

A photograph of a woman with curly brown hair and red-rimmed glasses, smiling warmly. She is wearing a black long-sleeved shirt and has her hand resting on a white surface. She is looking towards a man whose back is to the camera; he has short brown hair and is wearing glasses and a blue shirt. The background is a blurred clinical or office environment with white walls and a door.

**Patient Dignity,
Experiences
and Outcomes
in Continence
Care**

Foreword

Chris Whitehouse



As Chair of the Urology Trade Association (UTA), I am pleased to introduce this survey report, which shines a much-needed light on the experiences of people living with continence conditions across the United Kingdom. These conditions affect millions of individuals, yet they are often misunderstood and stigmatised, leaving many to manage their challenges in silence. Behind every statistic is a person whose dignity and quality of life depend on the care they receive.

It has long been recognised that there are significant challenges in continence care. Reports such as Excellence in Continence Care have highlighted these issues for many years, yet progress has been limited. This is despite the clear evidence that getting continence care right not only improves patient outcomes, experience and quality of life but also reduces the financial and resource pressures on an already overstretched NHS.

This report offers valuable insight into how people experience continence care, drawing on responses from individuals living

with continence difficulties, many of whom also have pre-existing neurological or mobility-related conditions and rely on continence products. While there have been some positive developments in recent years - including greater recognition of continence care as a clinical priority, improved guidance, and increased focus on patient-centred approaches - the findings highlight that significant gaps remain. Many respondents spoke of limited choice in products, gaps in clinical support, and a sense that their voices were not always heard in decisions about their care.

With ongoing reforms that will impact how continence care is delivered in the future - including Part IX of the Drug Tariff, value-based procurement, NHS England's review of clinical pathways for continence and stoma care, and the MedTech Commercial Strategy - policymakers must engage directly with patients, listen to their experiences, and consider their views at every stage. These reforms must ultimately seek to improve patient care and outcomes and must not lead to any further decline in the quality or accessibility of services.

By drawing on the lived experiences of people with continence conditions, this report reminds us of the ultimate goal of all healthcare reforms: improving outcomes for all patients, wherever they

live in England. It is a call to policymakers, clinicians, industry partners, patient organisations and patients themselves to work collaboratively, ensuring that reforms deliver value for the NHS while reflecting the priorities and needs of the individuals they are intended to serve.

As a trade association, the UTA is proud of the role industry plays in supporting continence care across the NHS, working in close and ongoing partnership with healthcare professionals and service providers. Through this collaboration - from developing innovative, high-quality products to supporting clinical practice and investing in initiatives such as nurse education and training - the UTA's member companies contribute to improving both patient care and outcomes.

This work is part of a shared effort to respond to the needs of patients and to support a health system facing increasing demands. It reflects a collective commitment to enhancing patient experience, improving outcomes, and ensuring the sustainability of services. We are committed to continuing to build on this partnership, engaging constructively with the NHS and wider stakeholders to help ensure that reforms deliver meaningful and lasting improvements in care.

Chris Whitehouse
Chair of the Urology Trade Association (UTA)

Foreword – Chris Whitehouse	3
The Urology Foundation – Rebecca Porta	4
Spinal Injuries Association – Nik Hartley	5
Executive Summary	6
Background and context	8
Objectives	12
Key findings	13
Demographics	13
Product and product choice	14
Patient experience	17
Conclusions	22
Recommendations/next steps	24
References	26



The Urology Foundation has made it our mission to revolutionise the quality and delivery of urology care for the benefit of the 1 in 2 of us who will experience a urology condition. We've been making a difference in people's lives for over thirty years. We do this in three ways: we invest in groundbreaking research; we advance urology skills through providing and supporting education and training programmes for all urology healthcare professionals; and we achieve impact through raising awareness, improving understanding, providing patient information and driving change through policy and campaigns.

Millions of people live daily with the weight of urinary incontinence (also known as bladder leakage). 1 in 5 people in the UK are impacted by bladder problems while 1 in 3 women are living with bladder leakage, and we expect this figure to continue to rise in the coming decade. All too often, they face personal costs for products and

a lack of access to specialist nurses and physiotherapists. As with many services across the NHS, continence services are incredibly stretched, and we understand that the healthcare professionals involved are often under incredible strain.

People experiencing bladder leakage require holistic care and a manageable plan to get back to enjoying their lives. The right products can make all the difference to a person living with the daily realities of urinary incontinence, and we know that many people are not able to receive the right products for their needs. Access to appropriate products is one crucial part of good continence management, together with access to the right continence services, access to specialists - which for many people should include urology and continence nurses and physiotherapists - and some may also require appropriate treatment.

Everyone experiencing bladder leakage deserves the right information and support (including access to continence services, specialists, treatment and products), and no one should be left to manage alone or with inappropriate products. That's why we believe action is needed now to ensure that people get the care they need.

This survey report adds a powerful dimension to our understanding of continence care by exploring the lived experiences of people living with continence issues. It highlights how important it is not only to ensure that treatment decisions are informed by the needs and preferences of those affected but also that services are supported by transparent and nationally approved pathways that provide consistency and clarity of care, helping to ensure that people receive equitable support wherever they live.

On behalf of The Urology Foundation, I hope this report encourages those involved in policy, clinical care, education and research to use these insights as a foundation for change - working together to ensure that services not only treat conditions but also support people in leading their lives with dignity and confidence.

Rebecca Porta,
Chief Executive
The Urology Foundation



Living with a spinal cord injury means paralysis for life; it also brings a multitude of lifelong physical and health challenges. Continence care is one of the most impactful. It shapes independence, confidence, and everyday life in ways that are easy to overlook but impossible to ignore. At the Spinal Injuries Association, we hear these experiences every day, and this survey captures that lived reality in data that cannot be ignored.

The findings reveal what many of our community know well: people too often have limited choice in their care, feel excluded from decisions, and navigate support gaps on their own. These insights are a reminder that patient experience must guide clinical pathways and policy decisions if care is to meet real-life needs.

Our collaboration on this survey is our commitment to amplify patient voices and ensure that services and policies respond to the realities of life after spinal cord injury.

We hope these insights inspire and drive change in the way continence care is delivered, so people feel understood, supported, and able to get on with their lives with confidence.

Nik Hartley
CEO
Spinal Injuries Association

Executive Summary

Continence care refers to the prevention, assessment, diagnosis, treatment and ongoing management of bladder and bowel conditions. It encompasses a wide range of conditions, including neurological conditions, urinary incontinence and other long-term conditions that impact bladder or bowel function.

This report focuses on urinary incontinence, which affects an estimated 14 million people in the UK. Despite its prevalence, continence issues remain highly stigmatised, leading to underreporting, delayed diagnosis and unmet care needs.

The consequences of poor continence management are far-reaching, affecting patients' dignity, independence and quality of life, while placing substantial and avoidable pressure on the NHS. For example, urinary tract infections alone cost an estimated £604 million annually and contribute to around 1.2 million bed days, with catheter-associated infections a leading driver of prolonged hospital stays.

Beyond improving outcomes for those living with urinary incontinence, good continence care plays an important role in the effective use of healthcare resources by preventing avoidable complications, reducing system pressures on the NHS and supporting the intentions of the 10 Year Health Plan to move care from sickness to prevention, and from hospital to community. As care shifts further into community settings, continence services will need the workforce, training, data and pathway support to deliver this ambition in practice. Optimising product choice and clinical practice has been shown to reduce catheter-associated infections and cut hospital bed stays, delivering better outcomes for patients and better value for the NHS.

The survey findings draw on a UK-wide survey of 232 individuals living with continence conditions, many of whom have complex, long-term neurological or mobility-related needs. The survey was conducted by the UTA in partnership with The Urology Foundation and the Spinal Injuries Association (SIA).

