**Catheter Support:** Responses indicate that people use a range of routes for catheter support, most commonly GP practices and district nursing services, with fewer accessing specialist continence or urology teams.



**Other please state:** most frequently cited hospital based support, including spinal injuries units, UTCs and A&E, often due to difficulties accessing timely community or GP support..

Question: If you have a problem with your Catheter, where would you go? (59 responses)

**Catheter supplies at home:** Most respondents reported keeping two to four weeks supply of catheter products at home, with around one third holding more than one months supply and very few reporting low stock levels.



Question: How much stock of your Catheter supplies do you keep at home? (52 responses)

# What **worked well** about the Catheter supplies ordering process

What worked well	Summary of 52 comments (in order of mention)
<b>Overall satisfaction / service works well</b>	This was the most frequently expressed sentiment. Many respondents stated that the service “works well”, “works fine”, or that they were satisfied with the ordering process,
<b>Easy and straightforward ordering (including online)</b>	Respondents commonly described ordering as easy, simple and convenient. This included online, phone calls, email ordering, and straightforward repeat ordering. Online ordering was frequently mentioned positively as well as ordering and reviews over the phone. Some respondents likes having multiple ways to order allowing them to choose what worked best for their circumstances.
<b>Direct ordering via DACs / suppliers</b>	Many respondents valued being able to order directly from specialist suppliers. They highlighted confidence in ordering directly, with suppliers managing the process efficiently and supporting repeat and regular orders.
<b>Supplier professionalism and product knowledge (DAC-specific)</b>	Several respondents specifically praised DAC staff for being knowledgeable, trained, understanding catheter products, and giving time to answer questions.
<b>Reliable and timely delivery</b>	Respondents frequently mentioned deliveries being reliable, prompt, dispatched the same day, next day delivery, or arriving on time. Home delivery was described as convenient.
<b>Good communication and updates from suppliers</b>	Respondents valued suppliers contacting them regularly, checking stock levels, reminding them to order, correcting mistakes, and providing delivery updates by text or email.
<b>GP surgery or dispensary support (less frequent)</b>	A smaller number of respondents reported positive experiences where GP repeat prescriptions, GP dispensaries, or pharmacy collection worked efficiently and supported timely ordering.

Question: What works well about your ordering process for your Catheter supplies? (52 comments) analysis of free text responses

# What **improvements** to the Catheter ordering process could be made

<b>Suggested improvement</b>	<b>Summary of 44 comments (in order of mention)</b>
<b>No improvements needed / satisfied</b>	This was the most frequent response. Many respondents stated “no improvements needed”, “excellent”, or “leave well alone”, indicating general satisfaction with the current ordering process.
<b>Faster GP prescription authorisation</b>	Several respondents highlighted delays and unpredictability in GP approval of prescriptions, including slow processing, missed authorisations, and delays between GP approval and suppliers receiving prescriptions.
<b>Automatic monthly or repeat ordering</b>	Respondents suggested automatic monthly deliveries or repeat ordering unless changes are needed, to reduce the need to reorder manually and avoid disruption.
<b>Reduced reliance on GP approval / streamlined prescribing</b>	A number of comments asked for suppliers or services to prescribe directly, rather than requiring GP approval, describing the current process as “long-winded” and involving unnecessary back and forth
<b>Improved access to ordering via NHS App</b>	A small number of respondents suggested the ability to reorder via the NHS App, particularly when ordering the same items as the previous month.
<b>More responsive options when needs change suddenly</b>	A small number reported needing rapid access to supplies when needs changed, noting occasions where lack of timely access led to A&E attendance.
<b>Avoid over-supply and expired stock</b>	A small number of comments suggested improvements to ensure only required quantities are sent, to avoid storage issues or products going out of date.
<b>Alternatives when items are out of stock</b>	A small number of respondents requested clearer or quicker alternatives when products are unavailable.

