

# The Australian Journal of Cancer Nursing

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#### International Keynote Speaker

**Dr. Linda Watson** has been an oncology nurse in Calgary, Alberta, Canada for over 25 years. She has held a variety of nursing and inter-professional leadership roles within the Cancer Control Alberta (CCA) provincial program and is currently the provincial Lead for Person Centred Care Integration within Alberta's provincial cancer care program. Dr. Watson completed her doctoral research in 2014, where she explored the family's experience of living with incurable but treatable cancer.

Dr. Watson holds an adjunct professor position with the Faculty of Nursing at the University of Calgary, but her passion for improving the patient experience has kept her committed to her full time position as a transformational leader within the Alberta cancer system. Committed to enhancing the person centredness

of the cancer care system she has worked closely with the Canadian Partnership Against Cancer (CPAC) and the Alberta Cancer Foundation (ACF) to develop new processes, systems, and programs to enhance clinical capacity to deliver tailored, individualised care to cancer patients in the ambulatory cancer setting. These include using Patient Reported Outcomes (PROs) to improve patient experience, the implementation and evaluation of a provincial cancer patient navigation program to improve the rural cancer patient's access to cancer care, and a provincial post-treatment transitions program that aims to improve the transition between the cancer program and primary care.

Dr. Watson is also currently the President of the Canadian Association of Nurses in Oncology (CANO), providing national leadership to the specialty area of oncology nursing across Canada.

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### Editorial

The *AJCN* aims to provide a forum where debate and the exchange of views can take place. We welcome papers on contemporary professional policy or practice issues of concern and interest to cancer nurses.

### Notes for contributors

All correspondence relating to the journal should be directed to the editors. Guidelines for contributors to the journal can also be obtained from the editors. The *AJCN* is published twice a year.

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# The Australian Journal of Cancer Nursing

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## Editorial

# The role of professional organisations

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Last month I attended the International Conference on Cancer Nursing, hosted in Auckland by the International Society of Nurses in Cancer Care (ISNCC). I first attended this conference in New York in 1986 and recall it as a defining moment in deciding upon a career as a cancer nurse.

At that time, I had been working in oncology for about three years and while I had started to feel comfortable in what I was doing, I hadn't thought of it as a career choice. Not only did I hear presentations at that conference by some world-renowned cancer nurses whose clinical problems were similar to ours, but it also opened my eyes to health care disparities around the world. Over the ensuing years, I've developed a keen interest in how nurses care for cancer patients in other countries. Visits to clinical units in hospitals in the US, Panama, Denmark, Singapore and India have further enriched my perspective and I've come to appreciate that, despite some shortfalls, Australia does indeed have a world-class health system.

Five years ago I represented ISNCC at the International Council of Nurses Congress in Melbourne. It was the first non-cancer related conference I had been to in 30 years and it opened my eyes to some of the different challenges for other specialties and in some cases for all health professionals. A session on human trafficking drew attention to the insidious practice of organ trafficking and surrogacy from low- to high-income countries. Another on health care responses to natural disasters highlighted the devastation to populations and entire health services after the Haiti earthquake in 2010 and the Japanese tsunami in 2011. Not only were health services stretched by increased presentations of severely injured people, but many health care workers or their families had been killed or injured; many lost their homes and possessions; workplaces were severely damaged or destroyed and colleagues were killed or injured. It's hard to imagine sustaining any sort of health service under such circumstances.

Many of my career opportunities have been through membership of professional organisations such as CNSA, COSA, ISNCC and the NSW College of Nursing (now the College of Nursing Australia). My involvement with these organisations began

passively in the 1980s through senior nurses with whom I worked who encouraged me to go along with them to professional evenings and then conferences. I was amazed, not only by the knowledge of these nurses, but also by their commitment and passion for cancer nursing. Much of the discussion and debate in the 1980s was about advancing nurses' roles beyond the bedside or clinic and it was through those sorts of discussions that CNSA was born. I can't emphasise enough the benefits of membership of specialty professional organisations. I have learnt more than any classroom or textbook could teach, broadened my outlook and developed a wide collegial network and great friendships.

I've also had the benefit of some fine mentors from within those organisations who have seen possibilities in me that I hadn't necessarily seen in myself. They have tapped me on the shoulder to join committees and working parties and, in some cases, pushed me way out of my comfort zone, but always with the adage 'I'm here for advice if you need it'.

For those of you who are keen to be involved in your specialty beyond the workplace, start by volunteering for various activities. If you're a member of CNSA or other specialty organisations, encourage colleagues to come to meetings with you. If you have a senior role within an organisation, be generous with your time, share your skills and knowledge and tap up-and-coming nurses on the shoulder for similar activities. You'll all be rewarded with a widening professional network, opportunities for career advancement beyond the workplace and, in some cases, life-long friendships.

