

Evidence Brief: Cancer Support Workers

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Produced by the HEE Knowledge Management team Evidence Briefs offer a quick overview of the published reports, research and evidence on a workforce-related topic. A starter for 10 on the evidence if you will.

Please acknowledge this work in any resulting paper or presentation as:

Evidence Brief: Cancer support workers. Katie Nicholas. (February 2021). UK: Health Education England Knowledge Management Team

Key publications – the big picture

[Cancer services recovery plan](#) NHS England, December 2020
See p. 18 “Cancer alliance will support clinical nurse specialists to work at the top of their licence by deploying an effective skill mix model, including cancer support worker and volunteer roles.”
The coronavirus pandemic has presented major challenges for all healthcare systems. At the start of the pandemic, this resulted in some people facing longer waits for diagnosis, some treatments being delivered in different ways or being interrupted or stopped on the grounds of clinical safety, and some follow-up care being disrupted. One of the most significant impacts was a sharp reduction in the number of people coming forward and being referred urgently with suspected cancer and referred from screening programmes.

[Estimating the cost of growing the NHS cancer workforce in England by 2029](#) October 2020, Cancer Research UK
Over the last 50 years, the UK has made significant progress in improving survival outcomes for people diagnosed with cancer. In the 1970s, only 1 in 4 cancer patients would survive their disease for ten years or more. By 2010, this had risen to 2 in 4, and survival outcomes continue to improve.¹ There are several drivers for this, from the introduction of screening programmes and innovative treatments to ongoing improvements to health care pathways –all of which has been underpinned by the continued and tireless efforts of staff from across the NHS.

[Key worker policy to support people living with cancer](#) June 2020, East Midlands Cancer Alliance
See section 8.1 The Role of a Cancer Support Worker
8.1 The Role of a Cancer Support Worker/ Cancer Navigator in supporting a Key Worker
The term Cancer Support Workers (CSW) is used in this document however it also includes the roles of Cancer
HEE Knowledge Management Team, Updated February 2021

Navigators. CSW’s often work as part of the cancer care team alongside registered practitioners, usually a Clinical Nurse Specialist (CNS). They can support with delegated non-complex tasks to enable the CNS to focus their expertise on managing the complex care needs of people affected by cancer at different points of the pathway:

- being investigated for a cancer diagnosis
- receiving treatment for their cancer
- living with and beyond cancer following treatment

[Interim NHS People Plan](#) June 2019, NHS
Our Interim NHS People Plan, developed collaboratively with national leaders and partners, sets a vision for how people working in the NHS will be supported to deliver that care and identifies the actions we will take to help them.

[Making workforce change at scale in Cheshire and Merseyside: guiding patients to quality outcomes by expanding the role of the Cancer Support Worker](#)
May 2019, Cheshire and Merseyside Cancer Alliance
The implementation of the cancer support/navigator role (CSW/CN) is enabling more holistic care whilst responding to the changing demands of cancer services. When correctly developed the CSW/CN can help to build effective teams around patients and facilitate continuity and coordination of care across primary and secondary care.

[NHS Long Term Plan](#) January 2019, NHS
The NHS Long Term Plan was developed in partnership with those who know the NHS best – frontline health and care staff, patients and their families and other experts.

See pp. 56-61 for “Cancer” including “all patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.” p. 61

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[Strategic Framework for Cancer Workforce: Interim working paper \(phase 2\)](#) July 2018, HEE

In July 2018, the NHS was tasked with developing the Long Term Plan (LTP) setting out how the service intends to deliver major improvements in key areas including transforming cancer care. This was followed by a multi-year workforce plan – the interim People Plan.

NHS England and Health Education England should encourage providers to work with Macmillan Cancer Support and other charities to develop and evaluate the role of support workers in enabling more patient centred care to be provide (p. 35)

The expansion of Clinical Support Workers (CNSs) (Macmillan pilot to free up senior CNS time in oncology, so that we can support oncologists in an increasingly complex role that relies on connections between many disciplines and organisations) could release valuable oncologist time and productivity (p. 54)

[Thinking Differently: Macmillan's vision for the future cancer workforce in England](#) February 2017, Macmillan

See pp. 20-21 “Trained support workers are another new role Macmillan has been exploring. These roles work alongside registered practitioners to support people with cancer who have non-complex needs. While the specifics vary, the overall aim of their role remains the same: to offer the right post-treatment support to patients at the right time, and to support people to manage their own care. For instance, support workers can coordinate care or provide a single point of access in order to allow patients to easily re-enter the system when they need to. In addition, they can provide appropriate advice and escalate any issues to a specialist where necessary. The role, which is focused on a partnership with the patient, allows the support

worker to empower the patient to self-manage – which is ever more important as people live longer with the consequences of cancer treatment.”

[Cancer Workforce Plan – Phase 1: Delivering the cancer strategy to 2021](#) 2017, HEE

In it we set out the key developments to increase supply through speciality training, to create new routes into the cancer workforce and to upskill existing staff. See also [Cancer Workforce Plan – Phase 1 progress update](#)

[Cancer workforce in England: a census of cancer, palliative care and chemotherapy speciality nurses and support workers in England](#) 2017, Macmillan

See p. 66 for numbers on “Cancer Support Workers”

This section describes the cancer support workers workforce in England. To be included in this report the posts had to be on Agenda for Change Bands 3 to 4, and the post holders had to spend over 50% of their time directly supporting adult cancer patients. This means many administrative roles and Band 2 support workers and healthcare assistants have not been included in these numbers.