The survey reveals that involving patients in decisions about their continence care is often limited. Nearly half of the participants reported either no involvement or only minimal involvement in decisions about their continence care, and over a third felt that clinicians did not take their priorities into account when developing treatment plans. Limited product choice was also widely reported, with many participants indicating they were offered few or no options regarding the products prescribed to manage their condition.

Gaps in clinical support have pushed many respondents to manage their care independently, often without adequate guidance. While healthcare professionals remain the primary prescribers of continence products, a substantial proportion of respondents, particularly those using absorbent continence pads, reported purchasing products privately when prescribed options did not meet their needs. At the same time, 83% of respondents reported not having had a clinical review of their continence products in the past year, suggesting limited opportunities to reassess treatment and ensure care remains aligned with changing patient needs.

Beyond the clinical picture, continence conditions have a significant emotional and social impact. Respondents frequently described feelings of embarrassment, anxiety and a loss of dignity. Many also reported curtailing everyday activities due to concerns about bladder leaks or unreliable toilet access. These findings underline the direct link between effective continence care and patients' independence, participation in daily life, and mental well-being.

Finally, the survey highlights that access to appropriate products underpins effective continence care. Although many respondents reported being somewhat or very satisfied with their continence products, the wider findings suggest that this satisfaction often reflects self-directed decision-making rather than consistent NHS-led provision. Many respondents who reported improved confidence or independence indicated that this occurred after finding, often on their own initiative, products better suited to their needs. This highlights the importance of ensuring that clinicians can prescribe a range of clinically appropriate products, allowing care to be tailored to the individual.

Building on these findings, the survey identifies clear opportunities for policymakers, the NHS, and wider stakeholders to strengthen continence care provision and ensure reforms are truly patient-centred.

For Policymakers: Ongoing reforms should protect and promote appropriate patient and clinical choice, recognising that continence products are not interchangeable and must meet individual needs. Product provision should focus on whole-pathway value, with procurement and care management reflecting clinical outcomes and patient impact. Increased investment is needed in continence services, including more specialist nurses and better access to treatment, care management information and support.

For DHSC: Continue developing local formulary guidance to support access to products, and update the Excellence in Continence Care guidance, in line with ongoing issues.

For the NHS: Strengthen shared decision-making to ensure people are informed and involved in their care management. Clinicians should be supported through appropriate training, guidance and decision-support tools to understand the breadth of products available, including those listed in Part IX of the Drug Tariff, and to apply

value-based principles in treatment and/or care management planning and product prescribing that reflect clinical need, patient outcomes, including greater self-management, and whole-pathway value, including moving more care into the community. The NHS should also ensure equitable access to Part IX products across geographies by safeguarding patient and clinician choice and avoiding unnecessary restrictions through local formularies or prescribing guidance. Addressing unwarranted variation in continence care should be a priority, including improving access to specialist continence services, clinical advice and best-practice pathways, so that everyone can benefit from consistent, high-quality care regardless of where they live.

For Industry: Continue to work in partnership with the NHS to provide high-quality products, education and clinical support to improve patient outcomes and system efficiency.

For Charities and Patient Organisations: Continue to play a key role in raising awareness of continence issues, reducing stigma and supporting earlier patient engagement with care. Charities and patient organisations need to work collaboratively with policymakers, clinicians, industry and patients to ensure reforms are informed by lived experience and improve outcomes while delivering value for the NHS.

Background and context

Continence care refers to the prevention, assessment, diagnosis, treatment and ongoing management of bladder and bowel conditions that affect an individual's ability to maintain continence. It encompasses a wide range of conditions, including neurological conditions such as multiple sclerosis and spina bifida, spinal cord injuries, urinary incontinence and other long-term conditions that impact bladder or bowel function.

This report focuses on urinary incontinence, a condition affecting an estimated 14 million people in the UK, who experience some degree of urinary incontinence, representing over 21,000 individuals on average in each parliamentary constituency¹. Among those affected, approximately 50,000 people in the UK manage their condition by using intermittent catheters². Every hour, 9 people are diagnosed with urological cancer³. Over 1 billion absorbent continence pads are used in the UK every year.

Despite how widespread urinary incontinence is, the condition remains highly stigmatised. As a result, incontinence can often go undiagnosed, with many people reluctant to raise symptoms with healthcare professionals, or even to family and friends⁴. Poor continence care can increase the risk of infection, undermine dignity, and contribute to social isolation. It also drives avoidable hospital and nursing home admissions and places pressure on GP services⁵.

For example, poor-quality continence care can drive significant avoidable demands on the NHS, with

urinary tract infections alone costing hospitals an estimated £604 million in 2023-4 and accounting for around 1.2 million lost bed days⁶. Catheter-associated urinary tract infections (CAUTIs) are among the most common healthcare-associated infections, contributing up to 40% of cases⁷, prolonging hospital stays and costing the NHS tens to hundreds of millions annually⁸. Evidence shows that catheter-related infections cost over £50 million in direct hospital costs each year in England⁹, with far wider economic impacts, underlying system-wide consequences of suboptimal continence care. CAUTIs develop for several reasons, including inadequate continence management, such as patients not being properly taught how to self-catheterise, not having the correct environment to safely self-catheterise (e.g., no clean toilets or ability to properly wash hands) or implementing unnecessarily in-dwelling catheterisation, particularly in hospital environments.

The Excellence in Continence Care strategy provides practical guidance for NHS procurement leads. It states clearly that continence-related care pathways should be commissioned to ensure early assessment and effective management of incontinence and associated bladder and bowel conditions. The strategy emphasises the broader impact of continence issues on social, physical and mental wellbeing, as well as individuals' other health conditions¹⁰. It further highlights the importance of patient empowerment, including genuine choice regarding

treatment options¹¹. Empowerment requires access to information, advice and appropriate treatment, alongside recognition that individuals have a right to manage their condition effectively and live with dignity¹². The strategy also underscores the importance of workforce capacity and education to ensure that people are adequately supported¹³. Despite the clear direction set out in the strategy, progress in implementation has been limited, and variation in access and patient experience persists across the system.

The National Institute for Health and Care Excellence (NICE) defines shared decision-making as a joint process in which a healthcare professional works together with a person to decide on care¹⁴. This process, built on open discussion and shared information, empowers people to make decisions about the treatment and care that is right for them at that time, including choosing to continue with their current treatment.

There are clear examples of how high-quality continence care can deliver improved patient outcomes in practice. For example, an NHS Supply Chain pilot on catheter care¹⁵ demonstrated that optimising product choice and clinical practice led to a near elimination of catheter-associated urinary tract infections, alongside significant reductions in hospital bed stays.

Despite this evidence of what good care can achieve, the NHS faces sustained structural pressures that make consistent delivery difficult. The King's Fund has highlighted that NHS performance has declined since 2010 due to comparatively low funding growth, limited funds for capital investment and insufficient attention to workforce planning¹⁶. A lack of a sustainable workforce has serious consequences for patient

care and safety. Understaffing is closely associated with increased risks, including a reduced capacity to monitor the most unwell patients adequately. At the same time, staff turnover and the time required to recruit and train new staff are contributing to longer waiting times, with growing backlogs in elective care and mounting pressure on already overstretched services. These pressures also affect the quality of care. Despite the dedication and professionalism of those working within continence services, many are operating under considerable strain. Heavy workloads and workforce gaps mean staff often have less time to provide the compassionate, person-centred support that underpins effective continence care, with interactions too often reduced to a series of tasks. This undermines continuity of care, which is critical to achieving better patient outcomes¹⁷.

