

# Sustaining colorectal cancer nurses' specialist practice

## Abstract

To function optimally in specialist practice, colorectal cancer nurses require sufficient resources as well as organisational support. The authors examined how well this is borne out in practice by conducting a small electronic survey with members of the National Colorectal Cancer Nurses Network in December 2013. Feedback from the 25 colorectal cancer nurse specialists (CRC CNS) who responded highlights that over half (60%) of the nurses perceive their services to be inadequately resourced. Many stated that their services were being stretched beyond their capacity to respond. Despite the majority identifying a need for additional staffing within their service, nearly all respondents were experiencing difficulty in securing such provision. In addition, many felt that their role was under threat. There was general agreement that managing increasingly complex colorectal cancer care pathways with inadequate administrative support was not sustainable. The implications of these findings are discussed by examining the contribution CRC CNSs can make and offering recommendations to sustain the CRC CNS in practice.

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The specialist nursing role is well established within coloproctology, with approximately 500 colorectal cancer clinical nurse specialists (CRC CNSs) working across the UK. The CRC CNS is regarded as a core member of the colorectal cancer multidisciplinary team. While the details of the role vary, most CNSs have taken on responsibilities that were formerly the preserve of their medical colleagues, such as pretreatment and follow-up clinical care. In general, specialist nurses have a much greater role in the delivery of health care than they had 5 years ago (Macmillan Cancer Support, 2011). GPs and consultants are now more likely than ever to refer patients to specialist nurses (Santry, 2011; Vidall et al, 2011).

Owing to existing NHS pressures to deliver timely, cost-effective cancer care, the CRC CNS is often expected to crisis manage patient care to avoid complaints, clinical incidents, and/or a service breach, as well as take the lead on service improvement issues. In addition, an increased incidence and a doubling of 5-year survival rates over the last 40 years has translated into

a greater number of people living with and beyond bowel cancer. Therefore, CRC CNSs are addressing the care needs of those living through a more complex and much extended treatment pathway.

The continued financial cutbacks imposed by many NHS Trusts have put specialist nursing roles back under the spotlight. While this threat might seem less acute than that in 2006—when nearly one in four specialist nurses faced the risk of redundancy—it is apparent that, today, many specialist nurses are being asked to take on additional responsibilities and often fill shortages in other settings within their Trust (Royal College of Nursing (RCN), 2010). This lack of investment in specialist nursing roles was highlighted in the RCN's Frontline First campaign (RCN, 2012).

To assess the effect these changes may have had on the CRC CNS role, a small email survey of members of the National Colorectal Cancer Nurses Network (NCCNN) was conducted. Its aim was to ascertain perceived levels of organisational support in sustaining the intensified clinical demands now experienced. This paper will discuss

## Key words

- Clinical nurse specialist
- Colorectal cancer
- Survey
- Specialist practice
- Patient care

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some of the challenges and constraints CRC CNSs currently face and highlight possible solutions to improve future working.

### Background to the CRC CNS role

The CNS role was introduced to improve patient care through application of advanced knowledge, specialist skill, and experienced clinical decision-making (Ball, 2005). It was the first advanced practice nursing role to be described, implemented and fully evaluated (Hopwood, 2006).

The CRC CNS role was developed following the publication of the Calman–Hine Report (Calman and Hine, 1995), which recommended that patient-centred care should be strengthened. In cancer care, there was growing recognition that people living with and beyond cancer had unmet needs, particularly those of a psychological nature (Thomas et al, 2001). Further support for CRC CNS posts came through sources such as the ‘Improving Outcomes in Colorectal Cancer’ guidance (Department of Health (DH), 1997), which stated that this role should ‘provide ongoing support for patients and carers’, leaving job definition open to local interpretation.

The CNS role and patient referrals to these services continue to grow. Alongside this, expectations from policymakers, professional groups, and patients have escalated the role requirements, e.g. the recommendation from Macmillan Cancer Support (2012) that a patient should have one-to-one support throughout the care pathway. As a consequence, some colorectal nursing teams have started reviewing their skill mix and debating what aspects of the role are essential.

