

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

Rapid appraisal of the evidence

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Introduction

Stoma surgery is primarily performed to treat cancer or inflammatory bowel disease (IBD), or to resolve obstructions or diseases of the bowel or bladder. Stoma formation is intended to improve quality of life (QoL). However, it poses considerable challenges to the patient and caregivers alike. 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} Exact numbers are not known due to the lack of good quality recording and documentation. Compounding this information gap is a significant number of ostomates who do not attend a regular stoma review and can be lost to follow-up.³

Clinical pathways are tools used to guide evidence-based healthcare.⁴ They translate clinical practice guideline recommendations into clinical processes of care, with consideration given to the unique culture and environment of a particular healthcare institution. However, although various National Health Service (NHS) Foundation Trusts across England have independently established management flowcharts covering four phases of stoma care – pre-operative, in-hospital, returning home and life with a stoma – there is still no nationwide standardised fully integrated stoma care pathway that Integrated Care Boards (ICBs) across the country uniformly adhere to. The current pathways are based on the standards set by the Association of Stoma Care Nurses United Kingdom (ASCN UK)⁵ but are becoming outdated and may not reflect recent evidence-based findings.

A truly comprehensive 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. Such a pathway would be implemented at the organisational level, with a structured, collaborative approach to treatment, management and follow-up from the multidisciplinary team.

According to the World Health Organization, integrated care service is a method of improving people-centred health systems by offering comprehensive, high-quality care across a lifespan, tailored to the needs of both the population and individuals. It is delivered by a coordinated team of healthcare providers across different settings and levels of care, and managed efficiently using the best available evidence to ensure optimal outcomes and efficient use of resources. Feedback is used to continuously improve performance and address the root causes of illness through inter-sectoral and multi-sectoral actions to promote overall wellbeing.⁶

It is time to build on best practices with a cohesive and holistic approach, that also incorporates the prevention and health inequalities agenda promoted by the NHS Long Term Plan.⁷ 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. This goal highlights the need to establish a standardised, integrated pathway for stoma care.

This rapid appraisal of the evidence covers a selection of literature with the aims of highlighting the unmet needs of individuals with a stoma during their pre and post-operative journey and outlining the essential criteria for designing an optimal standard stoma care pathway.

The appraisal is organised into five sections:

1. The current situation of stoma care nurses (SCNs) and stoma care in the UK. The evolution of training and education, the role of SCNs, and an examination of current models of stoma care delivery.
2. The unmet needs of existing stoma care pathways, organised into six key themes: access to care and health equity, patient activation and self-management, clinical standards, education provision, psychological burden and psychosocial impact, and changes in response to COVID-19.
3. Evaluation of several 'best practice' stoma care pathway case studies, and establishment of the criteria required for a stoma care pathway, which are organised into four key pillars: quality of care, costs, patient experience and health equity, and efficient improvement in clinical outcomes.
4. A summary of the key recommendations for standardised stoma care delivery.
5. The case for an informed, evidence-based approach to stoma care delivery. An examination of existing pathways in stoma care and IBD, and proposals for the future, plus inclusion criteria and additional factors that a stoma care pathway would require.

Methodology

This rapid appraisal of the evidence uses a selection of identified literature, directed by keyword search, and a set of grey literature accrued over the past decade, to identify the evidence to enable the essential components of a stoma care pathway to be explicated.

Search strategy: A comprehensive search of the PubMed, CINAHL, Embase, and Science Direct databases was performed using a combination of keywords related to stoma care service delivery and unmet need. (stoma care, specific unmet needs, and healthcare inequities). Further potential studies were identified through screening references of relevant articles. The search was limited to studies published in the last 10 years and written in English. In addition, case reports, implementation guidelines issued by regional facilities, survey results and reports commissioned or sponsored by several stakeholder companies, institutions and organisations were also included.

The following search terms were used singly or in combination in all fields: “accessories”; “acute care”; “adjustment disorders”; “anticipatory education provision”; “appliance”; “aids”; “body image”; “body profile”; “clinical standards”; “colostomy”; “community nursing”; “continent diversions”; “continuous care”; “continuous professional development”; “COVID-19”; “cultural diversity”; “culturally sensitive counselling”; “depressive disorders”; “developmental stage”; “face-to-face”; “flange”; “follow-up”; “health-care delivery”; “health-related quality of life”; “home-based”; “hospital-based”; “ileostomy”; “incidence”; “interventions”; “mental health”; “nursing-led education program”; “obesity”; “ongoing education provision”; “ostomates”; “ostomy”; “patient activation”; “patient education”; “patient rights”; “patient self-management”; “patient-initiated follow-up”; “peer-based support”; “peristomal skin complications”; “peristomal skin”; “physiological problems”; “post-acute care”; “post-discharge care”; “post-operative”; “preoperative care”; “pre-operative”; “prevalence”; “product choice”; “product selection”; “professional training”; “psychological burden”; “psychological problems”; “psychosocial adjustment”; “psychosocial impact”; “psychosocial wellbeing”; “quality of life”; “regional database”; “registry data”; “registry”; “SCN”; “self-efficacy”; “sexual dysfunction”; “sleep disorders”; “social problems”; “social support”; “standards of care”; “stoma appliances choice”; “stoma appliances”; “stoma care nursing”; “stoma care”; “stoma complications”; “stoma formation surgery”; “stoma formation”; “telecare”; “telecommunication”; “teleconsultation”; “telephone contact”; “urostomy”; “web-based support”; “sleep quality”.

Inclusion criteria: No formal search criteria were applied.

Outcomes of interest: The main outcome of this rapid appraisal of the evidence included the identification of evidence of the unmet needs of patients with a stoma and the impact on patient and carer self-efficacy or QoL. Other outcomes included individual and treatment-related factors adversely affecting the QoL, for which studies published between 2013 and 2023 were considered. These add to a comprehensive evaluation of the current state of knowledge on the unmet needs of individuals living with a stoma and help identify potential opportunities for improvement in addressing these needs. The findings of this appraisal will inform the development of a standardised, integrated pathway for stoma care, taking a cohesive and holistic approach that incorporates the prevention and health inequalities agenda promoted by the NHS Long Term Plan.

Study design and language restrictions: A wide range of literature was included: studies with prospective, cross-sectional, and descriptive designs; randomised clinical trials; studies with retrospective designs; case studies; conference abstracts; letters to the editor; literature reviews; and systematic reviews and meta-analyses. Grey literature included policy statements and issues papers; research reports produced by government departments, academics, business, and industry; guidelines; white papers; preprints; working papers; and conference proceedings. These were identified via a grey literature search plan with four different searching strategies: grey literature databases, customised Google search engines, targeted websites, and consultation with contact experts. Only studies published in English were included, and no geographical restrictions were imposed.

Data extraction and synthesis: Characteristics of the included studies and attributes of participants were not reviewed against any specific criteria. The extracted data were examined to identify common themes and trends related to the unmet needs of individuals living with a stoma and the role of healthcare providers in addressing these needs.

A note on the clinical studies cited in this rapid appraisal of the evidence

Many of the studies presented here are small-scale. The literature search identified very few that included large numbers of patients, highlighting the urgent need for more research in the field of stoma care. The Best Practice Pathway Project Advisory Board and Project group is committed to addressing these information gaps to improve the lives of people who have a stoma and to support the wider stoma care community.

Section 1: SCNs and stoma care in the UK: the current landscape

Professional training and education

The first training course for SCNs was held in 1973.⁸ In the 1980s, the English National Board (ENB) developed two national courses specific to stoma care, a basic course for novice, and a longer, more advanced course for more experienced SCNs

The training moved to university-level diploma and degree qualifications around 2012. To meet the standards set by the ASCN UK, nurses must complete an educational programme at a degree or master's level and pass clinical practice and competency evaluations. Although there is no further specialised stoma education required, nurses must complete 35 hours of continuing education every three years to remain registered with the Nursing and Midwifery Council (NMC).⁹

However, as many continuing education events are principally theory-based with an occasional practical element, they do not cover all of the learning requirements to ensure competence in a clinical setting. There are aspects of stoma care, for example stoma siting, which also require training in the workplace. A nationwide survey conducted to understand the educational needs of SCNs showed that the main reasons for taking courses were professional development, enhancing clinical knowledge and improving patient care. The SCNs' individual needs were very varied due to the wide range of their clinical experiences, physical location and previous education. However, respondents generally wanted high quality, tailored content, with a clinically-relevant presenter.⁹

The value of nurse-led stoma care

As experienced general nurses and expert specialists, SCNs offer a comprehensive approach to holistic patient care, bringing knowledge from both formal education and experiential learning.¹⁰

In outlining what a good stoma care support service looks like, the *Excellence in Stoma Care* guideline shows how SCNs add value by:¹⁰

- Providing expert quality care with efficiency and reduced costs
- Providing expert advice and clinical leadership for integrated care within a case management role
- Monitoring other aspects of patient care
- Taking a holistic approach, with physical and psychological care for the individual's needs
- Bringing care closer to home and reducing the burden of long-term conditions
- Preventing stomal complications
- Achieving cost efficiency savings through expert product knowledge and reduced prescribing costs
- Facilitating timely discharge and preventing delayed discharge and potential readmission
- Educating patients and carers, and staff, students and colleagues on the ward

The case of the Nurse-Led Stoma Care Clinic at Royal Glamorgan Hospital and Ysbyty Cwm Rhondda showed that an ~£86K investment (the sum of staff running costs, staff travel costs and stoma appliance costs) annually resulted in productivity savings of £200K for the healthcare system in 2015. Nurse-led care also provided an evidence-based structured follow-up programme that reduced the rate of peristomal skin complications (PSCs) from 48% to 19.6%. This improved patient and family care while also enhancing

the overall quality of the organisation through the education of healthcare professionals and the delivery of an efficient and patient-centred clinic that met key targets and guidelines.¹¹

SCN value has been demonstrated further using patient surveys: patients report greater satisfaction with care when SCNs are involved, because of improved access to coordinated care, and more education and support for families and carers.¹²

SCN-led services support patients to maximise their rehabilitation while providing numerous cost-effective and cost-efficient benefits.¹¹ A comprehensive stoma care pathway, led by SCNs, must meet national framework standards to address the clinical and social needs of patients living with long-term conditions.¹⁰ This includes community stoma care: SCNs can assess the patient and their home circumstances to help prevent falls, provide pre-operative stoma education in the patient’s home, monitor the patient’s nutritional status post-discharge, carry out telephone consultations, help with product selection, support psychosocial wellbeing, and ensure continuity of care to reduce hospital readmissions.^{11,13}

Current stoma patient management and care delivery

Delivery of stoma services is done at a local and regional level,⁵ which has led to inequities in the delivery of services across the UK. *The voice of ostomates: an exploration of stoma care in England (2021)*,^a a nationwide survey of people with stomas, highlighted the significant variation across England in stoma care received and services available in hospital and at home. Although some patients rated aspects of their care as excellent, others provided comments showing that clinical care remains suboptimal for many:¹⁴

- Didn’t receive visits from the stoma team, or received visits that were irregular, short and untimely
- The nurse did not allow sufficient time for their care needs, or did not have the training to help with the stoma-specific issues that arose
- The SCNs were not available out of hours, at weekends, or during bank holidays
- Lack of counselling to help cope with the body changes and demands of having a stoma