Continence services are particularly impacted by these systemic challenges. While continence professionals consistently go above and beyond to deliver high-quality care, services are constrained by persistent staff shortages, limited time and insufficient specialist capacity¹⁸. There is a notable lack of continence nurses, and crucially, no clear or structured pathway for nurses to train and progress into continence specialisms¹⁹. As a result, workforce shortages are not only a current issue but are likely to worsen over time without targeted intervention.

An ageing population, often living with multiple co-morbidities, has further intensified demand. Successive governments have required NHS providers to deliver cost efficiencies, which can directly affect patient and clinician experience and outcomes²⁰.

The government recognises that patients frequently experience late diagnoses, that acute treatment often takes precedence over prevention and community-

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based care and that health inequalities remain widespread²¹. This includes regional variations²² in product availability, driven by the diverse ways in which Integrated Care Boards (ICBs) manage local healthcare systems. In response, NHS England and the Department of Health and Social Care (DHSC) have introduced a series of reforms to strengthen the system. Central among these is the 10 Year Health Plan, launched by DHSC in July 2025. The plan outlines a transformation of the NHS in England, built around three core shifts: moving care closer to home, embracing digital innovation, and prioritising prevention over treatment²³. These shifts are underpinned by systemic reforms, including a revised operating model, greater transparency, workforce modernisation, a focused innovation strategy, and financial reform.

The plan also seeks to transform the patient relationship, moving people from “passive recipients of care” to “active partners”, through more personalised care planning, and a stronger emphasis on quality of care²⁴.

This ambition is set against evidence that limited patient participation in decision-making is often linked to inconsistent or insufficient explanation of available options, meaning individuals do not always receive full information about the range of products or services available to them. This results in reduced awareness of choice and, consequently, limited understanding of their ability to influence decisions about their care, constraining meaningful participation in care planning²⁵. The plan further commits to advancing value-based healthcare over the coming decade, aiming to improve efficiency while delivering better outcomes²⁶.

NHS England is also reviewing the stoma and continence patient pathway, a process that may affect how continence products are procured and supplied. These changes are intended, in principle, to improve

patient access and support clinicians in prescribing appropriate products, including catheters and stoma appliances. Among the most consequential ongoing developments is the review of Part IX of the Drug Tariff. Part IX of the NHS Drug Tariff lists medical devices that may be prescribed in primary care settings, including stoma appliances and catheters. Following a consultation between October 2023 and January 2024, DHSC is updating the categorisation and assessment framework for devices listed in Part IX.

Ongoing reforms have generated uncertainty within the sector and raised concerns about potential unintended consequences. In particular, there is concern that some reforms place disproportionate emphasis on item price rather than product value or the overall outcome for those who need to use these products. Such pricing constraints may result in suppliers withdrawing products from the UK market if they are no longer commercially viable. Some might also decide not to market innovative products in the UK. This would reduce the range of products available to clinicians and people living with urinary incontinence, risking impacting their ability to use the most appropriate products to manage their condition.

In continence care, product suitability is highly individual. Medical devices that significantly improve one person’s quality of life may not be appropriate for another, due to an individual’s physical condition, daily tasks and preferences. Suitability is not determined by diagnosis alone, but it is influenced by broader contextual and functional factors, including mobility, care environment, level of carer support, rehabilitation potential, skin integrity, and acceptability of use. These factors affect whether a product can be used effectively in practice, meaning that individuals with similar symptoms may still require very different products to achieve comfortable and independent management of their condition^{27 28}.

Limiting product choice risks undermining patient-centred care by reducing the ability to match products to these varied needs. A reduction in available options could prevent people from using the products best suited to their clinical needs and personal preferences.

As set out in Excellence in Continence Care, people should have access to appropriate assessment and treatment interventions delivered through a person-centred approach. This involves a comprehensive, individualised assessment of continence needs and ongoing review, ensuring that management strategies, including the selection of continence products, are matched to the person’s clinical condition, functional ability, lifestyle, and preferences²⁹.

Moreover, reforms driven primarily by unit price risk disrupting established urology care pathways, particularly for those living with long-term conditions in the community. If patient choice and clinical judgement are constrained, this may generate unintended system pressures, exacerbating the very problems these reforms are intended to solve. For example, an inappropriate product for a person might cause discomfort or prevent proper use. This can reduce independence and quality of life, while increasing the stress of managing the condition day to day. Inappropriate products can also cause infections and increase healthcare system resource use through GP appointments or hospital visits.

Ensuring that clinicians can prescribe the most clinically appropriate product for each individual supports better outcomes, helps people to maintain independence and quality of life, and reduces the risk of infections and urinary tract complications. In turn, this can help reduce avoidable GP appointments and hospital admissions, thereby supporting NHS efficiency and sustainability. Many of these reforms need to strike a careful balance between modernising the system without restricting patient access to a variety of appropriate products for the management of their continence care.

A welcome reform is the introduction of value-based procurement (VBP), a methodology that focuses on the value of a product across the whole patient pathway rather than focusing just on the item’s price³⁰. Due to be launched in England in June 2026, VBP requires NHS procurement teams to assess products across multiple dimensions, such as patient pathway improvements, safety of the product for patients and clinicians and the product and companies’ social value, and whole-life cost. The aim is to ensure that

patients can access the most appropriate product for their needs and preferences, rather than simply the lowest-cost option.

For VBP to be implemented effectively across the NHS in England, all stakeholders, including industry, people living with the conditions, and clinicians, will need to understand the framework and their role within it. Industry will need to prepare to provide the required product evidence, while healthcare professionals should receive thorough training in VBP principles, including how to present patients with the full range of options suited to their needs and preferences. This will help to ensure that there is appropriate shared decision-making between healthcare professionals and people living with urinary incontinence, and that people are given information on the most clinically appropriate products to meet their needs and preferences.

People living with urinary continence conditions often rely on a combination of products to manage their condition effectively, including intermittent catheters, drainage bags, sheaths, skincare products and absorbent pads. These products are accessed through a variety of procurement and supply routes. Some specialist appliances, particularly intermittent catheters and associated urology devices, are prescribed and reimbursed through Part IX of the NHS Drug Tariff. Many other commonly used products, particularly absorbent continence pads, are typically commissioned through local NHS procurement routes such as NHS Supply Chain frameworks, regional tenders, or community continence services. In addition, some individuals choose to purchase products privately to supplement NHS provision.

This variation is important context for this report: while Part IX plays a significant role in access to certain urology devices such as intermittent catheters, many survey respondents primarily use products such as absorbent pads, which fall outside these arrangements. Other reforms, such as the MedTech Commercial Strategy and wider NHS procurement changes, may also directly impact access to continence products, particularly those commissioned through NHS supply chains and local contracting arrangements, meaning that those who need continence products may be at risk of not receiving the most appropriate products for their needs. As such, the findings of this report should be understood in the context of the full continence care pathway and the broader policy landscape.

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Objectives

The survey was launched by the UTA in partnership with The Urology Foundation and the Spinal Injuries Association to understand more about people's experiences with urinary continence care, including how it impacts patients' day-to-day life, dignity and how well the care and products work for them.

The results provide a valuable set of data that has been used to make recommendations to key stakeholders, such as government officials, industry and the third sector, as well as leaders within the NHS.

The results offer an overview of the current experiences of those living with continence, providing the opportunity to flag necessary improvements, as well as highlight best practices. The results have also led to the development of recommendations for the future.

Methodology

The survey comprised a combination of multiple-choice, single-choice, and open-ended questions, exploring people's lived experiences of continence care. It examined both the impact of treatment on quality of life and respondents' reported clinical outcomes.

