

Raising the voice of specialist stoma care nurses: a call for a national strategy in stoma care

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ABSTRACT

Specialist stoma care nurses (SSCNs) are highly educated professionals who play a critical role in the care of people living with a stoma. However, they experience some unique challenges. Currently in the UK, stoma care has no national standards, targets or best practice pathway, resulting in significant variation and an undervalued service. As members of an evidence-based profession, SSCNs need to demonstrate their value. Specialist nurses in cancer care and inflammatory bowel disease are supported by nationally, with pathways, targets and standards of care, as well as career and education frameworks. This system could be used for SSCNs. A national approach is needed to develop an evidence-based best-practice pathway, commissioned and implemented across the UK for all stoma patients and with SSCNs at its heart. SSCNs need to demonstrate their value through data and evidence. Working with Getting it Right First Time, a taskforce aims to review the evidence and establish minimum standards of care for all stoma patients. SSCNs should be co-ordinators and drivers of change at the highest level of national innovation, policy and decision-making. The work of SSCNs should be recognised and valued because what they do matters.

Key words: Stoma care ■ Nurse specialists ■ Specialist stoma care nurses

The specialist nurse role was developed to meet the changing needs of patients and the evolving healthcare workforce. It enables nurses to expand their clinical knowledge, expertise and skills to inform high-level, autonomous clinical reasoning and decision-making to improve care for patients with complex diseases or conditions (Chan, 2014).

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Fundamentally, specialist nurses can be described as having advanced expertise in a branch of nursing that includes clinical, teaching, administrative, research and consultant roles. Nonetheless, the role has extended beyond this to include quality improvement, service and system management, as well as staff education, training and leadership (Leary et al, 2008).

Specialist nurses often have sole responsibility for a care episode or defined group so directly affect the experiences and outcomes of patients and their families. There is evidence they have a positive effect in terms of patient outcomes and satisfaction, from symptom control to liaison and communication with other health professionals, as well as an indirect impact on systems and processes of care (Royal College of Nursing (RCN), 2009; Leary, 2011).

Multifaceted role of specialist stoma care nurses

Specialist stoma care nurses (SSCNs) are no exception regarding having this positive impact, being experienced and highly educated professionals in an autonomous nursing role. There are thought to be approximately 600 expert SSCNs working within acute and primary care settings (Hodges, 2022; Bird et al, 2023), providing holistic, patient-focused care to the estimated 176 000–205 000 people in the UK living with a stoma (East of England NHS Collaborative Procurement Hub, 2019; Hodges, 2022; Osborne et al, 2022) from preoperative counselling to postoperative discharge planning from hospital to the community (Association of Stoma Care Nurses (ASCN) UK, 2018).

The formation of a stoma is a life-changing event, so long-term care can involve evaluating interventions, identifying and managing complications (ASCN UK, 2016; Bird, 2023) as well as providing psychosexual and social support. At each stage of the care pathway, SSCNs are likely to be involved in advanced clinical reasoning and tailoring their decision-making, knowledge and skills to the individual needs of patients, some of whom have comorbidities that may impact their ability to cope with a stoma, such as arthritis or dementia (Black, 2015; ASCN UK, 2016; Coston and Pullen, 2021; Jarratt-Barnham, 2022). However, this part of the role is only the tip of the iceberg. SSCNs also lead and manage teams, conduct research and promote clinical excellence. They support and teach patients

and their families, as well as educating colleagues. They also advocate for patients and generate evidence for commissioning and funding.

As with all nurses, caring and compassion are central to the values and beliefs of SSCNs. The role requires close contact with patients, and SSCNs' compassion and care can reduce the stress and anxiety around having a stoma. Some patients may find it hard to communicate when experiencing anxiety, so it is important to be sensitive to their needs. SSCNs are committed to providing the best possible stoma care to help patients live a full and active life with confidence. They work closely as a team with each other as well as with other health professionals to ensure that the patient journey is as seamless as possible.

Stoma care in the UK

Lack of national focus

While some of the issues highlighted here apply to many areas of nursing and even healthcare in general, stoma care faces some unique challenges.

Stoma care is an entirely nurse-led service that lacks national standards to demonstrate outcomes, has no comprehensive best practice stoma care pathway, no national data to recognise the value and contribution of SSCNs and no stoma care-specific targets, tariffs or Commissioning for Quality and Innovation (CQUIN) framework.

