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Evaluation of the Role of the Clinical Nurse Specialist in Cancer Care

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Study Team

Prof. Seamus Cowman, RCSI, (Principle Investigator)

Dr. Georgina Gethin, RCSI, (Chief Investigator, project manager)

Ms. Mary O'Neill, RCSI

Ms. Stephanie Lawrence, RCSI

Ms. Kathleen Kinsella, RCSI

Ms. Aine Lavelle, St. Luke's Hospital

Ms. Aidin Roberts, St. Luke's Hospital

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Summary

In 1998, The Report of the Commission on Nursing *a blueprint for the future* identified the need for the development of Clinical Nurse Specialist(s) (CNS), and outlined the educational and clinical experience requirements for such post holders (DoHC, 1998). Since then, over 1,487 CNS have been appointed, with approximately 370 in cancer care. Ten of these are employed in St. Luke's Hospital in Dublin. St. Luke's Hospital is a 140 bed specialist oncology hospital and is the primary national centre for radiotherapy in Ireland.

The National Council for the Professional Development of Nursing and Midwifery (NCNM) has provided a definition of the CNS and has established the experience and educational requirements for post holders. It has defined the role under five core competencies: clinical, education, consultation, advocacy and research and audit. While nationally and internationally some research has been conducted which has evaluated the role of the CNS there is a paucity of studies which has evaluated it from multiple stakeholder perspectives or from an Irish perspective. This study aimed to conduct an evaluation of the role from the perspective of the CNS, other health professionals and the patient.

Given the potentially wide ranging specialist nursing activities and the requirement to incorporate a plurality of perspectives, methodological triangulation was deemed to be the most appropriate research design. In methodological triangulation convergence of information from qualitative and quantitative sources serves to assist in the validation of data and study findings. We achieved this through the use of questionnaires and focus groups incorporating all stakeholders. Data collection was completed in 2009 following approval by the research ethics committee.

The CNS in St. Luke's Hospital are a highly trained group of nurses who have all attained, at a minimum, a Higher Diploma in their specialist area of practice. Three currently hold an MSc while five have a professional development plan. The majority of their time is dedicated to clinical issues. The CNS is a key member of the multidisciplinary team (MDT) and is regarded by all stakeholders as being an expert and autonomous practitioner. Symptom control in the form of pain management strategies and lymphoedema care were among the two most frequently cited elements of the role. The role of educator was viewed by many to be a core competency of the CNS. This was reflected by the patient as they saw the CNS as a source of knowledge and advice and was acknowledged by other professionals as sixty percent had received education from the CNS in the past year.

The CNS was seen as central to the patient journey and a key element in the provision of quality care. This contribution to quality was achieved through the provision of patient support in the form of advice, skills, education, listening, organisation of care, organisation of referrals and follow-up. The research element of the role was often frustrating as the CNS used research to underpin their practice but did not have the time to engage in the conduct of research. Importantly, the CNS felt supported by nursing management and by the MDT. However, the CNS at times felt 'concerned' and apprehensive as to the future of the role in the restructuring of cancer care services.

The CNS in cancer care is an active member of the MDT and provides specialist nursing care to patients across a range of diagnostic groups and at different stages of their treatment plan. They fulfilled their title of specialist nurse across all domains evaluated and identified areas for further research and role development. The CNS are highly trained, knowledgeable and enthusiastic specialist nurses with a clear goal of providing quality patient care.

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Section 1: Background

Cancer, its prevention, diagnosis and treatment are a major challenge for our society (DoHC, 2006). It is a significant cause of morbidity and is a leading cause of death worldwide accounting for 7.4 million deaths in 2004 (OECD, 2009). Ireland ranked sixth out of sixteen countries in 2004 for cancer related deaths with 357.6 deaths per 100,000 people (OECD, 2009). Importantly, the numbers of cancer survivors is increasing and in 2002 it was estimated that there are 120,000 cancer survivors in Ireland equal to 3.3% of the population (OECD, 2009). As the risk of cancer increases with age, Ireland faces many challenges due in part to the fact that the number of persons over 65 years is expected to double by 2025 and life expectancy is greater than the European average, both of which raises the potential for greater numbers of cancer cases (DoHC, 2006; HSE, 2007).

A Strategy for Cancer Control in Ireland was launched in 2006 (DoHC, 2006). A key action arising from this report is to create a single, focused, integrated cancer control programme in Ireland. This will be achieved, in part, through the development of eight centers of excellence. Central to this plan is the formation and continued development of multi-disciplinary teams (MDT) which includes clinical nurse specialist (CNS). The strategy places emphasis on the role of the specialist nurse in this team and states: '*A focus on the development of cancer nursing roles that reflects recent successful developments in oncology nursing and maximises the potential role that nurse can play in all aspects of cancer care*' is recommended.

In 1998, The Report of the Commission on Nursing *a blueprint for the future*, identified the need for the development of Clinical Nurse Specialist (s) (CNS) and outlined the educational and clinical experience requirements for such post holders (DoHC, 1998). Since then, developments have occurred in Ireland both within nursing and midwifery education and research and in the configuration of the health service. More specifically, the National Cancer Strategy and the Transformation Programme (HSE, 2007) both place significant emphasis on improving the patient journey within the health system, and emphasise the need for delivery of quality, evidence based care from trained professionals in appropriate environments.

Within the literature, the development of the role of the CNS has been well document from its early inception in the 1940s through to the present day (Raja-Jones, 2002; LaSala *et al.*, 2007). When these posts were being developed in Ireland, much was already learned from international experience and this led, in 2000, to the National Council for the Professional Development of Nursing and Midwifery (NCNM) laying down criteria for the CNS and heralded the establishment of the first CNS posts in Ireland.

The clear, unambiguous guidelines in regard to the role definition and education preparation for the CNS in Ireland provide a robust foundation upon which the capacity of nursing and midwifery specialist posts can be built (NCNM, 2004). The NCNM defines the CNS as: '*a nurse or midwife specialist in clinical practice who has undertaken formal recognised post-registration education relevant to his/her area of specialist practice at higher diploma level. Such formal education is underpinned by extensive experience and clinical expertise in the relevant specialist area*' (NCNM, 2004).

Internationally, the CNS has continuously evolved to meet a clinical gap in patient care and consequently the role of a CNS is frequently nebulous or poorly defined (Bousfield, 1997). This renders evaluation of the CNS problematic and fraught with difficulties. According to Pollard *et al* (2010) the first task in evaluating the CNS is to clearly lay down the responsibilities which the CNS is expected to perform. However, this 'task orientated' approach is open to challenges as research identifies that it is not 'tasks' that patients identify with the CNS but other roles such as being a named contact

person, a co-ordinator of care, a confidant, a person to talk to, a person who listens and importantly a person who empowers them through education and knowledge about their condition (Jack *et al.*, 2003; Wolf, 2004; Ream *et al.*, 2009).