See also [Considering the numbers](#) May 2018, British Journal of Nursing”

[Indicative role specification for a macmillan cancer support worker – care coordination](#) August 2011, Macmillan

Purpose: Macmillan has developed an indicative role specification to outline the tasks, skills, knowledge and behaviours required, which are transferable across the UK and across all care settings. This has been based on Agenda for Change National Job Profiles Band 4 and Skills for Health Core Standards for Assistant Practitioners. The purpose is to set the

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minimum standard for all Cancer Support Worker posts. Additional content can be added to this role specification according to local requirements. So this is the minimum expected of the role rather than an exhaustive list of everything a Macmillan Cancer Support Worker might undertake.

Case Studies

[The Transforming Cancer Care in the Community \(TCCC\) Programme – Testing the shift of Cancer Care Provision and Patient Support from Secondary to Primary Care](#) 2015, East of England Strategic Cancer Networks

In response to the national evidence³, in 2011 the Anglia Cancer Network and Macmillan launched the Transforming Cancer Care in the Community (TCCC) programme, in recognition that current secondary care service provision models cannot continue to sustain this increasing demand, and that patient satisfaction levels with today's services are already on the decline. See p. 3-4 for Case Studies from Cambridgeshire and Huntingdonshire

[Support Worker – Impact Brief](#) n.d., Macmillan

Support Workers work as part of the cancer care team alongside registered practitioners to improve care for people with cancer. They work with other professionals and provide support by dealing with non complex tasks to allow registered practitioners to focus their expertise on managing the complex care needs. They provide coordination of care to people mostly after cancer treatment, who can be enabled to self-manage their own care with support, with open access back to the MDT.

See also p. 36 of the [Care Navigation Competency Framework](#) (Health Education England, 2016) for more case studies

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See p. 18 "[Velindre Cancer Care](#)" and their Health Care Support Worker (HCSW)

HEE Star

More resources and tools are available in the **Cancer** section of the [HEE Star](#)

Statistics

You can find relevant statistics on the [Health and Care Statistics Landscape](#) under "**Health and Care**" and use the "**Cancer**" filter

[Cancer Research UK](#) also have a wealth of statistics for the UK

[Using cancer data](#) Macmillan

HEE National Data Programme

HEE staff can look at the [National Data Warehouse \(NDL\)](#) SharePoint site to find out more about datasets and Tableau products.

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Published Peer Reviewed Research

Role Specification

[Specifications for the Macmillan Cancer Support Worker](#)

December 2017, British Journal of Healthcare Assistants

*Abstract only**

Macmillan has developed a role specification to outline the tasks, skills, knowledge and behaviours required, transferable across the UK and across all care settings. This has been based on Agenda for Change National Job Profiles Band 4 and Skills for Health Core Standards for Assistant Practitioners. The purpose is to set the minimum standard for all cancer support workers. This is the minimum expected of the role, rather than an exhaustive list.

Role Scope

[Expertise, advocacy and activism: A qualitative study on the activities of prostate cancer peer support workers](#)

January 2020, Health

Peer support workers are now working with patients in a variety of settings, coming into close contact and even work alongside health professionals. Despite the potentially influential position peer support workers hold in relation to those engaged in support activities, their role, duties and their relationship to peers and health professionals lack clarity and is often defined by other actors. This study explores how peer support workers interpret and define the activities, responsibilities and knowledge associated with their work. Using methods of membership categorisation analysis, we analysed interview materials generated by conducting individual semi-structured interviews

during the autumn of 2016 with prostate cancer peer support workers (n = 11) who currently volunteer as support workers in Finland. Although the peer support workers acknowledged the psychosocial aspects of the work, we argue that their interpretations extend far beyond this and encompass expertise, advocacy and activism as central features of their work. These can be used to strengthen their position as credible commentators and educators on issues relating to cancer and men's health; raise awareness and represent the 'patient's voice' and attempt to influence both policy and clinical practice. These findings suggest that by categorising their work activities in different ways, voluntary sector actors such as peer support workers can attempt to portray themselves as legitimate authorities on a range of issues and influence decision-making ranging from individual level treatment decisions all the way to health policy.

[Scope of Practice, Role Legitimacy, and Role Potential for Cancer Care Coordinators](#)

2019, Asia-Pacific Journal of Oncology Nursing

Objective The cancer care coordinator (CCC) role has become a priority in providing coordinated, patient-centered, supported care for patients, and their families experiencing cancer. The CCC role exists with heterogeneity across tumor streams, clinical disciplines, and institutions. This study explored CCCs perceptions and experiences of their role, scope of practice, and potential for future role development. **Methods** This research used a mixed methods design. Focus groups and individual interviews were conducted with a purposive sample of 16 CCCs from two tertiary public teaching hospitals in Melbourne, Australia. A thematic analysis approach was used. A quantitative record of relative time spent on tasks was also collected. **Results** Three major themes were identified: (1) Perceptions of role legitimacy, (2) Structure and funding of the role determines

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scope of practice, and (3) Reflections on the potential for the role. Variability was evident in predominant tasks undertaken, integration into the unit, level of patient contact, and regard from other professional colleagues. Variability appears to relate to employment time assigned to the role, and history and structure of the role. Conclusions The findings underline the need when establishing and reviewing CCC roles for explicit attention to be given to the reporting, integration, structural, and collegiate support for the role as this will profoundly influence its success.