### Defining the CRC CNS role

The ad hoc development of CRC CNS roles in the UK has, not surprisingly, created diversity in function and a lack of clarity regarding both the scope and the priorities of this role (Audit Scotland, 2005). The organisation and remit of the CNS role is dependent upon factors such as line management structure, role boundaries, and the key result areas set out for the post at its outset (Knowles, 2007). It is clear that, as the role has evolved, many CNSs have taken on responsibilities that were formerly the preserve of their medical colleagues. Though the details of the role vary (Taylor and Whayman, 2009), the basic remit is to assess and address individuals’

health needs at key stages of the care pathway (Box 1).

The level of practice and core clinical functions that can be reasonably expected of any CNS have been well articulated within nursing, e.g. RCN, 2010; 2012. There are four main components:

- Clinician
- Manager/leader
- Educator
- Researcher.

While all four components are integral to the delivery of specialist practice, a CRC CNS should primarily focus on being a clinical expert within the specialty, integrating knowledge of cancer and its treatments with knowledge of the patient and their health concerns. Indeed, it seems that the perceived demands upon specialist nurses are predominantly clinical, with evidence indicating that most CNSs spend about 60% of their time in clinical activity, 17% in education, 14% in management activity, and 4% in research (RCN, 2005). It is also suggested that the increasingly administrative responsibilities associated with clinical practice are taking CNSs away from their core role functions, with an estimated 12% of the specialist nursing week spent on duties that could be performed by a clerical support worker (Frontier Economics, 2010).

### The work of the NCCNN

The NCCNN was established in 1997 with the aim to support new post holders, develop the specialty, and enable members to exchange ideas and share innovation. Its membership has been increasing, bolstered by support from the charity Beating Bowel Cancer (from 2010 to date). Members receive regular e-letters and invitations to attend the annual conference and other relevant educational events. Current membership is over 300 CRC CNSs, and comprises UK CRC CNSs and specialist screening practitioners.

#### Box 1. Scope of the colorectal cancer clinical nurse specialist role

Lead diagnostics: order investigations, carry out endoscopy, perform abdominal and rectal (PR) examination

Break bad news

Perform holistic needs assessments and plan individualised care

Coordinate surveillance

Liaise and refer to other specialties

Recruit into trials

**Table 1. Job titles of survey respondents**

Job title	Number
Screening nurse practitioner	1
Colorectal nurse practitioner	1
Advanced nurse practitioner	2
Senior CRC CNS/Lead CRC CNS	3
Macmillan CRC CNS	4
Colorectal/Coloproctology CNS	14

CRC CNS: Colorectal Cancer Clinical Nurse Specialist

Back in 2008, a small electronic survey ( $n=25$ ) was conducted to examine the scope of NCCNN members' roles and their perceived priorities for practice. The results revealed their concerns with clinical workload pressures, with most feeling they had insufficient time to satisfy the demands of not only their patients but also professionals with whom they worked. High patient caseloads and/or intensity of involvement with individual patient pathways were perceived to limit their role commitments; the majority (17; 68%) of respondents estimated that they saw over 100 colorectal cancer patients each year.

### The 2013 CRC CNS survey

In the 5 years since the last NCCNN survey, the demands upon the CRC CNS have changed considerably. It thus seemed appropriate to ask NCCNN members about their workload and what degree of support they could rely upon in their organisation to help them function effectively.

The questionnaire was designed by the authors and tested on two CRC CNSs working at Beating Bowel Cancer. It consisted of 12 questions, 9 of which were checkbox responses to enable speed of response. Following feedback, the wording of two questions was simplified and three questions reformatted for clarity.

The survey was sent as an electronic link in the December 2013 e-letter sent out to 354 member email addresses. Members were asked to reply within the week, in the hope that they would respond immediately. They were assured

**Table 2. Caseload per CNS as indicated by respondent data**

Caseload of new patients each year per CNS:	
Over 200 patients	3
150–200 patients	5
100–150 patients	9
Up to 100 patients	8

that their responses would be anonymous and that a summary of the results would be both presented in the following month's newsletter and submitted for publication.

Completed responses were received and collated by the secretariat from Beating Bowel Cancer. Answers were recorded anonymously on an Excel spreadsheet.

### Survey results

A total of 25 questionnaires were returned. This is a low response rate of 23%, since 110 nurses opened the link. The survey contained two demographic questions: (1) the respondent's place of work and (2) his/her job title. Twenty three of the 25 respondents worked in England, 1 worked in Scotland, and 1 in Wales. The survey asked for the respondent's job title since it could indicate the focus of the role and possibly its responsibilities (*Table 1*). As expected, there was much variation in the job titles, although 'Colorectal CNS' was the most commonly used.

