
Role Development: Clinical Nurse Specialists

Quality Impact *Evidence Summaries*

Measurable evidence of the impact of policy interventions on quality

A rapid evidence review for
The Health Foundation

Laura Barrett, Elaine Robinson, Research Matters
Aoife Molloy, Policy Associate, The Health Foundation
February 2018

Quality Impact *Evidence Summaries*

Measurable evidence of the impact of policy interventions on quality

About Quality Impact *Evidence Summaries* (QIES)

Quality Impact *Evidence Summaries* (QIES) present measurable evidence of the impact of policy interventions within the NHS. Distinctively, impact is viewed through the lens of quality, using the Institute of Medicine (IOM) domains of quality as a framework.¹

QIES began as a series of structured reviews featured in [A Clear Road Ahead](#), a 2016 Health Foundation project delivered in collaboration with Professor Sheila Leatherman, to shape a quality strategy for the NHS.² The Health Foundation re-commissioned Research Matters in 2017-18 to develop the structured reviews further, with the aim of exploring the potential to develop a sustainable tool or service to support and promote evidence-based policy and decision making across the NHS in England.

Scope

QIES focus exclusively on national policy interventions in the English health care sector. Typically, these are centrally developed by the Department of Health, NHS England or other national bodies and rolled out nationally, albeit with local variations in implementation. Some interventions may have initiated at a local or institutional level and been adopted nationally. The time period for both policies reviewed and evidence used is from 1997 onwards.

NHS Taxonomy

As the scope and volume of relevant policy interventions is significant, a Taxonomy of Policy Interventions for the NHS in England was developed. Policies are grouped into four policy areas - governance, finance, delivery and improvement - split further into focus areas. Groups of policy interventions combine as policy levers, which forms a thematic basis for a series of QIES. Each individual QIES focuses on a single policy intervention as an example of the use of that policy lever. This enables groups of policy interventions which share conceptual or practical similarities to be described alongside each other, allowing for comparison about what works.

For further information, see the separate working paper: *Taxonomy of health care policy interventions for the NHS in England, Working paper for Quality Impact Evidence Summaries (QIES) project*, February 2018.³

Impact on quality

In assessing and presenting the impact on quality of policy interventions, we have used the Institute of Medicine (IOM) framework for the quality of health care.¹ This describes six domains (or aims), across which improvements in quality can occur. These are:

- **Safe:** avoiding harm to patients from the care that is intended to help them.
- **Effective:** decision-making and service provision based on clinical and scientific evidence and knowledge, as well as refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- **Patient-centred:** providing care that centres on the patient, respecting and responding to individual patient preferences, needs, and values and ensuring the patient is in control.
- **Timely:** reducing waits and delays for both those who receive and those who give care.
- **Efficient:** providing care that is cost-effective and avoids waste.
- **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Evidence about a policy intervention is reviewed and findings which show impact against one or more domain of quality form the basis of results gathered and presented in a QIES. Assessments of the level of impact within each domain are made: impact on quality can be positive, uneven and can also be unintended.

Methodology

QIES identify the key and most relevant evidence, only where measurable impact on quality is demonstrated, resulting in a sufficiently secure evidence base for conclusions to be tested and drawn. The approach is time-limited and pragmatic and is not intended to be comprehensive or meet the academic standards of a systematic review.

For each policy intervention, a structured search of published literature is conducted using, key databases, such as NHS Evidence, PubMed and Cochrane Library, as well as relevant sources of grey literature and stakeholder reports. Searching combines database searching, reference scans, looking at recommended studies/authors and targeted desk research. Full texts of reports and studies are obtained and viewed for the majority of studies, but sometimes the abstract provides sufficient information.

A discussion of the evidence used describes the key sources used to produce the QIES, including the number of relevant studies and different evidence types. Results are presented thematically, based on the IOM domains and describe the measurable impact of the policy intervention on aspects of quality of care in the English NHS. This is supported by a summary table with judgements about the strength of the impact for each IOM domain.