While the ASCN UK has developed guidelines, standards and frameworks (ASCN UK, 2016; 2018; 2021), the major organisational issues at a national level result in variations in service provision and application, and also mean SSCNs are less protected as a profession. The lack of a CQUIN means a lack of focus at a structural level on rewarding excellence or encouraging a culture of continuous quality improvement to deliver better outcomes for patients.

Further problems include staffing, recognition, redeployment, funding and a poor understanding of the role. These are long-standing issues that have been exacerbated by the pandemic, which also highlighted that nurses are often seen as interchangeable; nurses were asked to cover other areas, including taking on junior doctor responsibilities. Indeed, nurses are often asked to fill the gap, which is not without personal and professional cost.

This lack of a national focus means SSCNs are producing their own local standard operating procedures and pathways. While this can facilitate the development of innovative services to meet local needs, it can also result in duplication. Developing local frameworks adds to SSCNs already excessive workload, but not to their professional standing at a national level. Local services can be flexible to adapt to change but it can be difficult to implement wider service improvements that are visible and valuable to policymakers.

There are regional variations in how services are commissioned and funded, with some areas having only acute or outreach teams, and others having only having primary care or in-reach teams. SSCNs might be employed by a hospital or in the community, depending on which organisation provides stoma services and, in some areas, specialist but unregistered positions are being established. Some services are funded by secondary

care although the majority of the work is conducted in the community where there may be additional costs and any potential cost savings may not be apparent to the payer's budget.

Furthermore, some community care is delivered by stoma industry nurses so the costs may not be apparent to those paying for and commissioning stoma care services. Nurse-led services seem to be harder to quantify and therefore difficult to set tariffs for or cost, despite improved outcomes such as enhancing flow, preventing deterioration and admissions, managing long-term conditions such as skin changes and psychological effects, as well as teaching other health professionals. A lack of appropriate structure and funding means that services are underestimated and undervalued.

This regional variation, with diverse activities, varying evolution and development of the role, and different settings across the UK, makes defining the precise role of SSCNs difficult.

More than 'bag changers'

In addition to the lack of appropriate pathways and structure, there seem to be fragmented perceptions of the role, with some colleagues and patients seeing SSCNs as 'bag changers' who deliver only basic stoma care to inpatients and outpatients.

Hospital colleagues might see only aspects of care within their setting and not those in the community and vice versa. As highlighted above, SSCNs have a vital safety role in keeping people and the NHS safe, so theirs is a safety-critical profession (Leary, 2017). In reviews of preventing future deaths, coroners have reported that missed, delayed or uncoordinated care is their greatest concern so, although SSCNs may find their work often seems frustrating and time-consuming, they are delivering the essence of good care, improving outcomes in patients' lives.

In addition, the unique, holistic relationship between SSCN and patient means that the SSCN plays a critical role in brokering on their patient's behalf to ensure appropriate and timely access to other services, such as inflammatory bowel disease (IBD) and colorectal services as well as dermatology, cardiology or social services (Leary, 2008). SSCNs are therefore instrumental in delivering seamless integrated care (Virgin-Elliston, 2019; ASCN UK, 2021) with the aim of preventing missed, delayed or uncoordinated care.

In a safety-critical profession, how services are funded matters. In the NHS, service provision is based on the budget available rather than a consideration of the right skill mix or safety margins. This clearly impacts outcomes and the patient experience – evidence shows us that patients are more likely to survive with more degree-level educated nurses (Gkantaras et al, 2016).

The primary function of SSCNs is delivering intimate, clinical care, which seems to be significantly undervalued in nursing and healthcare in general. The full extent of their role is so much more, going from supporting self-care and patient empowerment to brokering, rescue work and vigilance. SSCNs can deliver tangible improvements in care, having a key role in detecting deterioration, preventing readmission and ensuring effective flow of patients to and from hospital and between services, as well as preventing harm and long admissions (Boyles and Hunt, 2016; O'Flynn, 2018; Burch et al, 2023).

The role requires advanced education, experience, critical thinking, reasoning and reflection (RCN, 2018; NHS Education for Scotland, 2021), with SSCNs applying their education at the highest level and ensuring it is consistently reinforced and refreshed. The assessments they make are complex and require them to make daily decisions that have a direct impact on the patient's emotional dimension (ASCN UK, 2016).

Value unrecognised

While some of this work is complex and largely hidden, the experience and skills required are relevant and vital, so why is the value of SSCNs not recognised? Is it a lack of evidence?