An audit by Northampton ICB found that:¹⁵

62% of patients had not seen a nurse about their stoma in over 2 years	21% of stoma prescribing costs were for supporting products that were not contributing to improved outcomes	35% of patients reported sore skin	62% of patients reported leakage	63 products were stopped when found to be inappropriate to needs/wastage
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^a n=2504 total responses; 41 questions on demography, interactions with the SCN, stoma products and delivery service, and personal experience¹⁴

Stoma care products are supplied by FP10 prescription and dispensed via community pharmacies or dispensing appliance contractors (DACs) that manage and deliver products directly to patients. However, Rotherham ICB found that in some cases patients were:¹⁵

- Having to modify equipment
- Receiving equipment they didn't want or order
- Remaining housebound due to poor continence equipment

An estimated 80% of patients experience equipment-related problems (including skin irritation/soreness, blockage, leakage, difficulties with attaching and removing) at some point.¹⁶⁻²⁰

Recent changes to the NHS Supply Chain model for procurement were introduced under the Department of Health Procurement Transformation Programme.²¹ The Collaborative Procurement Partnership (CPP) is responsible for the procurement of products in several therapy areas including stoma care. Clinical teams work with clinicians, end users, and suppliers to ensure patient safety standards.²² NHS England's commissioned guide, *Delivering Excellence in Stoma Care* (2020), highlights four common issues with stoma product delivery:^{3,22}

1. While company-sponsored SCNs operate independently of the sponsor company, patients may switch to sponsored products upon discharge if they receive support materials from the sponsoring company, leading to increased costs in primary care and limited patient choice. These products may not be listed in local formularies or have been assessed for cost-effectiveness
2. Patients may be prescribed stoma products in the hospital that they cannot access in the community due to formulary or cost issues
3. Over-prescription by general practitioners (GPs) leads to oversupply and wastefulness
4. DACs ordering products before a prescription is issued can result in patient disappointment and waste

Prescribing appropriate products and managing complications requires ongoing clinical assessment. Patients should be reviewed annually to ensure that they are managing well and using the right equipment, and have no issues such as infections needing clinical care.¹⁵ *Delivering Excellence in Stoma Care* recommends the development of a Stoma Support Service and a Prescribing Hub for effective prescription management and control so that patients receive tailored product decisions, including product type and quantity. Other recommendations include:¹⁵

- A single stoma support service across both primary and secondary care settings
- The use of NHS-funded nurses vs industry-sponsored nurses where possible
- A clinically approved formulary between ICBs and providers
- SCN-approved prescription changes via a patient partnership
- ICB should insist that acute trusts buy stoma products from the NHS supply chain or via a contract that has been awarded the public sector procurement regulations, and to which the ICB has had input, even if they are not a stakeholder.

Other methods of Stoma Prescription Service approaches include those implemented by Cheshire and Merseyside ICB, which takes a DAC-sponsored approach.^{23,24} It offers expert advice, product changes and supporting products usage. This service is provided outside of the commissioned community continence service and has enhanced the patient experience by streamlining how products are ordered. Patients

Speak to a trained call centre operator who carries out a screening checklist before ordering products; those identified as experiencing issues are scheduled in for a call with an SCN for advice. Patients may receive a face-to-face review if necessary.²³

It is recommended that these actions are integrated into the stoma care pathway to improve the patient experience and the quality of care, and reduce cost.

Coming changes to the NHS

The NHS continues to face many challenges in areas such as capacity, finance, workforce and integration. Changes in three major areas will impact future industry engagement with the NHS.²⁵

Policy changes and new stakeholders

The updated planning guidance includes reduced central monitoring with fewer targets (35 instead of the previous 130). It has three central aims: to improve activity levels, reducing the backlog and waiting times; to continue to implement the NHS Long Term Plan; to continue to drive forward service transformation. The Hewitt Review of integration may result in devolved authority, accountability and commissioning, which is likely to happen in stages as different services are at varying levels of readiness for this change. The Long Term Plan is to be refreshed, with a focus on areas including more joined-up community-based and preventative care, transformed access to urgent, emergency and planned care, and tackling health inequalities – all particularly relevant to the stoma care community.²⁵

Finances and commissioning

It is likely that yet more “efficiencies” will be required from the systems and services that make up the NHS to try to cope with inflation and increased prescribing costs. For example, emergency admissions are costly and more could be done to reduce those arising from manageable long-term conditions. Industry partners could add value by demonstrating benefits for staff and time pressures and reduced system costs.²⁵ Despite proven cost efficiency and cost effective service delivery, financial and workforce challenges mean SCN’s are facing down banding at a time when older SCN’s are retiring.

Pathways and service redesign

Cost and workforce constraints combined with growing demand for services are resulting in a need for service redesign. Drivers of pathway change include requirements for more patient involvement, increased home-based care, improved diagnostics, reduced unnecessary referrals, better patient access, and better health equity, and the technological advances that allow remote consultations and monitoring.²⁵

Section 2: A thematic exploration of unmet needs: establishing an evidence base

The diverse unmet needs of people living with a stoma can be grouped into seven overarching themes.

Theme 1: Access to care and health inequities

The weakest link in community services for the rehabilitation of patients with stomas is the lack of equitable access and continuity of care. Good communication and teamwork among district nursing teams are vital for supporting patients through their stoma surgery recovery.²⁶⁻²⁸ Continuing care is recognised as a key element of high-quality health services and is considered essential to patients.^{29,30} This includes all elements of stoma care that help patients live independently after discharge and resume a normal life in a shorter period.³¹

Patients can receive comprehensive and continuous care from SCNs throughout the post-operative recovery period.³¹ This is essential to ensure that patients are discharged from the hospital with education on stoma care, which promotes a positive QoL.³² The effectiveness of different continuous nursing care interventions varies.³³⁻³⁵ The ideal approach and level of stoma care needed remains unclear due to a lack of standard protocols and comprehensive research analysis.³¹

A meta-analysis evaluating the effectiveness of continuous care by SCNs versus routine care has demonstrated improved health outcomes and care satisfaction in patients with stomas (9 studies, 1134 participants).³¹ Stoma self-efficacy and QoL significantly increased one month after discharge; stoma adjustment (the process of adapting to the new challenges) and care satisfaction also showed a trend toward improvement, while stoma complications decreased significantly. These align with previous findings in a range of chronic diseases (e.g., osteoporosis,³⁶ dementia,³⁷ and alcohol use disorders³⁰).

Given the variability in the effectiveness of continuous care interventions, an integrated continuing care programme should include five key elements: patient-centeredness, continuity of care, evidence-based practice, multi-professional teamwork, and continuous quality improvement. An adaptable approach that allows for variation in intervention intensity, frequency, and duration is crucial.³¹ This is supported by a UK CPP survey, which highlights the differing needs of individuals with a stoma and should be a key consideration in stoma care planning and delivery.¹⁴ Therefore, future stoma care pathways must provide equitable and continuous care, with a variety of follow-up options and patient-centred branches, aligned with the new statutory guidance for working with patients and communities.³⁸

Hospital- and home-based visits

The voice of ostomates: an exploration of stoma care in England survey found significant variation in service provision and patient experience outcomes, including the frequency of face-to-face or telephone contact, and long-term support needs. Although 47% of patients receiving home-based care had positive experiences, 40% reported negative experiences. The survey highlighted the need for long-term physical and psychological support beyond initial recovery from surgery. The provision of visits, ease of patient-directed access, and quality of care were found to be linked to patients' perceived inadequate psychological support.¹⁴

In the hospital setting, 40% stated 'everything was excellent'; however, 8% provided candid and detailed negative personal experiences and reflected limitations in visits, psychological care, specialist stoma

knowledge, and products. Among them, physical care and information-sharing in the hospital were raised as positive elements of hospital-based care.¹⁴

These experiences will be further explored in detail in the following sections. Given the variation in the preference and experience of care, it is therefore necessary to enable greater flexibility via a discharge model that best meets local needs, including an approach known in England as 'discharge to assess'.^{39,40} This complements the overarching conclusion that equitable access and continuity of care in a future fully-integrated stoma care pathway involves a flexible approach to follow-up review.¹⁴

Theme 2: Patient activation and self-management

'Patient activation' is the knowledge, skills and confidence that individuals have in managing their own health.⁴¹ Highly activated patients understand their role in the care process and are more likely to engage in positive health behaviours and manage their health conditions effectively, while those with low levels of activation are less likely to take an active role in their health and may have difficulty seeking help and following medical advice.⁴¹ Understanding the drivers of patient activation can allow better tailoring of patient support and interventions.

Research indicates that patients with higher levels of activation have better health outcomes and care experiences.⁴² A study of patients with moderate to severe depression found that level of patient activation was a predictor of remission or improvement within 12 months. Patients with higher levels of activation were also more likely to adopt healthy behaviours, such as smoking cessation and weight loss, and more likely to attend screening tests for cancer.⁴³

To understand the effect of patient activation in the UK, 13-item Patient Activation Measure (PAM) questionnaires were sent to an existing cohort of NHS England-identified patients aged 65+ with long-term conditions.⁴⁴ The PAM questionnaire comprises 13 statements that gauge the patient's beliefs about healthcare, confidence in managing health tasks, and self-assessed knowledge of their condition, using a response scale of 1 to 5 (1 = "strongly disagree", 4 = "strongly agree", 5 = "not applicable" [treated as missing data]). The patient must answer at least 10 questions, and the final score ranges from 0 to 100, where higher scores indicate greater patient activation.⁴⁵ Of 4,377 participants, 15% reported PAM level 1, 16% level 2, 45% level 3, and 25% level 4 at baseline. Depression was the strongest factor associated with patient activation, followed by older age, retirement, poor health literacy, health-related quality of life (HRQoL), social support, and number of comorbidities. Patient activation scores were relatively stable over 6 months ($r = 0.43$), but almost half of the participants changed their activation level during that time, with few variables predicting the change. The researchers concluded that levels of patient activation in this population vary, with low activation observed in depressed, older, retired patients with poor health literacy and those lacking social support. If patient activation proves to be a valuable concept for targeting interventions, these findings may aid in identifying patients who require activation and suggest potential methods for improving activation levels to enhance outcomes.⁴⁴

A three-year, randomised trial examined the effect of adding a telehealth-based Ostomy Self-Management Training (OSMT) programme to usual care (standard stoma care, written materials, contacts for support) for cancer survivors and their carers.^{†46,47} The aim was for the patients to attain self-efficacy, with a focus on building self-management skills and confidence in managing stomas through goal-setting,

[†] n=216, of which n=118 completed the 6-month survey (55 in the OSMT group and 63 from the usual care group)⁴⁷

problem-solving and mutual support. The OSMT was delivered via group videoconferencing, with three survivor sessions, a carer session, and a booster session for both survivors and carers, led by trained SCNs and peer stoma patients.^{46,48-50} Early findings suggest that patients benefited from the OSMT, reporting fewer challenges in psychological wellbeing, social wellbeing, spiritual wellbeing, ostomy-specific issues, and healthcare issues than patients who received only usual care.⁴⁷ This illustrates the need for long-term care and support for all cancer survivors with a stoma.^{47,51,52}