About Research Matters

[Research Matters](#) is a small, well-established research company delivering high quality, client-focused research to tight time-scales for clients across many sectors. Our work is bespoke, pragmatic and insight driven and our style is always friendly, flexible and professional.

We have completed a number of rapid evidence reviews for the Health Foundation, as well as developed a methodology for Quality Impact Evidence Summaries and an NHS taxonomy to facilitate a structured approach to producing of evidence reviews. Most recently, we have completed a review on retention in the health and social care workforce.

* * *

Role Development: Clinical Nurse Specialists

In this Quality Impact Evidence Summary (QIES), we examine the impact on quality of the clinical nurse specialist (CNS) role. This policy intervention sits within the policy lever of Role Development within the NHS Taxonomy.

NHS Taxonomy: Positioning of Policy Intervention

Policy area	Policy focus	National policy levers
Governance		
Finance		
Delivery	Service provision	
	Workforce strategy	Workforce planning
		Role development <i>Adjustments to NHS roles, including developing existing roles, task shifting and creating new roles</i>
		Team-based-working and collaboration
	Patient involvement	
Public health programmes		
Improvement		

Related evidence summaries within the policy lever of role development are: Emergency Care Practitioners, Modern Matrons, Community Matrons, Physician Associates and Clinical Pharmacists.

Description of intervention

Role description

Clinical Nurse Specialists (CNS) are generally experienced nurses, educated to at least degree level and possessing specialist knowledge, skills, competencies and experience. Many CNS are based within acute trusts, but they can also work in primary care and community settings or private and voluntary sector organisations. The specialty of an individual nurse may focus on a patient group, type specialty (e.g. cancer) or type of care (e.g. palliative).⁴ There is currently no defined career structure or national frameworks of competencies or skills for the CNS role.

In this QIES, the focus is on cancer CNS. In this speciality, CNS generally operate as key workers, using their skills and expertise in cancer care to provide patients with physical and emotional support, coordinate care services and inform and advise patients.

Policy context and implementation

The CNS role in cancer has been recommended as best practice in most national cancer policies, from the *NHS Cancer Plan 2000*, through to the independent cancer taskforce five-year strategy for cancer, *Achieving World-Class Cancer Outcomes: A Strategy for England 2015- 2020*, published in July 2015. This recommended that providers should be encouraged to ensure that “all patients have access to a CNS or other key worker from diagnosis onwards, to guide them through treatment options and ensure they receive appropriate information and support.”⁵

While central policy has been consistent, variations in local implementation has led to different approaches, models and service developments, and therefore “considerable confusion and inconsistency surrounding the titles, descriptions, qualifications and grading of CNS posts.”⁶ This continues to be so, with the latest NHS Cancer

Workforce Plan acknowledging problems facing the CNS role as: no nationally agreed competency and skills framework for CNS; no defined route for a nurse to become a CNS; and an expanded role, but insufficient time to utilise specialist skills due to administrative burdens and general nursing work.⁷ The Workforce Plan goes some way to addressing this by developing national competencies and a clear route into training. A more detailed report on nursing and cancer is due to be published this year, taking into account new CNS census data due to be published in spring 2018.⁷

The latest numbers for CNS are from a 2014 census, which found that the NHS specialist adult cancer nursing workforce for England in 2014 was 3,088 WTE, an increase of 10% from 2,805 WTE in 2011.⁸

Funding

Most CNS posts are funded locally by trusts or by the cancer charity Macmillan. Macmillan support the position of CNS in cancer care by 'pump-prime' funding, typically funding a CNS post for 3 years or less until the partner organisation is able to continue supporting the role. These CNS are often referred to as 'Macmillan nurses' and retain this title when charitable funding ends. Macmillan claim that as of October 2017, there were 4,555 Macmillan nurse posts across the UK, both in hospitals and in the community.⁹

In 2010, the Department of Health (DoH) commissioned an economic analysis of the impact of providing enough posts for 'one to one' support for all cancer patients in England. This estimated that around 1,200 new posts, a combination of specialists and support staff, would be required, with a cost of about £60 million per year.¹⁰