Evaluation of the role of the CNS is complex as it must consider the patient, the service, the policy and legislative parameters which influence the role. Understandably, any evaluation of the effects of the specialist role has proved surprisingly difficult and a range of methodological difficulties have been reported (Read & Shewan, 1999). One of the main problems has been in isolating the effect of the nurse on patient care and attributing patient outcomes to the contribution of the nurse (O'Connell & Warelow, 2001). Evaluating the impact of the CNS on patient outcomes is further challenged as this can be assessed under five subheadings: clinical, psycho-social, function, fiscal and satisfaction (O'Connell & Warelow, 2001). Notwithstanding this, there is an increasing body of evidence that the CNS has a positive impact on patient outcomes as they contribute to patient care through education, advice and support, decreased length of stay, decreased complications, decreased health care use, health care cost and mortality rates (Wheeler, 1999; O'Connell & Warelow, 2001; Allen, 2003; Szwajcer *et al.*, 2004).

An extensive evaluation of the role among 1,487 CNS and clinical midwife specialist in addition to eighteen focus groups with nurses and midwives in front line and managerial roles, and focus groups with patients was completed in 2004 (NCNM, 2004). This report identified that the clinical and educational component of the role was perceived by all to be the greatest contribution to patient care. The CNS was seen as a link person and one who brings a team together. The CNS saw themselves as empowering and acting as a vehicle for passing on knowledge and expertise to their colleagues.

The NCNM has set out five core competencies of the role: clinical, advocacy; consultation; education; audit and research. Internationally there are many similarities with these competencies with clinical and education being agreed by all as key components of the role (Bamford & Gibson, 2000; Ream *et al.*, 2009). Less agreement exists for other elements of the role such as research and audit and consultation (Bamford & Gibson, 2000; Ream *et al.*, 2009; Pollard *et al.*, 2010).

The CNS is seen to have a prominent role as an information provider and educator. However, there is no evidence on how they compare to other professionals as educators and some evidence that patients prefer nurses as information providers at specific times in their treatment and in particular for symptom management (Koutsopoulou *et al.*, 2010). Patients have reported education delivered by the CNS as being easy to understand, very useful, addressed patient centered concerns and that the CNS was easy to ask questions of. The CNS was seen to deliver 'individualised information' to the patient. While most patients received information from the consultant or physician early on in their diagnosis and treatment stage the CNS plays a large role in follow-up education (Szwajcer *et al.*, 2004; Wolf, 2004; Koutsopoulou *et al.*, 2010).

In a study by Bamford and Gibson (2000) the CNS was asked 'if their role made a difference?' The CNS believed they made a difference to patient care and two main issues emerged. Firstly, the problems of measurement were identified and importantly from whose perspective the information about quality care was to be measured. Secondly, what to measure was nebulous, therefore compounding other measurement difficulties? Nurses felt that methods through which to evaluate the post were limited.

While research on the impact of the CNS on various aspects of cancer care has been conducted, there is little research that evaluated the role concurrently from multiple perspectives. This study will address this issue and aims to evaluate the role of the CNS in cancer care from the perspective of the CNS, the patient and other health professionals.

Section 2: Methodology

2.0 Search strategy

Databases searched included Medline, CINAHL, PubMed, CancerLit, Web of Science and Cochrane Library. Studies were retrieved using the following key works in a variety of combinations: evaluation, role, clinical nurse specialist, specialist nurse, cancer, oncology, palliative care. References of identified studies were also checked for relevancy to the aims of the study. Limits were set to include only research papers published in English. As the CNS posts were not established until 2000 in Ireland we limited our search from 1999 to present time.

2.1 Methods

The research question set out to address the role of the CNS in cancer care. Given the potentially wide ranging nursing activities base of cancer care nursing and the requirement to incorporate a plurality of perspectives, methodological triangulation was considered to be the most appropriate research design. Methodological triangulation involves the use of one or more methods at the level of design or data collection with an aim of ensuring rich and productive data. In methodological triangulation convergence of information from qualitative and quantitative sources serves to assist in the validation of data and study findings (Cowman, 2008). In our study, the use of questionnaires and focus groups incorporating all stake holders provided a means of comprehensively describing and understanding the role of the CNS in cancer care.

2.1.1 Study Site

St Luke's hospital is a 140 bed specialist oncology hospital and is the primary national centre for radiotherapy in Ireland. In 2007, they recorded 63,571 out-patient visits and 2,930 day case procedures. Ten, site specific CNS are employed in the hospital. Two CNS were part of the study steering committee and were excluded from the survey. 223 health care professionals work within the hospital. Recruitment commenced in July 2009 once ethical approval was granted by the local research ethics committee.

2.1.2 Questionnaires

Questionnaires have been used extensively within research and are a valuable means of providing data to inform policy, practice and education and are used for evaluative and comparative purposes (Parahoo, 2008). They offer the possibility for respondents to remain anonymous and are suited for sensitive topics which people may be reluctant to talk about (Parahoo, 2008). The data elicited can be analysed in numeric terms, but at times may not be in-depth enough to provide appropriate insight into the topic in question. However, they provide little scope for probing and clarifying responses and rely heavily on self-reports.

Two questionnaires were used in this study. A 24 item, anonymous, postal questionnaire adapted from a previously validated questionnaire was used to evaluate the role of the CNS (NCNM, 2004). As the previous questionnaire was designed for CNS in all clinical settings we adjusted the questions so as to be specific to the CNS in cancer care. This questionnaire sought responses on their role under the five core competencies of the CNS: clinical, education, consultation, advocacy, research and audit (Appendix 1). One free text option was included to facilitate open comment or feedback. Currently 10 CNS posts were in place in the hospital. Two of the CNS were on the steering group and were excluded from data collection. One post was vacant, thus seven CNS were surveyed.

A second, 12 item, anonymous, postal questionnaire was developed for all other health care professionals (Appendix 2). This was similar to the CNS questionnaire but with non-applicable items removed. Respondents were invited to reply in

free text, what they perceived were the benefits of the CNS. Additional comments were also facilitated in an open question. All 223 health care professionals within the hospital were sent this questionnaire.

Issues of validity and reliability of the questionnaire were addressed in many ways. Firstly, a previously validated questionnaire which was used among CNS was used in this study. Minor amendments to the format were made to make it appropriate to our population. Secondly, once adapted, the questionnaire was reviewed by the study team and by CNS to ensure content and face validity. Reliability was ensured through the use of an established questionnaire which demonstrated that the questionnaire design could measure the items within it consistently.

2.1.3 Focus Groups.

The focus group is defined as a group of individuals selected and assembled by researchers to discuss and comment on a research topic from their personal experience (Powell & Single, 1996). According to Joyce (2008) the main advantages of a focus group is that it provides an opportunity to observe a large amount of interaction and discussion on a topic in a limited period of time. In addition, focus groups encourage a greater degree of spontaneity in the expression of opinion whilst providing a safe forum for the expression of views on a topic (Vaughn *et al.*, 1996). However, focus groups are not without limitations. In particular, a dominant 'talker' may prevent other 'shyer' participants from getting their view point across. Therefore, the focus group format may not be seen as empowering for all participants and consequently some conflicts may arise in the group (Kreuger & Casey, 2000).

In this study, two separate focus groups were convened to evaluate the role of the CNS in cancer care. Group one included the patients and group two the CNS. The focus groups were organised and managed by a moderator and an assistant moderator both of whom were members of the research team. Each focus group followed a similar format. At the outset, the moderator outlined the procedure for the focus group. The participants were informed that the group discussions would be recorded and transcribed. In both groups, the moderator asked the questions and co-ordinated the discussion. The assistant moderator recorded notes during the discussion and assisted with planning and implementation of each group.