These findings complement those of an earlier pilot study evaluating the effectiveness of a five-session stoma self-care curriculum aimed at improving HRQoL and self-management for cancer survivors with stomas. Thirty-eight participants, mostly with a history of rectal or bladder cancer, took part in the study and rated the programme highly. Results showed significant improvements in patient activation, self-efficacy, total HRQoL, physical and social wellbeing, and reduced anxiety by follow-up. The programme can help cancer survivors adapt to their stoma and its implementation in the community would be beneficial.⁵³

Patient-initiated follow-up

Patient-initiated follow-up (PIFU) gives patients control over their post-discharge care, allowing them to be seen quickly when needed and eliminating clinically low-value appointments. The NHS 2022/23 operational planning guide aims to accelerate the shift towards this more personalised approach, reducing outpatient follow-ups by at least 25% compared to 2019/20 levels and expanding the uptake of PIFU in all major outpatient specialities (moving or discharging 5% of outpatient attendances to PIFU) by March 2023.⁵⁴ PIFU implementation in outpatient services should be locally led and supported by strong leadership from the system and trust.⁵⁵

There is no research examining the effect of PIFU in stoma care. Current practice places the SCN at the helm of care. The *Excellence in Stoma Care* guideline offers evidence-based recommendations for delivering consistent and appropriate stoma care services.¹⁰ This guideline, funded by Coloplast and independently authored, is based on the NHS Outcomes Framework and is intended to inform commissioners of cost-effective ways to provide the best possible care for stoma patients. Additionally, the complementary document *Stoma Care Nurse Specialist* (Virgin-Elliston et al, 2019b) highlights the positive impact of SCN interventions.⁵⁶ Both guidelines position SCNs as responsible for identifying and referring patients to other specialists such as psychologists and dermatologists as needed, to address altered body image, social exclusion, anxiety and other related issues.^{10,56}

The preferences of stoma patients are varied (for example *The voice of ostomates: an exploration of stoma care in England* survey found that 40% wanted an annual review, but 28% did not want any routine follow-up¹⁴) and a standard stoma care pathway should aim to accommodate these differences. As such, PIFU is a concept that should be considered in tandem with the SCN-led approach.

Theme 3: Clinical standards: follow-up and complications

Stoma complications such as leakage, PSCs, hernia, infection, stoma retraction, ischaemia and prolapse can occur early, within one month of surgery, or late, after the first post-operative month.¹⁸ The reported incidence ranges between 2.9% and 81%; there is a negative impact on patient QoL and an added financial burden on the healthcare sector.¹⁸

PSCs are the most commonly reported morbidity.⁵⁷⁻⁵⁹ Over 80% of people living with a stoma will develop PSCs within two years of surgery.⁶⁰ The majority of these are related to leakage due to a poorly secured

pouch.⁶¹ The development of PSCs during the 120 days following stoma formation is associated with hospital readmission and longer lengths of hospital stay.^{62,63} Moreover, leakage or PSC of any severity are associated with a significant reduction in HRQoL – stoma patients have even expressed willingness to trade remaining life-years for reduced stoma complications.⁶⁴

Additional problems may develop, including excessive time committed to stoma management, damage to clothing, stigma and social embarrassment, and limited participation in interpersonal and social activities.⁶⁵⁻⁶⁷ Therefore, confidence in producing and maintaining a firm, leakage-free pouch seal from application to removal is central to successful patient self-management.⁶¹

Despite the knowledge and understanding of all these potential complications, the level of support and follow-up varies across the UK; even where individualised care plans are in place, patients may be overlooked and suffer as a result.⁶⁸ An audit conducted in 2014 demonstrated a range of follow-up reviews carried out by SCNs; these varied between one and ten visits in the first year following surgery.^{†69} The ASCN advocates long-term support for patients,⁵ as not all problems occur within the first year. Incidence of complications is highest during the first five years after stoma creation⁷⁰ and so an annual evaluation is recommended for ongoing preventive care, which includes making any necessary changes to the stoma pouching system and providing continuous emotional support.⁷¹

SCNs are critical to management of stoma complications: for example, lack of access to SCNs places patients at the greatest risk of developing PSCs. This extends to the pre-operative phase. Many issues associated with poorly sitting stomas, such as leakage, PSCs or the discomfort of having an ill-fitting appliance, are seen in patients undergoing emergency surgery or in those whose stoma site was not selected by the SCNs. Patients whose site was selected by SCNs were found to suffer fewer complications than those whose site was selected by other healthcare professionals;⁷²⁻⁷⁴ literature suggests that stomas should ideally be placed by an SCN to minimise the risk of complication.⁷³ Indeed, the role of the SCN in stoma site identification has been highlighted in the *High Impact Actions for Stoma Care* report, which reveals that the ‘textbook definition’ of the optimal stoma site is rarely attained, and appropriate selection requires collaboration between the surgeon, the SCN and the patient.¹³

Without SCNs, minor issues with stoma fitting can lead to an increased use of products and supporting products, extended hospital stay, continued reliance on community nursing services and more expensive treatment.^{13,75} Audits from 2010 to 2012 support the value of SCN-led stoma care clinics, with a 40% reduction in the rate of PSCs.¹¹ Moreover, SCN-led approaches were predicted to produce an estimated 90% cost reduction to the NHS over two years.¹¹ Effective PSC management was estimated in 2015 to have saved £157,996 over two years. Hence, periodic check-ups and follow-up care with an SCN can address the need for long-term, supportive care for patients and their families.⁶⁵

SCNs have been central to the understanding of new PSC’s and development of a risk factor model and (Leblanc K et al, 2019,Hansen et al, 2022). Identified risk factors were grouped under three main areas. Examples from each include:^{76 (a) (b)}

- Healthcare System – lack of stoma marking, lack of best practice guidelines, access to post-discharge programmes, level of education in stoma care of the healthcare professionals involved

† n=16 SCNs; outcomes of 1027 visits were recorded and analysed⁶⁹

- Individual with a stoma – peristomal body profile, stoma type, impact of concurrent treatments such as immunosuppression, ability to self-care, available support network, standard of living
- Ostomy product solutions – fit to body profile, wear time, adhesive properties, range and type of product available

The risk factor model and the consensus management of medical adhesive related skin injury, have the potential to be included in guidelines for healthcare professionals and to be used as a tool in daily clinical practice.^{76(a,b)}

Reduced sexual function

When considering the impact of a stoma on the patient, there is often a focus on the physical changes, with less attention given to the psychological effects. Sexual problems have been little-studied,⁷⁷ and many patients with a stoma are not fully informed about the possible problems they may encounter, or about sexual counselling and appropriate medical treatment options.⁷⁸ Yet reduced sexual function is widespread and can negatively affect the QoL of patients with a stoma who can experience severe sexual dissatisfaction and dysfunction.^{78,79} The causes are determined by both psychological (deterioration in body image, lack of control, concern about the stoma) and physical factors (type of surgery, treatment, type of stoma).⁸⁰ There is a need for recognition of sexual problems by patients and healthcare staff, and different models (PLISSIT and 5A) have been developed to promote dialogue.^{77,81}

There are several validated questionnaires and interviews to assess sexual function but no specific questionnaire for patients with a stoma. Commonly used questionnaires for women include the Female Sexual Function Index (FSFI), Expanded Sexual Arousalability Inventory (SAI-E), Brief Index of Sexual Functioning (BISF-W); for men there are the International Index of Erectile Function (IIEF), the Brief Sexual Function Questionnaire (BSFQ), and the Brief Sexual Function Inventory (BSFI). The recommendations of a systematised review include creating a specific, standardised questionnaire for this population to help address the changes in sexual function that occur after stoma formation.⁸⁰ Available resources to improve sexual function include increased security and control of the stoma, specific recommendations for problems like decreased libido, vaginal dryness, pain or arousal disorders, and avoidance of pressure on the abdomen or stoma bag during intercourse.^{82,83}

A registry for people living with a stoma

Clinical registries collect patient data that can be variously used to describe the course of diseases or conditions, measure quality of care, monitor patient safety, assess the effectiveness of healthcare products and services, and examine costs.⁸⁴ An example is the role of registries in the management of familial adenomatous polyposis, where their original aim was to identify at-risk relatives and ensure their lifelong participation in the surveillance programme.⁸⁵ Although a national stoma registry would undoubtedly be useful, there is not one in the UK.⁸⁶

Other countries have stoma registry data that have been mined for large cohort studies to report long-term outcomes and to develop predictive models of stoma complications.⁸⁷ They have also been used to compare outcomes in patients with and without a stoma.⁸⁸ In Italy, the proof-of-concept SYSTEMIC (oStomY regiSTry prEdictive ModellIng outCome) project introduced a conceptually novel stoma registry tailored to aetiological investigations and prospectively improving patient-oriented outcomes. Information from 52 participants in the newly established registry was used to develop an algorithm for

predicting the onset of stoma complications. The resulting tool had moderate accuracy (70%) in identifying at-risk patients.⁸⁷

A regional database in Denmark, with 1,123 patients registered by 2013, contains information on PSCs, entered by stoma care clinicians at multiple collaborating medical centres. The database is fully operational and has a high rate of data completeness, and provides data about patients with a stoma from before surgery up to 12 months after surgery. It is used for professional learning, systematic assessment of care quality and benchmarking. In real terms, the database showed evidence of an increase in the adoption of the practice of stoma marking in elective surgery, which is known to have a significant impact on patients' post-operative QoL.⁸⁹

Finally, reported results from the now-closed United Ostomy Association Registry (UOAR), which was based in the United States (US) and Canada, describe demographics, stoma types, self-reported complications and QoL for a cohort of over 16,000 individuals. The UOAR data suggest that the number of ileostomies and colostomies has decreased in the last ten years; this could be due to new advances in surgical techniques alongside improved operative techniques for rectal cancer. The authors of the study further note that if the UOAR can make surgeons fully aware of a patient's stoma function after surgery, then a contribution will have been made by the registry. This is because quality construction of stomas can be ensured only when surgeons have complete knowledge about a patient's function post stoma surgery. Hence, a registry such as the UOAR evidences the utility of information and data provided and the significant contribution that registries can make in improving or redesigning stoma care.⁹⁰

It is important to note the limitations of the active stoma registries worldwide. They rarely capture data concerning the specifics of stoma products (e.g., manufacturer, type, stock number), making cost analyses difficult.⁹⁰ The inclusion of such parameters is therefore important in future patient registry approaches.

