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Stoma care crisis: the urgent need for nationwide pathways and patient-centric policies

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ABSTRACT

Many people living with a stoma face challenges beyond their physical needs. Although stoma care products and services have advanced, significant gaps persist in national policies and equitable access. Current policies appear to prioritise cost savings over the wellbeing of people living with a stoma, not appreciating the expertise of specialist stoma care nurses (SSCNs) and the experience of people living with a stoma. The absence of an established, evidence-based treatment pathway in stoma care and the lack of standardised practices leave many people susceptible to inconsistent care and unmet needs. The authors call for a shift in focus to empower SSCNs to advocate nationally for people living with a stoma and to challenge inconsistent, inequitable practices. The authors highlight an urgent need to establish and implement a nationwide, long-term, evidence-based treatment pathway that provides a standardised approach with ongoing monitoring to deliver optimum, personalised care for people living with a stoma.

Key words: Stoma care ■ Evidence-based stoma care ■ Specialist stoma care nurses ■ Stoma care advocacy ■ Best practice stoma care pathways

Stoma care nursing services, patient management and product availability have evolved to improve the care provided to people living with a stoma and their quality of life (QoL). Despite improvements, people living with a stoma face significant challenges, which have a negative effect on their QoL and cause increased anxiety. (Bowles et al, 2022).

Natasha Rolls, Lead Stoma Care Nurse Specialist, University Bristol and Weston Foundation Trust, natasha.rolls@uhbw.nhs.uk

Paul Trevatt, Independent Nurse Consultant and Fellow of the Royal College of Nursing

Angie Perrin, Clinical Education Lead, Salts Healthcare and Acting Chair ASCNUK

Sarah Squire, Chair of the ACPGBI Patient Liaison Group, Patient Representative

Caroline Bramwell, Patient Advocate, Ostomy Triathlete

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Past challenges and current progress

Advances in specialist training, innovative technologies (for example, integrating digital tools and telehealth) and multidisciplinary collaborations have improved stoma care service delivery (Rolls et al, 2024). However, these advances have no standardised mandate; hence, they are not reflected nationwide and, until the NHS England Getting it Right First Time (GIRFT) programme adopts the Association of Stoma Care Nurses UK (ASCN UK) Advancing Stoma Care Services (ASCS) project, there will be no national policy framework. GIRFT is a national programme whose aim is to improve the treatment and care that patients receive by reducing variations in service. It does this through in-depth reviews of services, benchmarking and using data-driven evidence to support change.

Generally, stoma care products have evolved from basic designs, which are more prone to leaking (with limited customisation opportunities), to modern innovations with discreet designs and odour-reducing properties, which prioritise comfort, wellbeing and convenience. However, challenges for patients persist, with limited accessibility to services, skin complications and appliance leakage issues (Bowles et al, 2022).

Too many products for stoma care?

The Department of Health (DH) (now the Department of Health and Social Care (DHSC)) stated in a 2006 review that there were many stoma appliances and additional products, citing the 5800 types of stoma items and incontinence appliances from 68 suppliers that were available at the time. The review, *The Arrangements for the Reimbursement Pricing of Stoma and Incontinence Appliances under Part IX of the Drug Tariff* (DH, 2006), specifically considered these products.

In 2023, the then Conservative government launched a 'late stage assessment' (LSA) process, to evaluate technologies registered in the UK that have been in widespread use for some time (DHSC, 2024a). In conjunction with the DHSC, the LSA committee selected a number of technologies for review, among them colostomy bags (NICE, 2024; 2025). The stated aim of the reviews is to assess products and innovations over time, to evaluate high-cost products or low-cost, high-volume products, and to assess if the value added by incremental innovation of existing products justifies any price variation. Its scope included gathering information from clinicians, patients and manufacturers.

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However, to date, the findings of the 2006 review have continued to underpin much of government policy and guidance, with the impression remaining that the wide range of products available challenges standardisation and cost control.