### Caseload

The caseload per CNS varied, ranging from a CNS supporting over 200 patients diagnosed each year ( $n=3$ ) to CNSs with a more manageable caseload of up to 100 new patients a year (*Table 2*). Nine respondents (35%) worked alone in their service, supporting caseloads varying from less than 100 to up to 200 new patients per year. Twelve respondents worked with colleagues, of whom two worked with two other CNSs and two stated that they worked in a team of four.

Only 8 of the 25 respondents indicated that they considered their service to be adequately resourced in order to meet patient needs; more than half (60%,  $n=15$ ) did not. Of the 15 respondents who stated they were under-resourced, all but 1 requested further help from the Trust in order to better meet patient need. While these CNSs appreciated the cost pressures upon their departments, many did not report any prospect of their staffing improving.

Members were then asked whether they felt the future of their roles had ever been threatened. Seventy five percent ( $n=18$ ) stated that they had, with most respondents explaining that this threat ranged from being asked for further information to role redesign and downgrading (*Figure 1*).

None of the 15 CNSs who indicated a need for further resources in their service had been able

to secure it, although 5 respondents did state that they were still working on business cases. A further three respondents stated that some progress had been made in agreeing to additional funding or cover. The comment below illuminates the difficulties associated with this process for one CNS:

**'A business plan has been agreed for a further 22.5 hours but being delayed to save money!'**

### Support structures

The survey asked four questions on the support structures that enabled CRC CNSs to function optimally. The first of these was to ascertain the level of administrative support received. Sixty percent of the respondents stated they did not have secretarial support. Of those who did have support, the free text comments indicated that this support was generally shared across a team or by virtue of developing good relations with one of the colorectal surgical consultant's secretaries. The best level of provision indicated was one full-time secretary between four CRC CNSs.

In acknowledging that only a proportion of a CNSs time should be spent in clinical care, the members were asked to indicate how many hours were set aside per week for non-clinical duties. Only 1 respondent recorded that 5 non-clinical hours were set aside, although several indicated that they made time for it as needed and that it could be as high as 15 hours a week. A few post holders stated that the amount of time would vary depending on the caseload requirements.

Members were then asked if they had any non-specialist clinical staff working within their service. Two respondents indicated that they had a Band 4 support worker in their team.

The third question in this section of the survey concerned the degree of cover they could rely upon when they took either annual or professional leave, as one of the stressors for a CRC CNS can be maintaining their service in their absence. Two thirds of CNSs ( $n=16$ ) reported that they had full service cover, possibly because they worked as part of a CRC CNS team, and two reported that they had a reduced service. Four indicated they had none, which was considered 'stressful for colleagues and frustrating for patients'.

The final question examining the CNSs' support structures asked about clinical supervision,