Registries have the potential to be SCN-led, as illustrated by the Danish National Patient Register. This is a major factor underlying the validity and completeness of the database and is attributed to the collaboration between SCNs. A registry that allows participants to self-report data could enhance patient engagement and promote a patient-centred focus. An example is the Observation Study of Ostomy Consumers (OSO) registry, which collects self-reported data on perceived unmet needs via repeated electronic surveys completed by adults with a stoma, in the US and UK. The OSO registry thereby provides a continuous data stream that can be mined to enhance understanding of the patient experience over time. This longitudinal overview can facilitate clinical practice and research, healthcare utilisation and product innovation.⁸⁸

Registries can have broad inclusion criteria that allow the participation of individuals who might not be eligible for clinical trials, giving a more accurate representation of real-world experiences. Willingness to participate in a registry is believed to be positively influenced by factors such as convenience, trust, and a desire to share experiences, which can lead to increased enrolment and retention rates.⁸⁸ Lee et al. (2016) held discussions with three focus groups (23 participants in total) to determine their views, motivations, and potential barriers towards participation in a registry, uncovering several key themes.⁹¹ These included the desire to help others, the ability to connect with others in a similar situation, the desire to gain a better understanding of their condition, and the opportunity to build a more comprehensive picture of their health between doctor visits.⁹¹ These reported outcomes provide a strong argument for a registry alongside a standardised, fully-integrated stoma care pathway.

Stoma care needs can change over time

When developing a fully integrated stoma care pathway, the dynamic nature of stoma management should be factored into service delivery.¹¹ Stoma care may change across a patient's lifespan: as the body contours change, the stoma pouching system may need altering, updating or changing.

Factors affecting stoma complications include age, gender, obesity, stoma type and body profile, stoma site, the reason for surgery, comorbidity, and, in the ageing population, frailty and cognitive impairment.^{13,18,58} Two of the most important are comorbidities and obesity.^{72,74,92} In obesity, excessive subcutaneous fat and abnormal skin folds increase the risk of retraction, which requires further surgery and revision to rectify.⁹²

The consensus advice of practice guidelines is that the patient's ultimate security and comfort is best achieved by assessing the patient's peristomal body and stoma profiles and selecting the best-suited product type.⁶⁰

Currently, product selection and management support is usually led by the SCN and based on multiple factors, including the person's body shape, skin integrity, stoma construction, stoma output and patient dexterity. A standardised, fully integrated stoma care pathway must be flexible enough to allow for variation in the needs of people living with a stoma.¹⁴

Continuing research into clinical outcomes

A recent publication highlights the need for, and value of, more research into all aspects of stoma care. Loop ileostomy is a common surgical procedure to allow downstream tissue healing, with the aim of re-joining the bowel approximately 12 months later. However, the reversal procedure is associated with up to 40% morbidity. Beamish et al (2023) looked at the possible factors that could be increasing the rate of complications.⁵ They found that tissue changes such as atrophy and fibrosis, length of time the temporary stoma was in place, and age of patient did not correlate with increased risk of complications. Instead, patients with reduced abundance of commensal bacteria were more likely to experience problems. The work also established that diversity of microflora did not correlate with higher risk. The authors concluded that future trials should work to optimise ways of reestablishing the microbiota in defunctioned bowel prior to reversal surgery.⁹³ This is just one example of how high-quality research can directly improve stoma care.

Theme 4: Education provision

The ability to manage stoma care is a recognised predictor for positive adjustment to life with a new stoma.⁶⁵ Results of an international consensus and studies support the SCN's role in providing post-operative follow-up care to stoma patients: support, information and resources reduce complications.^{10,94} SCNs contribute to the adaptation process to a stoma and thus improve long-term outcomes, overall QoL and better patient-recorded outcomes.^{10,13,61,70,95}

A systematic review of ostomy care pathways found that including preoperative education and counselling on the surgery, daily living and self-care, and post-operative education on stoma self-

⁵ Clinical data for the total duration of hospital stay was obtained from 35 patients (from a cohort of 44 eligible patients) undergoing loop ileostomy reversal surgery.⁹³

management and possible complications, may contribute to improved patient outcomes.⁹⁶ This is in line with prior studies that concluded that education is a central component of stoma care.⁹⁷

The effects of such anticipatory and ongoing education provision are demonstrable. Patients in receipt of appropriate education present fewer complications, fewer hospital readmissions and higher QoL scores.^{98,99} Follow-up visits in the community promote independent patient self-care and successful adaptation.¹⁰⁰

The voice of ostomates: an exploration of stoma care in England survey highlighted the need for greater information provision – particularly, information that could help people living with a stoma manage independently, such as dealing with skin soreness, available products and diet.¹⁴ Patient-centred and self-care-focused post-operative education decreases the rate of readmission.¹⁰¹ Wu et al. (2007) suggested that people living with a stoma who have at least secondary education have higher self-efficacy.¹⁰² A higher level of education has also been associated with improved sexual function in people with a stoma.¹⁰³ It is important, therefore, not only to provide information but also to empower the people living with a stoma to access it, such as via an official stoma support group websites. Moreover, patients receiving nurse-led follow-up reported favourably on their outpatient experience in terms of information and support, helping them understand what to expect and what was ‘normal’ in their situation.^{**104}

Further studies have corroborated the importance of discussion of education in the pre-operative phase, addressing how patients will adapt and integrate their stoma. Other forms of education delivered in the post-operative phase may include post-surgical restrictions on diet and exercise with the projected advancement of diet and activity in acute care. Moreover, quality-of-life indicators covering physical and emotional adaptation, activities of daily living, diet and sexuality are all important elements that may be included in the pre- and post-operative educational process.^{100,105-107} Hence, patient education across all stages of care should be incorporated into a standardised, fully integrated stoma care pathway.

Product choice and selection

Adequate discharge planning is needed to ensure that people living with a stoma have appropriate supplies.¹⁴ In line with this, international consensus for the development of practice guidelines noted the need to select and change products as necessary in the event of stoma or skin complications.⁶¹

Moreover, the consensus of stoma experts highlights patient education and autonomy as critical factors in effective stoma care.⁶¹ Significant causes of psychological and physical impact on patients are insufficient product supplies and appliance failure.¹⁰⁸ Post-operative product selection support, education and guidance from the SCN may minimise the risk of appliance failure and the aforementioned downstream consequences.¹⁴

The current view of product choice and selection suggests patients are not offered a choice of dispensing services and sometimes experience restrictions when choosing a product. With regards to the choice of obtaining products (including prescribing) and customisation, *The voice of ostomates: an exploration of stoma care in England* survey revealed that 93% of participants received their stoma products from a DAC; 55% did not believe they had the autonomy of choice regarding where to obtain their stoma products, suggesting SCN-led selection of the DAC.¹⁴ This is important as the consequences of insufficient

^{**} Thematic analysis of in-depth interviews conducted with 27 patients who had completed treatment for colorectal cancer.¹⁰⁴

product supplies and appliance failure can have a significant psychological and physical impact on patients.¹⁰⁸

Regarding product choice and availability when transitioning from the hospital to home-based care, people living with a stoma commented that prompt delivery of, easy access to, and unrestricted choice of the product were important needs to be fulfilled.¹⁴ The physical and psychological impacts of poorly selected stoma appliances, combined with the new statutory guidance that mandates working in partnership with people and communities supported, indicates that patient-informed product choice and selection must feature prominently in future fully integrated stoma care pathways.³⁸

Inclusive counselling, care and educational instruction

Religion, ethnic grouping, age, gender, sexuality and learning disabilities can affect how stoma care is approached and supported. A review of diversity in stoma patients indicated that the cultural and ethnic needs of patients must be considered to provide sensitive and appropriate treatment.¹⁰⁹ This also ensures that healthcare professionals uphold the principles enshrined in the 6Cs framework – care, compassion, competence, communication, courage and commitment.¹¹⁰ A focus on diversity and inclusivity would also allow the SCN to empower patients to regain confidence and their QoL.¹¹¹

Other factors to consider when developing a fully integrated stoma care pathway are language barriers, learning difficulties, stoma siting requirements, issues around excretion and dietary needs. The adaptations to stoma care delivery are summarised by Cooper-Gamson (2017); the article expands on the need for cultural awareness in stoma care under the guidelines set out by the NMC and ASCN.¹⁰⁹

Learning disabilities and dementia may require modification of educational provisions to accommodate alternative teaching strategies and also dictate the inclusion of caregivers and family support in the overall process.¹¹²

A fully integrated stoma care pathway must incorporate diversity and inclusivity considerations for provision of appropriate care.

Theme 5: Psychological burden and psychosocial impact

The fifth theme, arguably the most important, is the psychological burden and impact of living with a stoma, and the current gaps that must be bridged when designing a fully integrated stoma care pathway.

Living with a stoma negatively affects overall QoL.¹¹³⁻¹¹⁶ The presence of a stoma can be associated with a variety of complex problems including altered body image, stool or urine leakage, social isolation, stoma-related dermatitis, sexual dysfunction, psychological distress and perceived loss of control.¹¹³⁻¹¹⁵ Changes in body image can lead to feelings of mourning for altered or lost body parts; for some, these psychological effects can be greater than the physical effects.¹¹⁷

The proportion of people living with a stoma who experience clinically significant post-operative psychological symptoms may be as high as 20%,^{115,118} and anxiety and depression are predominant areas of concern. The level of the patient's technical expertise in stoma management is a strong indicator of their emotional, social and sexual rehabilitation.¹¹⁷ Moreover, psychological symptoms are more likely to occur when patients experience stoma-related complications.¹¹⁴

Factors such as gender, age and time since treatment may affect stoma-specific QoL; however, the existing literature is inconclusive about this effect.¹¹⁹ Women appear to experience a lower QoL versus

men; this is in part related to changes in body image, rejection sensitivity and inability to carry out household tasks.¹²⁰ Ageing is also a significant factor affecting people living with a stoma, as elderly patients face greater constraints in terms of physical ability, while younger patients are predominantly concerned with emotional issues and future economic perspectives.¹²⁰

In England, people living with a stoma have reported inconsistent access to counselling, a need for improved signposting to peer support, and feelings of abandonment (possibly associated with the absence of pre-operative information/post-surgery follow-up).¹⁴

While a system-wide reform and revision of services is needed,^{117,121} the ability of healthcare professionals to recognise patient coping mechanisms predicts the success of interventions as the stoma experience is highly individualistic.¹²²

People living with a stoma are at risk of experiencing perceived stigma (reflecting the individual's belief about the attitudes of others).¹²³ Interventions aimed at improving patient education, reducing economic burden and strengthening social support were noted as means to improve the living conditions of IBD-related stoma patients.¹²⁴

A review of several studies concluded that intensive follow-up by monthly review was of greater benefit than ad hoc SCN-initiated standard care to help people adjust to life with a stoma.¹²⁵ Results from the Dialogue Study also suggested that regular contact with the stoma specialist nurse improved HRQoL.^{††126}

SCNs are registered graduate nurses with specialist skills, expertise, education and training in stoma care, who can provide physical and emotional support for the patient and family, coordinate care services and inform and advise patients.¹²² Psychological and psychosocial care are currently inadequately provided but must be incorporated into a fully integrated stoma care pathway. Peer and web-based support are both useful interventions that could be included.

