OSTOMY in EUROPE

POSITION PAPER

INTRODUCTION

This position paper is a collaborative document developed by multiple patient associations representing the following European countries: Italy, Spain, Germany, Poland, Denmark, Bulgaria, Croatia, Romania, Greece, The Netherlands, Czech Republic, Portugal, Malta and Cyprus. The paper outlines key areas of concern and proposes actionable recommendations for European policymakers to ensure equity, dignity, and quality of life for all individuals living with stomas.

Ostomy patients face several widespread challenges across Europe profoundly impacting care and quality of life.

- **Unequal Access to Medical Supplies & Care**. Regional disparities in reimbursement and procurement policies limit access to essential ostomy products, creating financial and logistical barriers.
- **Shortage of Specialized Healthcare Professionals**. Lack of trained stoma therapists and informed caregivers affects both hospital and home care, making self-management more difficult.
- **Insufficient Psychological & Social Support**. Absence of structured psychological care (despite some best practice examples), combined with persistent stigma, leads to social isolation and workplace challenges.
- **Inadequate Public Infrastructure**. Many public spaces, including restrooms, fail to accommodate ostomy patients' needs, affecting their mobility and independence.
- **Limited Patient Involvement in Decision-Making**. Weak patient representation in healthcare policies and the absence of comprehensive epidemiological data usually hinder advocacy efforts.
- **Lack of Awareness & Prevention Policies**. Insufficient public education on ostomy conditions and screening programs for colorectal cancer and IBD contributes to delayed diagnoses and inadequate support.

These recurring issues call for **greater policy harmonisation following established high standards within the EU, funding, and awareness campaigns** to improve ostomy patients' quality of life and rights across Europe.

Adjusting to life with an ostomy

Approximately **700,000 people in Europe** live with a stoma, and this number is expected to rise due to an ageing population and increasing cases of colorectal diseases and chronic bowel diseases/IBD. A **stoma** is a surgically created opening that allows bowel movements or urine to exit the body into an ostomy bag, bypassing the typical digestive or urinary systems. Ostomies are often necessary due to conditions like bowel cancer or inflammatory bowel disease. Adjusting to life with a stoma is a significant transition that affects **physical, mental, and social well-being**. Proper support is essential to help individuals regain independence and maintain a fulfilling life, including work, family, and hobbies.

- **Physical Factors** – Body shape, scars, hernias, and skin reactions influence stoma care and appliance fitting.
- **Ostomy Type and Placement** – The type of ostomy (ileostomy, colostomy, urostomy), its location, and whether it is placed above skin levels, significantly affect management strategies and the effectiveness of medical appliances.
- **Lifestyle Considerations** – Age, work, hobbies, physical activity, and dexterity impact daily care routines.
- **Medical Conditions** – Additional health issues (e.g., diabetes, mobility limitations) may require specialised care.
- **Emotional and Social Well-being** – Mental health, self-esteem, and access to social support are crucial for adaptation.
- **Resource Availability** – Access to high-quality medical supplies, healthcare guidance, and financial aid varies across regions.
- **Cultural and Environmental Factors** – Diet, climate, and societal attitudes toward ostomy care influence individual experiences.

By addressing these diverse needs, individuals with a stoma can improve their quality of life and effectively manage their condition.

Fundamental Rights of Ostomates

Issued by the International Ostomy Association (IOA), the **International Charter of Ostomates' Rights** provides comprehensive guidelines to uphold ostomates' dignity, health, and autonomy. It outlines fundamental rights to support them throughout their healthcare journey, from preoperative counselling to postoperative care, and aims for universal implementation.

However, we are experiencing that many countries do not live up to and know about these rights.

Call to Action

We encourage the European Parliament to take immediate and coordinated action to address the disparities faced by individuals living with stomas. By encouraging member states to implement the recommendations outlined in this paper, the EU can ensure that all citizens enjoy equal access to healthcare, economic security, and social inclusion regardless of their medical conditions. For ostomates to participate in society as equal citizens, we call to action for:

1. **Availability of a broad range of solutions that allows us to self-manage** our condition and carry on with life without putting us in financial strain. Bodies are different and change over time. This point is crucial for us as ostomates since we need a solution that fits our body shapes for daily and nightly use to avoid physical complications, increased hospital visits and mental burden (such as depression and isolation).
2. **Implementation of quality-of-life measures** in the procurement and reimbursement processes (make sure these medical devices do not go into the same processes as medicines). We need the freedom to choose solutions that fit our bodies. Bodies that have already undergone a lot due to treatments of cancer, inflammatory bowel disease and more. Bodies that often have physical and mental scars. After a long course of treatment, our lives still need to be worth living. Quality of life matters.
3. **Inclusion of patient associations in the healthcare decision-making processes**. Due to high stigmatisation, awareness about living with an ostomy is extremely low among decision-makers and the general public. As a result, decisions about us are often made without us, sometimes by people unaware of the full picture.