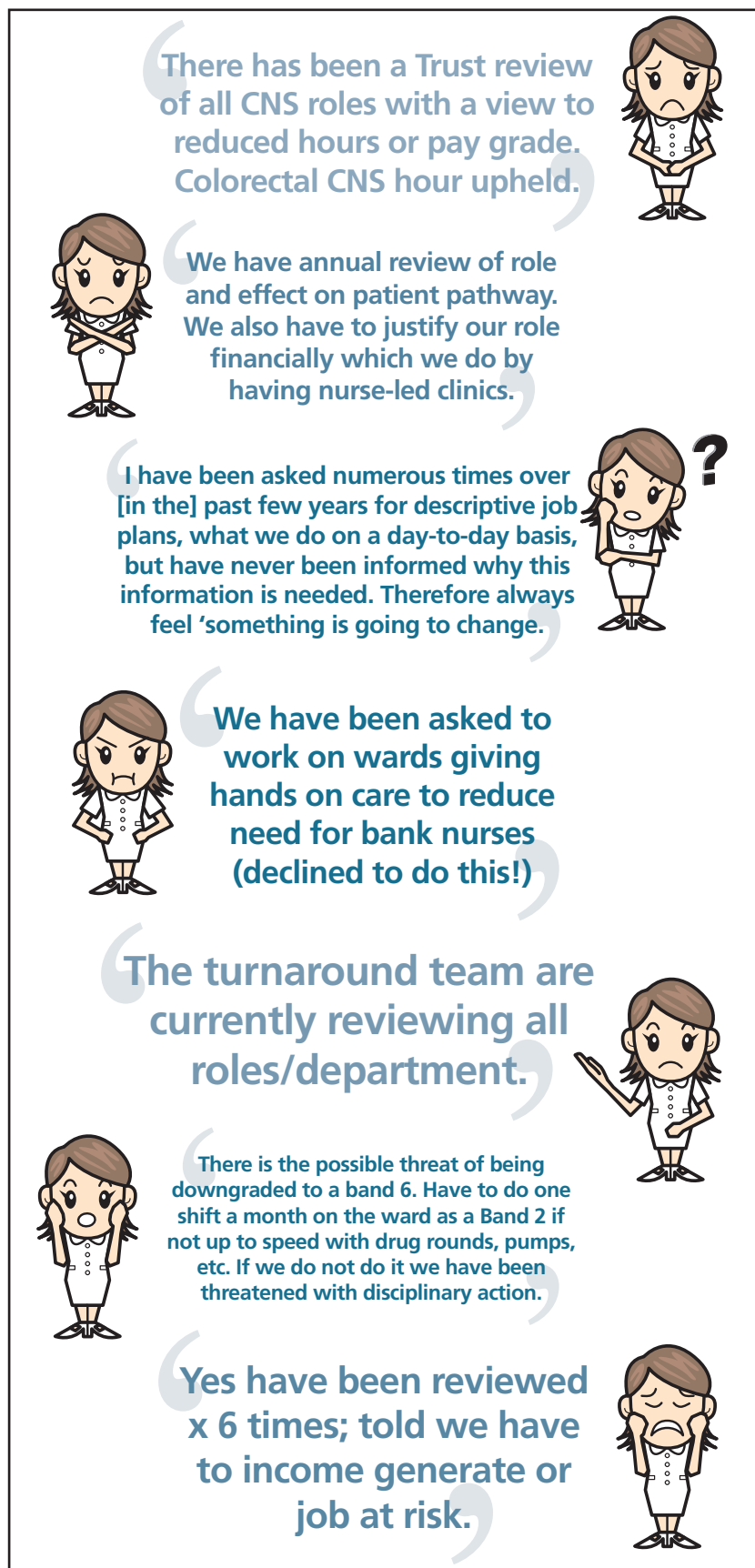


Figure 1. Respondent comments indicating the nature of the threat to the Colorectal Cancer Clinical Nurse Specialist role experienced.

since this resource has been shown to enable the necessary environment to sustain and protect cancer nurses in therapeutic practice (Butterworth and Faugier, 1992). Half the number of respondents ( $n=12$ ) reported that they did not have clinical supervision.

### Discussion

This small survey highlights four important issues concerning CRC CNS roles:

- The clinical pressures being felt in practice
- The perceived lack of organisational support for the role
- Limitations of administrative support in the role
- The requirement for clinical supervision.

The first issue relates to workload since the majority of respondents believed their services were under-resourced, replicating the findings of the survey conducted 5 years ago (Taylor and Whayman, 2009). The findings reveal the insecurity felt by CRC CNSs about their role and the constant need to defend their value. External review of both their roles and departments was highlighted. Cancer waiting-time targets, cost pressures, and implementation of new performance indicators are additional stressors. A level of uncertainty about future service delivery within their departments was also apparent.

Currently, much of a CRC CNS's time is spent coordinating care for patients on increasingly complex cancer treatment pathways. Treatment choices, increased expectations, and improvement in cancer survival rates all require CNSs to offer patients a high level of commitment throughout their treatment and follow-up care pathway. As CNSs become trapped in pathway management, much of their work becomes less visible, as they spend hours on the phone resolving clinical issues and smoothing out bureaucratic blunders due to sheer demand upon the system (Oliver and O'Leary, 2012).

Such 'behind the scenes' work may be contributing to the second issue, which is the most disturbing finding from this survey: a perceived lack of recognition of the value of the role. The expectation from management that CNSs can provide a 'back up' for shortfalls in ward nursing numbers and leave aside their own clinical commitments indicates a lack of role awareness. In addition, constant requirements to justify the role are unsettling and demoralising. Without assurance that current service provision

can be sustained, CNSs may become sceptical about service development. There is clearly a mismatch between the value placed on the CNS role by patients and that of the management.