[Health professionals involved in cancer care coordination: nature of the role and scope of practice](#) August 2018, *Collegian Abstract only**

Background Cancer treatment can be complex; and coordination of cancer care across different treatments and health settings is essential to high quality health care. **Objective** The aim of this study was to determine the location and scope of practice of health professionals involved in cancer care coordination in Victoria, Australia. **Methods** The study design was cross-sectional. An online survey was disseminated through 14 peak organisations for oncology health professionals to individuals whose work involved coordinating the care of cancer patients. **Findings** Analysis was conducted on a sample of 91 survey respondents. Only 26.4% (n = 24) reported a job title of Cancer Care Coordinator. Overall, 67.0% (n = 61) reported they were specifically funded to coordinate the care of cancer patients and 30.8% (n = 28) devoted all their time to this role. The majority worked in public health services (n = 73, 80.2%) and 37.4% (n = 34) were located in rural areas. Compared with their metropolitan counterparts, rural coordinators were more likely to be funded by philanthropy (p = 0.002); work part-time (p = 0.017); and work with patients in the community (p < 0.001). In 37.4% (n = 34) of cases patients were required to have a particular type of cancer to receive care coordination. Positions funded by philanthropy

were more likely to have this requirement (p = 0.002). Conclusion Health professionals undertaking cancer care coordination are diverse and the service offered differs according to location and funding source. There may be inequities in care, with people living in particular areas, attending particular health services or with certain tumour types more likely to receive cancer care coordination.

[Role of care co-ordinators in cancer clinical nurse specialist teams](#)

April 2016, *Cancer Nursing Practice Abstract only**

Strategic interest in the skill mix of the healthcare workforce has acknowledged the increasingly important role of non-registered staff, with care for cancer patients provided by teams comprising clinical nurse specialists (CNSs) at bands 6 and 7 and care co-ordinators at bands 3 and 4. This article outlines the development and role of care co-ordinators in cancer CNS teams in Leeds Teaching Hospitals NHS Trust, using the example of a gynaecological oncology care co-ordinator as a case study. With the support of CNS colleagues, the Leeds care co-ordinators provide high-quality patient care through telephone and face-to-face contact and holistic needs assessments. Care co-ordinators act as named key workers for patients, developing good relationships and providing support at diagnosis, through treatment and beyond to survivorship. Patients and carers have welcomed the role and its development has enabled CNSs to focus their specialist skills on those patients requiring higher level interventions.

[Opinion: Giving a helping hand to cancer survivors](#) (the role in the UK) May 2016, *Cancer Nursing Practice Abstract only** The article discusses the scope and criteria of the support worker's role in cancer care in Great Britain. Topics covered include identification of the optimal skill mix in specific cancer

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care teams, the Shape of Caring review of Health Education England in 2015, and clear identification of the scope of practice of each support worker.

Reviews

[Is care really shared? A systematic review of collaborative care \(shared care\) interventions for adult cancer patients with depression](#) February 2019, BMC Health Services Research
BACKGROUND Collaborative care involves active engagement of primary care and hospital physicians in shared care of patients beyond usual discharge summaries. This enhances community-based care and reduces dependence on specialists and hospitals. The model, successfully implemented in chronic care management, may have utility for treatment of depression in cancer. The aim of this systematic review was to identify components, delivery and roles and responsibilities within collaborative interventions for depression in the context of cancer. METHODS Medline, PsycINFO, CINAHL, Embase, Cochrane Library and Central Register for Controlled Trials databases were searched to identify studies of randomised controlled trials comparing a treatment intervention that met the definition of collaborative model of depression care with usual care or other control condition. Studies of adult cancer patients with major depression or a non-bipolar depressive disorder published in English between 2005 and January 2018 were included. Cochrane checklist for risk of bias was completed (Study Prospero registration: CRD42018086515). RESULTS Of 8 studies identified, none adhered to the definition of 'collaborative care'. Interventions delivered were multi-disciplinary, with care co-ordinated by nurses (n = 5) or social workers (n = 2) under the direction of psychiatrists (n = 7). Care was primarily delivered in cancer centres (n = 5). Care co-ordinators advised primary care physicians (GPs) of medication changes (n = 3) but few studies

(n = 2) actively involved GPs in medication prescribing and management. CONCLUSIONS This review highlighted joint participation of GPs and specialist care physicians in collaborative care depression management is promoted but not achieved in cancer care. Current models reflect hospital-based multi-disciplinary models of care. PROTOCOL REGISTRATION The protocol for this systematic review has been registered with PROSPERO. The registration number is CRD42018086515.

[Patient navigators for people with chronic disease: a systematic review](#) February 2018, PLoS One

People with chronic diseases experience barriers to managing their diseases and accessing available health services. Patient navigator programs are increasingly being used to help people with chronic diseases navigate and access health services. OBJECTIVE: The objective of this review was to summarize the evidence for patient navigator programs in people with a broad range of chronic diseases, compared to usual care. METHODS: We searched MEDLINE, EMBASE, CENTRAL, CINAHL, PsycINFO, and Social Work Abstracts from inception to August 23, 2017. We also searched the reference lists of included articles. We included original reports of randomized controlled trials of patient navigator programs compared to usual care for adult and pediatric patients with any one of a defined set of chronic diseases. RESULTS: From a total of 14,672 abstracts, 67 unique studies fit our inclusion criteria. Of these, 44 were in cancer, 8 in diabetes, 7 in HIV/AIDS, 4 in cardiovascular disease, 2 in chronic kidney disease, 1 in dementia and 1 in patients with more than one condition. Program characteristics varied considerably. Primary outcomes were most commonly process measures, and 45 of 67 studies reported a statistically significant improvement in the primary outcome. CONCLUSION: Our findings indicate that patient navigator programs improve processes of care, although few studies assessed patient

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experience, clinical outcomes or costs. The inability to definitively outline successful components remains a key uncertainty in the use of patient navigator programs across chronic diseases. Given the increasing popularity of patient navigators, future studies should use a consistent definition for patient navigation and determine which elements of this intervention are most likely to lead to improved outcomes.