The survey was designed for adults living with continence issues in the United Kingdom, with a particular focus on respondents in England. The draft survey was shared with The Urology Foundation and Spinal Injuries Association for feedback before being finalised and disseminated via email, websites and newsletters.

A broad range of stakeholders were invited to distribute the survey within their respective networks. These stakeholders included:

- Members of Parliament;
- Local Healthwatch organisations;
- UTA members;
- The Urology Foundation networks and SIA members;
- Patient organisations whose membership includes individuals or carers for individuals receiving continence care. These included SIA, The Urology Foundation, Shine, Age UK, Bladder and Bowel Community, Carers UK, Bladder and Bowel UK, Disability Rights UK, Spinal Research, Back Up Trust, MS Trust, The Patients Association and Pain UK.
- Professional bodies such as the British Association of Urological Nurses.

In total, the survey received 232 responses from individuals across the UK. Fieldwork was conducted between 1st August 2025 and 30th November 2025.

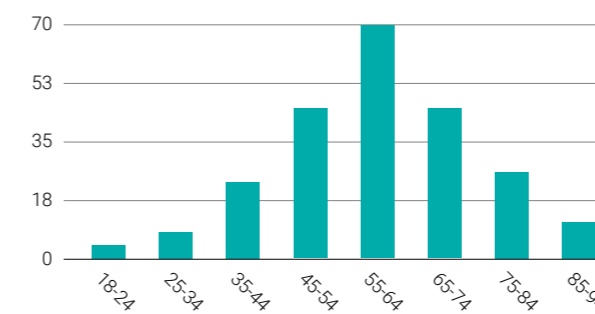
While the sample size is modest, the findings offer valuable insight into challenges that are likely to affect a much larger population receiving urinary continence care.

Key Findings Demographics

Age, Gender and Underlying Conditions

The majority of respondents were over 55 years old, accounting for 66% of the sample, with 30% aged 55–64 years. Around 15% of participants were under 45 years old, including 5% aged 18–34.

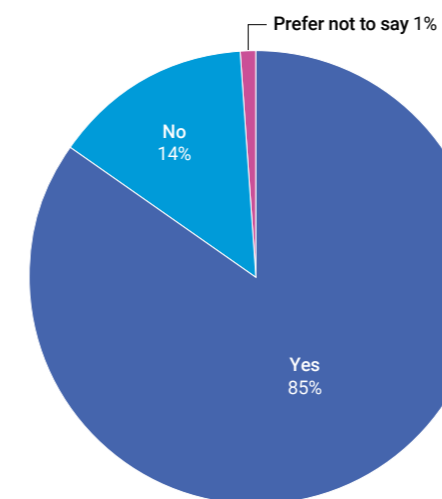
Participant Age Range



67% of participants were women, reflecting a predominance of female respondents in this sample.

A substantial proportion of participants (85%) reported having a long-term condition in addition to continence-related issues.

Disability prevalence among respondents



Among these, 66 participants (28%) reported spina bifida, 38 (16%) reported a spinal cord injury, 38 (16%) reported hydrocephalus, 14 (6%) reported mobility-

related limitations, and 13 (6%) reported paralysis, including paraplegia, quadriplegia, or tetraplegia. Respondents had the opportunity to choose multiple conditions in their responses. This distribution reflects the survey's partnership with the Spinal Injuries Association and its circulation through charities focused on spina bifida and hydrocephalus, such as Shine.

Geographical Distribution

Participants were drawn from constituencies across all four UK nations, with the majority based in England and smaller numbers from Scotland, Wales, and Northern Ireland (4%).

London constituencies were particularly well represented, accounting for over 13% of the sample. Around 19% of participants came from other major metropolitan areas, including Birmingham, Leeds, Nottingham, Bristol, Liverpool, and Manchester.

By contrast, the largest proportion of participants - approximately 68% - came from smaller towns, coastal areas, or rural constituencies, including Torbay, North Cornwall, Torridge, South Norfolk, North Norfolk, Tonbridge, Reigate, Fareham, and parts of Yorkshire and Lincolnshire.

Key Takeaways

Overall, while participants over 55 years make up the largest proportion of the sample, the survey demonstrates that urological and continence issues are experienced across all adult age groups, with younger participants also engaged and motivated to share their experiences.

In this sample, continence difficulties are frequently experienced alongside pre-existing neurological or mobility-related conditions, rather than as standalone issues. This underlines the multifaceted, interconnected needs of participants, who may require support for both continence and underlying conditions.

Participants were drawn from across all regions of the UK, spanning both urban centres and rural areas alike, reflecting a broad range of experiences and perspectives.

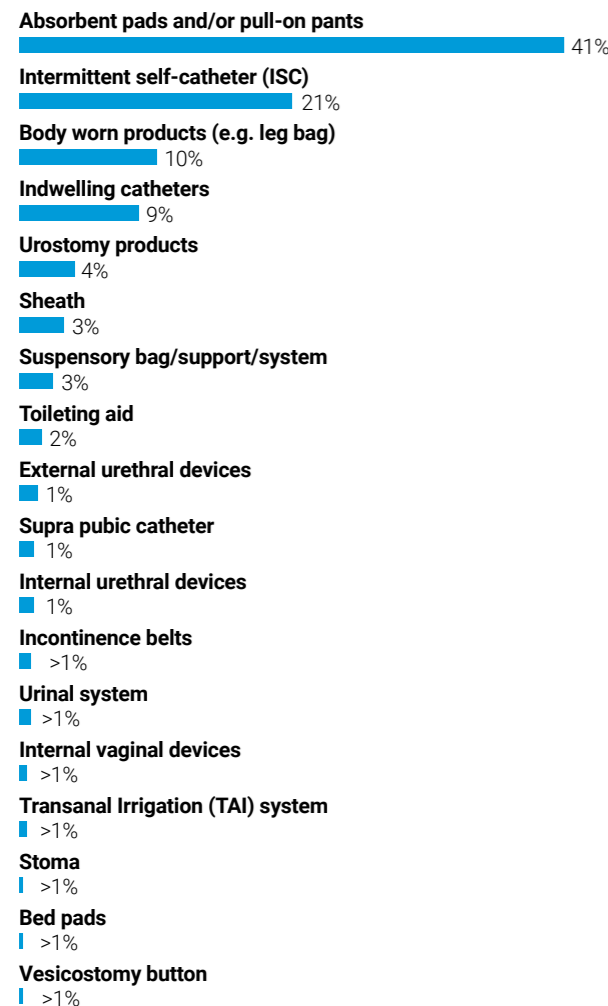
Product and product choice

Overview of Continence Products in Use

The survey explored the types of continence products used by participants, alongside their experiences with product choice and involvement in care decisions.

Absorbent pads, including pull-on pants, were the most used products, accounting for over 41% of products reported by respondents. Catheters were the second most used, representing 30% of all products reported. Of these, intermittent self-catheters (ISCs) were used by 21% of participants and indwelling catheters by 9%.

Types of urinary continence products used by respondents.



Body-worn products, such as leg bags, accounted for 10% of the products used. Notably, over 37% of participants reported using multiple products to manage their continence, highlighting the complexity of individual needs and the limitations of a one-size-fits-all approach to provision.

It is important to acknowledge the range of products used by respondents, as patients may experience different referral and follow-up pathways depending on their product type, and care can vary considerably between areas. Therefore, the data and findings may not reflect all continence pathways.

Prescription Patterns

While healthcare professionals play a central role in prescribing continence products, the data indicate that people's involvement in decisions about their care is often limited. This may be partly due to chronic workforce shortages across the NHS and social care system, particularly in continence services. Overstretched staff may have less capacity to provide the care needed, which can negatively impact quality and patient experience. Lack of time and resources can mean people are not always involved in decisions about their care.