Challenges & Recommendations on improving life for Europeans living with stomas

Challenges	**Recommendations**
1. Disparities in Healthcare Access, Affordability, and Level of Stoma Care - Limited availability of specialized stoma care nurses and clinics poor distribution in the territory and lack of stoma care follow-up when the patients have left the hospital. - Across member state there's unequal access to stoma care and personal choice of ostomy solution that fit individual body types, with high personal costs due to inadequate procurement procedures, limited reimbursement policies, variations in national healthcare policies leading to financial strain for individuals. - Even in countries with a right to sufficient care, ostomy patients often lack information about alternative stoma supplies - mainly due to cost pressures and rigid insurance contracts. - Increased healthcare costs due to frequent doctor visits, surgeries, and other medical treatments.	**1. Improving Access and Standard of Care Across Europe** - Develop and implement EU-wide guidelines for stoma care, including training for specialized healthcare professionals to ensure uniform access. - Implement treatment and care pathways for people with ostomy from pre-surgery to continuous home care to standardize care across member states and ensure that the minimum standard is at least equivalent to the highest existing level within the EU. - Full reimbursement for ostomy supplies by standardizing policies across member states, including accessory stoma care products under national health care systems. - Establish facilities for medical services in psychology, dietetics and physical well-being to provide holistic support for individuals with an ostomy. - Integrate evidence-based practices into the procurement process to ensure informed decision-making and guarantee people with ostomies the freedom of choice for solutions that fit their body type and individual needs.
2. Social Stigma and Lack of Advocacy Representation in Decision-Making - Persistent stigma around living with a stoma, leading to social isolation, higher rates of anxiety and depression due to societal attitudes and lack of public awareness - Discrimination against individuals with stomas, impacting employment opportunities - Lack of patient association representation in decision-making procedures - Lack of preventive action in disease awareness education and information materials. - Lack of recognition for caregivers	**2. Increase Awareness and Strengthen Advocacy** - Launch independent, EU-wide public awareness campaigns free from corporate influence, to reduce stigma around living with a stoma - Ensure the presence of patient associations in health care decision-making processes - Create training paths for association volunteers to foster empowerment - Promote initiatives focusing on early detection of diseases leading to stomas, e.g., inflammatory bowel disease and colorectal cancer. - Recognise the role of caregivers as well as supporting empowerment programmes - Promote flexible working conditions for ostomates, including access to private restrooms and options for remote work

3. Data, Research and Innovation Gaps - Limited EU-wide data on the prevalence and needs of individuals with stomas - Inadequate research on long-term outcomes and best practices for stoma care - Lack of data linking primary and secondary care, which makes it difficult to quality assure care - Inadequate investment in technological solutions for quality of life improvements of people living with stomas - Limited use of HTA in decision-making processes for ostomy devices	**3. Establish and Implement Research and Data collection to promote innovative solutions** - Fund EU-level research initiatives to collect data on the prevalence, needs, and challenges of people with stomas - Create a centralized database to inform policy decisions and improve care delivery including data linking primary and secondary care - Encourage the development of digital health solutions, such as mobile apps, to help patients track their stoma condition, manage equipment changes, and access healthcare professionals quickly - Promote the adoption of an HTA approach that focuses on devices impact on health and quality of life of ostomates - Comply with GDPR and protection of personal data of ostomates during data collection

5 CHALLENGES FOR OSTOMATES IN ITALY

1. Access to **care** and **assistance inequalities** in different areas
2. **Lack of** reliable epidemiological **data**
3. **Low patient association involvement** in decision-making processes
4. Purchasing methods **limiting** device selection
5. **Lack of** large-scale **education** and **awareness** policies

5 CHALLENGES FOR OSTOMATES IN POLAND

Lack of systemic psychological support for people with stomas – the need for regular and easily accessible psychological care during the adaptation process.

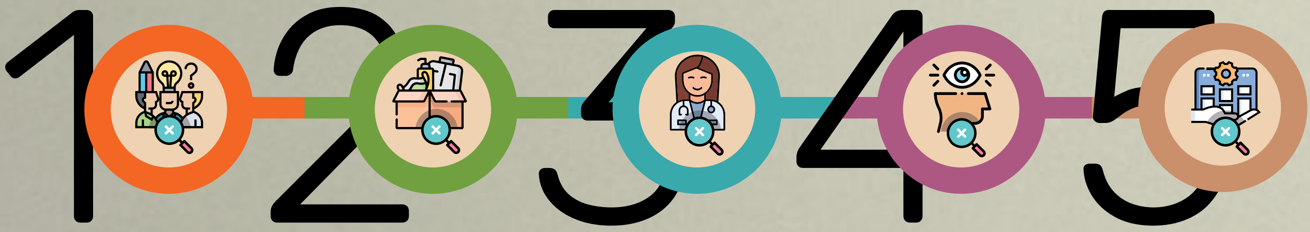
Limited quantity and value of reimbursed stoma supplies and accessories – the need to tailor support to the individual needs of stoma patients.