[Cancer care coordination: building a platform for the development of care coordinator roles and ongoing evaluation](#)

2015, Australian Journal of Primary Health *Abstract only**
Continuity of care is integral to the quality and safety of care provided to people with cancer and their carers. Further evidence is required to examine the contribution Nurse Cancer Care Coordinator (NCCC) roles make in improving the continuity. The aim of the present study was to clarify the assumptions underpinning the NCCC roles and provide a basis for ongoing evaluation. The project comprised a literature review and a qualitative study to develop program logic. The participants who were purposively sampled included policy makers, practitioners, patient advocates, and researchers. Both the literature and participant reports found that NCCC roles are diverse and responsive to contextual influences to coordinate care at the individual (patient), organisational, and systems levels. The application of the program logic for the development of NCCC roles was explored. The conceptualisation of NCCC roles was also examined in relation to Boundary Spanning and Relational Coordination theory. Further research is required to examine how NCCCs contribute to improving equity, safety, quality and coordination of care. The project has implications for research.

Cost

[Cancer Care Coordinators to Improve Tamoxifen Persistence in Breast Cancer: How Heterogeneity in Baseline Prognosis Impacts on Cost-Effectiveness](#)

December 2016, Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research *Abstract only**

Objectives: To assess the cost-effectiveness of a cancer care coordinator (CCC) in helping women with estrogen receptor positive (ER+) early breast cancer persist with tamoxifen for 5 years. METHODS We investigated the cost-effectiveness of a CCC across eight breast cancer subtypes, defined by progesterone receptor (PR) status, human epidermal growth factor receptor 2 (HER2) status, and local/regional spread. These subtypes range from excellent to poorer prognoses. The CCC helped in improving tamoxifen persistence by providing information, checking-in by phone, and "troubleshooting" concerns. We constructed a Markov macrosimulation model to estimate health gain (in quality-adjusted life-years or QALYs) and health system costs in New Zealand, compared with no CCC. Participants were modeled until death or till the age of 110 years. Some input parameters (e.g., the impact of a CCC on tamoxifen persistence) had sparse evidence. Therefore, we used estimates with generous uncertainty and conducted sensitivity analyses. RESULTS The cost-effectiveness of a CCC for regional ER+/PR-/HER2+ breast cancer (worst prognosis) was NZ \$23,400 (US \$15,800) per QALY gained, compared with NZ \$368,500 (US \$248,800) for local ER+/PR+/HER2- breast cancer (best prognosis). Using a cost-effectiveness threshold of NZ \$45,000 (US \$30,400) per QALY, a CCC would be cost-effective only in the four subtypes with the worst prognoses. CONCLUSIONS There is value in investigating cost-effectiveness by different subtypes within a disease. In this example of breast cancer, the poorer the prognosis, the greater the health gains from a CCC

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and the better the cost-effectiveness. Incorporating heterogeneity in a cost-utility analysis is important and can inform resource allocation decisions. It is also feasible to undertake in practice.

[Cancer care coordinators in stage III colon cancer: a cost-utility analysis](#) August 2015, BMC Health Services

Background: There is momentum internationally to improve coordination of complex care pathways. Robust evaluations of such interventions are scarce. This paper evaluates the cost-utility of cancer care coordinators for stage III colon cancer patients, who generally require surgery followed by chemotherapy. METHODS We compared a hospital-based nurse cancer care coordinator (CCC) with 'business-as-usual' (no dedicated coordination service) in stage III colon cancer patients in New Zealand. A discrete event microsimulation model was constructed to estimate quality-adjusted life-years (QALYs) and costs from a health system perspective. We used New Zealand data on colon cancer incidence, survival, and mortality as baseline input parameters for the model. We specified intervention input parameters using available literature and expert estimates. For example, that a CCC would improve the coverage of chemotherapy by 33% (ranging from 9 to 65%), reduce the time to surgery by 20% (3 to 48%), reduce the time to chemotherapy by 20% (3 to 48%), and reduce patient anxiety (reduction in disability weight of 33%, ranging from 0 to 55%). RESULTS Much of the direct cost of a nurse CCC was balanced by savings in business-as-usual care coordination. Much of the health gain was through increased coverage of chemotherapy with a CCC (especially older patients), and reduced time to chemotherapy. Compared to 'business-as-usual', the cost per QALY of the CCC programme was \$NZ 18,900 (\approx \$US 15,600; 95% UI: \$NZ 13,400 to 24,600). By age, the CCC intervention was more cost-effective for colon cancer patients < 65 years (\$NZ 9,400 per QALY). By ethnicity, the health gains were larger

for Māori, but so too were the costs, meaning the cost-effectiveness was roughly comparable between ethnic groups. CONCLUSIONS Such a nurse-led CCC intervention in New Zealand has acceptable cost-effectiveness for stage III colon cancer, meaning it probably merits funding. Each CCC programme will differ in its likely health gains and costs, making generalisation from this evaluation to other CCC interventions difficult. However, this evaluation suggests that CCC interventions that increase coverage of, and reduce time to, effective treatments may be cost-effective.

[Cancer care coordinators: what are they and what will they cost?](#)

August 2013, The New Zealand Medical Journal *Abstract only** Health care resources are scarce, and future funding increases are less likely than in the past; reorientation of health services to more efficient and effective delivery is as timely as ever. In this light, we consider the recent funding decision by the Government to provide \$16 million over the next 4 years for cancer coordination nurses. While the intricacies of the role are still being defined, it is likely that cancer care coordinators could benefit patients in terms of access to and timeliness of care, and patient satisfaction. Our research into the role shows that many coordinating activities for cancer patients are already being done, but often in an ad hoc manner by a number of different personnel. Thus, we estimate that the likely 'true' incremental cost of cancer care coordinators is in fact relatively low when considered in opportunity cost terms because the cancer care coordinator will be able to free up time for other staff enabling them to provide care elsewhere in the health system and reduce tasks being unnecessarily repeated. The funding of cancer care coordinators is a great opportunity to improve the timeliness of care and improve the experience of patients through their cancer journey, but the success of these roles depends on the

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leadership provided, peer support, continual appraisal and the resources available.

