

Supporting People with Stomas to Live Life to the Full: *A Call to Action.*

Whilst the formation of a stoma is a life-saving procedure for many, it also poses considerable, life-changing challenges. A lack of access to quality stoma care can make managing stoma-related complications, such as leakage, even more difficult.

Addressing these difficulties and improving access to specialist care will support the NHS to achieve key ambitions aligned to the Long Term Plan. Providing equitable access to defined specialist pathways will improve consistency in quality of care and patient outcomes. Supporting both prevention and self-care agendas will impact positively on in and out of hospital care, reducing pressure on emergency hospital services¹. Finally, by working in partnership with patients and charities, healthcare leaders can enable providers to deliver best practice integration. This integration is key to the successful delivery of the evolving healthcare system for people living with a stoma, and forms the basis of high-quality stoma care.

To realise these outcomes, decision makers must be aware that people with a stoma believe that:



Healthcare professionals need to...

- > Provide high quality preoperative to postoperative care, aligned with national best practice.
- > Deliver individualised and holistic care based on advanced specialist stoma assessment.
- > Identify pathways of care to ensure transparent, ongoing lifelong care and support.
- > Offer people with a stoma an annual review with a specialist stoma nurse, which includes assessment of skin health, routine and product choice².
- > Ensure any changes to a prescription for stoma related products are made in consultation with a specialist stoma nurse in collaboration with the person with a stoma³.
- > Provide regular educational insights on living with a stoma, including product innovation information.
- > Deliver positive education throughout the healthcare service to understand how stomas affect people and their carers.



Healthcare providers need to...

- > Enable the commissioning of transparent preoperative to postoperative stoma care pathways, including ongoing lifelong patient care and support.
- > Facilitate and enable equitable access to specialist stoma care, support, education and advice across the population.
- > Safeguard primary care social prescribing and third sector accessibility for continued peer engagement and support.
- > Ensure people with a stoma are given direct access to additional specialist support i.e. mental health support, dermatology and dietetics.



Policymakers need to...

- > Commit to reviewing stoma care pathways and ensure equitable access to optimal, specialised care for every person with a stoma.



Manufacturers and suppliers need to...

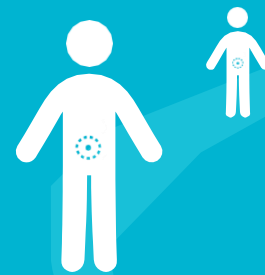
- > Improve information made available for people with a stoma to help them better understand products and innovations available.



Communities and employers need to...

- > Be aware and educated on how to support people with a stoma.
- > Be aware that a stoma is a hidden condition and ensure disabled toilet facilities are clean, spacious and accessible.

Supporting People with Stomas to Live Life to the Full: *The Method.*



1. The challenge...

People with a stoma face many physical and emotional challenges in their post-surgery lives. However, at present, access to specialist stoma care is highly variable across the health system.

We wanted to clearly articulate the challenges people with stomas face, particularly that of leakage, in the hope of inspiring conversations amongst patients, clinicians, and policymakers on how to solve them.



2. What we did...

To articulate the challenges faced by people with a stoma, a modified Delphi panel used the output from several patient focus groups to create a set of 'calls to action', with a particular focus on the issue of leakage.

The three leading UK stoma charities – Colostomy UK, Ileostomy and Internal Pouch Association (IA), and Urostomy Association (UA) – were invited to participate, in an effort to bring together all parts of the UK stoma community.



3. What we found...

Stoma-related complications present many challenges. For example, leakage can have a significant impact on daily life and can be the cause of physical and mental health challenges, as well as unique social anxieties.

Access to peer support and specialist care can be a significant aid in dealing with these complications. However, there is a lack of equitable access to these resources, and non-specialist healthcare providers need more information.

Meaningful conversations between patients, clinicians and policymakers are vital for articulating and resolving these challenges.

4. Why this matters...



21,000

Between 165,000 - 205,000 people in the UK live with a stoma, with an estimated 21,000 requiring stoma formation surgery each year ^{4,5,6}.



Leakage

can lead to painful skin complications, unpleasant odour, isolation, as well as career and relationship difficulties ^{7,8}.



Although stoma care is generally of a high standard compared to other countries,

there are still significant health inequalities across the country ⁹.



Accessible and good stoma care

can improve patient outcomes, reducing impact on the workforce and workload, whilst delivering cost efficiencies to the NHS ^{10,11}.

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