Two units within the hospital were randomly selected for the patient focus group. Each unit had both male and female patients with a variety of diagnosis. An open letter of invitation to attend a focus group, which outlined the nature and purpose of the study, was sent to each nurse manager for distribution anonymously to patients (Appendix 3). Nine patients agreed to participate. Patients were not requested to provide any personal information with regards diagnosis, age, full name or duration since diagnosis.

2.1.4 Follow-up

Once data analysis was completed the results were presented at two separate sessions to the CNS and to nursing management for further discussion.

2.2 Data analysis and interpretation

Quantitative data from the questionnaires were entered into SPSS version 15. Cross checking of data with original sources and examination of frequency tables were used to ensure accuracy. Results were summarised through descriptive statistical analysis.

The data from the focus group were analysed using an inductive approach based on content analysis, in keeping with other forms of qualitative data analysis (Sim, 1998). The verbatim data were transcribed and the content was reviewed and coded for analysis to find patterns within each of the group discussion. Burnard's framework for data analysis was used, and when this process was completed, the themes in the interviews were linked together to form a rational in-

depth category system (Burnard, 1991). This central element of qualitative analysis provides meaning to the data and raises the level of understanding required (Kreuger & Casey, 2000).

In addition, the group dynamic and the notes recorded by the moderator and assistant moderator were incorporated to provide a detailed analysis of the data (Sim, 1998). Finally, the findings from each focus group were reviewed by the assistant moderator to ensure the interpretations in the final analysis of the data were consistent with the opinions and sentiments expressed in the focus groups.

Section 3: Results

3.1 CNS survey

Profile of CNS

All seven CNS participated in the study. Academic qualifications and age profile of the CNS who participated are summarised in Figure 1 and 2. All CNS were graduates and held, at a minimum, a higher diploma in addition to their initial registration as RGN. Three held a MSc. and five currently hold a professional development plan (PDP).

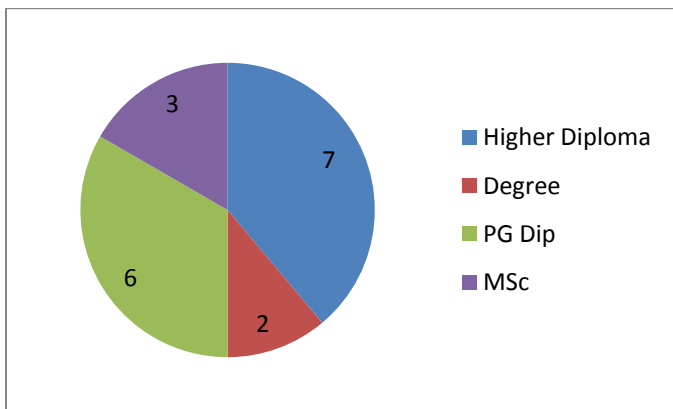


Figure 1: Academic Qualifications of CNS

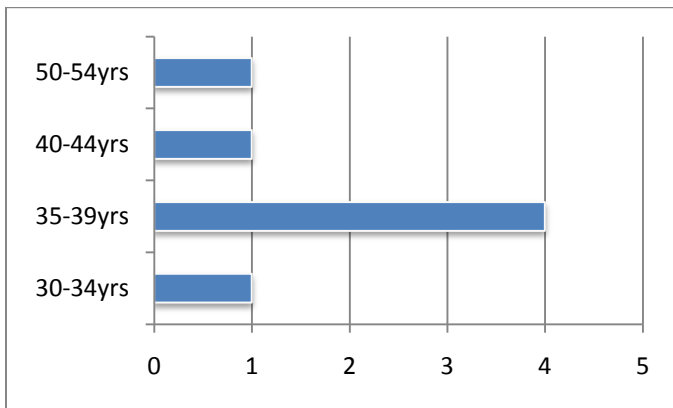


Figure 2: Age Profile of CNS

CNS service involvement

All CNS wrote an annual report of their activities while five contributed to the hospital service plan. CNS were active in completing audits of their work with audits of the numbers of patients seen being conducted by all nurses. Other audits included: referrals received (n=6); effectiveness of interventions (n=3); referrals made

(n=3); phone consultations (n=3); waiting times (n=2); patient satisfaction (n=1).

The CNS received patient referrals from all other disciplines and made referrals mainly to complementary therapists; social workers; community nurses; medical staff and other CNS throughout the hospital. As the CNS worked within a multidisciplinary team (MDT) they commented within the questionnaire that the need for referrals was often initiated by them at team meetings but the actual referral was made by a medical staff member.

CNS received feedback on their performance mainly from family and patients with five (71%) citing formal feedback from their line manager or Director of Nursing. In addition, 43% (n=3) received informal feedback while no CNS had clinical supervision or mentorship. The source of this feedback was the:

a) Director of Nursing	86%
b) Families of patients	86%
c) Patients	71%
d) Multidisciplinary Team	57%
e) Assistant Director of Nursing	43%
f) Clinical Nurse Manager	28%
g) Medical Staff	28%

Core competencies

The questionnaire evaluated their role under the five core competencies of the CNS. When asked to rank order the competencies, clinical work was number one (highest ranked) followed by patient advocacy; education; consultation and audit and research fifth. This was reflected also in the percentage of time spent in each area which they estimated at 47% in clinical work; 14% education; 13% advocacy; 13% audit and research and 10% consultation. It was difficult to separate out each of these sections as education on medication management for example may be incorporated into the clinical work. The CNS was asked to estimate the number of hours per month on different aspects of their work. Approximately 60 hours were spent on direction patient interventions; 30 hours on

patient education; 14 hours on professional development; 14 hours on nurse led interventions; 13 hours on discussion with other nurses (in particular community nurses); 12 hours on phone consultations.

Role development

The CNS rated the following as being barriers to the development of their role [descending order]

- a) Lack of understanding of the role by staff nurses 86%
- b) Lack of secretarial support 71%
- c) Lack of understanding of the role by nursing management 57%
- d) Lack of multidisciplinary support 28%
- e) Lack of nursing support on professional issues 14%
- f) Lack of resources to set up/ develop the role 14%
- g) Lack of support from other CNS 14%

In developing their role, none of the current CNS were the first to hold the post. The factors which assisted them in developing their role were:

- a) Own communication skills 100%
- b) Clinical expertise 100%
- c) Academic qualifications 100%
- d) Personal motivation 100%
- e) Colleagues 86%
- f) Acceptance of role by MDT 86%
- g) Understating of role by self 86%
- h) Support from other CNS 86%
- i) Continuous professional development 86%
- j) Support from management 86%
- k) Networking with nursing colleagues 86%
- l) Acceptance of role by medical staff 71%
- m) Good organisational structure 57%
- n) Acceptance of role by nursing 43%
- o) Good introduction/orientation 28%

3.2 CNS Focus Group

According to the CNS the main benefits of their role was their contribution to the quality of life of the patient and provision of support to the patient throughout their journey from initial presentation through to follow-up post discharge. Table 1 summaries the main benefits of

the role as perceived by the CNS and what, in their view, was the greatest contribution to patient care.