The view of those working in the specialty, however, is that the wide range of stoma products available reflects the diversity and preferences of people living with a stoma. The DH/DHSC perspective shows a lack of understanding of the unique nature of stoma care product use – these are not 'just' medical appliances, but products that significantly impact a person's way of life and wellbeing. People's bodies change and their stoma appliance will need to change as a result. As such, the DH – and now DHSC – perspective demonstrates that national policies affecting people living with a stoma are not aligned with individual need.

Product access has been reported to be an important factor for people living with a stoma (Bowles et al, 2022). Yet the significant number of products highlighted are not accessible to everyone with a stoma. In other healthcare areas such as incontinence NHS trusts ration the daily supply of hygiene products (Francis, 2024). This would have a significant impact within stoma care.

The availability and rationing of these products may relate to access to specialist stoma care nurses (SSCNs). Contact with SSCNs is key to reducing appliance leakage; however, access to their expertise varies widely across different regions of the UK (Aibibula et al, 2022). Across England, the landscape of specialist stoma nursing services is unclear: in some areas, people may have consistent, easy access to specialised stoma care. In other areas, services may be limited or unavailable due to factors such as funding differences, healthcare resource allocation, or SSCN availability. This negatively impacts patient outcomes (Aibibula et al, 2022; Osborne et al, 2022), including product accessibility. It is the views and challenges highlighted by experts by experience (people living with a stoma) that inform this article.

The right to mandated access to SSCNs

Ideally, everyone living with a stoma should have access to a named SSCN from diagnosis to surgery, following the procedure, and throughout their pathway. However, in reality, access varies. Due to the lack of a mandated best practice care pathway, people living with a stoma can report feelings of abandonment and isolation, especially after surgery (Aibibula et al, 2022; Osborne et al, 2022), further emphasising the need for reliable resources and support at each care stage when dealing with stomal complications and the impact on quality of life.

Based on these unmet needs, we are advocating for policy reforms to prioritise the lived experience and the needs of people living with a stoma. We aim to highlight the importance of implementing a defined, nationwide care pathway to improve postoperative support and access to products, and to reduce the feelings of confusion, anxiety and abandonment that can be experienced by people living with a stoma. Our intention is also to highlight the integral role of SSCNs in ensuring that patients receive the best and most clinically appropriate products and services, guaranteeing ongoing support, and protecting them from inappropriate marketing and inaccurate product sampling.

Ultimately, we are advocating for the need for a long-term, evidence-based patient pathway in stoma care. This pathway will be cost-effective, ensuring that people use the correct products in the correct volumes and order from the correct sources.

Gaps in the UK guidelines for stoma care

Different NHS organisations across England have developed their own stoma care processes, with some stoma care departments devising pathways that aim to cover four key phases of stoma care: preoperative, in-hospital, postoperative, and living with a stoma (Coloplast, 2023). However, there is no standardised, nationwide pathway (especially after a diagnosis that causes stoma formation) to which all Integrated Care Boards can adhere. ASCN UK quality statements are only guidance: they are intended predominantly to guide practice for the SSCN members the society represents and have no mandatory or enforced applications; they also do not reflect the current evidence-based outcomes (ASCN UK, 2021; Coloplast, 2023).

The Norwegian Professional Recommendations on the Follow-up of Patients with Ostomy consider that follow-up by ostomy nurses reduces the frequency of skin complications (Olsen et al, 2020). The guideline recommends that all patients receive follow-up support and services from an educated, qualified ostomy nurse with updated knowledge (Olsen et al, 2020) – this is not mandated in the UK.

Cost over care: neglecting the realities of stoma care

The DH (2006) review and the National Institute for Health and Care Excellence (NICE) LSA final scoping document (*GID-HTE10045 One-Piece Closed Bags for Adult with a Colostomy*) (NICE, 2024) cited the economic aspects of stoma care products, placing little emphasis on service needs, potentially because service needs – and existing provision – are poorly understood by those not directly involved in the specialty and because of their complexity.