Question: What improvements to your ordering process could be made? (44 comments) analysis of free text responses

# Catheter Management: what worked well

What worked well	Summary of 43 comments (in order of mention)
<b>Self management /independence</b>	Respondents described self catheterising, managing their own stock, flexibility to order when needed, becoming proficient over time, and maintaining independence at home and in daily life.
<b>Ease of ordering and delivery</b>	Respondents highlighted ease of ordering, hassle-free processes, professional supplier companies, delivery from DACs, regular emails from suppliers, free accessories, and prompt home delivery.
<b>Everything works well / no problems</b>	Some respondents stated that everything works well, that there were no problems, or that catheter management was hassle free or had no current issues.
<b>Support from specific services / teams</b>	Positive experiences were described with specialist nurses, consultants, urology departments, bladder teams, and spinal units, particularly where concerns could be escalated or appointments arranged.
<b>Routine and consistency of care</b>	Some respondents valued predictable routines and consistency, such as regular catheter change intervals and stable prescriptions.
<b>District nurse support</b>	A smaller number of respondents reported trust, professionalism, and supportive experiences with district nursing teams in the community.
<b>Adequate equipment and accessories</b>	Respondents noted having a good supply of necessary goods, free sundries such as wipes and bags, suitable devices, and accessories that supported daily living.
<b>Knowing what to do and who to contact</b>	Some respondents stated they know what to do and who to contact if a problem arises, which supported confidence in management.
<b>Care provided by family members</b>	A small number of respondents described catheter care being provided by a family member.

Question: What works well about the management of your Catheter? (43 comments) analysis of free text responses

# Catheter Management: what could be improved

What could be improved	Summary of 41 comments (in order of mention)
<b>No improvements needed / satisfied</b>	Many respondents stated “nothing” or they were happy with the current service.
<b>Better access to appropriate clinical support</b>	Access to nurse specialists, urologists, or doctors (including face-to-face appointments), with some respondents noting long gaps without review or difficulty getting appointments.
<b>Improved staff training and competence</b>	Several respondents highlighted the need for more training, experienced clinicians, improved aseptic technique, safer practice, and more confidence in catheter care, particularly for district nurses.
<b>Clearer information, advice and communication</b>	Respondents described needing more help, clearer advice, better information, better explanation of options, communication with those managing care (including carers), and not having to find information out themselves.
<b>Reliable, timely response to catheter problems (including out of hours)</b>	Multiple respondents highlighted long waits for help with blocked or expelled catheters, the need for out of hours contacts, quicker responses, and alternatives to being sent to urgent care.
<b>Single point of contact / knowing who to contact</b>	Some respondents requested a single, clear point of contact for catheter issues, direct contact with departments.
<b>Better pharmacy and prescription communication</b>	Some respondents raised concerns about pharmacy staff removing items from prescriptions without discussion, delays in prescription processing.
<b>More support when needs change or recur</b>	Respondents described uncertainty about how to manage changes or recurrence of problems, and the need for quicker intervention in changing circumstances.
<b>Choice and alternatives (devices, stock, packaging)</b>	A smaller number of comments mentioned the need for alternative device choices, alternatives when items are out of stock, less excessive packaging, and better advice on device selection.