Discussion of evidence

26 relevant studies were identified as reporting on impact on quality. Aside from a couple of early studies, the main body of work was from 2009-2012, with research continuing since then but at a slower rate. In addition, various expert and interest groups, have produced case studies, evidence summaries and reports highlighting the impact of CNS can have on patient care. These were not typically using original empirical research, but were adept at gathering the key resources together.^{4,11-13}

Given that improved patient experiences underpinned the aims of the new CNS role, it is unsurprising that evidence gathering patient views predominates. This included specific questions in the bi-annual National Cancer Patient Experience Surveys,¹⁴⁻¹⁶ questions in national clinical audits including the Lung Cancer Audit which provided strong information about the link between contact with CNS and accessing treatment,^{17,18} and a number of smaller scale patient surveys, usually focused on one particular cancer.¹⁹⁻²¹

Several studies examined the implementation of CNS,^{8,22,23} including a workload analysis of Lung CNS,²⁴ whilst a single-site audit of a CNS within a Hepatobiliary Unit measured whether CNS were providing an adequate service.²⁵

An economic evaluation of providing 'one-to-one' care for all cancer patients, commissioned by the DoH, provided costs of a CNS and then estimated the potential offset savings in other areas.¹⁰ Two randomised controlled trials (RCT) were identified, both relatively small-scale, comparing outcomes and treatment of a group of patients who received treatment or follow-up from a CNS-led service compared to a control group who received conventional service.^{26,27}

Gaps in the evidence

Quantitative assessments of CNS impact on patient outcomes were limited, with most studies using qualitative techniques. One study on CNS described how despite "*many descriptive studies of the role, little quantitative research has been published examining the work of CNS in the UK.*"²⁸ More research identifying the true health system costs and savings would provide a stronger evidence base on cost effectiveness. There was no evidence examining the direct impact on patient safety or timeliness.

Strength of evidence

There is a solid and secure base of evidence demonstrating the positive impact of CNS on patient experience, supported by significant evidence of cost-effectiveness, leading to commentary that "*the figures are not lacking.*"

*Study after study has provided strong evidence of the financial case for specialist nurses.*²⁹ However there was a need for more evidence about impact on patient outcomes and cost-effectiveness.

Impact on quality

The evidence seen demonstrated that patients were generally positive about the experience of being treated by a CNS. There are some estimates suggesting that investing in CNS is an efficient use of resource, but less clarity around the impact on effectiveness, although indications are that CNS are at least as effective as other healthcare staff. The uneven distribution of CNS by geography, demographics and cancer type has led to some inequalities.

Safety

Research did not focus on the safety of healthcare provided by CNS, but a few observations were made. The National Cancer Action team felt that *“CNSs help improve patient experience and safety,”*⁴ whilst a large study of the workload and activity of all CNS (not just cancer nurses) concluded that *“CNSs also act as ‘fail safes’ in preventing injury, detecting symptoms and preventing sequelae, preventing or dealing with iatrogenic events and often dealing with issues before they become complaint.”*²⁸ A narrower RCT examining the impact of a nurse-led follow-up found that specialist nurses were able to do this safely.²⁶

Effectiveness

Evidence showed that impact on the effectiveness of healthcare was not always direct. A series investigating results of the 2010 National Lung Cancer Audit, covering 37,000 patients, found a strong correlation between patients who were seen by a Lung CNS and the likelihood of receiving anti-cancer treatments: *“65% of people with lung cancer seen by a lung CNS received cancer treatment compared to 30% of those who did not see a lung CNS.”*¹⁷ One team examined the audit data and found that contact with a lung CNS was also associated with increased rates of active treatment, particularly chemotherapy or radiotherapy, although not increased rates of surgery.¹⁸

Another research team drew on multiple case studies to understand the how the CNS role operated and can influence access to treatment. It was able to produce *“qualitative evidence to illustrate the ‘ways of working’ which provide clear and plausible mechanisms by which LCNSs can increase access to anticancer treatments,”* and conclude that the findings *“clearly demonstrate the contribution CNSs can make to treatment access and uptake.”*³⁰