As members of a strongly evidence-based profession, SSCNs need to demonstrate their worth but there is rarely time to be involved with, devise, drive and evaluate our own research. There is barely time to produce audits, patient feedback or quality-of-life surveys. Only direct clinical care is recognised as work, with non-clinical efforts such as service development considered optional. However, these aspects of the role are essential in improving patient care and service delivery and are generally completed in SSCNs' own time and largely unrecognised. This is reflected in a trawl of the literature which identifies a dearth of information or evidence on stoma care services, let alone on this specialist role.

Yet SSCNs continue to do all this in a climate of pay disputes, inadequate funding and national dissent. The NHS workforce is fractured and divided, and there seems to be little in the way of succession planning or retention strategies. Current conditions mean colleagues are retiring early and novices are leaving the profession prematurely, resulting in a loss of valuable experience and an unsatisfactory skill mix which negatively impacts services and, ultimately, patients. We need to ensure that training and education are in place so future nurses can safeguard services. What little support is offered tends to be well meaning but sporadic and rarely relevant or helpful. Perhaps SSCNs are victims of their own success, as the few problems that arise tend to be solved before they are escalated to others and are often cost neutral, so they are below the radar of decision-makers.

All this might leave SSCNs feeling tired and maybe a little broken at times. Perhaps this feeling is not unique to SSCNs; let us look at the landscape of other areas of specialist nursing.

Learning from others

Standardised approach for cancer nurse specialists

While many issues are common across healthcare, some clinical teams have had success in developing and implementing standards of care at a national level.

Patients with a cancer diagnosis anywhere in the UK can rely on receiving a standardised approach to their treatment and care through nationally stratified pathways, targets and standards of care, which protect patients as well as the nurses who implement them. Nurses specialising in cancer, including those working in colorectal cancer (CRC), can draw on established pathways and standards to deliver safe and effective care as well as to support their career progression (RCN, 2022; Health Education England, 2023).

Cancer care is supported by data generated by the National Cancer Registration and Analysis Service, a part of NHS

England, which aims to collect data on all cancer patients living in England to support public health, healthcare and research. The data can be used to look at cancer in the population, outcomes and survival, as well as trends and geographical patterns to detect risk factors and cancer clusters. This information can then be used to help the NHS to assess the quality of care for all individuals treated for cancer at national and local levels that commissioners and other managers can set local policy and manage health services. Specialist nurses have been shown to not only improve patients' experiences of cancer care, which is a high priority in the national cancer strategy in England, but also deliver better care and survival, clearly illustrating their vital contribution (Alessy et al, 2022).

Cancer nurse specialists benefit from career and education frameworks to guide their practice. The RCN's (2022) Career Pathway and Education Framework for Cancer Nursing incorporates cancer-specific nursing outcomes as part of its professional, educational and workforce development work to support improvements in the delivery of high-quality care to people affected by cancer. The Aspirant Cancer Career and Education Development programme (ACCEND) programme aims to transform the career pathways and associated education, training, learning and development opportunities for the workforce providing care to people affected by cancer. ACCEND has published a career pathway framework for nurses and allied health professionals (Health Education England, 2023) to support workforce development by providing guidance on routes into cancer care and career progression, along with a detailed capabilities and education framework. It offers the opportunity for the workforce to develop and evidence their knowledge and capabilities to support the highest standards of practice as well as providing a structure for career and role development within specialist cancer services.

Clear pathways for inflammatory bowel disease

Similarly, for patients with IBDs such as Crohn's disease and ulcerative colitis, access to a specialist IBD nurse has been shown to improve the patient experience as well as clinical outcomes. Their scope of practice includes areas such as telephone advice lines, rapid access clinics, follow-up clinics, inpatient care, managing an immunotherapy service and administering and monitoring therapies.

The IBD standards (IBD UK, 2019) set out what high-quality care should look like at every point of a patient's journey from first symptoms to diagnosis, treatment and ongoing care. There are 59 standards across sections from diagnosis to monitoring and managing complications, with the aim of removing variation in care. The standards were designed to ensure that people with IBD receive safe, consistent, high-quality, personalised care, whatever their age and wherever they live in the UK. The IBD standards clearly map out the service requirements to deliver evidence-based care to a local population including the composition of the multidisciplinary team, namely 2.5 whole-time-equivalent clinical nurse specialists with a special interest and a competency in IBD and 1.5 whole-time-equivalent clinical nurse specialists with a special interest and competency in stoma therapy and ileoanal pouch surgery.