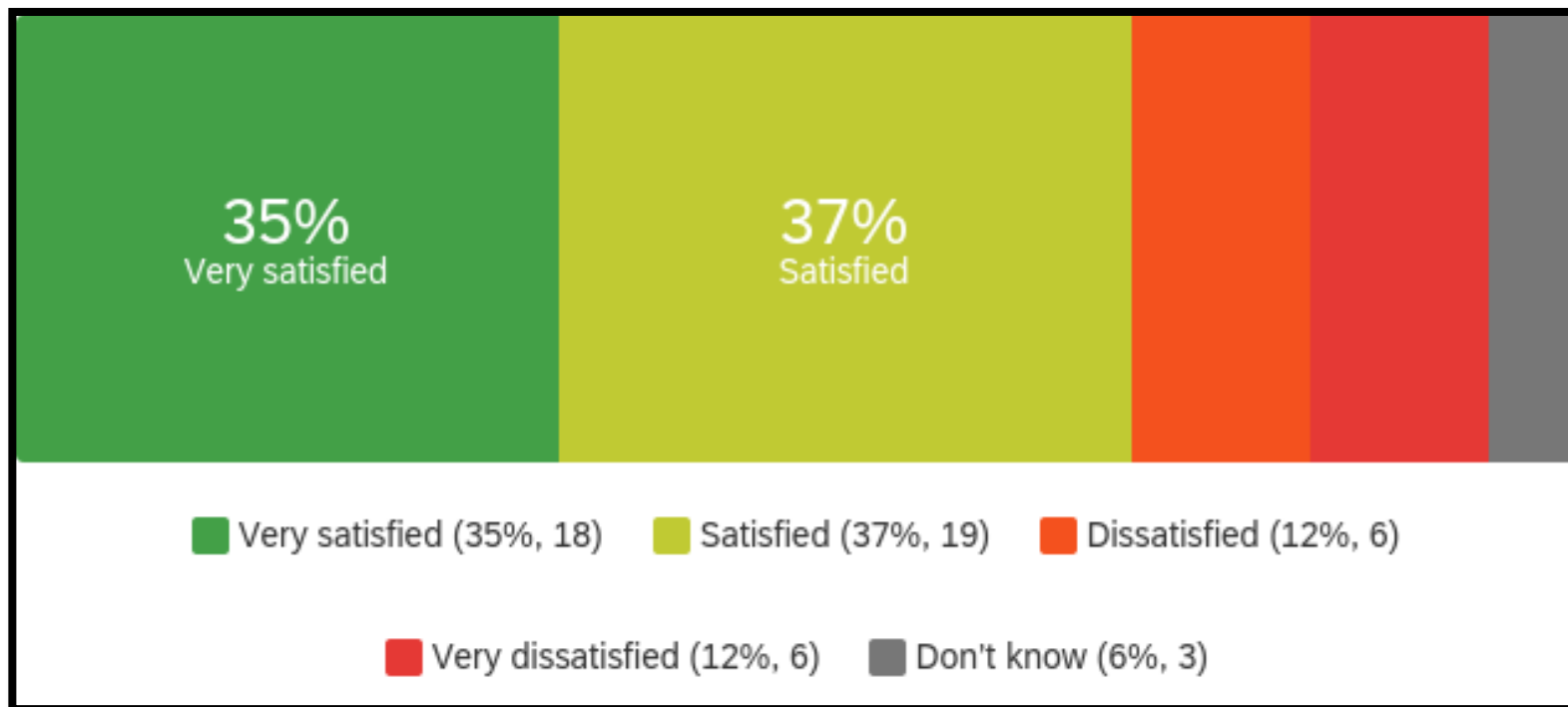
Question: What improvements to the management of your Catheter could be made? (41 comments) analysis of free text responses

**Overall satisfaction:** Most respondents were satisfied with the service they received for their catheter, with 72% (37/52) reporting they were very satisfied (35%, 18/52) or satisfied (37%, 19/52).

-Respondents who reported being very **satisfied or satisfied** described the service as working well overall, due to easy ordering, prompt home delivery, reliable availability of supplies, and situations where qualified staff, GP practices, community nursing teams, and specialist services were working effectively together. Some also highlighted family support and familiarity with the system as contributing to their confidence.

-A small number of respondents who were **dissatisfied or very dissatisfied** described significant difficulties accessing timely and appropriate support, particularly when problems occurred. Issues included lack of clear information on who to contact, long waits for help with blocked or expelled catheters, limited access to specialist clinicians, perceived poor training or unsafe practice in a small number of cases and feeling isolated or unsupported. Several respondents also reported poor coordination between hospital, community, and specialist services, leading to repeated referrals, A&E attendance, or distressing experiences.

- Respondents who selected **don't know** described confusion about responsibility between services, difficulty accessing advice when circumstances changed, and uncertainty about where to go for support outside planned or routine care.