The primary focus of the DH review and the LSA's final scope on cost efficiency over care, with the omission of patient follow-up needs in the LSA document – despite the inclusion of the perspectives of stakeholders in these reviews (including that of two of the authors) – could be seen to demonstrate less awareness of the lived experiences of those living with a stoma, the crucial role of SSCNs, and reality of the stoma care landscape in practice.

By placing the emphasis on cost these documents also sideline the crucial role of SSCNs in selecting the appropriate products to suit the individual needs of people living with a stoma, and do not recognise SSCNs' expertise in preventing stoma bag-related complications.

The DH (2006) identified pharmacy and appliance contractors as the main groups affected by reimbursement proposals, sidelining those who are truly affected by any DH decision on product availability – people living with a stoma. In doing so, the DH may not have fully appreciated the variety and differences in prescribing models or the impact on the users of the products. The DH review rightly stated a need to improve the quality of care provided, but it did not mention the value of stoma care nurse expertise or the disparity in nationwide service provision. The term 'specialist nurses' was mentioned only once in the document with reference to providing patients with stoma care items (DH, 2006).

On a positive note, the completed HTE29 LSA (NICE, 2025), published in July, includes a broader discussion of the role of the clinical nurse specialist in stoma care. In response to the feedback from clinicians, patients and industry, HTE29 LSA (NICE, 2025) also gives patient choice and preference more weight.

Responses to a consultation on proposals to update Part IX of the Drug Tariff Medical Devices (DHSC, 2024b) included the need to ensure adequate funding for stoma specialist nurses, increased nurse training, and a need for annual clinical examinations with a stoma nurse to improve patient knowledge.

The 2006 DH review reported NHS spending of £631 million a year on the 5800 types of stoma and incontinence care products, along with related appliance and service items; spending of £169 million on stoma and incontinence appliances in primary care was identified. To give a more recent figure, in 2023 a parliamentary debate on the 'Future of Stoma Care', a health minister cited an annual expenditure on stoma products in the NHS at around £350 million (UK Parliament, 2023) .

In the 2006 review, product choice was cited as a driver for increased costs (DH, 2006). This approach did not consider that the stoma-specific needs of people may change over their lifetime or that some stoma skin care products trigger peristomal contact dermatitis (Cressey et al, 2017); neither did it consider that, as individuals' body shape changes over time, there would be a need for different products to prevent leakage. It is welcome that HTE29 LSA (NICE, 2025) has now recognised that the needs of individual patients vary over time and that this should be reflected in the choice of products available.

Beyond cost savings: safe and effective stoma products

Understandably, costs need to be managed, but it is imperative to prioritise optimal stoma care services, such as offering the best possible products. This ensures that people living with a stoma can manage without compromise and that manufacturers can uphold the quality of their products while developing innovations. Matching the right product to everyone may help to ensure the appropriate use of resources.

From a financial perspective, low-cost, low-quality product options may seem favourable but they are not always ideal, lacking the more innovative elements that carry a cost in development. Although all products must meet certain criteria to be listed on the tariff, to ensure they are safe for use, they are not necessarily reviewed by experts in the field or judged on these new elements: eg, those that improve fit, wear time, comfort, skin health and QoL through aesthetics. Cost efficiencies through lower cost products could be undermined with more frequent changes, or skin issues due to leakage. As a result, low self-esteem can lead to isolation and social care costs. Alternative products are sometimes provided without SSCN input to people living with a stoma without consideration of their needs or providing them with sufficient support – anecdotal reports of this are too numerous not to consider or mention.

Many people living with a stoma report a high incidence of peristomal skin conditions and appliance leakages (prevalence of 70%) when using stoma care products, reducing their QoL (Osborne et al. 2022). Introducing routine skin and body profile assessments before introducing or switching products may help address these issues, allowing people to receive more suitable stoma products, in the correct volumes and ordering frequency. These assessments should then be reviewed annually and only by a designated SSCN (Russell Roberts, 2020).

Beyond product specifications, raising awareness of stomal problems would empower SSCNs and their patients to make better informed decisions, placing patient safety and comfort over cost-saving measures.