Limited patient involvement may also stem from constraints within local supply systems. For example, product availability can be influenced by cost pressures or the use of local formularies, which offer only a selection of products. A local formulary for intermittent catheters, for instance, may include only a subset of products listed in Part IX of the Drug Tariff, rather than the full range available, which means people in that locality may not be able to access the most clinically appropriate product for their individual needs.

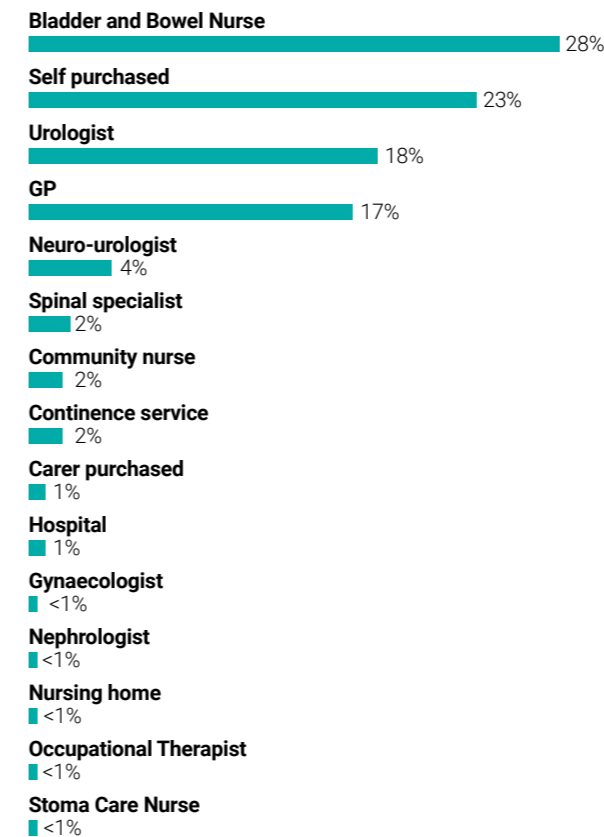
ICBs are responsible for managing both healthcare provision and funding in their respective areas, meaning that decisions about which treatments and MedTech products are available can differ substantially from one region to another. Variations in how ICBs manage local healthcare systems, including the development and maintenance of formularies, can therefore contribute to regional disparities, resulting

in a "postcode lottery" in access to different products, including continence ones³¹.

Among participants, 63% received prescriptions from healthcare professionals, including bladder and bowel nurses (28%), urologists (18%), and GPs (17%).

However, over 23% of products were self-purchased, with the large majority of these relating to absorbent continence pads, indicating that a substantial proportion of respondents are navigating choices independently, often without professional guidance or support.

Prescribers of current continence products

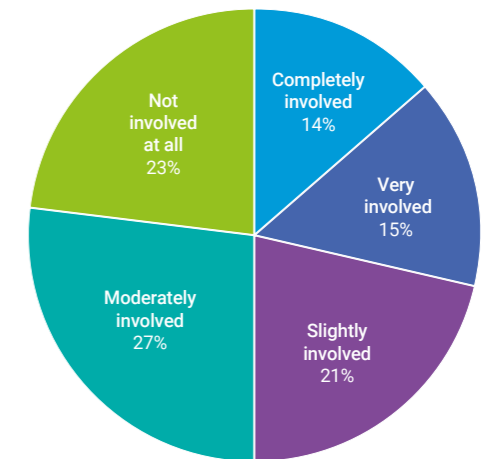


Patient Involvement and Patient Choice in Continence Management

The survey also explored how involved participants felt in decisions about their continence care management.

Results indicate limited engagement in decisions about their care. Nearly a quarter of participants (23%) reported no involvement at all in decisions about their care, and a further 27% reported only minimal involvement. Just 29% felt engaged in decisions about their continence care management.

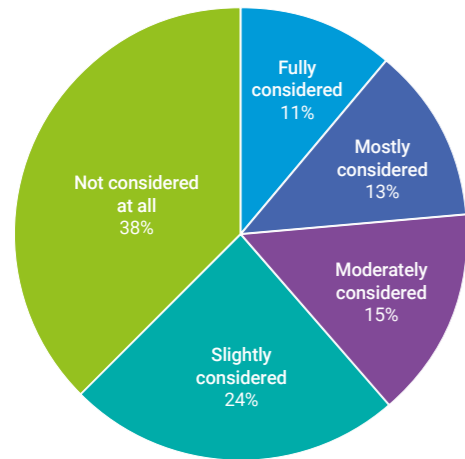
Respondents' involvement in decisions over management care



These responses align with the finding that 38% felt that healthcare professionals did not consider respondents' priorities when developing treatment plans.

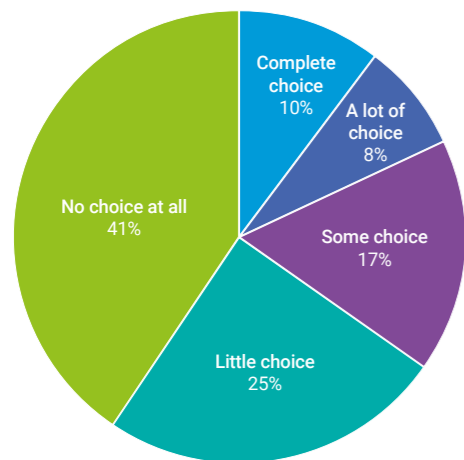
31 Bivdanewsletter.com. (2025). DHSC launch survey on local formularies for medical devices – BIVDA Newsletter. [online] Available at: <https://bivdanewsletter.com/membership-news/dhsc-launch-survey-on-local-formularies-for-medical-devices/>

Patient perspectives on treatment planning



Limited choice over products was also reported, with 40% of participants given no choice and 25% given little choice regarding the type and quantity of products they use.

Extent of patient choice in product type and quantity provided



When asked what could have been improved in their treatment or management strategy, 17% of respondents indicated that they were unable to access the full range of options available for their condition, attributed either to insufficient information about the available options or because their clinician was unable to offer a wider range of choices.

A further 17% of respondents reported that they had hoped for clearer explanations from clinicians, particularly regarding the products they were expected to use and the potential future implications of their care and treatment, indicating that information provision may be insufficient to fully support shared decision-making. In addition, 25% of respondents raised concerns about the lack of ongoing care. This included difficulties in accessing GP or specialist appointments as frequently as needed, and long waiting times between referrals and the next stage of care.

As mentioned in the context section, this may be due to chronic workforce shortages across the NHS and social care system. Despite the dedication and professionalism of those working within continence services, many are operating under considerable strain, including over the product supply provided within their areas.

Key Takeaways

Taken together, these findings indicate that many participants have not been given the opportunity to be involved in making decisions about their continence care. While healthcare professionals remain central to prescribing and guiding care, many individuals encounter restrictions in their ability to influence choices, leaving them to navigate complex management decisions with uneven levels of guidance and support.

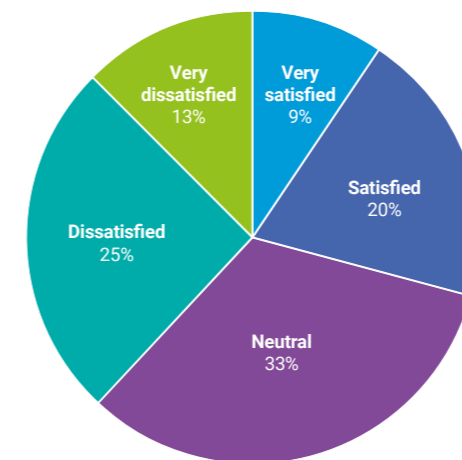
Participants identified areas for improvement, including the need for access to the full range of clinically approved management options, a need for clearer explanations from healthcare professionals about what approach is right for them and what impact this might have on their life, and the need for better access to ongoing support and appointments.