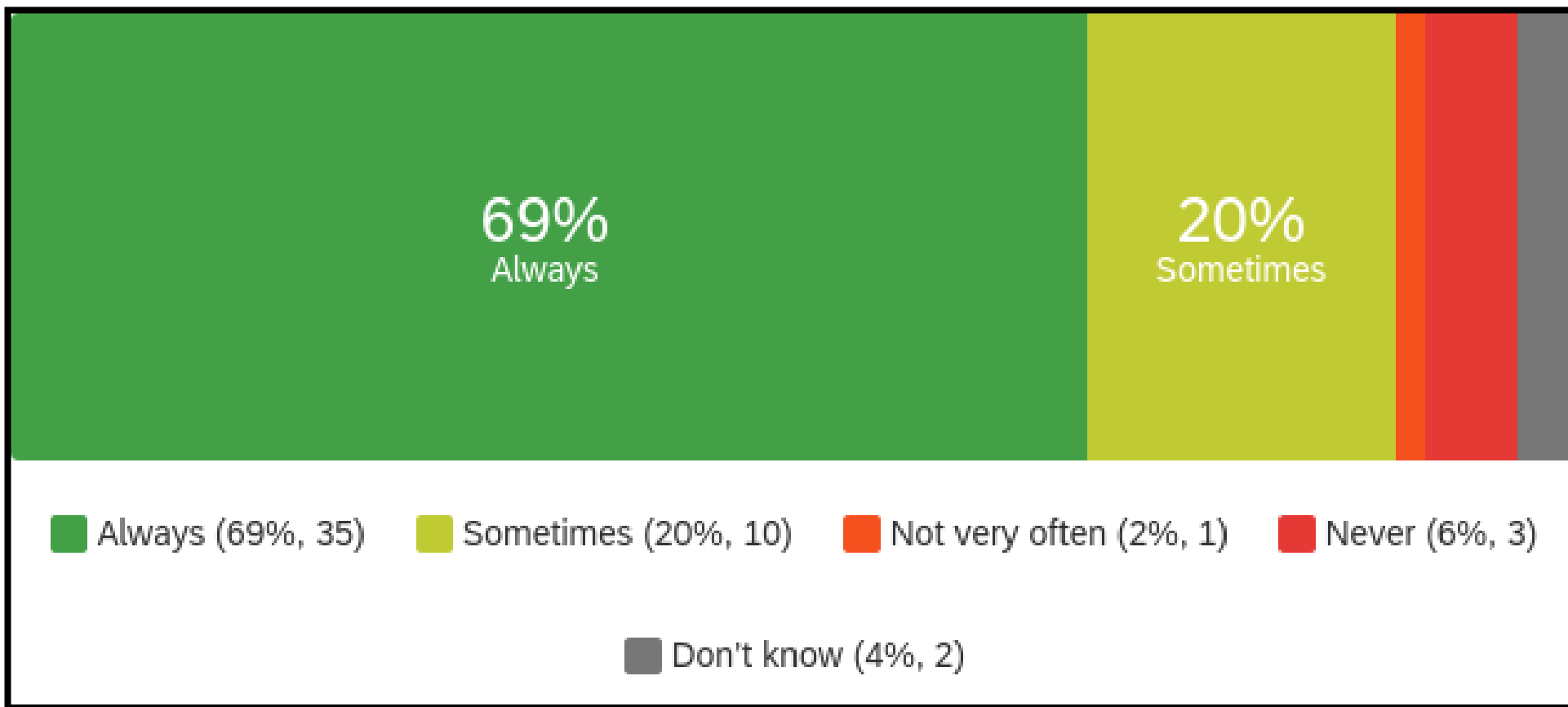
Questions: Overall, how satisfied are you with the service you receive in relation to your Catheter? (52 responses)

Please give the reason for your answer:

**Dignity and Respect:** Most respondents said they were always treated with dignity and respect in relation to their catheter care (69%, 35/51).