Peer support

Talking to another person who has undergone bowel or bladder diversion can help patients accept changes in their body image and make the necessary physical and emotional adjustments to their stoma.¹⁰⁰ People already living with a stoma can share experiences and provide practical and emotional support that contributes to improved QoL and emotional balance for those with a new stoma.¹²⁷

Investigation of QoL for patients and subsequent development of the stoma management programme by a team of multi-disciplinary researchers identified peer-to-peer support and education in tandem with stoma nurse facilitation as key. This is particularly relevant in settings where cultural beliefs around body waste present a barrier to accepting stoma adaptations to function.^{65,128} People living with a stoma who participate in a support group tend to function at a higher level and experience a sense of belonging, reducing their feelings of otherness.^{129,130}

Web-based support

Support groups are one of the most effective ways to meet social support needs, positively affecting individuals and improving their QoL.^{127,128} An analysis of free web-based patient support resources

†† North American subset (n=743 people living with a stoma) of an open-label, noncomparative, multicentre study in >3000 people living with a stoma and >500 nurses in 18 countries.¹²⁶

designed for those who have recently undergone stoma surgery found that online resources that provide educational content and self-management training for people with stomas are a practical way to supplement patient education after surgery, for adults of all ages.¹³¹ This reflects a growing trend of older adults using the Internet as a source of health information.^{132,133} Indeed, some patients with a stoma prefer to find their own information on the internet.¹³⁴

Sleep

According to studies, sleep-related problems affect 30-50% of individuals living with an ileostomy, colostomy or urostomy.^{135,136} The causes can vary, with individuals expressing concerns about how to manage their stoma while sleeping.^{‡‡136,137} Participants in a study by Kara and Aslan (2017) reported difficulty sleeping on their first day home post-operation due to fear of bursting or leaking from their pouching system.^{§§138} In another study of people who had been living with a stoma for at least five years, individuals reported problems such as difficulty falling asleep or not getting enough sleep, as well as avoidance of sleeping in certain positions due to fear of leakage.^{***139-141} In a qualitative study of 169 individuals with stomas, they reported anxiety about spending the night away from home, including fear of disturbing others due to gas emissions and fear of leakage.^{141,142}

Sleep health is described as a sleep-wake pattern that supports overall wellbeing and is influenced by individual, social and environmental factors.¹⁴³ Poor sleep quality can lead to physical, cognitive and emotional issues, and accidents and difficulties in professional and daily life. People with stomas who have poor sleep quality also report decreased HRQoL and experience professional and daily life incompatibilities.^{†††144} While some studies evaluating the QoL of individuals with stomas and addressing sleep problems have been published, studies specifically targeting stoma-related sleep problems or quality are limited.^{136-139,145}

One recent study which did investigate sleep problems and sleep quality among individuals with intestinal stomas was conducted from September 2018 to September 2019 at three university hospitals in Ankara, Turkey. Of the 222 involved, 52.3% reported current sleep problems, 59.5% reported that their stoma affected their sleep, and 64% had problems at night due to their stomas. Sleep quality was assessed by a researcher-designed instrument measuring the descriptive characteristics of patients with a stoma, the Pittsburgh Sleep Quality Index (PSQI), and the Epworth Sleepiness Scale (ESS). The results showed that the mean PSQI score was above 5 (13.42, SD: 3.01), indicating poor sleep quality, and the mean ESS score was 7.54 (SD: 6.37), indicating daytime sleepiness. The mean PSQI scores for individuals with ileostomies and temporary stomas were significantly higher, indicating worse sleep quality compared to those with other types of stomas.¹⁴⁶

‡‡ A descriptive pilot study in people who had had stoma surgery within the last 30 months. 34 of 43 surveys returned were analysed to identify stoma-related difficulties experienced after discharge from hospital, who they sought help from, and if the advice was perceived as helpful.¹³⁶

§§ A qualitative phenomenological study in 18 people. Interviews were guided by a semi-structured 8-part questionnaire and aimed to find out patients' experiences of their first day at home after stoma surgery.¹³⁸

*** A secondary analysis of data collected in the Health-related Quality of Life in Long-Term Colorectal Cancer Survivors Study (n=679) from the subgroup of people living with a stoma (n=286).^{139,140}

††† A qualitative study in 14 people who had been living with a stoma for at least 6 months. Data on quality of life were gathered by semi-structured interviews.¹⁴⁴

The authors suggest the need for further research and the development of methods to improve sleep quality for individuals with stomas. Possible interventions include keeping the pouch flush with the skin, wearing a support garment, reducing oral intake before bedtime, setting an alarm to empty the pouch, reducing leaks, exploring alternative sleeping positions, and practicing relaxation techniques to reduce anxiety.¹⁴⁶ These strategies should be a component of post-operative patient education and incorporated into a fully integrated stoma care pathway.

Theme 6: Increase in digital access

The use of digital technology such as smartphones, computers, tablets and smartwatches, linked to digital applications, is now part of everyday life, including healthcare.¹⁴⁷

Changes in response to COVID-19 and digital transformation programmes

The COVID-19 pandemic prompted increased investment and speed of improvements in digital technology to enhance communication with patients and care teams, provided personal development opportunities, and improved training and education.¹⁴⁷⁻¹⁵⁰ The digital transformation programmes were used as exemplars and the dissemination of learning was significantly widened.

Cambridge University Hospitals NHS Foundation Trust had previously implemented a recognised pathway of stoma care based on the four phases identified by Davenport (2014).^{69,151} During the pandemic, many in-person appointments were switched to 30-minute telephone appointments. A patient experience survey was carried out to determine the future of the service and identify potential adaptations to the pathway.^{***151} Results showed that 96% of respondents strongly agreed or agreed that their appointment started on time and 97% felt that the allocated interval was adequate. Operational benefits included allowing the clinical nurse specialists to work from home (important during the pandemic) and extended hours to carry out the telephone clinics, with no interruptions. Some patients appreciated not having to go to hospital during the pandemic. However, it was more difficult to assess stoma complications; some patients would have preferred a mix of telephone and face-to-face appointments. It was felt that non-verbal cues were missed when assessing psychological issues and how a patient might be feeling.¹⁵¹ It is therefore evident that a fully-integrated stoma care pathway needs to be flexible to adjust to patient preferences.¹⁵¹

Indeed, D'Antonio et al. (2020) reported that although telemedicine (implemented during the Covid-19 pandemic) was not suitable for all patients or all medical scenarios, it can be effective in people who live a distance from the hospital.^{§§§152} Some issues necessitate face-to-face appointments or hospital admission.¹⁵² This discerning use of telemedicine was echoed in conclusions drawn in the tertiary care setting by the University College London Hospitals referral centre. Before the pandemic, patients would travel a considerable distance to see their colorectal surgical team for follow-up appointments. But even after the pandemic, many patients actively chose to continue with video or telephone appointments. Digital submissions of the stoma site followed by a structured telephone/video assessment enabled solutions to be reached without the need for a home visit or a journey to the clinic.¹⁵²

*** 72 of 160 eligible people living with a stoma returned answers to the patient experience survey.¹⁵¹

§§§ A retrospective analysis of 17 (of 23 eligible) patients with colostomy or ileostomy, whose primary reason for consultation could be completely solved virtually or if in-person/on-site services were expected to be reduced.¹⁵²

However, a Norwegian study found that although teleconsultation follow-up by SCNs decreased the readmission rate and burden of travel, it did not improve the QoL of patients. ****¹⁵⁴

In brief, telephone follow-ups are convenient and cost-saving, but they cannot show the local status of the stoma. Outpatient follow-ups can provide post-discharge care, but may not address all the patient's psychological and informational needs.¹⁵² In the context of a fully integrated stoma care pathway, using telemedicine may provide valid support for patients with a stoma in the future and should be considered where appropriate.

Mobile applications

Smartphones offer the opportunity for a home healthcare service platform that can be used in stoma care, as demonstrated by a project in South Korea.¹⁵⁵ An application (app) for the patient allows them to get immediate information and advice on physical and psychological wellbeing (stoma management, diet, physical activity; management of fatigue, anxiety and depression, and guidance on self-management) and provides links to support groups. The app also allows patients to upload stoma pictures, details of stoma and skin complications, and information about their stoma bag cycle. The data are monitored by the clinicians via a web-based function, giving them a comprehensive overview of the patient's current condition and allowing them to identify issues that will need a face-to-face appointment. The creators expect to continue developing patient-oriented functions for the app and hope that these will bring improvements in QoL for the patients.¹⁵⁵

Theme 7: Urostomy

A systematic review of nursing care for improving self-efficacy and HRQoL in patients with a urostomy revealed that this is a neglected demographic despite urostomy being one of only three types of stoma.^{156,157} HRQoL was lower in this group compared to population norms, and factors such as age, employment, and living status were identified as contributors. Preoperative education was found to be important for meeting psychological needs, while the postoperative nursing intervention improved self-efficacy and HRQoL, particularly when there was continued nurse-patient interaction.¹⁵⁷⁻¹⁶¹ The review identified three major essential components for designing a comprehensive nurse-led education programme:¹⁵⁷

1. Stoma education: self-care skills, preventive measures
2. Psychological counselling: cancer diagnosis, body image, sexual problems
3. Consideration of patient factors: age, employment, living status

Some vulnerable patients may need special attention with tailored interventions.¹⁶²⁻¹⁶⁴ For example, older participants may have a better acceptance of their condition, but have difficulty with dexterity, impacting their independence in self-care.^{162,164} Previously employed patients experience greater challenges in adjusting to their new lives versus those without prior employment and may require additional psychological support.¹⁶² Living status (living alone, with a spouse, or with a spouse and children) has also been shown to impact the QoL outcomes.^{162,163} Finally, interventions should include primary carers, taking

**** A randomised clinical trial of telemedicine for postoperative follow-up of people with a new stoma (STOMPA trial). 110 patients received follow-up either by teleconsultation or in hospital.¹⁵⁴

into account their psycho-emotional wellbeing, which may affect the global health status and QoL of the patient.¹⁶⁵

A consensus view from people living with a stoma: calls to action for improved care

A panel of 12 people with a stoma, plus one carer, identified via Colostomy UK, the Ileostomy and Internal Pouch Association, and the Urostomy Association, were invited to discuss a set of research-based statements and establish a consensus on calls to action around the problems faced by people with a stoma, with a particular emphasis on the issue of leakage. The results support the conclusions described in this rapid assessment of evidence. The project was funded by Coloplast UK.¹⁶⁶

The calls to action

Healthcare provision

- The delivery of individualised and holistic care is fundamental for people living with a stoma
- Positive education is needed throughout the healthcare service to understand how stomas affect people
- To reduce the impact of leakage and its complications and improve quality of life, healthcare professionals need to have access to information regarding product innovations. This will enable them to provide the best holistic care for people with a stoma
- Stoma care nurses' lifelong support and engagement is important to reduce leakage. Access to this specialist support should be consistent across the country
- Education covering the proper use of stoma appliances, lifestyle and mental health is important. Access to stoma care nurses is essential to receive this service
- People with a stoma should be offered an annual review that includes mental health, skin health, product choice, routines and self-care
- Primary care providers should not change stoma prescriptions without consultation with the person with a stoma
- People with a stoma should be offered care before and after surgery, and provided with ongoing lifelong support
- To reduce the impact of skin issues, people with a stoma need access to dermatology advice
- Psychological support is as important as physical healing: people with a stoma need access to mental health support.

Product

- Improve information for people with a stoma to understand products and innovations available.

Support

- Peer support saves lives. People with a stoma may benefit from engagement with others who have a stoma.