To counteract this, CRC CNSs need to demonstrate what they are doing and highlight the known benefits of their service to whom they report. Robust business cases are needed when competing for further resources. Service shortcomings must be made clear, supported by local data indicating what is not and cannot be provided as well as evidence that nurse specialists do make a difference. A resource called Apollo Nursing Resource (2014) aims to enable CNSs to prepare supporting evidence to demonstrate the complexity of this service and learn the language necessary to articulate the skill and complexity of this role.

Analysis of the National Cancer Patient Experience Survey data has demonstrated that patients with cancer have better care experiences at hospitals that employ more oncology specialist nurses (Griffiths et al, 2013). In addition, being allocated a CNS or a key worker makes a difference to patient-reported outcomes and experience (DH, 2010). A qualitative study by Nazareth et al (2008) confirms that patients perceive that their CRC CNS can provide continuity of care; alongside the patient's GP, the CNS is often the only constant health professional along their cancer pathway. A CNS can provide patients with a more personal experience, by offering a combination of empathy, knowledge, and experience to assess and alleviate any psychosocial concerns. This is becoming especially important when coordinating multimodal cancer treatment pathways over several localities. In overseeing and coordinating services, the CNS not only personalises the cancer pathway for individual patients but also reduces the risk of care not being implemented as intended.

The nurse specialist also influences the working of the multidisciplinary team in which he/she is assigned. The CNS often liaises across other agencies or disciplines to enhance patient care and communication, making timely referrals as appropriate. This has improved the efficiency of the team and has had a knock-on effect on patient care.

More recognition of the cost savings achieved by maximising the CRC CNS role is needed. In appealing to management priorities, CNSs can

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Homepage. <http://www.apollonursingresource.com> (accessed 30 June 2014)

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highlight how they represent an excellent return on investment in terms of income generation activity, patient safety, and efficiency. Arguably these outcomes are best achieved when CNS services are sufficiently resourced to be able to proactively manage the care of each patient referred (Leary et al, 2008). Proactive care involves being vigilant of patients on the pathway, anticipating possible outcomes and undertaking responsive rescue work as needed (Leary et al, 2008). CNSs can demonstrate how they avert emergency admissions and reduce outpatient attendance through telephone support and enhanced care coordination. Furthermore, CNSs can reduce the need for lengthy hospital stays as they equip patients on enhanced recovery after surgery programmes with the necessary support and information to manage their recovery at home.

If securing another CNS is too costly, an alternative approach is to make an adjustment to the skill mix within the team. Specialist nurses in this survey recognised this as a possible solution, but only two had recruited to this level; many others were interested in developing these roles.

This survey also showed that most CNSs had inadequate administrative support, and increasing this support could be another approach. A lack of administrative support can prevent CNSs from being able to take time out from clinical duties to deliver other important components of their role (Leary et al, 2014).

Finally, it is essential that CRC CNSs are offered effective clinical supervision to assist in reflection on practice and address emotional issues emanating from clinical practice. Clinical supervision offers opportunities for catharsis, reflection on practice, and professional development (Taylor, 2014). Given the large workloads and lack of perceived organisational support, there is a risk that CNSs may burnout if they continue to practice without it. It is undoubtedly a rewarding role, but one that is known to be stressful when work gets left undone and maintenance of usual service standards seems unachievable. Securing supervision is an important way by which CNSs can gain support, offload the stressors inherent in this role, and sustain themselves in practice.

## Conclusion

It is vital that CRC CNSs are given the support and resources they need to sustain their

delivery of skilled cancer nursing care. They are a valuable resource within cancer services, both to the multidisciplinary teams to which they are assigned and to those diagnosed with this cancer. There is now clear evidence that CNSs have a measurable effect on the quality and safety of the care that patients receive as well as evidence of their potential to generate income and achieve cost savings.

This survey has highlighted that there are a number of organisational factors impinging upon the effectiveness of CNS work, and action must be taken to sustain the CNS in practice. These factors need to be examined and should be revisited if a future survey of NCCNN members is undertaken.

While the survey findings cannot be generalised, they suggest that many nurse specialists feel unsupported in their roles and are also insecure about their future. Cancer managers must consider how to protect the CNS from role overload and role uncertainty and identify ways in which resources to support CNS services can be enhanced within existing financial budgets. The CRC CNSs must be prepared to defend their roles and have ready to hand the evidence they need to enable them to continue offering this beneficial specialist service.

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