**Positive experiences** related to professional, kind, and respectful behaviour from nurses, GP practices, specialist spinal injury units, and catheter supply companies, with respondents highlighting staff who listened, were caring, non-judgemental, and upheld dignity, including during emergency care.

**Negative experiences** were reported by a small number of respondents and were mainly associated with inconsistent standards of care, particularly in some hospital, urgent treatment centre, and community nursing settings, with respondents describing poor communication, dismissive attitudes, lack of dignity or privacy, and feeling overlooked, judged, or unsupported in certain interactions.



Questions: Overall, how satisfied are you with the service you receive in relation to your Catheter? (51 responses)

Please give the reason for your answer:

# Additional suggestions

**Question Are there any elements of the Catheter care pathway that you feel are missing at the moment?** (43 comments)  
in order of mention

- **No missing elements** Around a third of respondents indicated they did not feel anything was missing.
- **Staff training** Comments highlighted the need for improved training, ensuring all staff are properly trained, and specifically referenced hospital staff needing further training in caring for patients with catheters
- **Information and advice** Respondents requested more information, clearer advice, poor advice being addressed, and specific advice such as what not to drink and how much.
- **Support and access to help** Multiple comments referred to the need for more support, including general support, support helplines, and someone to talk to about the impact of living with catheters.
- **Adequate support during catheter problems (blockage or expulsion)** Respondents asked for adequate and timely support when a catheter is blocked or expelled, including help in emergencies. Some respondents wanted the ability to contact the urology department directly in an emergency
- **Lack of awareness or clarity about the care pathway** Some respondents stated they were not aware of a catheter care pathway, or questioned whether one exists at all.
- **Follow-up care** Comments included requests for check-ups, reviews, continuing support, follow-up care after discharge, and someone to approach for urgent review when needs change
- **Availability of supplies and stock issues** Occasional issues with items being unavailable or out of stock were noted.
- **Continuity of staff** One comment noted there being too many different nurses involved and suggested limiting this where possible.
- **Mental health support** One respondent specifically highlighted the emotional impact and the importance of being able to talk to someone for reassurance and support.

## Additional suggestions

**Question: Is there anything else you'd like us to be aware of or take into account?** (30 comments)

- Half of respondents said there was nothing else to take into account with several respondents also stating they were very pleased with the service
- Where additional points were raised, respondents highlighted the following (in order of mention in comments):
- **Better access to support** Including general support, someone to talk to, and help when needs change. Access to specialists in emergencies and ability to contact urology directly when needed.
- **Staff training and competence** Requests for better training, particularly in hospitals and ensuring all staff are properly trained.
- **Follow-up, reviews** continuing support, and follow-up after discharge needed to increase
- **Support during catheter problems** Adequate help in the event of blockage or catheter expulsion, including urgent situations. Mental health support is needed and an expert patient group was also suggested for peer support
- **Clearer information and advice** Including general information, improved advice, and guidance about fluids.
- **Clear catheter care pathway** Some respondents were unaware of a pathway or felt one did not exist.
- **Continuity between hospital, community, and GP** Improved coordination across services.
- **Supply availability** Occasional issues with items being out of stock.

