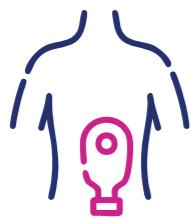


# ADVANCING DIGNITY IN STOMA CARE: PATIENT-CENTRED POLICY RECOMMENDATIONS FOR EUROPE

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Approximately 700,000 people in Europe live with a stoma<sup>1</sup>, with the number of cases rising due to an ageing population and increasing cases of colorectal and chronic inflammatory bowel diseases such as e.g. Crohn's disease or ulcerative colitis. The increase in cases of stomas of non-oncological origin involves a younger population of patients who are active both socially and career wise.



A stoma is a surgically created opening that allows body waste (stool or urine) to exit the body into a stoma bag. This can be necessary when the normal digestive or urinary system cannot function properly due to health conditions like **inflammatory Bowel Disease, colorectal, gynaecological, bladder and head-and-neck cancer etc.** In some cases, stoma surgery is also required due to traumatic or emergency situations,

where there is no time for the usual preoperative preparation and patient education<sup>2</sup>. While a stoma can be lifesaving, adjusting to life with one is a major physical and emotional challenge. It affects daily routines, work, self-image and social participation. **Managing the condition takes time, and strong support is essential to help people have independence and lead a fulfilling life.**

**57-61%**  
of people with a stoma experience leakage<sup>3</sup>.

**76%**  
have sore and irritated skin around the stoma without seeking help<sup>4</sup>.

**9/10**  
worry about leakage<sup>5</sup>, which affects every aspect of life.

**Only 33%** fully resuming their social activities one year after surgery<sup>7</sup>. The psychological impact of experiencing leakage can be long-lasting.

**This ongoing stress deeply impacts well-being, with 53% experiencing depression and anxiety<sup>6</sup>.**

## PHYSICAL AND EMOTIONAL CHALLENGES

## BRIDGING THE CLINICAL SUPPORT COMMUNICATION GAP

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wants to thank the specialist stoma care nurses for the invaluable help and support they give to patients.

Getting ready for planned stoma surgery can feel overwhelming, but having the expert support and guidance from the right healthcare professionals is essential. When patients receive proper education early on, they feel more confident about managing their new situation, face fewer complications, and better adjust emotionally to living with a stoma<sup>8</sup>. However, across Europe, access to such support is inconsistent and often inadequate, depending on the hospital, the type of surgery and the health condition of

the patient as they go into surgery. For example, in Poland, only 40% of planned surgical patients receive an education beforehand, dropping to just 15% for cases requiring emergency procedures<sup>9</sup>. Without structured guidance, patients are more likely to stay in the hospital longer, have increased frequency of hospital visits and emotional distress<sup>10</sup>. However, when people receive stoma management training as part of their recovery plan, they're much more likely to return home feeling confident and capable of managing their care independently.

Specialist stoma care nurses and stoma support charities and organisations are key to bridging this gap, providing vital education, emotional support, self-management and helping patients navigate health systems, especially for unexpected surgeries.

Not enough specialist nurses  
Nurses lack time to properly prepare their patients

Slower post-surgery recovery  
Lack of confidence & negative overall experience

Access to specialist nurses leads to a reduced downstream cost

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" To an ostomate, a medical device is not a commodity—it is the foundation of dignity and freedom. The free choice of medical devices by individuals and the right to have access to specific devices that guarantee quality of life is non-negotiable and must never be compromised by administrative regulations. A seat at the table where healthcare decisions are made enables us to enforce a fundamental principle: patient wellbeing must not be subordinated to the mechanics of public tenders. "

Pier Raffaele Spena

President of Federazione Associazioni Incontinenti e Stomizzati (FAIS)



## THE RIGHT FIT MATTERS

Bodies are different and change over time

For people living with a stoma, these natural changes are complicated by **surgical scars, individual body types, and daily activities**, all of which affect how well a stoma device fits.

A secure, well-fitting ostomy bag is not a preference or a luxury, but a medical necessity to avoid medical complications and psychological burden.