Timeliness of Care

[Timely access to medical oncology services closer to home for rural patients: experience from the Townsville Teleoncology Model](#) 2014, Australian Journal of Rural Health *Abstract only**
Problem: Prior to 2009, the teleoncology model of the Townsville Cancer Centre (TCC) did not achieve its aims of equal waiting times for rural and urban patients and the provision of reliable, local acute cancer care. From 2007-2009, 60 new patients from Mt Isa travelled to TCC for their first consultation and their first dose of chemotherapy. Six of these patients required inter-hospital transfers and eight required urgent flights to attend outpatient clinics. Only 50% these rural patients (n = 30) were reviewed within one week of their referral, compared with 90% of Townsville patients. DESIGN A descriptive study. SETTING TCC provides teleoncology services to 21 rural towns; the largest is Mt Isa, Qld. KEY MEASURES FOR IMPROVEMENT Specialist review of 90% of urgent cases within 24 hours, and 90% of non-urgent cases within one week of referral via videoconferencing. A 50% reduction in inpatient inter-hospital transfers from Mt Isa to Townsville. STRATEGIES FOR CHANGE Employment of a half-time medical officer and a half-time cancer care coordinator, and implementation of new policies. EFFECTS OF CHANGE Between 2009 and 2011, TCC provided cancer care to 70 new patients from Mt Isa. Of these new patients, 93% (65/70) were seen within one week of referral. All 17 patients requiring urgent reviews were seen within 24 hours of referral and managed locally thus eliminating the need for inpatient inter-hospital transfers. LESSONS LEARNT Provision of timely acute cancer care closer to home requires an increase in the rural case complexity and human resources.

[Factors delaying chemotherapy for breast cancer in four urban and rural oncology units](#) July 2013, ANZ Journal of Surgery *Abstract only**

Background: Delays in commencing adjuvant chemotherapy for early breast cancer beyond 12 weeks are associated with increased mortality. The aim of this study was to identify factors delaying chemotherapy in an inner metropolitan, outer metropolitan, small rural and large rural cancer centre in New South Wales, Australia. METHODS We retrospectively reviewed 400 consecutive patients that received adjuvant chemotherapy for stages I-III breast cancer. We evaluated factors affecting time from primary and definitive surgery until commencing chemotherapy. RESULTS The primary factor associated with chemotherapy delays was the geographic location of the cancer centre. The median time from primary surgery to chemotherapy was longer for the large rural centre (median 58 days), compared with the outer metropolitan (45 days), small rural (39 days) and inner metropolitan centre (33 days). Treatment delays in the large rural centre were associated with higher rates of multiple operations (43% versus 31% elsewhere), mainly because of more staged axillary dissections (34% versus 19%), and longer time from definitive surgery to oncology assessment. CONCLUSION Patients in the large rural centre, who are served by fly-in medical oncology services, are more likely to experience delays in receiving adjuvant chemotherapy for early breast cancer. Strategies to reduce delays include use of intraoperative frozen section analysis, multidisciplinary meetings, improving efficiency in pathology reporting and employment of a breast cancer care coordinator and an on-site medical oncologist.

[Using nurse navigation to improve timeliness of lung cancer care at a veterans hospital](#) February 2012, Clinical Journal of Oncology Nursing *Abstract only**

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The Connecticut Veterans Affairs Healthcare System (CT-VAHCS) sought to improve the timeliness of lung cancer care by filling the new position of cancer care coordinator with an advanced practice nurse (APN) functioning as a nurse navigator. The multifaceted nature of diagnosing lung cancer and the barriers encountered by patients and families as they access the complex healthcare system contributed to substantial delays in diagnosing and treating this disease. Beginning in January 2007 when the cancer care coordinator was hired, she recorded data regarding timeliness and stage at diagnosis for all patients diagnosed with non-small cell lung cancer. CT-VAHCS created and modified several processes to improve timeliness and quality of cancer care as soon as a patient's imaging suggested a new diagnosis of malignancy. The cancer care coordinator effected a measurable improvement in timeliness. In 2003, the average was 136 days from suspicion of cancer to treatment compared to 55 days in 2010, with a trend toward diagnosis of non-small cell lung cancer at an earlier stage. Oncology-certified APNs in the position of cancer care coordinator can engage multiple disciplines to generate process changes and improve timeliness of lung cancer care.

Patient Experience and Care

[Efficacy of the Breast Cancer Navigator Role in reducing distress in new diagnoses breast cancer patients: a pilot study](#) May 2018,

Journal of Oncology and Survivorship

Background: Breast Cancer Navigator (BCN) programs are considered best practice in cancer care, using the Commission on Cancer Standard 3.1. The diagnosis of breast cancer is often accompanied by extreme distress. Studies to date on the BCN intervention have primarily examined screening practices, cost measures, or downstream effects on care. Objective: Few primary studies have examined the effect of early intervention by

a Breast Navigator Nurse program on distress. We tested the effects of an early intervention by the BCN on distress. A secondary interest was how an early intervention might change practices. Methods: A convenience sample of newly diagnosed breast cancer patients was recruited for a descriptive, quantitative pilot study, incorporating anecdotal commentary. Constructs from Hildegard Peplau's Theory of Interpersonal Relations and the Social Ecological Model were adapted to the Johnson Bongiorno Model to guide the study. Distress levels were collected immediately pre- and postintervention, using the Distress Thermometer. A paired samples test was conducted to examine distress before and after the BCN intervention. Results: There was a statistically significant difference in scores between preintervention distress ($M = 7.44$; $SD = 2.68$) and postintervention distress ($M = 2.94$; $SD = 1.86$) conditions $t(8) = 8.27$ $p < 0.00$. Effect size was calculated, with a Cohen's d of 1.79. Conclusion: Findings suggest that the BCN intervention reduces distress in this population, although the sample size was small. This study helped to drive practice changes at the institution, allowing the BCN to intervene shortly after the diagnosis is delivered. There was a significant increase in the number of patients choosing to stay with care at the institution.