# Section 3: Survey results- Transanal Irrigation



# Transanal Irrigation Results (TAI) Summary

- A small number of responses were received (n=9). Feedback was considered indicative only and highlighted largely positive experiences where specialist support was available, alongside a need for clearer pathways and reviews.
- **Length of time using TAI** Most respondents had been using TAI long term, with 66% (6/9) reporting use for over five years, including 22% (2/9) using TAI for more than ten years.
- **TAI reviews** Two thirds of respondents (67%, 6/9) reported that they had never had a review of their TAI, despite long-term use.
- **Location of TAI reviews** Only two respondents reported having a review; one was in a GP practice and one was in secondary care.
- **Current hospital care for TAI management:** Most respondents were not currently under the care of a hospital or specialist team for their TAI (78%, 7/9).
- **Awareness of patient choice for TAI management** was mixed: 56% (5/9) were aware, while 44% (4/9) were unaware (33%,3) or unsure (11%,1).
- **Use of home delivery services for Catheter supplies** over half of respondents used a home delivery service (Direct Appliance Contractor) for their TAI supplies (56%, 5/9). 2 (22%) did not and 2 were unsure (22%).
- **Current ordering:** TAI supplies were most commonly ordered online via a Direct Appliance Contractor (44%, 4/9) or ordered on behalf of the patient by a supplier (33%, 3/9). 22% (2/9) were ordered online via a GP practice.
- **TAI Support** If problems arose with TAI, respondents reported contacting GP practices (33%, 3/9), asking to be referred to specialist bowel care teams (22%, 2/9) or contacting them directly (22%,2/9).One respondent said they would contact the direct appliance contractor and one would either contact their DAC or staff in secondary care.
- **Catheter Supplies at home:** Most respondents reported keeping between two weeks and over one month of TAI supplies at home (7/9), suggesting proactive stock management to avoid supply disruption.

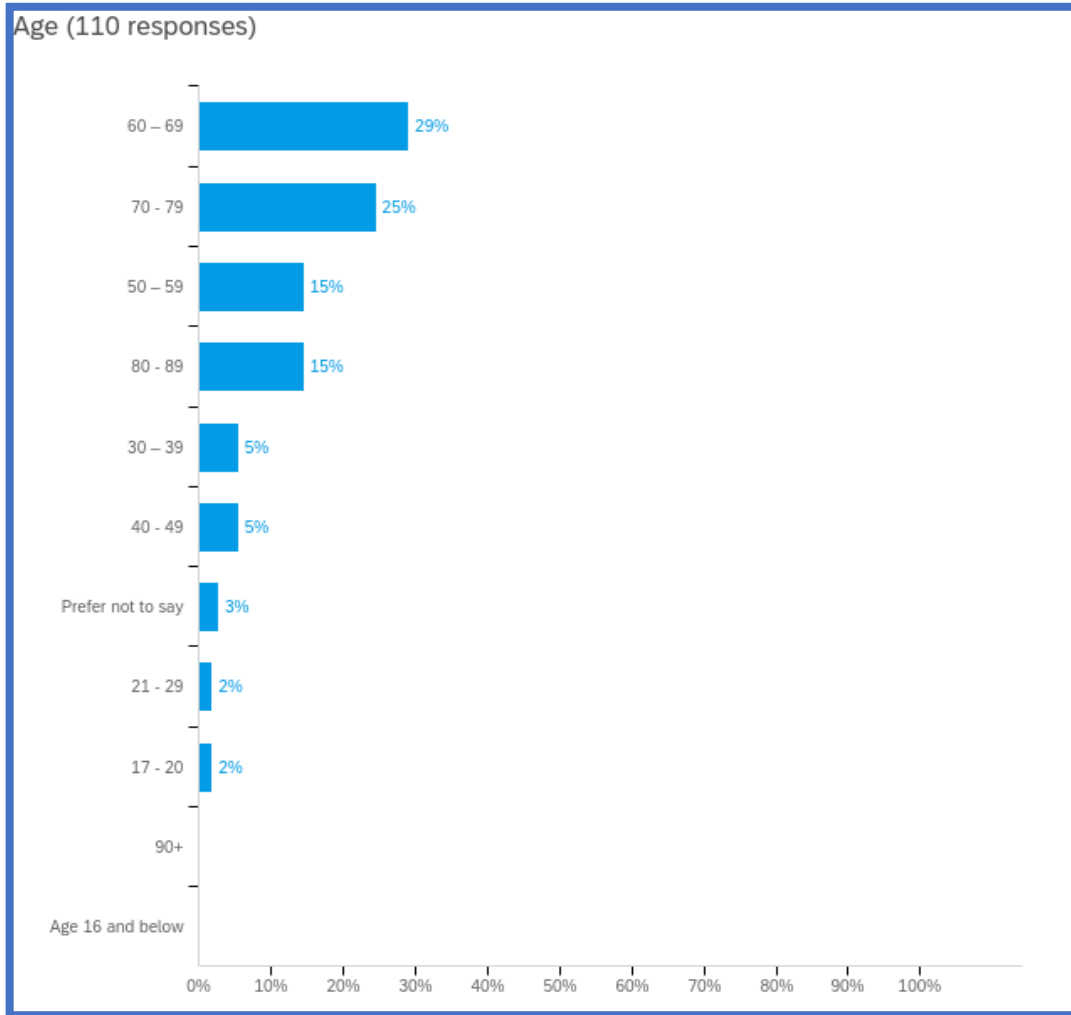
# Transanal Irrigation Results (TAI) Summary