When an ostomy bag does not fit correctly, it can cause leakage

Skin damage, and painful medical complications occurs

Lack of confidence leads to lower contribution to society<sup>11</sup>



## ► BEYOND COST-FOCUSED POLICIES

Across Europe, reimbursement models vary widely

In many countries, fixed allowances, generic product classifications, formularies or single-supplier tenders limit patient choice. Due to low awareness, cost-focused decisions risk being made without a full understanding of what life with an invisible and taboo condition like a stoma truly entails. Even in countries like **Denmark<sup>12</sup>**, where access is broader, restrictions exist hindering patient's freedom of choice. In **Italy** as well, public tenders have limited the choice of stoma devices, favouring the reduction of purchase cost to the detriment of the quality of care.<sup>13</sup>

What may seem like a budget-efficient solution can unintentionally make costs rise for the national healthcare system and cause long-term harm, leading to poor product fit, complications, and emotional isolation.<sup>14</sup>



Reimbursement policies must enable freedom of choice

Respect the decisions made in partnership between patients and professionals

Which leads to better health and social impact<sup>15</sup>

Choosing the right solution should be a clinical decision made jointly by the patient and a trained healthcare professional via **Shared Decision Making<sup>15</sup>**. Limiting choice undermines trust in the clinicians, reduces patient autonomy, increases complications, and drives avoidable costs.



**SDM**

# POLICY RECOMMENDATIONS

## AWARENESS AND HEALTH EQUITY



Require Member States to fully reimburse essential stoma supplies and supporting products with procurement policies ensuring quality and patient choice rather than generic cost-only classifications.



Guarantee equal access and security of supply of stoma products in every Member State, safeguarding patient choice and shared-decision making approach by preventing restrictive tendering.



Mandate EU-wide awareness and early detection campaigns for cancers frequently leading to ostomies beyond colorectal/IBD, including bladder, prostate, uterine, ovarian and other pelvic cancers, with a gender-sensitive and life-course approach, e.g. under the EU4Health programme or European Commission Initiative on Colorectal Cancer (ECICC).



Legally require EU and national Health Technology Assessments (HTA), procurement and healthcare policy committees that address stoma care to regularly have patients and patient organisations around the table.<sup>17</sup>

## SOCIETAL LIFE AND EMPLOYMENT



Update the EU Labour Directive to cover ostomies from digestive, urological, gynaecological and head-and-neck cancers (e.g. laryngeal) under disability and chronic illness protections, mandating flexible working hours, remote work options and break rights.



Amend EU accessibility standards to include stoma-friendly restrooms (private, hygienic disposal, and running water) in all newly built or renovated public buildings and transport hubs.

## CARE



Take a holistic health approach by mandating psychological counselling, dietary support and physical rehabilitation as reimbursed services, in line with Getting it Right First Time (GIRFT). Additionally, all surgical centres must provide pre-operative stoma education and structured post-operative follow-ups within the first 6 months.



Promote medical initiatives around early detection of diseases leading to stomas (e.g. IBD, colorectal, bladder, gynaecological and head-and-neck cancers). Policymakers should see patient charities as essential partners in the system.



Develop and implement EU-wide guidelines for all type of stoma care, including training for specialised HCP and informal carers, as well as guarantee the patient's freedom of choice for solutions that fit their body.



## POLICY RECOMMENDATIONS

## DIGITAL INNOVATION



Allocate Horizon Europe funding to establish a standardised EU stoma registry, tracking prevalence, complications, and patient-reported outcomes, regardless of the type of cause of stoma care needs.



Provide innovation grants for CE-marked digital health tools for stoma self-management, ensuring reimbursement and interoperability with national eHealth systems.



Establish an EU central database on stoma prevalence and outcomes, coordinated through the European Centre for Disease Prevention and Control (ECDC), with hospitals coding correctly to the stoma type (digestive, urinary, respiratory – e.g. tracheostomies post-laryngeal cancer), not generically.



Revise EU HTA methodology to include quality-of-life and patient-reported outcomes in device assessments, beyond cost-effectiveness alone, for all stoma innovations.



## A UNITED VOICE FOR EQUITY AND DIGNITY IN INTIMATE HEALTH

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### ABOUT INVISIBLE

**INVISIBLE** is a collaborative community uniting multiple stakeholders committed to improve the lives of people living with intimate health conditions. By focusing on lived experiences and priorities of those affected we provide a face, a voice and a story to those who are too often in the twilight.

We work towards a society where people with intimate health conditions are seen, heard and supported to live with dignity, confidence and to fully participate in society.

We unite voices across borders and sectors, currently including representatives from multiple European countries and welcomes partners who share our commitment to meaningful change.

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► The initiative is supported by