[Impact of breast cancer care RN-coordinator program on patients' distress level](#) 2018, Canadian Oncology Nursing Journal

The purpose of this study was to determine whether patients receiving navigation supportive care from a Breast Cancer Care Coordinator (BCCC), prior to initial oncology consultation at a British Columbia Cancer Agency, Abbotsford Centre (BCCA-AC), demonstrated different levels of anxiety and depression from those not receiving such support at the same BCCA centre. A retrospective review of the Psychological Screen for Cancer (PSSCAN) scores of new breast cancer patients seen for

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oncology consultation for the control cohort (receiving usual care) were compared to PSSCAN scores of those who had received care from a BCCC prior to the oncology consultation (the study cohort). A total of 91 PSSCANs were reviewed in the study, with 54 belonging to the treatment group and 37 to the control group. PSSCAN scores for anxiety and depression did not show significant differences between the two groups.

[Patterns and predictors of colorectal cancer care coordination: a population-based survey of Australian patients](#) January 2017, Cancer

Background: Improving care coordination is a key priority for health services. The aims of this study were to identify patient- and health service-related predictors of poorly coordinated care and to explore patient preferences to assist care coordination. Methods: Patients with incident colorectal cancer, identified from a state-wide cancer registry, completed a self-report questionnaire 6 to 8 months after their diagnosis. Care coordination was assessed with the Cancer Care Coordination Questionnaire for Patients. Multiple linear regression models were used to predict factors associated with a poor experience with cancer care coordination. Results: Among 560 patients (56% response rate), care coordination experiences were normally distributed (mean score, 76.1; standard deviation, 10.9). Patients who had 3 or more comorbid conditions (β , -4.56; standard error [SE], 1.46; $P = .006$), little or no understanding of the health system (β , -4.34; SE, 0.94; $P < .001$), and no regular general practitioner (GP; β , -4.09; SE, 2.07; $P = .049$) experienced poorer care coordination. At the health service level, patients who did not receive a written pretreatment plan (β , -4.15; SE, 0.95; $P < .001$) or did not see a cancer care coordinator (β , -3.29; SE, 1.03; $P = .001$) had lower scores. The most preferred resources included information packs (92%), written care plans (88%), and improved access to their own personal medical

records (electronic, 86; paper, 84%), with most patients preferring a shared GP and surgeon care model. Conclusions: There was wide variation in experiences across the state. The factors associated with lower scores provide a focus for targeted strategies for improving patients' experience with colorectal cancer care coordination.

[Colorectal cancer: care coordination in a tertiary referral centre in Saudi Arabia](#) July 2015, *Gastrointestinal Nursing Abstract only**

Colorectal cancer in Saudi Arabia is on the increase. From diagnosis through to completion of treatment and ongoing follow-up and screening, patients are required to undertake a long journey, involving visits to numerous specialists, and a variety of investigations, interventions and treatments. Unsurprisingly, patients feel lost, overwhelmed and anxious. There is an obvious need for ongoing communication, education, guidance, advocacy and help with navigation between services. Internationally, the need for expert cancer care coordination has been recognised for many years. Patients deserve standardisation of evidence-based care to help with the decision-making process. Cancer-care coordinators around the world have demonstrated improvements in patient low, patient experience and satisfaction. The King Faisal Specialist Hospital and Research Centre in Riyadh is a tertiary care facility, treating approximately 30% of all cancer cases in Saudi Arabia. This article aims to describe the experience of introducing colorectal cancer care coordination, using a patient-centred, multidisciplinary approach.

[An evaluation of the role of support workers in lung cancer](#)

February 2015, *Cancer Nursing Practice*

Aim: To map the prevalence and type of unregistered roles that have emerged to support lung cancer nurse specialists (LCNSs), and to explore the effect of support worker roles on the work of LCNSs and how this may affect multidisciplinary teams and

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service delivery. Methods A mixed methods approach was taken using an electronic survey and qualitative telephone interviews. Findings When appropriately planned and resourced, support worker roles can have a significant effect on practice and service delivery, enhance the work of the LCNS and have a positive effect on patient experience. Support workers create opportunities for service improvement initiatives that would not otherwise be feasible. Conclusion This study highlights the importance of planning and training to ensure the success of support worker roles.

[An evaluation report of the nurse navigator services for the breast cancer support program](#) 2015, Canadian Oncology Nursing Journal *Abstract only**

The purpose of this quality improvement project was to evaluate the effectiveness of breast cancer care support provided by breast cancer care navigators (BCCN) for women attending the breast health clinic (BHC). This evaluative process examined patients' satisfaction with the nurse navigator program that focused on addressing breast cancer patients' informational needs, emotional support, and guidance through the cancer trajectory. A survey approach using Likert-type scales and open-ended questions was utilized to gather data. Patients seen at the BHC between July 2011 and July 2013 were sent the surveys by mail. The 154 responses constituted a 69% response rate. More than 90% of participants understood the information provided by the BCCN and were satisfied with the information that had been received. Psychosocial support from patient/family counselling services at the agency and in the community were among the most common request for resources. Recommendations include contacting patients directly after their initial meeting at the clinic and at least once after their treatments began, to ensure continuity and support. BCCN role was identified as being valuable with a positive effect on patients' experience.