Overall, the findings make a compelling case for more inclusive and responsive care approaches. This means care that is personalised to individual needs, and adaptable to changes in a person's condition over time. Ensuring that individuals are actively engaged, well-informed, and supported throughout their continence management journey is essential to align treatment with personal preferences and to improve the overall experience of living with continence issues.

Patient experience

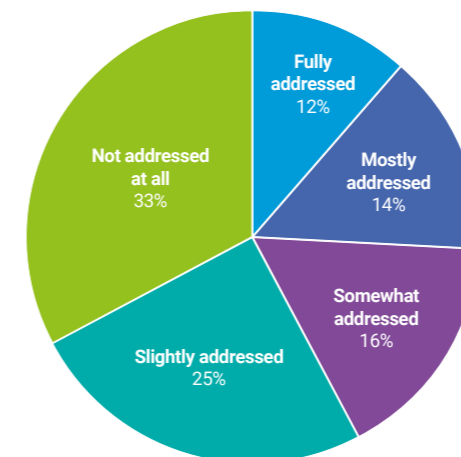
The findings indicate substantial gaps in information provision and clinical engagement from the outset of respondents' continence care. 38% of respondents reported being dissatisfied or very dissatisfied with the information provided about their condition and treatment options.

Satisfaction with information provided about condition and treatment options



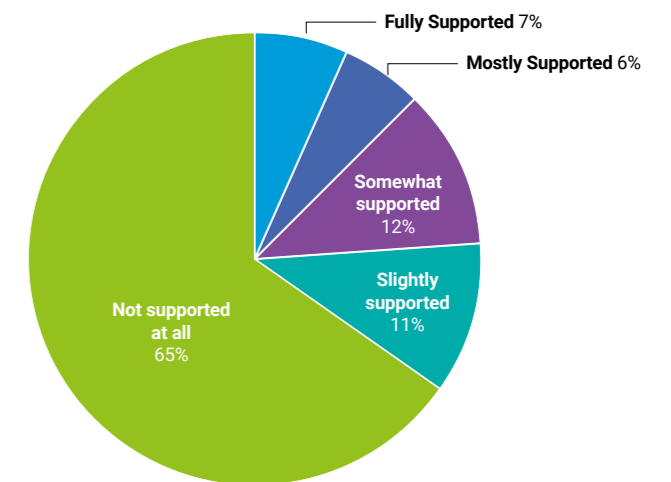
Furthermore, 57% of respondents stated that healthcare professionals either largely or completely failed to address their concerns and questions about their continence care.

Extent to which respondents' concerns and questions were addressed at start of continence care treatment



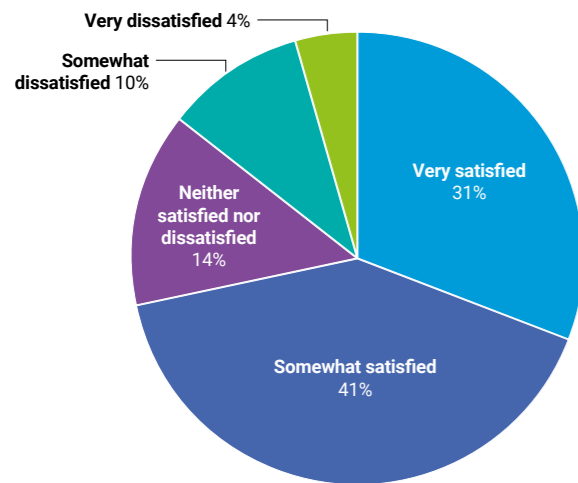
Emotional and psychological support was also perceived to be limited. Nearly two-thirds of respondents, equal to 65% of them, felt they were not receiving adequate emotional and psychological support for their continence care.

Patient perceptions of emotional and psychological support in continence care



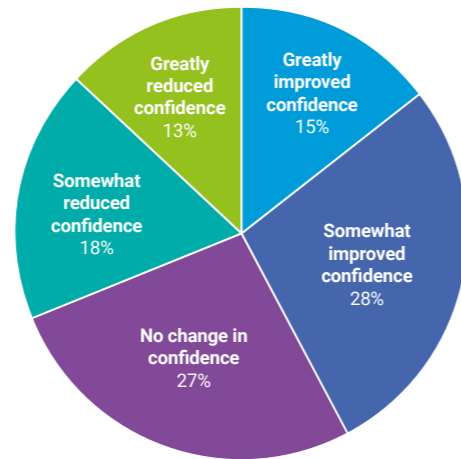
Despite these concerns, around 72% of respondents reported being somewhat satisfied or very satisfied with their product. However, this satisfaction figure requires careful interpretation. Almost a quarter of respondents (23%) reported purchasing products privately or independently due to limited choice, insufficient clinical guidance or the perception that prescribed products were not suited to meet their needs. This figure relates primarily to respondents using absorbent continence pads. The reported satisfaction reflects, in part, self-directed decision-making rather than satisfaction with NHS-led provision alone.

Respondents' satisfaction with continence products in use



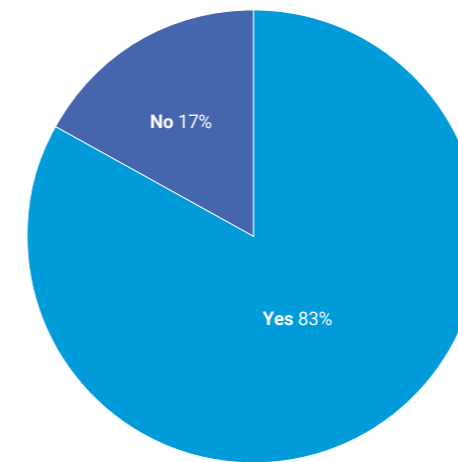
Confidence in product use was comparatively lower than satisfaction levels. 31% of respondents felt slightly confident or not confident at all in using their continence product regularly. This is particularly concerning given that a proportion of respondents reported selecting their own products, suggesting that many individuals are making decisions about product choice without sufficient clinical guidance or support. Respondents in this group reported using a range of products, including both pads and intermittent catheters. 42% of respondents reported somewhat or greatly improved confidence over time. Wider survey responses indicate that many individuals (around 25%) achieved improved confidence after independently selecting or purchasing products that better suited their needs. Within this group, 32 respondents used absorbent continence products, 21 used catheters, and the remainder used a combination of products.

Impact of Continence Products on Patient Confidence



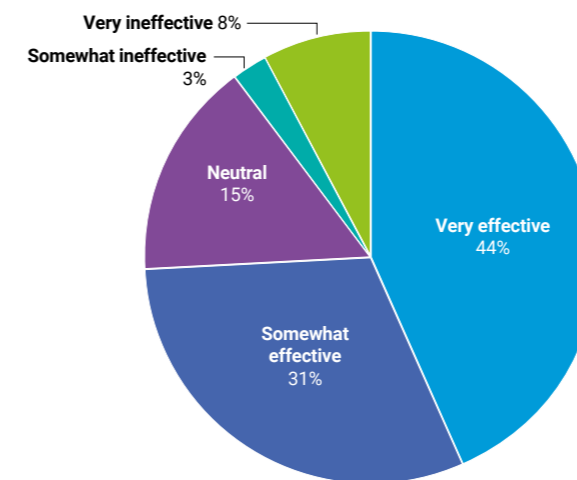
Clinical review also appears to be largely absent from ongoing care. A substantial majority of respondents (83%) reported that they had not had a review session with a clinician about the products they had been using in the past year. While some patients may not require changes to their care, the absence of regular review limits opportunities to reassess product suitability as needs evolve over time.