The weight of the power given to patients

The Labour government has proposed plans to provide 'power to the patients' by updating the NHS App (the smartphone application used to access primary care and other NHS services in England), to include medical guidelines (Labour Party, 2024). The aim is to give patients the power to understand their treatment choices and to hold health services accountable (Labour Party, 2024). However, this creates a paradox for people living with a stoma: how can they view medical guidelines for their long-term stoma care if there are none?

A desperate need for an evidence-based long-term care pathway in stoma care

Established pathways for other chronic conditions

There are well-established, evidence-based, and regularly reviewed follow-up care pathways for chronic conditions such as inflammatory bowel disease (IBD) and type 1 diabetes (Clinical Knowledge Summaries, 2024; IBD UK, 2024). Unfortunately, this does not exist for stoma care, especially following surgery, even though the prevalence of stoma formation and other chronic conditions in the UK is similar to that of other conditions: there are 218 670 people in the UK with type 1 diabetes (NHS Digital, 2021), whereas 205 000 live with a stoma (Burch, 2022).

In 2019, NHS England published a long-term plan and commitment to providing personalised care for everyone living with cancer by 2021, with access to a named clinical nurse specialist or a support worker (NHS England, 2019). The same commitment could be introduced to stoma care through an evidence-based pathway that includes a dedicated SSCN for everyone living with a stoma. This would provide better support and reduce uncertainty. Empowering ostomates to independence is not undermined by regular contact with services; choice around access and frequency of contact can still be individualised, but support needs to be overt to ensure uptake is equitable.

By comparing stoma care with the wider healthcare landscape, we can develop a much-needed, multifaceted infrastructure around the patient, ensuring optimal care.

Challenges for all stakeholders

People living with a stoma run the risk of getting lost within the stoma healthcare system due to a lack of follow-up and inconsistent appointments (Bowles et al, 2022). This results in a limited range of products available to meet an individual's specific needs, increasing the chances of appliance leakage, which, in turn, affects mental wellbeing and day-to-day life (Osborne et al, 2022).

A 2022 survey identified a need for mental health support following stoma surgery; feelings of abandonment and potential isolation for some were recorded (Bowles et al, 2022). Transitioning to life with a stoma can be physically and emotionally challenging for people as they are often left to navigate complex decisions about their care and products on their own, worsened by the lack of an established follow-up pathway.

This lack of a mandated pathway also negatively impacts healthcare systems. For example, people without access to an established care pathway and SSCN may experience increased product consumption and improper product application, leading to appliance leakage and skin complications. They may require additional SSCN assessments, alternative products, GP consultations, or emergency department visits. This puts further pressure on health services, which is not cost effective.

An evidence-based treatment pathway with regular follow-up appointments with a designated, up-to-date SSCN could help resolve these challenges. It could reduce the chances of people being lost to follow-up, reduce the number of wasted products, and increase education on product use.

The expertise of SSCNs cannot be understated. Their role is rooted in advanced education, expert practice and clinical experience; their input is key in addressing the above challenges. SSCNs are fundamental to maintaining high standards of care, challenging poor ethical practice, and ensuring that patient safety, wellbeing, and quality of care remain a priority. The Royal College of Nursing (2024) has recently clearly defined the scope of practice and expert skills of specialist nurses.

A potential long-term care pathway for stoma care

Wes Streeting, the Secretary of State for Health and Social Care, recently spoke on the Labour government's 10-year plan to deliver three big shifts in the NHS focus: from analogue to digital, sickness to prevention, and hospital to community (DHSC, 2024c). These shifts provide unique opportunities for stoma care:

- Analogue to digital: a digital transformation can be applied to stoma care by building on the existing NHS App. Software could be incorporated to allow people living with a stoma to take photographs of their skin around the stoma and send them to their SSCN to identify concerns. Having video calls rather than in-person hospital visits could reduce waiting times as they allow more flexibility in the SSCN's schedule as no clinic room is required
- Sickness to prevention: for stoma care, this could mean prioritising effective follow-up and proactive management strategies (eg, assigning named SSCNs to each person) to enhance patient experience and outcomes and reduce complications. Prevention could mean ensuring that people living with a stoma receive the correct supplies, such as well-fitting stoma bags and high-quality stoma appliances, to prevent common issues such as skin irritation, appliance leakages, and infections. This would enable SSCNs to address issues before they worsen
- Hospital to community: this shift could enhance outcomes and the QoL of people living with a stoma and prevent hospital readmissions by effectively managing issues and concerns within the community. After surgery, people living with a stoma face new challenges because the lack of a follow-up pathway makes them feel unprepared to manage their stoma independently. By strengthening primary care support, using existing outreach efforts, and optimising care during the hospital-to-community transition, people living with a stoma can receive ongoing guidance and access to specialised stoma care. This shift aligns with the long-standing goal of moving funding from acute (secondary) care to primary care – a shift that the current stoma care services are already prepared to support.

Conclusion

An established long-term, evidence-based treatment pathway in stoma care is required to reduce unwarranted variation in care for people living with a stoma. Although there is excellence in care and service delivery it cannot be ignored that the variation in provision, lack of national oversight and evaluation or audit may leave some ostomates vulnerable to physical and emotional complications and poor QoL. Existing NICE and government policies and guidance documents focus on logistical and cost-saving elements and overlook key factors such as QoL, product suitability, and the long-term challenges people living with a stoma experience.

A shift in focus is required to examine the wider health landscape to establish a care pathway, especially after surgery, to foster a higher standard of comprehensive care, and mandate the sharing of best practice and evidence-based specialist stoma care.

Healthcare systems do adopt cost-saving measures such as switching manufacturers for medications (Seidman and Atun, 2017). However, this cannot be applied to stoma care, specifically to stoma bags, as continuity in care and product consistency are equally important in addressing unmet needs.

SSCNs are the cornerstones and experts of stoma care but their expertise, as local and national advocates for ostomates, must extend beyond patient care to policy development and effective cost management to ensure that stoma care extends beyond the basics.

The authors attest that the Advancing Stoma Care services (ASCS) project, which will be adopted by GIRFT, will position SSCNs at policy level, allowing them to provide this vital insight and influence, with an understanding of the complexity and the skills to advocate for ostomates and the stoma care landscape.

To continue the stoma care evolution, we must adopt a nationwide evidence-based follow-up treatment pathway that benefits policymakers, healthcare systems and, crucially, considers and supports the journey of people living with a stoma. Professional response and reaction to national policy are essential, even when that can create discourse and disagreement. The recent call to action by Rolls et al (2024) raised the concept of a nationally recognised pathway, and called for recognition

KEY POINTS

- Gaps in policy documents for stoma care in the UK leave people living with a stoma susceptible to inconsistent care and unmet needs from diagnosis to the post-surgery phase
- There is no standardised, nationwide, evidence-based treatment pathway for stoma care, causing some NHS trusts to develop their own pathways, so people are subject to a 'postcode lottery' in care quality. It is therefore imperative to implement a standardised, evidence-based treatment pathway to ensure people receive appropriate support
- Cost-saving measures disregard the need for high-quality, individualised care; low-cost products are more prone to cause skin irritations and other complications
- Specialist stoma care nurses' advocacy at national levels is crucial to defend the rights of people living with a stoma to ensure their needs are prioritised in care delivery and policy decisions

of the critical role that SSCNs play in the care of people living with a stoma. This article seeks to continue the discussion and reflects the variety of ways in which the work of stoma care nurses is increasingly pertinent and relevant to policymakers and, crucially, patients living with a stoma across the UK. **BJN**

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CPD reflective questions

- What are the consequences of the current lack of a standardised, evidence-based, nationwide stoma care pathway in the UK for people living with a stoma and for health professionals?
- How does prioritising cost savings over high-quality products impact the quality of life of people living with a stoma?
- How can nurses be empowered to bridge the gap between cost-effective stoma care and the provision of high-quality, standardised care and support to people living with a stoma?