[Exploring patient experiences of cancer services in regional Australia](#) (study from Australia) 2010, Cancer Nursing *Abstract only**

Numerous previous studies have suggested that cancer care in rural and regional Australia is fragmented and that rural and regional patients have less access to services. However, knowledge concerning inequality of health and cancer care in regional and rural settings is still inconclusive. The social and economic disadvantages in regional locations are often linked to insufficient resources and infrastructures to support cancer care and treatment. The aim of this study was to explore cancer patients' experiences from the perspective of patients and healthcare providers in a regional area of Western Australia. It was found that patients who had the involvement of a cancer nurse coordinator and cancer support workers had better experiences and more streamlined care than did those who had to navigate the journey alone. This study endorses the function of cancer nurse coordinators and cancer support workers in providing better coordination of care in rural and regional cancer patients.

Peer Support

[Evaluating peer support for prostate cancer: The prostate cancer peer support inventory](#) 2005, BJU International

Objective: To develop and test a measure for assessing peer support for men attending prostate cancer support groups, and to describe socio-demographic, medical and adjustment characteristics of Australian men who attend these support groups. PATIENTS AND METHODS: In all, 1224 men (51% response) from 44 prostate-cancer support groups across Australia were recruited by mail. Men completed self-report measures that included the Prostate Cancer Peer Support

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Inventory (PCSI), the UCLA Prostate Cancer Index bother scales, psychological distress, quality of life (QoL), bother from pain and tiredness, perception of the clinician's support for group participation. Group-level variables were also included in the analyses. RESULTS: Peer support was rated positively by most men; a high satisfaction with support groups was related to better QoL, lower pain, younger age, higher perceived clinician support for group participation, use of alternative therapies, lower education, and regular attendance; dissatisfaction with support groups was related to higher psychological distress, lower QoL, and lower perceived clinician support for group participation. Group variables did not predict positive or negative support. Overall QoL was similar to community norms and psychological distress was low, with only 8% of men reporting high distress. The most common physical symptom was sexual bother, with 74% of men reporting moderate or high bother. CONCLUSIONS: The PCSI was a useful measure of peer support. Perception of the benefits of peer support was related to individual but not group differences. The clinicians' attitudes to participation in support groups influenced the men's experience of these groups, and this finding has implications for developing support services for these men.

CSWs and Multidisciplinary teams

[Cancer care coordinator: promoting multidisciplinary care – a pilot study in Australian general practice](#) 2013, *Collegian Abstract only**

Aim: We hypothesised that patients treated for breast cancer would benefit from targeted therapeutic action delivered by general practitioners on the recommendations of a multidisciplinary team based in primary care. METHODS Patients scheduled for follow-up visits at a hospital surgical clinic were invited to complete a self-administered care needs

assessment and be interviewed by a breast care nurse. Members of the multidisciplinary team discussed the audio-recorded interviews within 2 weeks. The team made recommendations for each patient, which were presented to the general practitioner as a suggested 'care plan'. Health status information was collected via the Short Form 36 and Anxiety and Depression data via the Hospital anxiety and Depression Scale at recruitment and 3 months later. RESULTS Among the 74 women who were invited to participate, 21 were recruited over a 6-month period (28%), 19 of whom completed the study (90%). The mean age was 55 years (range 38-61 years) and the mean time in follow-up was 23 months (range 16-38 months). The team identified a median of three problems per patient (range 2-7) and made an average of two recommendations per patient for referral to an allied health professional (range 0-5). At 3 months, 17 women had attended their general practitioner, 11 of whom felt their condition had improved as a result of the intervention. There was no significant change in Short Form 36 or Hospital Anxiety and Depression Scale score after the intervention. CONCLUSIONS Primary care-based multidisciplinary review of treated breast cancer patients is feasible and, for most, results in benefit. However, only a minority of eligible patients participated in this pilot study and the logistics of organising the reviews warrants careful consideration.

[Cancer care coordinators' relationships with the multidisciplinary team and patients: Everything to everyone](#) June 2012, *Australian Journal of Cancer Nursing Abstract only**

This study aimed to examine the role of cancer care coordinators (CCCs) by investigating what is practically involved in care coordination and what CCCs' perceptions of their role are. Using a qualitative approach with an action research design, two CCCs from a large regional hospital in Australia undertook a patient record audit, analysed using content analysis, and reflected upon

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within a reflective group process. In practice, cancer care coordination involves a variety of activities which support the multidisciplinary team, cancer patients and carers. The participants' perspective--that they were everything to everyone--was an acceptable way of defining the parameters of their role. Areas requiring consideration are multidisciplinary team function in regard to liaison and shared responsibility, strategies to reduce the potential deskilling of team members, increasing awareness of the importance of promoting patient self-management, critically reflecting on relationships with team members and patients, and endeavouring to gain organisational and multidisciplinary team support for what appears to be a role on which there is great reliance.

[Establishing a community-based lung cancer multidisciplinary clinic as part of a large integrated health care system: aurora health care](#) November 2010, Journal of Oncology Practice

A community cancer clinic, through cooperation with its parent health care system, developed a lung cancer multidisciplinary clinic (MDC) to enhance patient care and prevent out-migration to competing health care systems. The local medical and radiation oncologists collaborated with a thoracic surgeon from the tertiary care hospital in establishing the lung MDC. All the participating physicians are employed by the health care system. A cancer care coordinator assured that all necessary tests were obtained and available to the physicians at least 1 day before the clinic. The multidisciplinary team also included a pulmonologist and met every third week. Other sub-specialists were involved as necessary. Final treatment recommendations using National Comprehensive Cancer Network guidelines were made for each patient at the MDC visit. This clinic, once established, resulted in significant improvements in the quality of care, patient satisfaction and retention of patients. Time from diagnosis to initiation of treatment was reduced to a mean of 18 days from a

mean of 24 days. The community cancer clinic had an increase in lung cancer patient care by 28% and a 9.1% increase in gross revenue. The tertiary care hospital benefited by providing all patients with definitive surgery, including minimally invasive surgery. The tertiary hospital thoracic surgeon had a 75% increase in referrals from the lung MDC geographic area over the previous year. This collaboration in the development of MDCs demonstrates how patients, caregivers, and the health care system benefit from MDCs.