Other evidence highlighted that CNS were as effective as other health care staff. The Royal College of Nursing report *Specialist Nurses: Changing Lives, Saving Money* concluded that *“several studies have shown that as a substitute for other health care professionals, including doctors, specialist nurses are both clinically and cost effective.”*¹¹ An RCT of lung cancer patients found no differences in survival rate or progression of patients that received a nurse-led follow up when compared to conventional medical follow up.²⁷ Another RCT found no significant difference in symptom scores between nurse-led follow-up care and conventional medical care through the course of the trial.²⁶

Efficiency

CNS were seen as expensive and faced scrutiny over costs. As a result, several reports addressed the economic case for CNS:

- Economic evaluation estimated the total cost of providing one-to-one support, using combination of CNS and support staff, was around £60 million (central estimate, from a range of £47-£68 million). These costs were more than offset by a number of benefits, such as reductions in emergency bed days, routine follow-up appointments and GP visits: *“we estimate the total benefits to range between £26 million and £148 million per annum, with the central estimate of £89 million.”*¹⁰
- RCT of lung cancer patients compared specialist nurse-led to conventional medical follow up and found that specialist nurse-led care lead to more efficient use of resources. The patients supported by nurse-led follow up were: more likely to die at home; attended fewer consultations with a hospital doctor during the first three months; had fewer radiographs during the first six months; and had more radiotherapy within the first three months.²⁷
- Workload analysis found that pro-active and vigilant case management by CNS resulted in a significant drop in acute admissions, from an average of 4 a month to 0.3 a month. In the context of this small study, it was calculated that this would have led to savings of at least £66,500 a year. It concluded the *“Cancer nurse*

specialists play an important part in making services more cost-effective,” and that “clinical nurse specialists who practise proactive case management and re-focus services in line with best practice represent a good return on investment.”²²

- RCT evaluated a nurse-led follow-up service, in substitution for conventional medical-led service, reported savings in health care costs of over 30%, arising from reductions in service, microbiology and medication costs.²⁶
- 2008 study highlighted the value of unpaid overtime, estimating that Lung CNS worked on average 317 hours of unpaid overtime a year. Extrapolated to the wider English CNS workforce, this suggested an estimated 71,280 hours a year unpaid, a saving of approximately £1,475,500 to the health economy.²⁴

Patient-centred

There was a consistently positive response from patients about the role of a cancer CNS.^{19,25,26,31} This was echoed in annual National Cancer Patient Experience Surveys, which demonstrated that the *“impact of Clinical Nurse Specialists is profound and clearly very positive overall for the patient experience of cancer care.”¹⁴* In the most recent survey (2016), 90% of respondents said that they were given the name of a CNS who would support them through their treatment, 86% of respondents said that it had been ‘quite easy’ or ‘very easy’ to contact their CNS and 88% said that, when they had had important questions to ask their CNS they had got answers they could understand all or most of the time.¹⁵ These results re-enforced the conclusion of the 2014 survey, which found that *“key drivers analysis of the 2014 data shows that the single most important factor associated with high patient scores, in every tumour group, is the patient being given the name of a clinical nurse specialist in charge of their care.”¹⁶*

CNS were also seen to play a vital role in supporting decision making by promoting self-management, supporting specific physical and emotional needs and acting as a trusted source of information.³¹ The emotional support provided around the time of diagnosis and treatment decision making was particularly valued.^{23,32} One practical outcome of this was measured in a RCT of lung cancer patients, which found *“more patients who received nurse-led follow up from lung cancer CNSs died at home, which was their preferred location, rather than in a hospital or hospice: 40% compared to 23% receiving conventional medical follow up.”²⁷*

Timeliness

We did not see any evidence that measured the impact of cancer CNS on the timeliness of healthcare.