Benefits of the Role	Greatest contribution to patient care
Improved quality of life of patient	Support and advocacy
Patient support	Education
Specific services (eg pain management, lymphoedema management)	Pain and symptom management
Staff education	Patient centred service
Named link person	Patient confidence
Patient advocacy	Referral
	listening

Table 1: Benefits of the Role of CNS

The focus group highlighted the difficulty in separating out the various aspects of the role of the CNS and the difficulty in quantifying each aspect of the role. However, two particular themes emerged from the focus group. The first was education. The CNS provided education to: the patient; the family and/or carers; other staff within the hospital; health professionals external to the hospital and to students undertaking third level courses. A new challenge for the CNS was the multiple sources of information which the patients and family used and this put additional time pressures on the CNS, for example:

‘They (pts) come into the clinic with sheets of information – may not always be relevant. You have to go through it with them and always give them a recognised web-site to use’.

In addition, the CNS constantly engaged in their continued professional development and the CNS regularly attended conferences and education updates along with undertaking PG Dip and MSc in their own specialist areas of practice. They acknowledged the need for research to support their role as clinicians and education providers but were frustrated at not being able to engage in this to the extent they wished to. They cited lack of time as being a barrier to research development, for example:

'I spend 80% on symptoms and not enough on research'

The second theme was that of support. The CNS stated that they supported the patient in many ways. They provided emotional support, they made time to listen to and talk with patients either in person or by phone. They also supported the patient through education, sourcing of resources and organising referrals and follow-up care. The CNS as professionals felt supported by nursing management and by the MDT.

Other key findings from the CNS focus group were in relation to the core competencies of the CNS which included: support, advocacy, research, education and patient information, MDT working and audit. MDT working was important as it supported the wider remit of the CNS and the challenges therein. The CNS perceived the MDT as facilitating their role, the focal point through which they could contribute to and influence patient care and also as a source of learning and professional development.

3.3 Health professionals survey

Of the 223 health professionals who were sent the questionnaire, 52% (n=116) replied. The replies are broken down according to professional group in Table 2.

Seventy five percent of respondents stated that they referred patients to the CNS, while twenty percent received referrals from the CNS. The main reasons for referring patients to the CNS in descending order were: education and support; diagnosis specific issues; patient needs to talk; organising and liaison with others; CNS has more time; side effects of treatment; assessment and evaluation.

Physiotherapists	4	3
Social workers	6	4
Dieticians	4	2
Psychology	2	2
Complementary Therapist	3	2
Radiation Therapists	79	26
Nursing	100	69
Other	0	2
Total	223	116

Table 2: Health Professionals Surveyed

The questionnaire asked people to rank on a five point likert scale if they thought the CNS had an important role under each of the headings: clinical; advocacy; education; audit and research. Of note, the majority of health professionals agreed to strongly agree that the CNS has an important clinical and education role. A summary of results are presented in Table 3.

Question	Strongly agree %	Somewhat agree %	Agree %	Somewhat disagree %	Strongly disagree %
The CNS has an important Clinical role	42	27	18	3	8
The CNS has a role in patient education	48	25	18	0	2
The CNS has a role in staff education	27	17	27	2	24
The CNS is a patient advocate	39	23	22	2	15
The CNS has a role in audit and research	30	20	22	3	20

Table 3: Evaluation of the Role of CNS [non-CNS replies]

Sixty percent of staff had received education from a CNS in the past year. Ten percent had collaborated with the CNS for audit and sixteen percent for research in the past year. When questioned about advocacy, while respondents agreed that the CNS was a patient advocate many commented that all health professionals had a role as a patient advocate and thus this was not exclusive to the CNS.

Professional Group	Number surveyed	Number replied
Medical, including consultant and registrars	25	6

Within the open comment section and in the section under benefits of the role three main themes emerged. Firstly, the CNS was perceived to have:

'time for the patient', 'have time to spend with patients and the specialist knowledge to support, advise and educate patients, families and staff'.

The CNS had time to explain things, and also had time to listen to the patient and reduce anxiety. Their specialist knowledge was repeatedly identified by professionals. Secondly, they were seen as a vital member of the MDT;

'important part of patient care working with other specialist groups'.

This was reflected in many ways but an important consideration was that the CNS was seen as the 'link' person, the one who co-ordinated care, who liaised with the team within the hospital, who provided a link post-discharge:

'as patients come from wide geographical areas single motivated contact is essential for the patient both for co-ordination and counselling'.

Finally, the third most frequently cited benefit of the CNS was symptom management. This was exemplified mainly as having a role in pain management, lymphoedema management, post-radiation therapy symptom control and again in explaining to the patient what to expect about their treatment.

3.4 Patient focus group

Nine patients agreed to participate in the focus group; five attended the session. Four withdrew on the morning of the session for personal reasons. All five were females; four were in-patients and one an out-patient. While patients openly discussed their diagnosis they were not asked about their diagnosis or requested to discuss this.

Three main themes emerged from the focus group: knowledge, communication and support.

3.4.1 Knowledge

Patients perceived the CNS as having the knowledge to explain things and the time to dedicate to this. One patient commented:

'they know about treatments, better informed than the staff nurse, always go to the CNS as she is more informed'.

Because of this knowledge, the CNS was seen as a problem solver. The CNS would prompt the patient of questions to ask of the doctor during consultations. The patients were not aware of the special training or level of academic achievements required of a CNS.

3.4.2 Communication

The CNS was seen as having excellent communication skills, often cited as speaking 'lay' language. Patients had the opportunity to deconstruct the conversation they had with their consultant with the CNS in order to gain a greater understanding of their own situation. For example some commented:

'Always made sure you understood what the consultant says', 'Has time to spend with you', 'Able to talk freely with the nurse'.

The CNS also has good communication with other staff. This communication meant that the CNS could co-ordinate aspects of the patients care and that the CNS liaises with other professionals on behalf of the patient.

3.4.3 Support

All patients verbalised the feeling that the CNS was always present and there for 'us'. This provided security and an added resource. Some commented:

'At the beginning I felt I was the adult and could deal with things but now I feel special that she remembers me. It's a bit intrusive at the beginning but I like the idea of her minding me', 'they seem to have excellent memories and record keeping', 'I am always surprised that things happen quickly'.

The personality of the CNS was important to the patient as they were seen as approachable, supportive and having a keen interest in the needs of the patient.

3.5 Follow-up

The results of the surveys and focus groups were returned to the CNS at one additional group session. This facilitated verification of the findings and provided an opportunity for discussion. It was interesting to note that while patients and other health professionals perceived the CNS as *'having more time'*, the CNS often felt overwhelmed by their workload and were busy in completing many elements of their role. This was exemplified in the fact that many of them wanted to engage in more research but did not have the time. The CNS recognized that research was necessary to support practice and for professional development.

Because they viewed themselves as part of the MDT, this accounted for the low number of people to whom they formally referred patients to with the actual referral being written by medical staff. Some health professionals however would not accept referrals directly from the CNS. Overall the CNS felt valued as a group but they perceived that some individual professionals did not value their role and had little or no interaction with them.

The CNS spent a lot of time on the phone either co-ordinating care or talking with patients and relatives. They felt that this survey did not capture this element of their role and it was often an unseen aspect of their role. Two items were identified as challenging their role. Firstly, because patients and relatives were increasingly using the internet to source information on their diagnosis and management options the CNS had to

spend an increasing amount of time discussing this information with patients and helping them recognise the most trustworthy information sources. The second challenge surrounded inconsistencies of the follow-up care available. As St. Luke's was a national referral centre, patients were being discharged throughout the country and the follow-up support was inconsistent so that they spent a lot of time *'looking for what was not there'*. Again the CNS felt that this element of their work was unseen. The CNS viewed themselves as being a *'constant'* within the patient journey and this in turn enhanced the overall quality of care that the patient received.