[Results of a survey of the role of multidisciplinary team coordinators for colorectal cancer in England and Wales](#) 2007, Colorectal Disease (The official journal of the Association of Coloproctology of Great Britain and Ireland)

Objective: Over the last 6 years, multidisciplinary teams (MDTs) have been established and play a key role in organizing the delivery of cancer care in the UK. There are no published data on the roles of their co-coordinators. To seek the views of colorectal multidisciplinary team co-ordinators (MDTCs) on what they do and how they do it. METHOD: Questionnaires were sent to the colorectal MDTC, or equivalent, in all 180 NHS hospital trusts in England and Wales where colorectal cancer surgery is performed. RESULTS: There was a 70% response rate. Seventy-one per cent of trusts now have a dedicated MDTC, whereas in 2002, only 40% had one. MDTCs generally keep their information on databases, but these differ, and are not coordinated with data entry into the national colorectal cancer database of the Association of Coloproctology of Great Britain and Ireland. In only 26 trusts does the MDTC communicate decisions to primary care, and the patients seem almost completely excluded from this process. CONCLUSION: The recently formed national MDTC Forum should grasp the opportunity of coordinating all of this well-intentioned but pluralistic activity to the benefit of patients, primary care and

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hospital teams. An effective MDTC with a robust database will be the key in achieving cancer waiting time targets with useful audit, thereby improving patient care.

Competency Frameworks

[Macmillan Competency Framework for Nurses \(MCFN\)](#)

November 2020, Macmillan

The framework **does not**:

- set out to determine grades for specific roles. Indeed, some nurses will be working across the different levels within the framework – i.e. core level in some aspects of their work and specialised or highly specialised in others. It is anticipated that individuals working at specialised and highly specialised will have acquired all or most of the competencies at the preceding level/s
- **address the learning needs of the unregistered work force, including the Cancer Support Worker role or the Associate Nurse.** However some core competencies may be appropriate for unregistered and Nursing Associate roles, depending on their scope of practice and patient needs. It may be beneficial to also refer to the Macmillan competency framework for person centred care

[A competency framework for nurses providing care to people with breast cancer](#)

August 2019, Royal College of Nursing
Cancer is often considered to be a life-limiting illness, but is viewed increasingly as a long-term condition involving the individual with cancer, their family and carers. Enabling self-care and rehabilitation are viewed as a crucial component in developing future services. Health care services need to respond creatively to cancer strategies in the four UK countries to meet

patients' needs. This framework defines the standards of care expected for a competent registered nurse providing general breast cancer care or specialist breast cancer care. This publication is supported by a grant from Roche Products Limited.

See p. 51 "Career Framework Level 2 – Indicative or Reference title: Support Worker"

[Cancer Support Worker Competency Framework](#) April 2019, Salisbury NHS Foundation Trust

Macmillan Cancer Support developed the Cancer Support Worker role to work alongside the existing cancer workforce across the UK. The role has been piloted as part of a national evaluation called One-to-One Support, however other local evaluation and learning has also been drawn upon. The pilot of One-to-One Support involved working with 16 sites across the UK. The aim of One-to-One Support Workers is to enable people living with cancer with non-complex needs to self-manage. This helps registered clinicians focus on supporting those with complex needs. In the SWAG Alliance, Bristol was part of the One-to-One Support pilot with Cancer Support Workers working in both North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust. Macmillan are in the process of developing a Cancer Support Worker Competency Framework and this SWAG Cancer Alliance Framework is based on this work to date.

[Core Competency Framework: for Band 4 Support Workers caring Adult Patients with Cancer](#) January 2019, East of England Cancer Alliance

This document is recommended for Band 4 Cancer Support Workers who have been recruited to support delivery of the Personalised Care Package(formally known as the Recovery

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Package) and Patient Centred Follow-Up programmes within Trusts across the east of England

[Care Navigation Competency Framework](#) Health Education England, 2016

The word 'navigator' derives from Latin navis - 'ship' - and agere - 'drive' - meaning 'a person who steers a ship'. Charting stormy uncertain seas requires good navigation – with purpose and direction. Similarly, most people at some point in their life may benefit from 'navigation' through encounters with different health services, agencies and professionals, across an often confusing seascape of health, social and community care. And it's not just an issue for service users, there is broad consensus from healthcare professionals that such systems can be complex and difficult to navigate.

[The Cancer Support Worker Portfolio](#) n.d. Cheshire & Merseyside Cancer Alliance

First and foremost, this resource is about helping you as a Cancer Support Worker (CSW) to understand and recognise the opportunities and boundaries of your role. It aims to help you record the key skills and competencies that will enable you to be a safe, person-centred practitioner, working as part of a team to deliver high-quality, ethical and non-discriminatory care to patients and their families. The development programme has been created with the support of CSW's in Merseyside and Cheshire who have been able to identify key areas of education and training which are fundamental to providing optimal care coordination and support. Our portfolio is a collection of documents and resources that you assemble in order to demonstrate that you have undertaken or achieved the appropriate learning and development to deliver your role competently and offer care coordination for a person with a suspected cancer, a patient who is receiving cancer treatment

or those patients who have completed their treatment and require support with their continuing surveillance. The principles behind the portfolio development are those of adult learning, where the learner is self-directed, and experiences provide a rich resource for learning. A readiness to learn develops from everyday tasks and problems and the individual becomes self-motivated to grow and achieve.

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