Daily life

- A stoma is a hidden condition; disabled toilet facilities should therefore be clean, spacious and accessible
- Employers need to be aware of and educated on how to support people with a stoma.

Section 3: Case studies for informing future recommendations

This section presents case studies illustrating practical solutions that could be applied to the challenges of stoma care. They are aligned to four thematic pillars: 1) Quality of care, 2) Costs, 3) Patient experience and health equity, and 4) Efficient improvements in clinical outcomes.

Central components of an accredited pathway

The 2021 ASCN UK Standards provide flexible and professional guidance for SCNs across a range of clinical contexts and patient populations, and are particularly relevant at a time when decision-making is becoming more local and regional and there remain disparities in the provision and funding of services across the UK.⁵

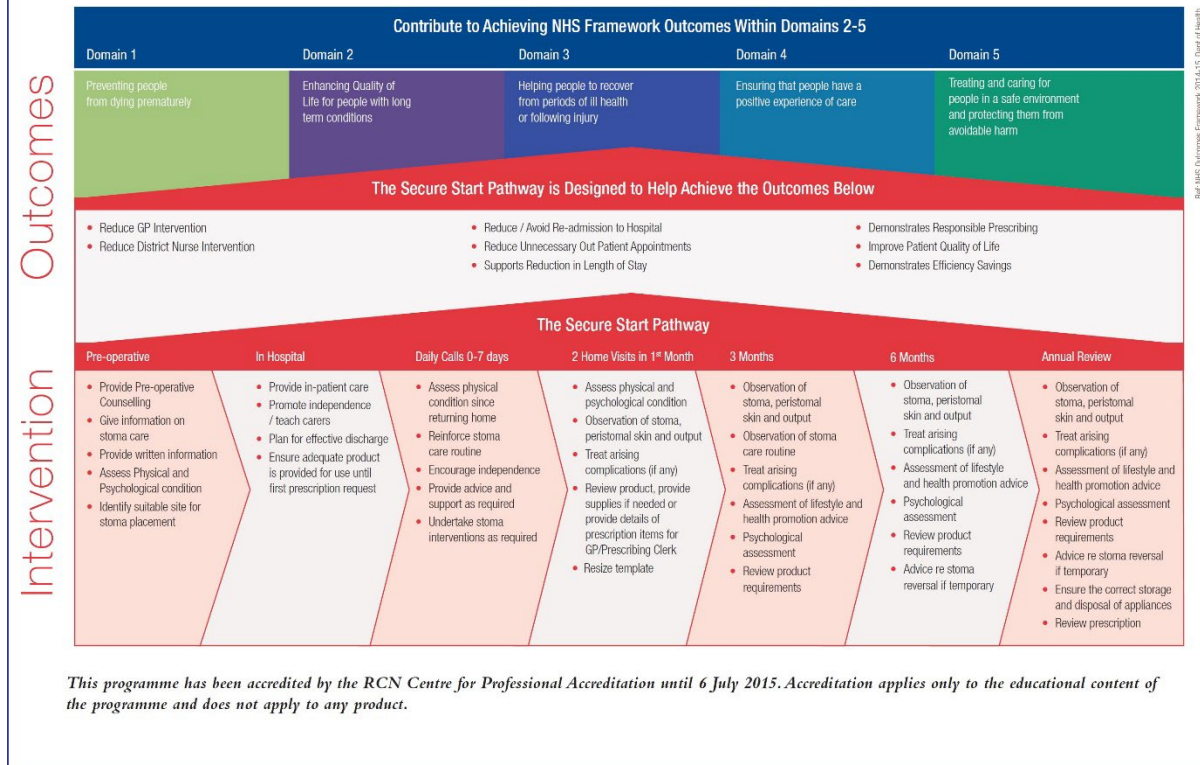
ASCN used the National Institute for Health and Care Excellence (NICE) guideline framework to create seven Quality Statements describing the structure, process and outcome of stoma care. This list should be considered the core framework of a structured pathway:⁵

1. Referral for potential/actual planned stoma formation
Patient/carer is referred to a specialist stoma care nursing service promptly to ensure adequate time for pre-operative information to be delivered
2. Pre-operative preparation for potential/acute stoma formation
Patient/carer is provided with relevant information and the stoma site is correctly selected by a registered nurse with a defined level of competency
3. Post-operative stoma care management (practical)
Patient is assessed by a nurse and an individualised stoma care plan formulated
4. Post-operative stoma care management (physical)
Patient is assessed by a nurse and an individualised stoma care plan is formulated
5. Preparation for discharge from the hospital
6. Short-term specialist SCN support for the patient for up to three months
Patient receives equitable access and continuity of care from the nurse after discharge
7. Long-term/lifetime specialist SCN support
Patient living with a stoma receives continued care and access to an SCN

An RCN-accredited clinical pathway for stoma care

In May 2014, the Royal College of Nursing (RCN) accredited a clinical pathway proposed by a specialist working group who considered their own working practices, and reviewed literature relating to follow-up care. The pathway has four phases: pre-operative, in the hospital, returning home and life with a stoma.⁶⁹ It provides clear anticipated care in an appropriate time-frame, agreed by the multidisciplinary teams to ensure optimum and standardised support is given to all patients. It was implemented in five pilot sites in 2013: a subsequent audit of 1027 visits showed that the early intervention of an SCN provided sufficient advice and support to prevent the patient from needing to consult other health professionals (saving 83 GP visits) or access NHS services (avoiding 185 outpatient attendances and 51 accident and emergency [A&E] attendances), thereby delivering cost savings for stoma-related issues.⁶⁹

Clinical Pathway for Stoma Care



The real-world outcomes of this pathway align with the four thematic pillars as follows:⁶⁹

(1) Quality of care and (4) Efficient improvements in clinical outcomes: 94% of patients reported that they did not see their GP or attend an accident and emergency department for a stoma-related issue within 30 days of discharge and 98% of patients found the home visits helpful.

(2) Costs: prescription amendments in the accessories segment generated an 8% reduction of the total stoma care spend in one audit undertaken of a group of 21 patients in one GP practice. In another group of 266 patients, cost savings through responsible prescribing were:⁶⁹

- Colostomy (110 patients, three bags per day) £11,548/£105 per patient
- Urostomy (50 patients, three–four per week) £2090/£42 per patient
- Ileostomy (106 patients, one bag per day) £4852/£46 per patient (per patient cost based on drug tariff pricing)

(3) Patient experience and health equity: 95% of patients said the pathway provided a valuable service, 97% of patients said their SCN provided helpful advice and 98% of patients found the support helpful after discharge.⁶⁹

The report stressed the role of the SCN and the need to provide patients with support and advice, particularly throughout the first year of their life with a stoma. Proactive support and advice were found

to be more beneficial than reactive treatment, and in the context of stoma care may result in less severe PSCs. Any structured follow-up for patients offered by the stoma care pathway is thought to reduce costs relating to stoma care management in the community.⁶⁹

This pathway was introduced nine years ago; now it is time to incorporate new solutions that reflect the most recent understanding of unmet needs. New insights can also be gained from examining care pathways involving specialist nursing in other domains. For example, the overlap between stoma and IBD patient cohorts means that the IBD Standards and their implementation in practice is a good model for the components of a fully integrated stoma care pathway

Learning from IBD

Launched in 2019, the 59 statements of the IBD Standards say what high-quality care should look like at every point of a patient's journey, set out how an IBD service should be organised and managed to deliver this, and align with the new BSG guidelines. Every IBD service in the UK should work to meet them.

IBD UK developed a UK-wide benchmarking tool to assess how the quality real-world care matched up to the IBD Standards, looking at hospitals' workforce provision and perception of the care they deliver, and measuring patients' views of the care they receive. The results were published in 2022.^{167,168}

In total, 166 adult and paediatric IBD services (72% of services nationally) completed the self-assessment, and survey data were collected from 10,222 patients. Communication, shared decision-making, and provision of information were cited as essential aspects of care. Problems included poor quality of diagnosis (reflecting long waiting times, slow referral to dietetics, and other disease complications in those newly diagnosed with IBD). The report gave some examples of quality improvement initiatives in five areas of IBD care, some of which are relevant to stoma care:^{167,168}

- Diagnosis:
 - Ensure that services are well resourced to enable diagnosis and treatment within the time frames set out in the IBD Standards

- Information
 - Provide personalised care plans tailored to patients' life goals and detailing available support and individualised actions in event of flares
 - Promote supported self-management for stable patients by reducing routine appointments, while offering more drop-in flare clinics and access to telephone advice
 - Regularly review and monitor IBD patients in ways that meet their individual needs

- Faster access to specialist advice and treatment:
 - Everyone with IBD should have a plan detailing steps to take in case of a flare, and have a response from an IBD advice line by the end of the next working day
 - Ensure rapid access to clinics and prompt access to investigations in every service, supported by flare pathways agreed between primary, secondary and emergency care
 - Have a clear process for admission to a specialist gastroenterology or colorectal ward in every IBD service. IBD nurse specialist job plans should include time for inpatient visits
 - Prioritise surgery, as delays result in significant risk to patients

- Expand specialist nurses and clerical support teams to improve telephone/email advice lines
- Increase access to surgeons and consultant physicians and increase specialist IBD clinic provision
- Leadership and regular meetings of a multidisciplinary team:
 - Ensure appropriate resourcing to meet staffing requirements for the whole IBD team; have regular meetings of the multidisciplinary team, supported by an administrator
 - Establish pathways to deliver coordinated care across specialities (joint medical or surgical clinics), between adult and paediatric services and between primary and secondary care

The report highlights that the current model of IBD care is largely reactive, leading to a high number of emergency admissions. Focusing on a proactive and personalised approach to care from diagnosis onwards should lead to improved outcomes and QoL. This can be done by equipping patients with the skills, information and confidence needed to self-manage effectively and become active participants in their own care.^{167,168}

This conclusion aligns with the recommendation of proactive rather than reactive support in stoma care outlined by Davenport (2014)⁶⁹ and supports the self-care agenda promoted by the NHS Long-Term Plan.¹⁶⁹ Moreover, the report demonstrates that, while multidisciplinary care is essential, the IBD nurse specialist is pivotal in coordinating care, supporting patient education and involvement, and driving the development of the IBD service.¹⁶⁸ The problem of under-resourced care teams is a growing nationwide issue that urgently requires addressing, as does the under-utilisation of it and data systems. If under-resourcing and under-utilisation issues are effectively addressed, they provide a significant means of transformation in IBD care.¹⁶⁸ Since SCNs perform a similar function to IBD nurses, these findings can be applied when designing a comprehensive stoma care pathway.

The quality improvements outlined here are highly applicable in the context of stoma care owing to the proportion of patients with IBD who require surgery. An investigation found the incidence of stoma in patients with Crohn's disease was 2.5%, and stomas were found to be more common in elderly-onset compared with a paediatric-onset disease, with a 5-year cumulative incidence of 3.6% vs 1.3%, respectively.¹⁷⁰ Although people with IBD represent a small proportion of stoma patients, there is considerable overlap between the unmet needs in IBD and stoma care, and the quality improvements cited in the IBD benchmarking assessment present solutions relevant to both.