The CNS expressed frustration in trying to quantify their role. They could not quantify their role in a similar manner to other healthcare professionals who could measure the number of treatments delivered, number of patients per clinic and consequently they felt that much of their role was unseen. The CNS felt there was a need to protect the role as it was a pivotal part of supporting the patient emotionally and physically in the trajectory of their journey. There was a concern that their role was under threat particularly at a time of changes in the organisation of cancer care services.

The CNS expressed the view that there was a lack of clarity and some ambiguity around some nursing roles in cancer care and more specifically the role of the nurse in radiation oncology. They believed that further research was required to evaluate the role of the nurse in radiation oncology and to provide some definitions of this role and that this would be beneficial to MDT working.

3.6 Summary of findings

- The CNS in cancer care are a highly educated, skilled group of nurses, many of whom hold an MSc in their specialist area of practice.
- The CNS are active members of the MDT and contribute to service planning.
- The majority of nursing time (47%) was spent dealing with clinical issues.
- Patient education was cited by all three groups as a key element of the role of the CNS.
- The CNS was active in staff and student education. Sixty percent of staff had received education from the CNS in the past year.
- Health care professionals and patients viewed the CNS as being an expert, a leader, a co-ordinator of care and central to the provision of quality patient care.
- The CNS was well supported by the DON and the MDT.
- The CNS receives referrals from most other professionals but many other professionals do not accept referrals direct from the CNS.
- The CNS has excellent communication skills.
- There is a need to develop the research role of the CNS further.

Section 4: Discussion

Following data analysis five key areas of the CNS role in oncology emerged: clinical; education; research and audit; support; co-coordinating of care. Such areas are reflective of findings of similar international studies.

4.1 Clinical

Consistent with other research, the CNS in cancer care dedicates the majority of time to the clinical elements of the role (NCNM, 2004; Leary *et al.*, 2008; Pollard *et al.*, 2010). The CNS is seen as an 'expert' clinician and autonomous practitioner. In our study the CNS was reported to have a significant clinical role in symptom management, most particularly in pain management and lymphoedema care. Similar to other studies the CNS was seen as having knowledge across a range of areas including medication, side effects of treatment and equipment usage (Jack *et al.*, 2003). Gagnon *et al.* (2010) explored oncology nurses' perceptions of autonomy and their understanding of how they developed and exhibited this role in everyday practice. According to Gagnon *et al.* (2010) autonomy is developed through professional and personal growth which is acquired over time. This is particularly relevant to our study in which each of the CNS held a professional development plan (PDP). Autonomy and autonomous behaviour are also based on social and contextual forces in the workplace. Gagnon *et al.* (2010) conclude that the research to date demonstrates a direct link between autonomy and patient outcomes.

The CNS was involved in the patient journey from early diagnosis through to follow-up post discharge. Lewis *et al.* (2009) points out that nurse-led follow-up is a promising alternative to conventional follow-up which puts a major burden on outpatient services due to increasing cancer survivorship. This is relevant to the CNS focus group findings which highlight that the CNS in our study provides extended follow-up to patients when they are discharged. Our findings also highlight the extended networks that the CNS links with and the support they provide to families and the extended multidisciplinary team in the community for all patients.

The CNS focus groups findings indicate that the nurses spend a considerable amount of time on symptom management as well as providing physical, social and psychological support to patients. Wells *et al.* (1998) evaluated nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer. Two groups of patients were reviewed, twenty by the consultant and twenty three by a nurse specialist. Patients valued the relationship which developed with the nurse specialist as they had longer consultations and were often referred to the multidisciplinary team. The findings indicated that oral and nutritional problems were managed more effectively in the nurse-led clinics. However, emotional functioning was greater in the medical group. The implications for practice suggests that nurse specialists are ideally placed to reduce the impact of symptoms for patients and improve their quality of life by providing information and advice. Furthermore, the increase of chemotherapy for head and neck cancer has further extended the role of the nurse specialist to include the co-ordination of complex treatment regimes and supporting patients with greater symptom burden. Wells *et al.* (1998) conclude that nurses have an important contribution to make to the care of patients with head and neck cancer during radiotherapy treatment, and furthermore those patients with head and neck cancer are physically, psychologically and socially vulnerable and they deserve specialist treatment.

The CNS in lung cancer has been shown to perform an average of 44 different activities in a day and of these activities clinical work accounts for 65% (Leary *et al.*, 2008). As shown through an examination of telephone conversations the clinical role is delivered through a variety of means including face to face contact and phone conversations (Szwajcer *et al.*, 2004). A prospective 11 week audit examining telephone consultations between CNS and patients showed that of the 91 contacts, 42 conversations directly impacted upon the clinical care of patients, the remaining being predominantly about reassurance (Szwajcer *et al.*, 2004).

As one of the five core competencies of the CNS as set by the NCNM, the clinical element predominates in terms of importance and time dedicated to it. This is consistent with the national trend for all CNS who cited clinical work as the second most important element of their role but one which they dedicated most time to (NCNM, 2004).

4.2 Education

The findings of our study support national and international research in which patients viewed the CNS as an educator and that this education was important to their care (Semple, 2001; Jack *et al.*, 2003; NCNM, 2004; Szwajcer *et al.*, 2004; Pollard *et al.*, 2010). Ream *et al.* (2009) have shown that the CNS in cancer care spends on average 3.94 hours per week on education. CNS of all disciplines report spending almost 20% of time on patient education (NCNM, 2004). This may indeed be higher as it is difficult to separate out the education role from other elements of the role such as clinical work. Patient education by the CNS is reported to be 'individualised' to the patient and while the patient relies on the consultant for information regarding treatment and diagnosis, they rely on the CNS in cancer care for follow-up information and education (Szwajcer *et al.*, 2004; Wolf, 2004; Koutsopoulou *et al.*, 2010). A survey among fifty women undergoing breast surgery showed that 70% had pre-surgery contact with the CNS and 90% reported positive contact while 91% identified the post-discharge contact by telephone or in person as helpful or very helpful (Szwajcer *et al.*, 2004).

It has been questioned whether nurses employ an intuitive rather than a systematic approach for the delivery of information, the content of which varies according to specific patient needs and queries (Koutsopoulou *et al.*, 2010). Indeed such an intuitive approach may be required as one has to be cognisant of the challenging emotional journey which the patient is going through and thus the patient may not be ready to learn when the nurse is ready to teach. Therefore, an adaptable and flexible approach must be taken.

Similar to other research (Jack *et al.*, 2003; Pollard *et al.*, 2010), the role of educator is embraced by the CNS in cancer care and was seen by other professionals as a significant element of their role with almost half (48%) strongly agreeing that the CNS has a role as patient educator. However, the variety of groups to whom the CNS delivers education must be a challenge for the individual. The CNS is not specifically trained on how to educate others and given the significant importance of this role and the diversity of groups to whom they deliver education the CNS warrants training to develop their own skills in this area.