- **What worked well about the Catheter supplies ordering process** Feedback on ordering processes was generally positive, with respondents describing systems as easy, convenient and reliable, particularly when managed by specialist suppliers. People appreciated delivery and online, email and telephone orders.
- **What improvements to the Catheter ordering process could be made.** 2/9 respondents suggested improvements these were focused on delays in stock availability and supply reliability. The remaining 7 comments were suggesting that no improvements were needed and the service works well.
- **TAI Management: what worked well** Respondents highlighted access to specialist support. Several respondents reported that TAI enabled them to manage their condition independently, supporting their confidence and control.
- **TAI Management: what could be improved** regular reviews, improved awareness and understanding of TAI among healthcare, better education for healthcare staff and more public awareness. 4/8 comments said that nothing needed to be improved.
- **Overall satisfaction:** Most respondents were satisfied with the TAI service, with 67% (6/9) reporting they were very satisfied (56%, 5/9) or satisfied (11%, 1/9). 22% (2/9) was not satisfied and 11% (1/9) did not know.
- **Dignity and Respect:** Most respondents said they were always treated with dignity and respect in relation to their TAI care (78%, 7/9) and the remaining 2 respondents did not know.
- **Additional suggestions - Missing pathway elements:** Respondents were asked if there is any missing elements. 2 respondents were not aware that there was a pathway, 2 respondents did not feel that there was anything missing, 3 respondents would like a point of contact for support.
- **Additional suggestions – Any thing else to take into account:** Respondents highlighted the importance of not changing products or services that are working well, the need for greater awareness of TAI among healthcare professionals, and suggested that TAI should be considered earlier as a treatment option when medicinal approaches are ineffective.

# Equalities Monitoring



# Respondent Demographics



Ethnicity	%	Count
Asian or Asian British: Indian	0%	0
Asian or Asian British: Pakistani	0%	0
Asian or Asian British: Chinese	0%	0
Asian or Asian British: Bangladeshi	0%	0
Any other Asian background (please state)	0%	0
Black or Black British: Caribbean	0%	0
Black or Black British: African	0%	0
Any other Black background (please state)	0%	0
Mixed or multiple ethnic groups: White and black Caribbean	1%	1
Mixed or multiple ethnic groups: White and Black African	0%	0
Mixed or multiple ethnic groups: White and Asian	0%	0
Any of mixed or multiple ethnic background (please state)	0%	0
White: Welsh / English / Scottish / Northern Irish / British	95%	99
White: Irish	2%	2
White: Gypsy or Irish Traveller	0%	0
Any other White background (please state)	0%	0
Other ethnic group: Arab	0%	0
Any other (please state)	0%	0
Prefer not to say	2%	2
White Roma	0%	0
<b>Total</b>	<b>100%</b>	<b>104</b>

# Respondent Demographics

Gender re-assignment	%	Count
Yes	2%	1
Prefer not to say	0%	0
No	98%	62
Total	100%	63

Gender	%	Count
Male	45%	49
Female	50%	54
Intersex	0%	0
Non-binary	0%	0
Prefer not to say	4%	4
Prefer to self-identify	1%	1
Total	100%	108

Religion	%	Count
No religion	22%	22
Atheist	7%	7
Buddhist	0%	0
Christian	59%	58
Hindu	0%	0
Any other religion	1%	1
Jain	0%	0
Jewish	1%	1
Muslim	0%	0
Sikh	0%	0
Prefer not to say	9%	9
Total	100%	98