Occurrence of product review sessions with clinicians (Past 12 Months)



Amongst those who had a review, it is positive to acknowledge that the majority of respondents (around 13%) have a somewhat or very effective review for their continence needs.

Perceived effectiveness of follow-up care and reviews for continence needs



Key Takeaways

Taken together, these findings indicate that patients are not receiving adequate information or clinical engagement during their care pathway and that emotional and psychological support remains insufficient for the majority of those living with continence issues.

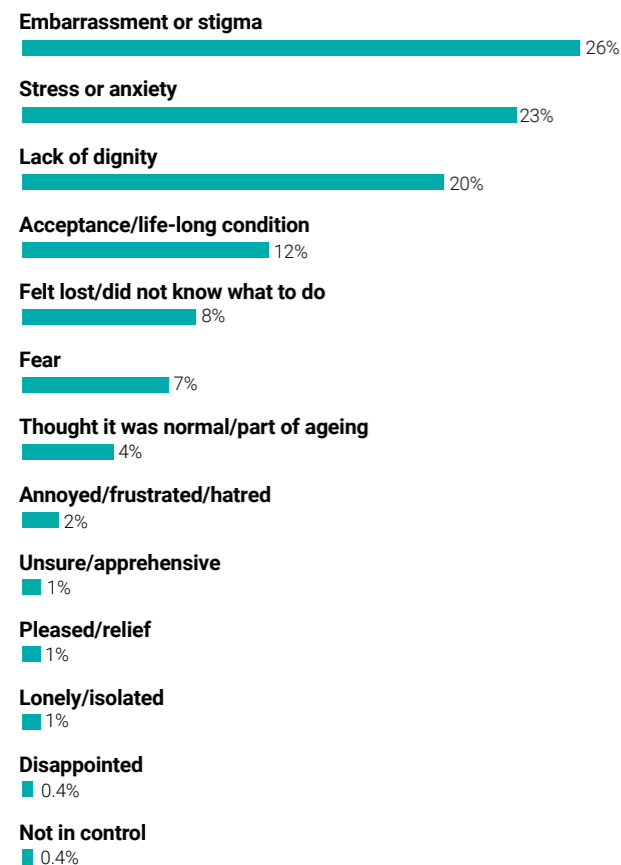
While healthcare professionals work hard to provide the best possible care, it is clear that more needs to be done to implement well-funded services that allow a sufficient number of clinicians the time and resources to meet the needs of those living with continence issues. Healthcare professionals should also be supported through further training and education to ensure they can provide clear, comprehensive information, address patients' questions and concerns, and signpost individuals to appropriate emotional and psychological support where needed.

Overall, the findings make a compelling case for more informed, responsive and holistic approaches to continence care. This means care that equips patients with the knowledge and confidence to manage their condition effectively, and that ensures regular, structured review as a standard feature of every patient's care pathway. Ensuring that individuals are actively informed, adequately supported, and given genuine opportunities to shape their care is essential to improving both outcomes and the overall experience of living with a continence condition.

Patient outcomes

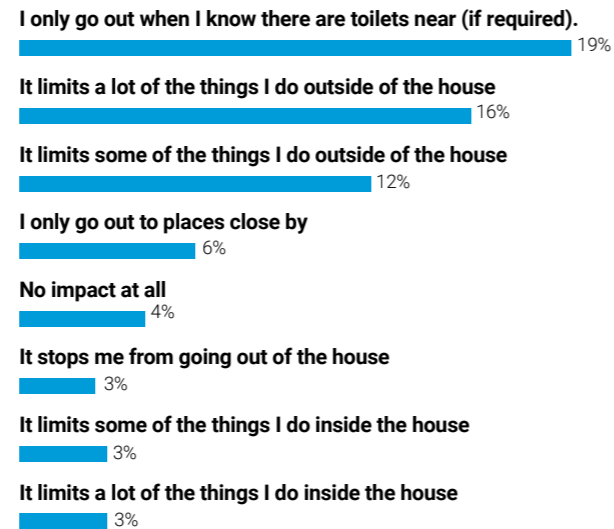
When respondents first realised they were experiencing urinary incontinence, emotional distress was common. Nearly six in ten (59%) reported feelings of embarrassment or stigma, around 53% experienced stress or anxiety, and 47% reported a sense of lost dignity. These findings underscore the profound psychological impact associated with the onset of urinary continence issues.

Initial emotional response to urinary continence issues



The ongoing impact on daily life is equally significant. Almost two in five respondents (39%) agreed that their continence issues affect their day-to-day activities, including limiting outings to locations where toilet access is assured.

Impact of continence issues on daily activities



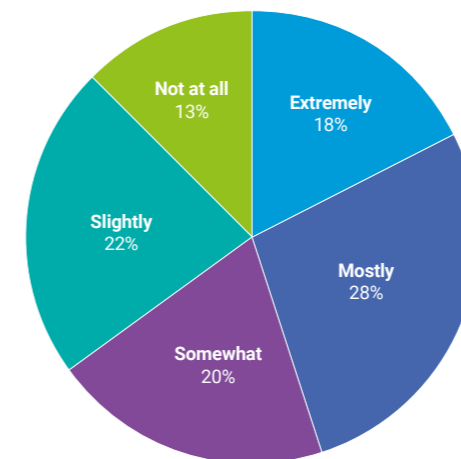
Additionally, 32% stated that their condition limits many of the activities they undertake outside the home. More than one-third reported anxiety about bladder leaks and unreliable access to toilets.

Emotions and actions since diagnosis and/or starting product use



46% stated that they felt confident and independent in managing their continence care, although qualitative responses suggest that, for some, this independence reflects enforced self-management in the absence of consistent clinical support, rather than a genuinely supported choice.

Confidence and independence in managing continence care



Most people, when appropriately informed and supported, develop a strong understanding of their own needs, preferences, and what works best for them in managing their condition. This reinforces the need for a genuinely person-centred approach to continence care, where clinical decision-making is undertaken in partnership with the person, and where appropriate, their carers.

People living with urinary incontinence should be actively involved both at the point of initial care planning and listened to at any stage where they raise concerns or request changes to their care pathway. Putting this into practice can help ensure that care remains responsive and aligned with individual needs over time. Where possible, supported self-management aligns with the key objectives of reforms such as the 10-Year Health Plan, particularly its ambition to move care from the acute into the community and bring the person to the centre of their own care.

Qualitative findings further underscore the emotional

and practical barriers faced by people living with urinary incontinence. When asked whom they would approach to change their continence products or seek additional support, some respondents indicated reluctance or resignation. Illustrative responses included:

“No one, as usual.”

“No one helps.”

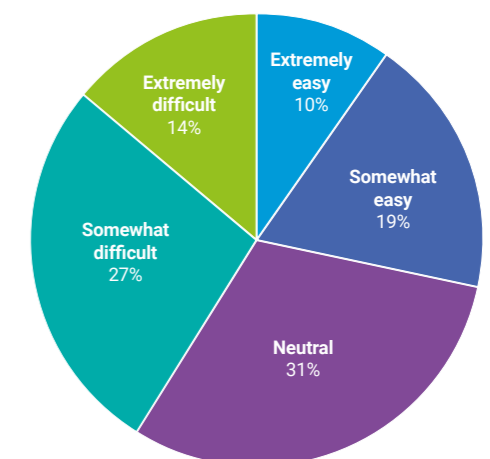
“Nothing, I find it embarrassing.”

“I don’t expect anyone to help me; nobody has so far.”