Equity

Uneven access to a cancer CNS service was the main impact on the equity of healthcare. Several reports highlighted variations in access based on demographics, geography, cancer types or illness.^{12,33}

- National Cancer Action team reported that patient advocacy groups felt that for some cancers - notably lung and urological cancers - CNS provision fell significantly short of patient need and that CNS face variable case-loads.⁴
- 2010 National Cancer Patient Survey reported *“evidence that some older patients in some tumour groups, and some patients who started treatment over five years ago, have unequal access to the support of a Clinical Nurse Specialist.”¹⁴*
- In 2014, there were significant differences in the proportions of patients saying they were given the name of a CNS - scores ranged from 93% (breast and gynaecological cancers) to 79% (urological cancer).
- Another recent report on CNS working with men with prostate cancer found *“there is wide geographic variation in the provision of specialist nursing for men with prostate cancer. This is reflected in available hours and caseload size.”²³*

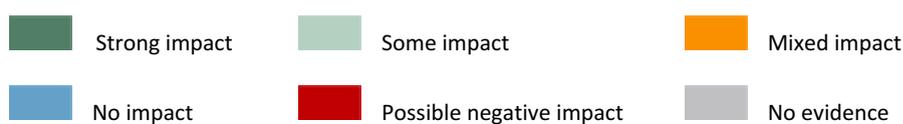
In summary....

- Cancer Clinical Nurse Specialists have a strong and positive impact on the patient-centredness of healthcare. Several national surveys have consistently reported strong patient satisfaction. This combined with evidence that CNS are cost effective makes a strong case for their implementation.
- There was little evidence of their direct impact on patient outcomes or on patient safety, although there has been no suggestion that that CNS have a detrimental impact in these areas.

- Funding is precarious as it relies on local trusts funding specific roles or on the charity sector providing the financing. This has led to an inequitable distribution of CNSs across different areas and types of cancer.

Summary of evidence of impact on quality: Clinical pharmacists in general practice

Domains of quality	Impact
Safe	<ul style="list-style-type: none"> • No direct measurable evidence of impact on safety • National Cancer Action team conclude they help improve safety
Effective	<ul style="list-style-type: none"> • Indirect impact through increased rates of treatments for patients seen by Lung CNS • Evidence suggests CNS are as effective as other health care staff
Efficient	<ul style="list-style-type: none"> • Strong financial case • Cost savings evidenced from reduction in GP time, consultant appointments freed and reduced emergency admission
Patient-centred	<ul style="list-style-type: none"> • Strong evidence of high patient satisfaction • Evidence that CNS promoted self-management and supported patients' decision making and patient wishes • CNS play a strong role as a trusted information source
Timely	
Equity	<ul style="list-style-type: none"> • Evidence of variations in access geographically and by speciality
Strength of evidence	<ul style="list-style-type: none"> • Secure evidence of patient satisfaction and efficiency, with need for more supportive quantitative evidence of impact across other domains • Evidence reviewed drawn from 26 studies
Funding	<ul style="list-style-type: none"> • The roles was funded locally either by NHS trusts or by charitable sector