Real-world case studies: examples from IBD

How can these changes be made in real-world settings? The national report for gastroenterology, *Getting It Right First Time* (2021), provides practical solutions for managing the demand for services and maximising the available capacity of services in England, with a special focus on overcoming challenges posed by the COVID-19 pandemic, such as the accumulation of patients waiting for endoscopic procedures and gastroenterology clinic appointments.¹⁷¹ The report includes several case studies that, although not specifically addressing stoma care, show how practical solutions can be put into action to address gaps in the regional stoma care pathways across the four pillars (Quality of care, Costs, Patient experience and health equity and Efficient improvements in clinical outcomes).

Case study: St Helens and Knowsley Teaching Hospitals NHS Trust

Aligns to Quality statement one of the ASCN UK Standards: Referral for potential/actual stoma formation⁵

The trust had an existing referral management system that vetted all clinic referrals and extended it to include consultant vetting. The triage process was further expanded to include a Virtual Referral Triage Clinic each day during the COVID-19 pandemic. This reduced the need for hospital appointments and follow-ups, freeing up clinic capacity. The team found that most patients could be managed remotely with advice and guidance from GPs, or go direct to the testing stage. Patients could then either be seen in the clinic for a single appointment, redirected to the relevant chronic disease clinic, or discharged without clinical review needed. The trust also reduced the need for gastroenterology follow-up appointments after patient investigations by initiating investigations at the first consultation, along with a care plan, notifying patients if follow-up was not required, and directing patients who needed long-term follow-up to nurse-led chronic disease clinics.¹⁷¹

Results:¹⁷¹

(2) Costs: the trust intended to audit the Virtual Referral Triage Clinic to determine the absolute benefits, and to ensure the system could be appropriately funded to allow it to be sustainable. There was the possibility that the system could eliminate the need for their commissioned referral management system

(3) Patient experience and health equity: more patients were seen in the most appropriate setting and the Virtual Triage Clinic reduced the need for gastroenterology follow-up appointments: 51% of outpatients were discharged after their first clinic appointment (double the national average according to hospital episode statistics [HES] 2017/2018 data)

(4) Efficient improvements in clinical outcomes: clinic capacity increased

Case study: Oxford University Hospitals NHS Foundation Trust

Aligns to Quality statement three of the ASCN UK Standards: Post-operative stoma care management⁵

The Oxford trust significantly reduced emergency admissions with a range of measures that increased responsiveness to patient needs and built resilience within the unit, including:¹⁷¹

- Encouraging senior clinicians and consultants to develop a special interest in IBD, supported by advanced training
- Having an email advice service for patients, managed by specialist nurses
- Monitoring patient progress through validated questionnaires on symptoms (daily), QoL (two-weekly) and outcomes (quarterly)
- Weekly multidisciplinary team meetings
- Audited performance targets
- Integrating and co-locating clinical and research teams

Results:¹⁷¹

(1) Quality of care, (3) Patient experience and health equity and (4) Efficient improvements in clinical outcomes: A&E admission rates for IBD at Oxford have fallen to half the England average, with additional improvements on key indicators such as length of stay.

Case study: East Sussex Healthcare NHS Trust: Using a nurse-led approach

Aligns to Quality statements six and seven of the ASCN UK Standards: Short-term specialist SCN support for the patient for up to three months; long-term/lifetime specialist SCN support⁵

In response to long waiting lists for consultant-led outpatient care, in 2011 the trust began delivering nurse-led IBD clinics. At the start, there was one clinic per week at each of its two main sites in Eastbourne and Hastings; it has since grown to seven face-to-face and two telephone clinics across the trust each week. The result was reduced consultant waiting lists, freeing up capacity and enabling patients to be seen more rapidly when their condition flared. Consultants were initially reluctant to refer their patients but have now embraced the clinics after seeing the benefits for patients and overall capacity. This nurse-led model has recently been extended to endoscopy clinics, with four per week established across the trust.¹⁷¹

Results:¹⁷¹

- (1) Quality of care: waiting lists for outpatient care have been significantly reduced
- (3) Patient experience and health equity: patients have rapid access to clinics in line with IBD Standards and nurses can work more closely with patients, supporting them and explaining their diagnoses
- (4) Efficient improvements in clinical outcomes: over 20% of all outpatient clinics in gastroenterology at the East Sussex trust are nurse-led versus the average of 5.1% in England (according to the HES 2017/2018 data)

Case study: Milton Keynes University Hospital NHS Foundation Trust: Managing patient follow-up appointments

Aligns to Quality statements six and seven of the ASCN UK Standards: Short-term specialist SCN support for the patient for up to three months; long-term/lifetime specialist SCN support⁵

The Milton Keynes University Hospital NHS Foundation Trust audited their gastroenterology clinic lists with the aims of seeing the right patients at the right time, reducing unnecessary follow-up visits to the hospital and increasing the clinic's capacity. The team removed duplicate requests and other administrative errors, then developed clinical validation criteria to identify patients who could be discharged. To reduce Did Not Attend (DNA) rates, patients are now given sufficient advance notice of appointments to allow them to reschedule in good time, and a text reminder service is provided.¹⁷¹

Results:¹⁷¹

- (3) Patient experience and health equity and (4) Efficient improvements in clinical outcomes: gastroenterology clinic DNA rates are now 5%, helping to make the best use of available capacity. Duplicate requests have been eliminated and clinical validation enabled discharge of up to 30% of patients on the outpatient waiting list.

Real-world case studies: stoma care

A survey of the literature returned a single case study that analysed how changes in the regional process helped organisations provide cost-effective and sustainable community stoma support services that met patients' ongoing needs. NHS England commissioned an implementation guide as part of its national Quality, Innovation, Productivity and Prevention programme to support regions to work collaboratively

and deliver system-wide efficiencies 'at-scale'. This work was centred on the Cheshire and Merseyside region to improve the management of patients' ongoing stoma care and prescribing needs while reducing spend on stoma appliances.¹⁵

Case study: Cheshire & Merseyside Health & Care Partnership

Aligns to Quality statements three, six and seven of the ASCN UK Standards: Post-operative stoma care management, short-term specialist SCN support up to three months and long-term/lifetime specialist SCN support⁵

The Merseyside Health & Care Partnership designed a pathway to improve management of patients' ongoing stoma care and prescribing needs, while reducing spend on stoma appliances (Other prescription services are available in the UK). A new Stoma Support Service model was designed to address these issues and to provide a responsive experience for patients needing products, advice on stoma support and prescriptions. It incorporated acute clinical care, coordination of care, prescribing, authorising, dispensing and patient registration. Particular problems tackled were sponsored stoma nurses, GP familiarity with stoma care products and DACs ordering on patients' behalf.¹⁵

Three variations of the model offer flexibility in how services are delivered:¹⁵

- (1) Stoma Prescribing Hub: patients contact the hub monthly to order products. No changes made to current acute and community stoma nurse provision
- (2) Community Stoma Support Service: the Stoma Prescribing Hub plus a community nursing workforce to ensure Stoma Support Service users receive annual clinical reviews
- (3) Seamless Stoma Support Service: the Community Stoma Support Service plus additional acute stoma nurses to provide a seamless Stoma Support Service spanning primary and secondary care

In those ICBs where this SPECIFIC model of specialist community appliance prescribing has been implemented, the following significant benefits have been achieved:

- (1) Quality of care & (3) Patient experience and health equity: monthly interactions with the Prescribing Hub address any issues that may arise, reducing the need for costly urgent care. Stoma nurse knowledge means that patients are provided with the most suitable products, thereby reducing waste and avoiding potentially inappropriate prescriptions
- (2) Costs: to reduce costs, the prescribing decisions involve clinical specialists, follow guidelines and formularies and ensure appropriate quantities are dispensed to reduce spending on unsuitable products and waste
- (4) Efficient improvements in clinical outcomes: delivering care more efficiently. Consolidating prescription management across the region within a single hub reduces variation in service. By working in an effective and scalable way, the model reduces GP and pharmacy time and improves the quality of care and convenience. Establishing a standardised formulary shifts the focus away from the secondary care teams and product manufacturers driving product initiation, to ensuring that prescribed products not only meet the needs of patients but are also cost-effective.

Looking beyond a fully-integrated stoma care pathway: profiling patients for personalisation

The formation of a stoma can negatively affect QoL. Although several factors may be involved, most research treats patients with a stoma as a largely homogeneous group. A recent pioneering study of 1419 participants has challenged this assumption, using latent profile analysis (LPA) to identify four distinct profiles of people with a stoma, based on their QoL, physical activity levels, and clinical and demographic characteristics:¹⁷²

1. 'Consistently good QoL' (62.8%): higher than average QoL scores across all subscales; generally older than patients in the other groups
2. 'Some QoL concerns' (13.0%): moderate QoL concerns across all subscales
3. 'Low QoL' (12.8%): less likely to have had their stoma for longer than 2 years; less physically active; more likely to have a hernia or bulge
4. 'Financial concerns' (11.5%): financial concerns; high scores on work/social function and sexuality/body image

LPA is useful for the multidimensional nature of QoL by showing whether there are distinct groups of people with similar patterns of QoL response. LPA has been previously used to indicate the subpopulations who may benefit from specific interventions in the field of diet, sexual health,¹⁷³ alcohol¹⁷⁴ and drug problems, hypertension,¹⁷⁵ and older adults.¹⁷⁶ For example, in the study of older adults, classification into the groups stable, physical disability, emotional disability and crisis enabled proposal of different programmes for each, such as functional mobility and balance training, or individualised mental health assistance.¹⁷⁶ Similarly, using LPA in stoma patients could help identify how to better tailor interventions to an existing stoma care pathway.

However, before such personalised interventions can be established, a fully integrated stoma care pathway must first be implemented on a national scale. It should be flexible to allow for organisational and individual differences. Variations in healthcare systems, medical resources and culture create disparities between institutions. Patient-specific factors, such as the unmet needs explored in the self-care agenda promoted by the NHS Long Term Plan, also play a role.¹⁶⁹

Section 4: Conclusion

The current literature shows the perspectives, experiences and unfulfilled needs of individuals with stomas in England, supporting the need for nationwide changes to stoma services. This review suggests that there is a significant variation in service provision both in hospitals and at home, highlighting ongoing inequality in health provision.

These findings provide a foundation for the design of future stoma care services that should be better at meeting the needs of people living with a stoma. The current research indicates that comprehensive and ongoing stoma care can lead to positive outcomes, particularly in improving the health and satisfaction of stoma patients.

The literature selected to support an identified hypothesis included published information across meta-analyses, interventional studies, case reports, implementation guidelines issued by regional facilities, survey results and reports commissioned or sponsored by several stakeholder companies, institutions and organisations.

The move to institutionalised learning for SCNs has improved the level of nurse education but has eroded the practical, hands-on elements of knowledge acquisition. There is a need for more high quality, tailored continuing professional development for SCNs.⁹ SCNs are valuable: SCN-led services rehabilitate patients while providing numerous cost-effective and cost-efficient benefits. This supports the argument that stoma care delivery should be led by an engaged, well-informed, expert SCN team that can deliver patient-centric care.^{9-11,14}

Strategic decisions about stoma patient management and delivery of care are increasingly taken locally and regionally.⁵ This has produced considerable variation in the UK in the provision and funding of services, and has impacted their delivery.^{5,14} This poses a considerable challenge when designing a fully integrated stoma care pathway suitable for national use.