Continuous professional development is central to best practice in health care and is essential to health professions in meeting the imperatives of practice change, regulatory agencies and public assurances. In our study each of the CNS respondents held a professional development plan (PDP). This is seen throughout the literature whereby the CNS whether novice or expert recognised their need for professional development yet, many focused on developing their present role rather than identifying additional roles for development though an expanding scope of practice (Bamford & Gibson, 2000; Semple, 2001). This is particularly pertinent in the current developments in nursing and midwifery whereby nurses and midwives can complete third level training as a nurse prescriber, again demonstrating further development of the role.

4.3 Research and audit

The research role of the CNS was poorly developed. According to Bamford and Gibson (2000) the research role is poorly interpreted and causes most frustration as often it is the most difficult to implement and least time dedicated to it. The CNS is reported to spend approximately 1.44 hours per week on research (Ream *et al.*, 2009) representing 3.6% of their time. Our findings are similar to the national trend in which research was cited as the least important core competency of the CNS and with the least amount of time dedicated to it (NCNM, 2004). According to Allen (2003) the CNS is so entrenched in day to day activities of their patients and education programmes, research does not play as big a part in

their role as they would like. Our study supports the findings that barriers to development of the research role are described as lacking in the necessary skills and time (Bamford & Gibson, 2000).

In our study the type of audits completed by the CNS would seem to reflect some of the challenges they experienced in justifying their role. Audits were predominantly on easily measurable items such as numbers of patients seen. Only one audit investigated patient satisfaction, a more nebulous concept. However, the CNS did engage with other professionals for audit and research thus, supporting their role within the MDT.

4.4 Support

The single most frequently cited benefit of the CNS from the perspective of all was that of 'support'. The word support is an imprecise term and may imply different things to different people. However, there was a sense that the CNS was the constant throughout the patient journey and provided support to the patient through education, being knowledgeable, prompting the patient to ask questions, co-ordinating care, post-discharge for advice and to answer questions. In addition they offered emotional support and were often a 'shoulder to cry on'. This was also recognised by the other professionals as they believe the CNS supported the patient mainly as they were seen to have 'more time' for the patient. The CNS themselves also stated that a main element of their role was to 'support' the patient.

Doyle (2008) highlights the importance of hearing patient's stories as cancer survivorship is a duality of positive and negative experiences for the patient and while the experience is unique to the patient it also has universal features. The consequences of cancer survivorship are divided into four main themes to include physical, psychological, social and spiritual health. The findings from the CNS and the patient focus groups indicate that the CNS and nurses in general spend a great deal of time with patients. Furthermore, Vivar *et al*, (2009) points out that fear of cancer recurrence is a major concern confronting survivors and families during remission and is described as one of the most distressing phases of cancer care. The CNS focus group findings highlight the contribution of the CNS in supporting families during their hospital stay and when discharged. At the CNS focus group many examples of extended care were highlighted.

A key component of the role of the CNS in palliative care is to provide emotional support to patients and families experiencing emotional difficulties as a result of a life-threatening illness. While there is extensive literature describing the role of the nurse specialist in palliative care there is insufficient examination of how these nurses deliver emotional care (Skilbeck & Payne, 2003). The authors illuminate the lack of clarity around the term emotional support. Instead they highlight the complexities involved in developing emotionally supportive relationships and the skills required by the CNS to manage these processes. LaScala *et al* (2007) concurs, adding that the CNS enhances patient care, promotes stability in a chaotic environment and supports professional nursing practice.

However, an emerging issue is; who supports the CNS? Whilst the CNS received formal feedback from their line manager and were supported in attending conference and updating their knowledge and education they described their role as a 'singular' one. As a small group they felt vulnerable to outside influences in the organisation of service delivery and the implications this may have for them in the future. Bousfield (1997) cited isolation as a common theme among the CNS grade and proposed that the power of the CNS is dependent on the relationship with his or her administrative peer and if they do not demonstrate confidence in the role then it is in jeopardy. In our study all the CNS reported to the Director of Nursing and engaged in formal performance review. This is important as the CNS should meet with their line of authority to set goals, mutually formulate plans and discuss progress (Bousfield, 1997).

Peer support from CNS networks within and outside an organisation is helpful to the CNS in which the CNS can share common interest regardless of specialty (Bamford & Gibson, 2000). It should be emphasized that the positive evaluation of their role from seven other groups of professional was in itself a form of support. Indeed medical professionals have

been cited as a major source of support for the CNS (Jones, 2005). Relationships with other health professionals are crucially important because many specialist and advanced nursing roles involve a significant element of liaison and coordination or consultancy and staff education (Bousfield, 1997; Jones, 2005). Conversely, Bousfield (1997) reported that the CNS felt unsupported in their role. In our study, the CNS cited lack of understanding of the role mainly by other nursing staff as a barrier to role development while they were well accepted and supported by the multidisciplinary team. This was referred to in the context of the radiation oncology nurse, a role which they felt was poorly defined and poorly understood.

4.5 Co-Ordinator

In our study patient follow-up via the phone and liaison with others via phone constituted a large unseen element of the CNS workload. Pollard *et al* (2010) identified that more than 90% of patients reported talking to the CNS about specific queries or fears either by phone or at clinics. In a study by Leary *et al* (2008) telephone contact accounted for a minimum of 26% of CNS activity. The highest number of calls was from patient and carers and involved discussing follow-up, support and reassurance (Leary *et al.*, 2008).

In Ireland The Health Transformation Programme (2007-2011) and National Cancer Strategy aims towards 'seamless care' being delivered throughout the patient journey (DoHC, 2006; HSE, 2007). This 'care' should be supported by good communication and appropriate use of the knowledge and skills of health professionals. In our study there can be no doubt that respondents viewed the CNS, as central to the patient journey. The CNS was frequently cited as a co-ordinator, a liaison person, a referral initiator. However, there is a danger here that the CNS could potentially become a 'signpost' for others and spend time directing and organizing care rather than building on their own specific clinical role and in delivering specialist nursing care. However, the commitment to on-going continuous professional development would suggest that this risk is minimised for the present time at least. According to Bousfield (1997) the CNS must learn to market their skills and services and demonstrate they are the vital force behind the quality of care of patients.

Good communication is fundamental to effective co-ordination and can facilitate or impede role transition (Jones, 2005). In our study we have shown that through the MDT, the referral networks, phone consultations, and speed with which the CNS can co-ordinate care that they have effective communication networks and are effective communicators. This is also supported by the attitudes of other professionals towards them as they saw the CNS as a strategic 'link' person.

According to Sullivan and Elliott (2007) cost cutting measures may impact on the role of the cancer care CNS in the National Health Service (NHS) and there is a danger that the role may be seen as a luxury. The authors point out that the CNS is a pivotal member of the multidisciplinary team and their posts require support from managers who are under considerable pressure to keep within specified budgets. Specialist cancer nurses play a crucial role in the overall quality of cancer care and the co-ordination of care ensures that standards are maintained and that the patient journey is direct from referral to treatment (Sullivan & Elliott, 2007).

In our study a level of concern was expressed by the CNS about the security of their role into the future. However, some points are worthy of comment. The National Cancer Strategy endorses the role of specialist nurse. Patients and other health professionals identified it as a significant contribution to quality patient care and quality care is the central theme of government targets for the health service. Importantly, in Ireland the post of CNS is developed out of service need and only those having met the educational and clinical experience requirements of NCNM can be appointed. However, according to Trevatt *et al* (2008) although it was suggested that each patient should have access to a CNS, no caseload guidance has ever been issued to nurse specialists. This is clearly demonstrated in that the ratio of CNS to specific cancers varies widely. For example, in the United Kingdom breast cancer has the largest provision of CNS with 434 whole

time equivalent posts (WTE) whereas lung and urology CNS have the highest mean incidence of cancer patients per CNS WTE (Trevatt *et al.*, 2008).

