

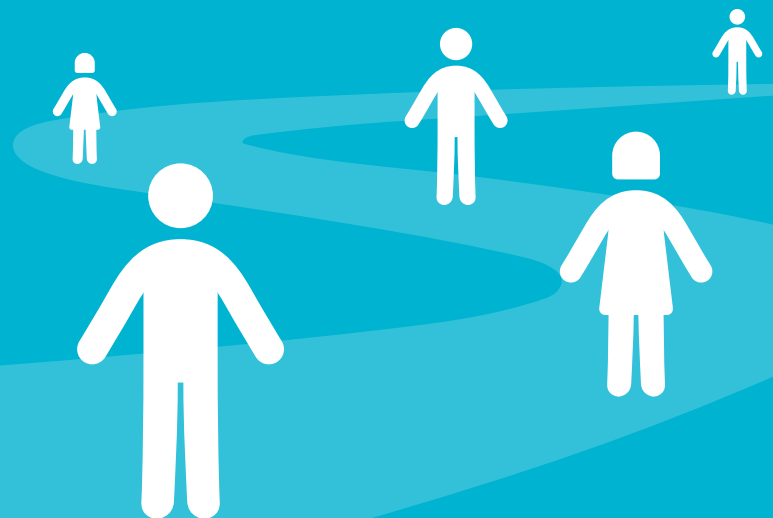
Advancing Stoma Care Services: evidence-based proposals for a best practice pathway

In the UK, an estimated **160,000–205,000** people live with a stoma and **21,000** people are thought to require stoma formation surgery each year.^{1,2} Various National Health Service Foundation Trusts have each developed their own stoma care management pathways covering the pre-operative period, hospital care, returning home and life with a stoma.^{3,4} However, they may not reflect recent evidence-based findings, and there is still no national, standardised, comprehensive stoma care pathway that all Integrated Care Boards can use.

A fully integrated stoma care pathway would:

- be based on, and consistently followed according to, a set of evidence-based guidelines or standards that ensure patients receive consistent, high-quality care regardless of where they receive treatment
- include a structured approach to treatment, management and follow-up provided by a multidisciplinary team

A cohesive and holistic approach to stoma care is needed that also incorporates the prevention and health inequalities agenda promoted by the NHS Long Term Plan.⁵ Preventive public health helps reduce the burden of healthcare in the longer term and ensures patients can access the right care in the right place at the right time.



The unmet need

A national, standardised, evidence-based, comprehensive stoma care pathway



What we did

We used keywords to select literature from the PubMed, CINAHL, Embase and Science Direct databases, and screened references of relevant articles to identify further potential studies. Case reports, guidelines, survey results and commissioned/ sponsored reports were also included. We limited the search to studies published within the last 10 years and written in English. Our review aimed to reveal unmet needs of individuals with a stoma during their pre- and post-operative journey, and to outline some criteria and considerations for an optimal standard stoma care pathway



What we found

There is significant variation in hospital and home stoma care services across the country.

The key unmet needs of people living with a stoma, and their care teams, are diverse and are influenced by the regional and local pressures that impact funding and subsequent service decisions. There is a clear need for continuous care interventions that integrate patient-centeredness, evidence-based practice, multidisciplinary teamwork and a drive towards continuous quality improvement⁶



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Key recommendations & considerations



Specialist stoma care nurses (SCNs)

- **SCNs should be the central figure in a care pathway for patients.** SCNs provide holistic care that caters for individual patient needs, with quantitative cost-effective and cost-efficient benefits⁷
- **There is a need for more high quality, specialised training in stoma care for the continuing professional development of SCNs,**⁸ whose expertise arises from a combination of formal education and experiential learning⁷



Patients

- **People living with a stoma should receive accessible information at all stages of their care,** and access to essential education through SCNs, web-based resources, patient organisations and peer support groups should be improved^{6,17-19}
- **Patients need urgent access to SCNs when necessary.** Prompt intervention can prevent or minimise stoma complications, avoiding the need for more expensive treatment and thereby reducing the healthcare burden^{6,20-22}
- **Patient activation and patient self-care facilitates improvements, helps adjustment to the new condition, increases feelings of empowerment, and reduces negative outcomes.** There should be a balance between promoting independence, ensuring regular follow-up, and providing flexible and patient-centred access to care^{6,23}



Flexibility of care provision

- **After discharge, patients should have regular reviews and monitoring** to ensure they receive care appropriate to their needs and preferences^{6,9}
- **A variety of modalities for follow-up should be offered,** including patient- and SCN-led options, to ensure equitable access and continuity of care¹⁰
- **Multi-modal education that accommodates cultural and demographic factors** can facilitate patient empowerment, with positive prognostic outcomes and reduced healthcare burden¹¹
- **Patient-informed product choice helps mitigate physical and psychological impacts** of living with a stoma^{6,12}
- **Stoma management must be dynamic:** stoma care needs change during a patient's lifespan⁸
- **Telemedicine, virtual clinics, email, web- and text-based services** should be considered where appropriate^{6,13-16}



Additional priority actions

1. **Strategic decisions about service delivery must increasingly be made at the local and regional levels** for improved outcomes⁶
2. **Product decisions should ensure that the type and quantity of product supplied is in line with patients' needs**⁶
3. **Commissioners and managers should ensure appropriate resourcing** to meet staffing requirements for the stoma team, with regular meetings of the leadership^{24,25}
4. **A registry for stoma patients should be created and should allow self-reporting:** registries have the potential to improve or redesign stoma care, enhance patient inclusivity and engagement, and facilitate clinical practice and research, healthcare utilisation and product innovation²⁶⁻²⁹

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