The key unmet needs of people living with a stoma and their stoma care teams are varied, and affected by the regional and local pressures that impact funding and subsequent service decisions.¹⁴ Equitable access and continuity of care is considered the weakest link in community services, with a clear need for continuous care interventions that integrate patient-centeredness, evidence-based practice, multi-professional teamwork and a drive towards continuous quality improvement. There should be flexibility to cater to the varied needs of people living with a stoma, owing to significant variation in stoma care patients' preference for follow-up and service provision at home and hospital.¹⁴

Supported patient self-management is a commonly used approach to addressing the difficulties presented by long-term conditions and multimorbidity.¹⁷⁷ Healthcare systems need to adopt a holistic perspective that involves patients, practitioners, and service reorganisation.¹⁷⁸ Patient activation is key: patients with knowledge, skills and confidence in managing their own condition have better health outcomes and care experiences.⁴⁴ However, there are few evidence-based, systematic stoma care self-management programmes available. Positive early results of a recent telehealth-based OSMT programme for cancer survivors and their caregivers designed to improve patient activation, self-efficacy, and QoL in the adjustment to living with a stoma provide evidence of the programme's impact.⁴⁷ If activation is proven to be a useful concept for targeting of interventions, further research may be useful in identifying those patients who need activation, and may suggest ways of raising activation to improve outcomes.⁴⁴

For patients with a stoma, adjustment is considered through the lens of their reaction to the psychological, social, and sexual impact of the condition. Factors such as age, unemployment, low income, inability to care for the ostomy, not participating in support groups, and shame or worry about smells, have all been associated with a low level of adjustment.^{179,180} Patients who are better able to manage their self-care tasks have better adjustment and can take care of their stoma more efficiently, leading to improved QoL.¹⁸¹⁻¹⁸⁵

An important aspect of all chronic illness, including having a stoma, is self-care. Self-care ability is a complex skill that significantly influences a patient's adjustment and is central to rehabilitation following stoma creation. Studies have shown that good levels of self-care are positively correlated with general health status and QoL, and negatively correlated with pain, disability and costs. Adopting validated and specific indices to evaluate self-care in patients with a stoma will help healthcare professionals to recognise individuals' self-care abilities, provide focused health education interventions, and monitor changes in patient behaviour.¹⁸⁶ This information can then be used to evaluate the effectiveness of educational interventions on patient outcomes, and contribute to the development of effective health policies and clinical services organisation.¹⁸⁷

Currently, there is no research examining the impact of PIFU on stoma care. Stoma care is currently led by SCNs, with guidelines providing evidence-based recommendations for delivering consistent and appropriate care.^{10,56} The guidelines position SCNs as being responsible for identifying and referring patients to other specialists as needed to address such issues as altered body image, social exclusion and anxiety.^{14,56} Some patients like routine follow-ups and others prefer annual reviews: PIFU can accommodate these varying needs, and a standard stoma care pathway should integrate patient preferences as and when appropriate.

A current challenge in clinical standards is the wide variation across the country in provision and funding of care, and support and follow-up.⁵ This impacts recovery, appliance and accessory product use, and ultimately patient QoL. PSCs is the most frequent outcome of inadequate care: over 80% of people living with a stoma are predicted to develop PSCs within 2 years of surgery.⁶⁰ The SCN should be included in the pre-operative care of patients in both elective and emergency surgery cases.⁷³ A patient registry of longitudinal data could provide the information needed to help elevate clinical standards by helping to understand the ongoing real-world patient experience.^{88,90} Moreover, a registry that allows participants to self-report could encourage participant engagement and facilitate a patient-centred focus in care provision.⁹⁰

Perhaps the most important of the current challenges of stoma care is the psychological burden and psychosocial impact of a stoma.¹¹³⁻¹¹⁶ A strong indicator of emotional, social and sexual rehabilitation is the level of the patient's technical expertise in stoma management.⁹⁶ SCNs have the skills, expertise, education and training in stoma care to be able to provide physical and emotional support for the patient and family, coordinate care services and inform and advise patients.¹²² This could improve both clinical and practical issues, which in turn lead to positive patient outcomes.^{10,11} Alongside the SCN, peers can provide the practical and emotional support that contributes to improved QoL and emotional balance for those with a new stoma – thereby suggesting a role for digital-focused learning and community building for stoma patients.^{104,128-130}

An additional issue explored was the impact of a stoma on the sleep quality of patients. People with intestinal stomas experience poor sleep quality and excessive daytime sleepiness, which can negatively

affect their daily life and QoL.^{147,146} The worst sleep quality was reported by women, people who work, people who have ileostomies or permanent stomas, and those whose sleep problems cause physical or psychological issues. Interventional methods such as wearing a support garment around the abdomen and reducing oral intake before sleeping may help. Addressing sleep issues should be included in a full integrated care pathway.

Digital health technology is becoming widespread. The COVID-19 pandemic increased the role of telephone clinics, which can save on time and travel costs for both healthcare professionals and patients. However, they cannot replace all face-to-face appointments. Instead, they should be considered as an extra option for accommodating patient preferences.¹⁵¹ Smartphone apps offer another option for improved monitoring and care of patients.¹⁵⁵ This flexibility should be included in a fully integrated stoma care pathway.

Although there is no national standard stoma care pathway, the RCN has an accredited pathway designed specifically for patient care in four stages (pre-operative, in hospital, returning home and life with a stoma).⁶⁹

Stoma care can learn from other areas. The IBD Standards of care, and pathways based on them, provide highly relevant case study examples of best practice.^{167,168} Key takeaways from gastroenterology include the need for:^{167,168}

1. Improvements in the diagnosis and provision of information
2. Personalised care and support for self-management
3. Faster access to specialist advice and treatment
4. Leadership and regular meetings of a multidisciplinary team

The case studies demonstrate how:¹⁷¹

- A nurse-led approach can increase consultant capacity and enhance patient care (East Sussex Healthcare NHS Trust)
- Validation of clinic lists increases clinic capacity and reduces DNAs (Milton Keynes University Hospital NHS Foundation Trust)
- Virtual triage can reduce outpatient appointments (St Helens and Knowsley Teaching Hospitals NHS Trust)
- Service improvements, including advanced training, email advice for patients and digital monitoring of symptoms and outcomes, can lower emergency admission rates (Oxford University Hospitals NHS Foundation Trust)

In summary, there is a need for an informed, evidence-based approach to fully integrated stoma care delivery to improve patient outcomes and organisational goals in the areas of quality of care, costs, patient experience and efficiency.

Section 5: Considerations for a fully integrated stoma care pathway

1. SCNs should be the central figure in a care pathway for patients. SCNs produce quantitative cost-effective and cost-efficient benefits and provide holistic care incorporating physical and psychological elements that cater for individual patient needs. SCNs provide patients with essential pre- and post-operative information. SCNs' expertise arises from a combination of formal education and experiential learning.^{11,12,18}
2. There should be customised training in stoma care available for the continuing education of SCNs that is required for retaining registration with the NMC
3. To ensure that patients receive the appropriate care according to their needs and preferences, discharge should provide regular reviews and monitoring, taking into account the variation in patient experiences and preferences for home-based and hospital-based care^{14,172}
4. A comprehensive stoma care pathway should encompass different routes for the patient with a 'stable' stoma who seldom needs contact with the healthcare services (annual review), and the patient with an 'unstable' stoma who needs much more frequent and intensive follow-up (prompt and direct access to the right specialist care)
5. Equitable access and continuity of care in a future standardised, fully integrated pathway should offer a variety of modalities for follow-up and consider patient-led branches – which is reflective of the new statutory guidance that mandates working in partnership with people and communities³⁸
6. Product decisions should ensure that the type and quantity of product supplied is in line with patients' needs. Strategic decisions about service delivery must increasingly be made at the local and regional levels for improved outcomes¹⁴
7. Patient activation is a highly important consideration in effective care management. There should be a balance between promoting independence, ensuring regular follow-up, and providing patients with flexible and patient-centred access to care, which may include options such as email or text messaging. The maintenance of skin health should be prioritised and there must be access to an SCN to manage any potential complications that may arise.¹⁴
8. Self-care by chronically ill patients, including stoma patients, facilitates improvements, helps adjustment to the new condition, increases feelings of empowerment, and reduces negative outcomes. Studies have shown that living with a stoma can negatively impact a patient's QoL, and healthcare professionals must consider this aspect.¹⁸⁶ To identify areas where self-care is lacking, healthcare professionals can use specific assessment tools and plan educational interventions to improve patients' ability to care for themselves. This can ultimately help to reduce negative impacts of living with a stoma and improve the overall QoL for patients¹⁸⁷
9. Among stoma-related complications, PSC and leakage incidence are a considerable burden on the individual and health systems; periodic check-ups and follow-up care with an SCN can address the need for long-term, supportive care for both patients and their families and produce considerable cost savings by preventing the need for more expensive treatment^{13,43}
10. People living with a stoma should receive accessible information at all stages of their care. This must meet their individual needs, as part of shared decision-making, and signpost to patient organisations for further information and wide-ranging support.^{14,128-130}

11. Patient empowerment, positive prognostic outcomes and reduced healthcare burden can be facilitated by multi-modal education that caters to cultural and demographic factors. Patient-informed product choice and selection help mitigate physical and psychological impacts and should be included
12. As well as system-wide reform and revision of services,^{117,121} improved access to web and peer support resources and nursing interventions are necessary, as these can help alleviate the negative effects of a stoma on HrQoL⁶⁴
13. The dynamic nature of stoma management should be factored into service delivery as reflected by the evidence that stoma care needs change during a patient's lifespan^{11,13,18,58}
14. Telemedicine may provide valid support for patients with a stoma in the future and should be considered where appropriate¹⁵¹⁻¹⁵³
15. Commissioners and managers should ensure appropriate resourcing to meet staffing requirements for the stoma team. There should be regular meetings of the stoma leadership team^{167,168}
16. A registry for stoma patients should be created. Case studies show that 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 innovation⁸⁷⁻⁹⁰

Abbreviations

A&E, accident and emergency
ASCN, Association of Stoma Care Nurses
COVID-19, Coronavirus Disease 2019
CPP, Collaborative Procurement Partnership
DAC, dispensing appliance contractors
DNA, did not attend
ENB, English National Board
GP, general practitioner
HES, hospital episode statistics
HrQoL, health-related quality of life
IBD, inflammatory bowel disease
ICB, Integrated Care Board
LPA, latent profile analysis
NHS, National Health Service
NICE, Health and Care Excellence
NMC, Nursing and Midwifery Council
OSMT, Ostomy Self-Management Training
OSO, Observation Study of Ostomy Consumers
PAM, Patient Activation Measure
PIFU, patient-initiated follow-up
PSC, peristomal skin complications
QoL, quality of life
RCN, Royal College of Nursing
SCN, stoma care nurse
UK, United Kingdom
US, United States of America
UOAR, United Ostomy Association Registry

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Notes



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