4.6 Limitations

The obvious limitation relates to this study being conducted in a single site, thus reducing the generalisability of the findings. However, St. Luke's Hospital is a specialist cancer centre providing treatment to patients from all over Ireland. The findings are in keeping with other research studies suggesting that we have achieved a fairly representative sample of CNS in cancer care. The use of diaries would have assisted us in probing deeper into the work practices of the CNS, unfortunately, this was not feasible within the resources of this study but does provide a basis for future research. We commend the CNS group in being such a small group of professionals for their willingness to have their role evaluated by all other health professionals and patients in their area of work. We believe this demonstrates a high degree of professionalism and a willingness to embrace challenges and potential change and supports research by Jones (2005) which saw performance measurement by other professionals as a facilitator to developing the role of the CNS.

4.7 Recommendations

Some recommendations for future research are provided here.

- The CNS should complete studies of patient satisfaction and evaluate their role in terms of patient outcomes.
- The development of advanced nurse practitioner roles in cancer care should be explored.
- Further support and encouragement should be generated for the role of the CNS as researcher.
- The role of the CNS as a clinical leader should be developed.
- A definition and evaluation of the role of the nurse in radiation oncology is recommended.

4.8 Conclusion

The CNS in cancer care is an active member of the MDT and provides specialist nursing care to patients across a range of diagnostic groups and at different stages of their treatment plan. They fulfilled their title of specialist nurse across all domains evaluated. All the specialist nurses held third level qualifications in their area of practice, engaged in continuous professional development and were viewed by patients and other professionals as very knowledgeable and that this knowledge supports patient care. The CNS are a group of highly trained, knowledgeable and enthusiastic group of individuals with a clear goal of providing quality patient care.

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Appendix 1: CNS Questionnaire



Research Centre

Faculty of Nursing and Midwifery

RCSI,

123 St Stephens Green

Dublin 2

Re: Evaluation of the Role of the CNS in cancer care.

Dear CNS,

The Research Centre in the Faculty of Nursing and Midwifery RCSI in association with St Luke's hospital have been asked to conduct a research study to evaluate the role of the Clinical Nurse Specialist in cancer care. The CNS is a member of the multi-disciplinary team and it is important to evaluate this role so that future developments can be strategically planned.

We would like to invite you to participate in the first phase of this study by completing the enclosed questionnaire. The study has been approved by the research ethics committee in St. Luke's Hospital. Please be assured that all responses will be treated as anonymous and confidential. When you have completed the questionnaire please return in the envelope provided.

The second phase of the study will include distributing a questionnaire to nurses and other healthcare professionals in St Luke's on the role of the CNS. Following this round of questionnaires it may be necessary to interview a small number of participants to clarify or expand on points of particular interest to the study

outcome. The participation of other healthcare professionals will enrich the findings. When the results of this questionnaire have been analysed you will be invited to a discussion forum with the study team. Details of this will be provided at a later date.

I would like to take this opportunity to thank you for your time and look forward to your participation.

Yours sincerely

Prof Seamus Cowman

Questionnaire

Please complete and return to the study team in the envelope provided

Confidential

1. Please rank in order of importance (i.e.1,2,3,4,5) the five core concepts of the CNS, as you perceive it: 1 = most important ---, 5 = least important.

Core Concepts

- | | |
|------------------------|--------------------------|
| Clinical | <input type="checkbox"/> |
| Education and Training | <input type="checkbox"/> |
| Audit and Research | <input type="checkbox"/> |
| Patient Advocacy | <input type="checkbox"/> |
| Consultancy | <input type="checkbox"/> |

2. On a monthly average can you give an estimate of the percentage of time spent on the following activities?

- | Activity | Time % |
|----------------------------|--------------------------|
| i. Clinical | <input type="checkbox"/> |
| ii. Education and Training | <input type="checkbox"/> |
| iii. Audit and Research | <input type="checkbox"/> |
| iv. Patient advocacy | <input type="checkbox"/> |
| v. Consultancy | <input type="checkbox"/> |
| vi. Other (Please specify) | <input type="checkbox"/> |

3. Please indicate to which age group you belong

- | | |
|----------|--------------------------|
| a. 20-24 | <input type="checkbox"/> |
| b. 25-29 | <input type="checkbox"/> |
| c. 30-34 | <input type="checkbox"/> |
| d. 35-39 | <input type="checkbox"/> |
| e. 40-44 | <input type="checkbox"/> |
| f. 45-49 | <input type="checkbox"/> |

- g. 50-54
- h. 55-59
- i. 60-64

4. At work do you have access to the following?

- a. A computer yes no
- b. The internet yes no
- c. E-mail yes no
- d. Library service yes no
- e. A bleep yes no
- f. A voice mail service yes no
- g. An office yes no
- h. Secretarial support yes no

5. How many hours per month do you spend on average with the following activities?

- a. Multidisciplinary clinics
- b. Nurse led clinics
- c. Direct clinical interventions with patients
- d. Writing guidelines/policies
- e. Discussion with multidisciplinary team
- f. Discussion with nurses regarding pt. care
- g. Education and training of patients
- h. Education and training of staff
- i. Education and training of students
- j. Education and training of multidisciplinary team members
- k. Clerical- making appointments, filing and finding notes
- l. Nursing research
- m. Medical research (collecting data not used for nursing purpose)
- n. Continuing professional development (formal courses)
- o. Continuing professional development (informal – reflection, accessing library, clinical supervision)
- p. Attending meetings
- q. Travelling whilst at work
- r. Telephone consultation with nurses

6. Did you experience any of the following barriers with your role? (you may choose more than one)

- a. lack of multidisciplinary support
- b. lack of nursing support on professional issues
- c. lack of other managerial support
- d. a lack of understanding of the role of the CNS by staff nurses
- e. a lack of understanding of the role of the CNS by yourself
- f. a lack of understanding of the role of the CNS by nursing management
- g. lack of access to continuing professional development
- h. lack of academic qualifications
- i. lack of resources to set up/develop the role
- j. lack of secretarial support
- k. lack of support form other CNS
- l. lack of clinical support
- m. other (please specify)

7. What type of feedback do you receive? (you may choose more than one option).

- a. Clinical supervision
- b. Mentorship
- c. Formal performance review
- d. Informal
- e. Ad hoc performance review
- f. Other (please specify).