Benchmarking has been developed to encourage IBD services to recognise what they are doing well and identify where they need to improve (IBD UK, 2023). It involves surveys for both IBD services and patients to deliver compelling data to drive up standards of care for everyone with IBD. Benchmarking in this way has led to service-specific reports that have been used as evidence for increased staffing and resources, and a national report (IBD UK, 2021) has opened the door for discussions at a high level on the need to improve care for people living with IBD.

The RCN (2024) has developed a framework for professional practice for nurses working in IBD, which provides guidance and support so they can develop themselves and their teams for the continued benefit of their patients. It also acknowledges the many and varied roles within the field of IBD nursing and the need for training and development, as well as ongoing continued from managers to enable growth within IBD nursing teams (RCN, 2024).

Furthermore, both IBD and CRC have National Institute for Health and Care Excellence guidance (NICE, 2019a; 2019b; 2021) and quality standards (NICE, 2015; 2022), which include high-quality care in priority areas for improvement, as well as various technology appraisals to inform evidence-based management. There are also all-party parliamentary groups (APPGs) for both conditions. The priorities of the Bowel Cancer APPG include procuring extra funding to improve bowel cancer survival and exploring how an NHS workforce plan can help make sure more bowel cancers are diagnosed earlier through screening. Similarly, the Crohn's and Colitis APPG works with parliamentarians and stakeholders to raise awareness and to ensure high-quality, sustainable, patient-centred clinical care and improved access to services across the UK.

None of this happens by accident – making this a reality involves hard work, evidence generation and collaboration at several levels to develop and establish best practice pathways and standards of care which then have to be advocated for at every level so they are embedded into the healthcare culture and landscape. Targets need to be agreed upon and systems such as CQUINs, benchmarks and minimum standards put in place to ensure adherence and compliance. This validates the nursing role because it is supported by evidence to show that well-educated, knowledgeable, highly skilled, specialist nurses are best placed to reduce risks and deliver care safely. It is the avoidance of risk to individual patients and consequently to the organisation that drives policy to ensure that safe, evidence-based, best-practice care is delivered at the right time, in the right way, by the right people.

This contrast between the specialisms highlights the lack of parity between SSCNs and their colleagues in CRC and IBD and establishes the need to bring stoma care up to the same levels.

What does good look like in stoma care and how can it happen?

National approach

How can experiences and learning from specialist nurses in IBD and CRC be used to improve stoma care? A national approach is needed to ensure stoma care has a standardised,

evidence-based, best-practice pathway, with SSCNs at the heart of it. The pathway should be commissioned and embedded to ensure patients receive consistent, high-quality care regardless of where they live, and should include a structured approach to treatment, management and follow-up provided by a multidisciplinary team. In time, this would then generate data to evidence the value of SSCNs.

To ensure that SSCNs and patients are at the heart of this project, the pathway should be developed in collaboration with the ASCN UK and the three patient organisations Colostomy UK, the Urostomy Association and the Ileostomy and Internal Pouch Association (known as IA Support). Drawing on the diverse skills and knowledge of these and other experts will ensure that specialist knowledge and skills are recognised, protected and defined within the stoma care pathway. SSCNs can also learn from other professionals experienced in developing service pathways and who work with statutory bodies, NHS standards, regulation, legal frameworks, CQUINs and accreditation bodies.

The Advancing Stoma Care Services: Evidence-based Proposals for a Best Practice Pathway taskforce has been established with the aim of driving an agenda to demonstrate the value of nurses in stoma care (Ileostomy and Internal Pouch Association, 2023). This multidisciplinary group comprises SSCNs (the authors of this article) as well as colorectal consultants, IBD and cancer specialist nurses, as well as representatives from the ASCN UK and patient groups. Many have experience in developing pathways and workforce planning, as well as some with backgrounds in activism.

The taskforce has held an initial meeting with colleagues at Getting It Right First Time (GIRFT) and believes that working together will result in increased awareness to drive this forward and deliver real change in stoma care. GIRFT is a national programme designed to improve the treatment and care of patients through in-depth reviews of services, benchmarking and presenting a data-driven evidence base to support change. It undertakes clinically led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved. It is part of an aligned set of programmes in NHS England and has the backing of the royal colleges, with workstreams in medicine, surgery and associated projects. The lead clinicians of the general surgical workstream have produced a report (not yet published) to bring about improvements for patients in terms of length of hospital stay, reduction in post-surgical complications, and fast-tracked stoma reversal procedures. While many of these initiatives may deliver cost efficiencies, GIRFT is not just about saving money – its focus is on improving the patient experience.