Pregnancy and maternity	%	Count
Yes	0%	0
No	98%	53
Prefer not to say	2%	1
Total	100%	54

Main Language	%	Count
English	100%	106
Bulgarian	0%	0
Hungarian	0%	0
Latvian	0%	0
Lithuanian	0%	0
Polish	0%	0
Portuguese	0%	0
Romanian	0%	0
Spanish	0%	0
Other (please specify)	0%	0
Russian	0%	0
Total	100%	106

# Respondent Demographics

<b>Disability:</b> Are your day-to-day activities limited because of a health problem or disability which has lasted, or expected to last, at least 12 months (including any problems related to old age)?	%	Count
Yes, the health problem/disability limits me a little	27%	24
Yes, the health problem/disability limits me a lot	42%	37
No	30%	27
Prefer not to say	1%	1
Total	100%	89

Do you have any specific needs or requirements?	%	Count
No	54%	43
Yes (please state)	46%	36
Total	100%	79

## Specific needs or requirements (31 comments)

Wheelchair use (5 comments), mobility or walking aids (8 comments), and clinical care needs such as stoma, catheter or nephrostomy support (6 comments) were the most frequently reported requirements. Respondents also highlighted the need for carer support (4 comments), medication or clinical monitoring (3 comments), accessible toilet facilities (2 comments), sensory or communication adjustments (2 comments), and support related to mental health or neurological conditions (2 comments).

If you answered 'yes' to the previous question, please indicate your disability - people may experience more than one type of impairment, in which case you may indicate more than one	%	Count
Physical impairment	72%	49
Sensory impairment	13%	9
Mental health condition	25%	17
Learning Disability/Difficulty	7%	5
Long-standing illness	51%	35
Other (please state)	19%	13
Total number of responses		68
Note: Respondents could select more than one option; therefore, percentages do not = 100%.		

**Other disabilities:** Free-text responses included: Incomplete spinal chord injury; Chronic Fatigue; Limited mostly by need to empty 8 - 10 times daily & a hernia; Stoma; Diverticulitis/Stoma; Memory; Catheter, require regular / weekly Community Nurse visits; Multiple sclerosis; Parastomal hernia; Parkinsons; Neurodiverse conditions

# Respondent Demographics

<b>Caring responsibilities</b>	%	Count
Primary carer of older person	38%	13
Primary carer of disabled adult (18 and over)	29%	10
Secondary carer (another person carries out the main caring role)	26%	9
Primary carer of disabled child/children	3%	1
Primary carer of child/children (under 18)	3%	1
<b>Total</b>	<b>100%</b>	<b>34</b>

<b>Amount of time spent in in relation to caring</b>	%	Count
Yes, 50 or more hours a week	43%	13
Yes, 1-19 hours a week	33%	10
Yes, 20-49 hours a week	13%	4
Prefer not to say	10%	3
<b>Total</b>	<b>100%</b>	<b>30</b>

<b>Employment status</b>	%	Count
Retired	62%	60
Employed full time	11%	11
Employed part time	8%	8
Not employed and not looking for work	7%	7
Student	3%	3
Self employed	3%	3
Other (please specify)	2%	2
Homemaker	2%	2
Prefer not to say	1%	1
Not employed and looking for work	0%	0
<b>Total</b>	<b>100%</b>	<b>97</b>

<b>Health Inequalities Information</b>	%	Count
Currently working in the farming/agricultural industry	3%	1
Have worked in the farming/agricultural industry.	42%	13
Currently homeless.	0%	0
Experience of being homeless.	16%	5
Currently serving in either the UK's regular or reserved armed forces.	0%	0
Have served in the UK's regular or reserved armed forces.	39%	12
I am a refugee, immigrant or asylum seeker.	0%	0
Previous experience of being a refugee, immigrant or asylum seeker.	0%	0
<b>Total</b>	<b>100%</b>	<b>31</b>