Date reviewed: February 2018

References

1. Institute of Medicine & Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001.
2. Aoife Molloy, Sara Martin, Sheila Leatherman, and Tim Gardner. *A Clear Road Ahead: Creating a coherent quality strategy for the English NHS*. The Health Foundation, <https://www.health.org.uk/sites/health/files/AClearRoadAhead.pdf> (July 2016).
3. Laura Barrett, Elaine Robinson, Research Matters, Dr Aoife Molloy, Policy Associate, Health Foundation. Taxonomy of health care policy interventions for the NHS in England Working paper for Quality Impact Evidence Summaries (QIES) project, <http://www.research-matters.co.uk/wp-content/uploads/2018/11/NHS-taxonomy-of-policy-interventions-RM-March-2018.pdf> (2018).
4. Team NCA. Excellence in cancer care: the contribution of the clinical nurse specialist.
5. *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020 - One Year On*. NHS England, 2015.
6. Jack B, Hendry C, Topping A. Third year student nurses perceptions of the role and impact of Clinical Nurse Specialists: a multi-centred descriptive study. *Clin Eff Nurs* 2004; 8: 39–46.
7. *Cancer workforce plan, Phase 1: Delivering the cancer strategy to 2021*. NHS England and Health Education England, 2017.
8. Macmillan. *Specialist Adult Cancer Nurses in England A Census of the Specialist Adult Cancer Nursing Workforce in the UK*. 2014.
9. Macmillan Cancer Support: Macmillan Nurses, <https://www.macmillan.org.uk/information-and-support/coping/getting-support/macmillan-nurses.html> (accessed 27 February 2018).
10. Frontier Economics for Department of Health. One to one support for cancer patients.
11. RCN. Specialist nurses Changing lives, saving money. *RCN Nurs Stand*, https://my.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf (2009).
12. Macmillan Cancer Support. Cancer Clinical Nurse Specialists Impact Briefs. 2014; 1–14.
13. All Party Parliamentary Group. *Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer*. 2009.
14. Department of Health. *National Cancer Patient Experience. Survey Programme. 2010 National Survey Report*. 2010.
15. Quality Health. *National Cancer Patient Experience Survey 2016: National Results Summary*. 2016.
16. Quality Health. *Cancer patient experience survey 2014: National Report*. 2014.
17. NHS Information Centre. Lung Cancer Audit, <http://www.hscic.gov.uk/catalogue/PUB02684/clin-audi-supp-prog-lung-canc-nlca-2010-rep1.pdf> (2010).
18. Beckett P, Woolhouse I, Stanley R, et al. Nurse specialist input is independently associated with anti-cancer treatment in lung cancer. *Thorax* 2011; 66: A42–A43.
19. Garvican L, Grimsey E, Littlejohns P, et al. Satisfaction with clinical nurse specialists in a breast care clinic: questionnaire survey. *BMJ* 1998; 316: 976–977.
20. Foster-Mitchell K. Brain tumour patients benefit from clinical nurse specialists. *Br J Nurs* 2016; 25: 196.
21. Tarrant C, Sinfield P, Agarwal S, et al. Is seeing a specialist nurse associated with positive experiences of care? The role and value of specialist nurses in prostate cancer care. *BMC Health Serv Res*; 8. Epub ahead of print 2008. DOI: 10.1186/1472-6963-8-65.
22. Baxter J, Leary A. Productivity gains by specialist nurses. *Nursing Times* 2011; 107: 15–17 3p.
23. Leary A, Brocksom J, Endacott R, et al. The specialist nursing workforce caring for men with prostate cancer in the UK. *Int J Urol Nursing* 2016; 10: 5–13.
24. Leary A, Bell N, Darlison L, et al. An analysis of lung cancer clinical nurse specialist workload and value. *Cancer Nursing Practice*; 7.
25. Pollard CA, Garcea G, Pattenden CJ, et al. Justifying the expense of the cancer clinical nurse specialist. *Eur J Cancer Care* 2010; 19: 72–79.
26. Faithfull S, Corner J, Meyer L, et al. Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy. *Br J Cancer* 2001; 85: 1853–1864.
27. Moore S, Corner J, Haviland J, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. *BMJ* 2002; 325: 1145.

28. Leary A, Crouch H, Lezard A, et al. Dimensions of clinical nurse specialist work in the UK. *Nurs Stand* 2008; 23: 40–44.
29. Waters A, Read C. *The Benefits of Specialist Nurses: Time for Some Advanced Thinking ?* Health Services Journal, <http://www.hsj.co.uk/download?ac=1298457> (2015).
30. Tod AM, Redman J, McDonnell A, et al. Lung cancer treatment rates and the role of the lung cancer nurse specialist: a qualitative study. *BMJ Open* 2015; 5: e008587.
31. Thornton M, Parry M, Gill P, et al. Hard choices: a qualitative study of influences on the treatment decisions made by advanced lung cancer patients. *Int J Palliat Nurs* 2011; 17: 68–74.
32. Macmillan Cancer Support. *Cancer Clinical Nurse Specialists Impact Brief*, https://www.macmillan.org.uk/_images/Clinical-Nurse-Specialists_tcm9-283175.pdf (2014).
33. Trevatt P, Petit J, Leary A. Mapping the English cancer clinical nurse specialist workforce. *Cancer Nursing Practice* 2008; 7: 33–38.