“I’d sort of given up.”

63% of respondents felt that it would be difficult or extremely difficult to switch to a different product if their current one became unavailable.

Perceived ease of changing continence products



Conclusions

These responses suggest that embarrassment, low expectations of support and perceived inaccessibility of assistance may prevent people from seeking adjustments to their care, even when their current provision is inadequate.

Respondents also identified areas for systemic improvement. Forty respondents expressed a desire for continence care to be less stigmatised in public discourse, and for greater openness from clinicians. Twenty-four highlighted the importance of raising public awareness, including through media coverage, about continence care and its wider consequences. In addition, 82 respondents indicated that they would like more consistent and regular access to expert clinical support.

Key Takeaways

Taken together, these findings illustrate the profound and lasting impact that urinary incontinence has on the lives of those living with the condition. The emotional toll of continence issues is immediate and significant. Overall, the findings demonstrate that continence conditions have a sustained emotional and practical impact on people's lives. Their ability to live with dignity and independence, and their ability to participate in daily activities, appear to be closely linked to whether they receive appropriate care, including support from healthcare professionals and access to appropriate products.

The findings of this survey confirm the scale and significance of urinary continence care challenges across the UK and underline the critical role of access to well-resourced continence services, with adequately trained, non-overstretched staff and appropriate product provision in supporting patient dignity, experiences and outcomes. While many people reported satisfaction with the products they use, the broader findings suggest this is often achieved despite system barriers, rather than due to consistent, person-centred care.

Across the data, a clear theme emerges. People frequently experience limited involvement in decisions about their care, restricted product choices, and insufficient ongoing clinical review. These challenges are compounded by wider NHS pressures, including workforce constraints and financial pressures, which may limit the time and flexibility healthcare professionals have to support shared decision-making, and for the NHS to provide necessary supplies of products to hospitals and in the community. Cost pressures across the NHS also mean that people may be denied access to certain products based on unit price alone, particularly for those who rely on NHS provision. The findings reinforce existing evidence indicating limited shared decision-making in continence management, largely driven by inconsistent provision of information. People at times lack clear explanations of the range of available continence products or sufficient detail about how different options may affect day-to-day management and longer-term outcomes. This restricts their ability to meaningfully compare choices, often resulting in decisions being made with minimal shared discussion and reduced patient involvement in selecting appropriate care options.

The survey also highlights the risk that current and proposed reforms, such as those in Part IX of the Drug Tariff, could exacerbate these challenges if not carefully implemented. Continence products are not interchangeable commodities. As with many medical technologies, their effectiveness depends on an individual person's needs, preferences and

clinical circumstances. Limiting product choice risks undermining the person-centred care that NHS policy increasingly seeks to promote. Price reduction pressures may result in suppliers withdrawing products from the market and may discourage companies from bringing innovative new products to the UK.

There is a clear opportunity for policymakers, the NHS and industry to work together to ensure that ongoing reforms, including for the review of Part IX and wider procurement reforms, support a person-centred approach. This should recognise the long-term clinical and economic benefits of ensuring people have access to the most appropriate products, where value can be demonstrated. This is particularly true for continence care, where relatively modest improvements in care can deliver substantial benefits for the wider NHS system.

Alongside this, survey findings point to the impact of fragmented or "broken" care pathways, where individuals experience inconsistent support, poor coordination between primary, community and specialist services, and limited access to regular review. These gaps can leave people managing complex conditions with insufficient clinical oversight, increasing the risk of complications and avoidable deterioration in quality of life.

Ensuring patient choice, supporting clinical discretion and recognising the role of appropriate products in preventing complications will be essential to improving outcomes for those with urinary incontinence, while also supporting NHS efficiency. Getting continence care right is not only a question of procurement, but of dignity, prevention and delivering truly personalised care, including by ensuring that the importance of appropriate continence care is recognised in policy reform.

Limitations

As with any survey of this kind, the findings should be interpreted with some consideration of their limitations. The relatively small number of responses means the analysis is more exploratory in nature. In addition, the survey was disseminated indirectly by sharing a link with selected contacts and encouraging onward distribution, rather than engaging directly with patients. This may have influenced both reach and response rates. The survey design also did not enable clear distinction between product use and patient outcomes or individual experiences, although it did broadly achieve its aim of gathering general insights into continence care. Because the survey was distributed through a limited number of charities, the responses may also reflect a narrower range of conditions, and a wider range of perspectives may have provided a more comprehensive understanding of patient pathways. This survey was intended as an initial overview of patient experiences and outcomes in continence care. Further research, including larger-scale quantitative studies and qualitative interviews, would help to build on these findings.

Recommendations and next steps

Based on the survey findings, this report identifies several opportunities for policymakers and NHS leaders to strengthen continence care provision:

For Policymakers

Ensure procurement reforms protect patient and clinician choice

Ongoing reforms, including the Part IX review and MedTech Commercial Strategy, should explicitly safeguard the ability of clinicians to prescribe the most clinically appropriate product for individual patients, recognising the personalised nature of continence care. Continence products are not interchangeable and must be selected based on individual clinical need and patient circumstances.

For DHSC to carry on with their work on local formulary guidance, as an important piece of work to ensure proper access to products for both clinicians and patients.

Strengthen investment to improve access and support in continence care

Further investment in continence services is needed, including increasing the number of trained continence nurses across the system to meet current demand and provide a future-proof service. Investment should also ensure that people requiring continence care can easily access appropriate treatments, and that they, along with any carers, have access to clear information and support when needed.

DHSC should review and update the Excellence in Continence Care guidance document to take on board the findings and recommendations of this survey.

Embed value-based approaches across continence care

Policymakers should ensure that product provision is assessed based on value across the whole patient pathway, rather than unit cost alone, and that medical devices are evaluated through procurement frameworks that properly reflect their clinical purpose and patient impact.

For the NHS

Strengthen shared decision-making in continence care

Shared decision-making should be strengthened to ensure people are actively involved in their care and fully informed about the range of appropriate treatment and product options available to them. Healthcare professionals should be supported through appropriate training, guidance and decision-making tools to understand the breadth of products available, including those listed in Part IX of the Drug Tariff, and to apply value-based principles in treatment and/or care management planning and product prescribing that reflect clinical need, patient outcomes, including greater self-management, and whole-pathway value, including moving more care into the community. Improve access to consistent and regular expert clinical support

The NHS should improve access to timely reviews, follow-up appointments and specialist continence expertise to ensure people receive ongoing support as their needs change. Strengthening continence pathways, including providing further investments, and improving coordination between primary, community and specialist services will be critical to avoiding fragmented or “broken” care pathways.

Improve equitable access to products across care pathways

The NHS should also ensure equitable access to Part IX products across geographies by safeguarding patient and clinician choice and avoiding unnecessary restrictions through local formularies or prescribing guidance. Addressing unwarranted variation in continence care should be a priority, including improving access to specialist continence services, clinical advice and best-practice pathways, so that all patients can benefit from consistent, high-quality care regardless of where they live.

For industry

Continue to engage with policymakers, patients and clinicians

Ongoing engagement between industry, policymakers, patient groups and clinicians will be essential to ensure reforms deliver both value for the NHS and improved patient outcomes, while supporting innovation and responsiveness to patient need.

For charities and patient organisations

Support awareness and stigma reduction around continence care

There is a continued need for awareness-raising efforts and support for open clinical conversations to reduce stigma, encourage people to seek help from healthcare professional earlier and improve understanding of the support and treatment options available to people.

Charities and patient organisations have a role to play in working with others across the sector to ensure the voices of those living with urinary incontinence are heard by policy makers and that their lived experiences feed into the way services set up and delivered.

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