Initially, the taskforce is planning to develop pathways across three workstreams based on GIRFT principles: planned care; emergency care; and longer-term ostomates who are re-accessing care. The aim is to establish minimum standards of care for all people living with a stoma around aspects such as contact with services, assessment of needs and evidence-based interventions.

The taskforce has already completed a comprehensive literature search of stoma care to generate evidence to understand

KEY POINTS

- Specialist stoma care nurses (SSCNs) are highly educated professionals who play a critical role in the care of people living with a stoma
- While SSCNs are autonomous, highly educated professionals, their role is often poorly understood
- SSCNs should be co-ordinators and drivers of change at the highest level of national innovation, policy and decision-making, raising their voices to protect their patients and profession
- A national approach is needed to develop an evidence-based best practice pathway, commissioned and implemented across the UK for all stoma patients and with SSCNs at its heart

what good care looks like to help patients understand what they can expect from services. Providing evidence of our vital role will ensure that all stakeholders, from integrated care boards and commissioners to clinical and surgical staff, know what they should commission, fund and protect.

All funding streams are regularly reviewed, and service funding and cost efficiencies will always have a high priority. Therefore, it is essential that SSCNs prove their value so they not only secure those services for our patients but also support and protect the SSCN role to ensure these nurses can cascade their knowledge and skills to the next generation of nurses. SSCNs will need protected time for service development and implementation.

The taskforce hopes this work will create a future where SSCNs are valued, protected and appreciated at the highest level, with a strong evidence base to ensure adequate funding for services to ultimately improve patient care.

Conclusion

Call to action

While it may feel there is a big hill to climb, there is a lot to be positive about. There are excellent local services providing high-quality care up and down the country, delivered by highly skilled and knowledgeable SSCNs. Nonetheless, the changing healthcare landscape requires a national response to the challenges faced by SSCNs and their patients as well as the development of an evidence-based best practice pathway, commissioned and implemented across the UK for all stoma patients.

Communicating value

There are several hurdles to overcome on this journey, starting with SSCNs demonstrating their value through data and evidence and communicating this to stakeholders. SSCNs need to think about the language they use to describe their role – rather than basic nursing skills, their role can be better described as fundamental or vital nursing care; they are more than ‘bag changers’. These specialist nurses should be co-ordinators and drivers of change at the highest level of national innovation, policy and decision-making, raising their voices to protect their patients and their profession.

The authors acknowledge that this sounds like a big ask, but do not expect this to add to an already overstretched workloads

with more paperwork or meetings, and do not want to take anything away from SSCNs or the care and services they have worked hard to implement.

This work is also not about the homogenisation of stoma care – there are differences in funding and commissioning across the UK including in the devolved nations, resulting in a variety of service models that have been developed to meet the needs of our specific patient cohorts. This is why the taskforce is working with GIRFT to develop pathways that will support their work, patients and profession. This is about celebrating the work of SSCNs, giving them the power and support to share and teach their valuable skills and experience.

Collaborative approach

As a profession, SSCNs have a wealth of expertise and specialist knowledge to draw on, supported by ASCN UK. By working together and collaborating with relevant organisations, SSCNs can improve the whole landscape and secure it for the future.

As discussed above, other areas of specialist nursing have standardised pathways and guidance. These are in place for specialist cancer and IBD nurses so should also be possible for SSCNs.

As specialist nurses, SSCNs deserve to be the future of NHS decision-making in stoma care at a national level, so the taskforce is considering:

- What policy changes would be needed to bring about change?
- What is the role of patient organisations?
- How can we develop a standardised treatment pathway for our patients?

This is the start of a new era for stoma care nursing and the ASCN UK, as the value of our role and contributions gains recognition at local and national levels. SSCNs can do better because what they do matters. **BJN**

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CPD reflective questions

- What are the existing disparities in access to stoma care services, including availability of specialist nurses, medical supplies, and support groups, in different regions of the UK?
- How can interdisciplinary collaboration and partnerships with community organisations and advocacy groups help address healthcare inequalities in stoma care and advocate for systemic change?
- What role can nurses play in advocating for policies and initiatives aimed at reducing healthcare inequalities in stoma care and improving access to stoma services?