8. If you do receive feedback, from whom do you receive if? (you may choose more than one option)

- a. Director of Nursing
- b. assistant director of nursing
- c. clinical nurse manager
- d. patients
- e. families of patients
- f. medical staff

- g. members of multidisciplinary team
 - h. other (please specify)
9. Do you have a personal professional development plan?
- a. Yes
 - b. No
 - c. Don't know
10. Can you identify the factors that helped you develop your role? (please tick all that apply).
- a. Own communication skills
 - b. Clinical expertise
 - c. Acceptance of role by nursing
 - d. Colleagues
 - e. Acceptance of role by multidisciplinary
 - f. Acceptance of role by medical staff
 - g. Good organisational structure
 - h. Understanding of role by yourself
 - i. Support from other CNS
 - j. Good introduction /orientation
 - k. Academic qualifications
 - l. Continuing professional development
 - m. Support from management
 - n. Personal motivation
 - o. Networking with nursing colleagues
11. Do you write an annual report of your activities?
- a. Yes
 - b. No
12. If you answered yes to the above, to whom do you send it?
- a. Clinical nurse manager
 - b. Director of nursing
 - c. Assistant director of nursing
 - d. Chief executive officer
 - e. Medical staff
 - f. Hospital consultant
 - g. Other (please specify)

13. Are you the first person to fill this clinical nurse specialist post

- a. Yes
- b. No
- c. Don't know

14. If you answered 'no' to the above question, how many previous post holders were there:

15. To whom can you refer patients? Please tick all that apply

- a. Dietician
- b. Physiotherapist
- c. Other CNS
- d. Occupational therapist
- e. Speech therapist
- f. Radiation Therapist
- g. Community nurse
- h. Social worker
- i. Complementary Therapist
- j. Psychologist
- k. Medical staff
- l. No-one
- m. Other (please specify)

16. From whom do you receive referrals? (tick all that apply)

- a. Dietician
- b. Physiotherapist
- c. Other CNS
- d. Occupational therapist
- e. Speech therapist
- f. Radiation Therapist
- g. Nursing Staff
- h. Community nurse
- i. Complementary Therapist
- j. Social worker
- k. Psychologist
- l. Medical staff
- m. No-one
- n. Other (please specify)

17. Do you contribute to your organisations service plan?

- a. Yes
- b. No

18. Have you ever measured the following performance outcomes for your patients? (please tick all that apply)

- a. numbers seen
- b. waiting times
- c. effectiveness of interventions
- d. referrals made
- e. referrals received
- f. telephone consultations
- g. patient satisfaction
- h. quality of life indicators
- i. reduction in hospital admissions
- j. other (please specify)

19. If you measure performance outcomes, do you change your clinical practice as a result?

- a. yes
- b. no
- c. don't know
- d. please give one example -----

20. What post-graduate education have you completed? Please give the full title and year of any course

- a. certificates in specialist area-----
- b. certificates (other) -----
- c. diplomas-----
- d. primary degree-----
- e. post-graduate / higher diploma-----
- f. post-graduate masters degree-----
- g. PhD-----

21. What do you perceive to be the greatest benefit the post of CNS gives to patient care:

- a. -----

22. As a CNS, what patient outcomes / factors do you perceive that you contribute most to:

- a. -----

23. In your role as CNS what specifically do you contribute to in terms of patient symptom control/management?

a. -----

24. In this section please feel free to provide additional information or comment on what you perceive is the impact of your role as a CNS on patient care and on patient outcomes.

a. -----

THANK YOU FOR YOUR TIME.

PLEASE RETURN IN THE ENVELOPE PROVIDED.

Appendix 2: NON-CNS Questionnaire



Research Centre

Faculty of Nursing and Midwifery

RCSI,

123 St Stephens Green

Dublin 2

Re: Evaluation of the Role of the Clinical Nurse Specialist (CNS) in cancer care.

Dear staff member,

The research centre in the Faculty of Nursing and Midwifery in RCSI in association with St Luke's hospital have been asked to conduct a research study to evaluate the role of the CNS in cancer care. The CNS is a member of the multi-disciplinary team and it is important to evaluate this role so that future developments can be strategically planned.

We would like to invite you to participate in the first phase of this study by completing the enclosed questionnaire. The study has been approved by the research ethics committee in St Luke's Hospital. Please be

assured that all responses will be treated anonymously and in confidence. When you have completed the questionnaire please return in the envelope provided.

I would like to take this opportunity to thank you for your time and look forward to your participation.

Yours sincerely

Prof Seamus Cowman

Questionnaire

Please complete and return to the study team in the envelope provided

Confidential

1. What is your profession

- a. Dietician
- b. Nursing
- c. Physiotherapist
- d. Occupational therapist
- e. Speech therapist
- f. Radiation Therapist
- g. Complementary Therapist
- h. Social worker
- i. Psychologist
- j. Medical staff
- k. Other (please specify)

2. Please state how many years experience you have working in cancer care

- a. < 5yrs
- b. 6-10 yrs
- c. 11-15 yrs
- d. 16-20
- e. >20yrs

3. Do you refer patients to the CNS?

- a. Yes
- b. No

4. Please indicate the most frequent reason that you refer patients to the CNS?

- a.
- b.
- c.

5. Do you receive referrals from the CNS

- a. Yes
- b. No
- c. Please indicate the most frequent reason for referrals from the CNS

6. Do you contribute to your organisations service plan?

- a. Yes
- b. No

7. The CNS is involved in many aspects of patient care and service delivery. Please consider each of the following statements and state your level of agreement or disagreement with each of them

a. The CNS has a very important clinical role

- i. Strongly agree ; somewhat agree ; agree ; somewhat disagree ; strongly disagree.

b. The CNS plays an integral role in patient education

- i. Strongly agree ; somewhat agree ; agree ; somewhat disagree ; strongly disagree.

c. The CNS plays an integral role in staff training and education

- i. Strongly agree ; somewhat agree ; agree ; somewhat disagree ; strongly disagree.

d. The CNS is a patient advocate

i. Strongly agree ; somewhat agree ; agree ; somewhat disagree ; strongly disagree.

e. Audit and research are core activities of the role of the CNS

i. Strongly agree ; somewhat agree ; agree ; somewhat disagree ; strongly disagree.

8. During the past two years have you attended an education session or received education from the CNS on any aspect of patient management?

a. Yes

b. No

9. During the past two years have you collaborated with the CNS in completing an audit?

a. Yes

b. No

10. During the past two years have you collaborated with the CNS in completing a research study?

a. Yes

b. No

11. What do you consider the greatest benefit the CNS brings to patient care?

a. -----

12. Please provide any additional comments about the role of CNS.-----

THANK YOU FOR YOUR TIME.

PLEASE RETURN IN THE ENVELOPE PROVIDED.



SAINT LUKE'S
HOSPITAL

Patient Information Leaflet



Letter of Invitation

Research Centre

Faculty of Nursing and Midwifery

RCSI

Dublin

Dear Sir/Madam,

The research centre in the faculty of nursing and midwifery in the RCSI in association with St Luke's Hospital are undertaking a study to evaluate the role of the clinical nurse specialist (CNS) in cancer care.

This letter is being sent to you by the clinical nurse manager on behalf of the study team and your name or details have not been given to anyone.

In order to get a broad understanding of this role we are trying to gather the view of patients.

You are invited to attend a discussion group:

Date:

Venue:

Time:

Refreshments will be available.

Two members of the study team will organise and run this session, which is only open to patients and will not include staff members. During the session some general questions will be asked about your experiences of the role of the clinical nurse specialist. Everyone is free to participate during the discussion. While the session will be recorded, it is important to emphasise that all information gained during the session will remain anonymous and confidential. The research ethics committee in St Luke's hospital has reviewed and approved this study.

If you wish to discuss this further or need more information please feel free to contact any of the names below.

Thank you for considering this request

Kind regards

Prof Seamus Cowman

RCSI

Contact details: Prof S. Cowman 01 4022180; Dr. G. Gethin (RCSI) 086 8560053; Ms Aidin Roberts (St Luke's Hospital).