Public toilets not adapted to stoma needs – a lack of appropriate facilities to ensure comfortable and safe use of toilets for stoma patients.

Low level of public awareness – the need to educate society to increase acceptance and understanding of living with a stoma in public places such as swimming pools, airports, or schools.

Insufficient knowledge of stoma patients about their rights – the need to disseminate information about the ability to choose supplies and providers, enabling patients to fully exercise their rights.

5 CHALLENGES FOR OSTOMATES IN CYPRUS



Lack of public understanding and stigma on the condition
Challenge: There is often a lack of public understanding about ostomies, leading to stigma, embarrassment, and social isolation.

Limited access to medical supplies for individual needs
Challenge: Limited access to ostomy appliances (bags, adhesives, cleaning products) that fit their individual needs.

Lack of healthcare professionals with specific knowledge of the condition
Challenge: Ostomates may encounter difficulties navigating the healthcare system, such as finding specialists (surgeons, nurses).

Lack of employers' awareness about ostomy-related needs
Challenge: Employers may lack awareness about ostomy-related needs, such as frequent bathroom breaks or a private space for maintenance.

Lack of stoma-friendly accessible facilities
Challenge: Public restrooms in Cyprus may not be well-equipped to accommodate the needs of ostomates, such as providing mirrors, sanitary shelf space or disposal bins for ostomy bags.

5 CHALLENGES FOR OSTOMATES IN GERMANY

Economic pressure limits individual access to medical aids.

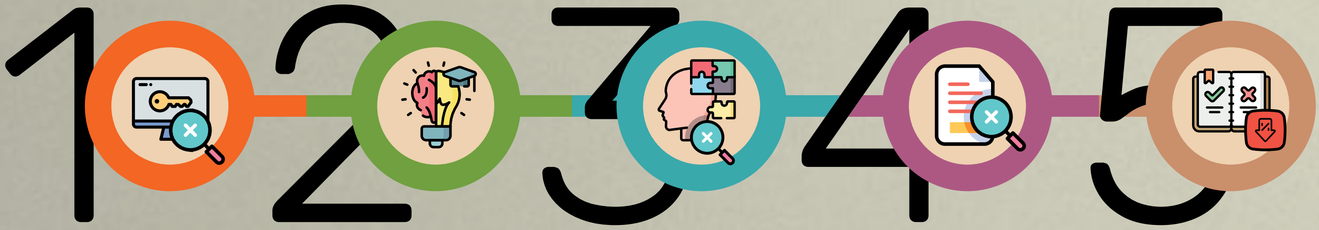
Lack of information hinders participation in choosing aids.

Lack of effective **quality criteria** and quality controls.

Lack of recognition for comprehensive and qualified training as a **stoma therapist** (care expert) harms the quality of care.

Lack of specialist medical aftercare.

5 CHALLENGES FOR OSTOMATES IN SPAIN



Lack of homogeneous access to a range of medical devices and services at a regional and national level.

Regularisation of the stoma therapist nursing **specialisation**; required to educate caregivers and patients in treatment and prevention of stoma-related risks.

Lack of psychological and social support to better cope with emotional, social and logistical challenges.

Lack of homogenisation of health protocols and policies on a national level.

Poor coordination between technological innovation and guidelines updates, leading to slow improvement in patient's quality of life.

5 CHALLENGES FOR OSTOMATES IN BULGARIA

1. **Lack of homogeneous access** to care and assistance in different areas.
2. **Lack of** reliable epidemiological **data** on the condition.
3. **Low patient association** involvement in institutional decision-making processes.
4. Regional and national purchasing **workflows limit the device** range and selection.
5. **Lack of** large-scale **national education** and **awareness** policies.

5
CHALLENGES FOR OSTOMATES IN ROMANIA

1. **Lack of awareness** of the conditions and the fact that it is an invisible disability.

2. **Poor awareness of screening programs** and the important role of prevention for colorectal cancer and IBD.

3. **Lack of trained staff** in public and private structures with awareness and knowledge of the condition.

4. **Lack of caregiver training** on the condition, complications and comorbidities to adequately support patients.

5. **Partial cover and reimbursement** on a national and regional level through National Insurance House schemes.

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