# Concurrent chemotherapy and radiation therapy for anal cancer: retrospective chart audit of treatment-related toxicities

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## Abstract

**Background:** The standard treatment for anal cancer is sphincter-preserving treatment, using chemoradiation.

**Aim:** This retrospective chart audit reviewed documented patients' toxicities during the course of treatment.

**Methodology:** All patients with anal cancer over a two-year period were reviewed at the Radiation Oncology Raymond Terrace site at the Princess Alexandra Hospital (PAH). Documentation was audited to assess reported toxicities across the course of treatment, allied health referrals and admission rates. Data was graded against the CTCAE-Version 5 using a visual toxicity display.

**Results:** Ten females and six males were identified. Toxicities included pain, diarrhoea, perianal moist skin desquamation, fatigue, dysuria and psychological distress. Forty-seven per cent of patients scored >5 on the Distress Thermometer at baseline.

**Conclusion:** The common toxicities resulting from concurrent chemoradiation affected all patients, with differences only in type, severity and timing. Improving bowel regimens, analgesia and weight monitoring as part of a formal clinical pathway may result in less toxicity during treatment.

## Background

Anal cancer has generally been considered a rare disease, affecting around 398 people a year in Australia<sup>1</sup>. However, there has been increasing incidence over the past 25 years<sup>2</sup>, and it is slightly more common in women than in men. Approximately 80% of cases are squamous cell carcinoma, which starts in the cells lining the anal margin and the anal canal<sup>3</sup>. The exact cause of anal cancer is unknown, but there is a known association between anal cancer and HPV infection (p16), older age, cigarette smoking, cervical cancer<sup>3</sup>, with risk increasing with age<sup>1</sup>. Clinician-reported acute toxicities have been as high as 80%, and late effects reported at approximately 10%<sup>2,3</sup>. Historically, surgery in the form of abdominal perineal resection was the mainstay of treatment<sup>3</sup>, but modern treatments combining radiation therapy and chemotherapy consisting of intravenous (IV) Mitomycin C and 5-Fluorouracil have become the standard of care<sup>3</sup>. Potential complications include radiation enteritis, diarrhoea, proctitis, skin desquamation, strictures, stenosis, sexual dysfunction, dyspareunia, pelvic fractures, induced menopause, lymphoedema, urgency and frequency of defaecation, stool incontinence, and urinary tract dysfunction<sup>2,4</sup>.

### Significance of the research

Combined modality treatment, with radiation therapy and concurrent chemotherapy, has improved loco-regional control, and the majority of patients have been able to preserve their sphincter<sup>5</sup>. However, there are significant toxicities associated

with this treatment protocol, both during the acute and later stages<sup>2,3,6</sup>. Much of the research on toxicities associated with this treatment has been objective, often utilising colorectal measures, and often with few patient-reported outcomes<sup>7</sup>.

### Literature review

Over the past decade or so, there have been improvements in radiation technologies, such as intensity-modulated radiation therapy (IMRT)<sup>7</sup> utilising volumetric arc radiation therapy (VMAT)<sup>8</sup>. This technology aims to optimise conformity of the radiation beam to the treatment site and lowers doses to nearby organs of risk (OAR)<sup>6,9</sup>. However, radiation dose has still been identified as a significant factor in radiation-induced toxicities<sup>2,9</sup>.

The impact of toxicity on quality of life (QoL) for patients undergoing concurrent chemotherapy and radiation therapy for anal and perianal cancer has been evaluated in studies at different time points. Treatment toxicity, QoL and outcomes in patients treated with IMRT and concurrent chemotherapy were evaluated and this regime was found to be an effective organ-preserving treatment for anal cancer<sup>7</sup>. This study also showed lower rates of acute grade 3+ haematologic, gastrointestinal (GI) and genitourinary (GU) toxicities compared to conventional radiation therapy techniques, returning to baseline by three months. Tournier-Rangard *et al.*<sup>9</sup> utilised the EORTC QLQ C30 with the Anal Sphincter Conservation Treatment (AS-CT) questionnaire pre-treatment and two months after treatment. They found that patients reported significant improvement in



emotional and global health status, and a decrease in a range of physical symptoms at two months following treatment compared to pre-treatment levels. Tom *et al.*<sup>10</sup> assessed the QoL of patients with anal cancer from clinician-reported and patient-reported symptoms. They found that there was poor agreement between patients and clinicians for proctitis, but good agreement for diarrhoea. Patients reported acute GI symptoms during weeks 4–5, while rectal bleeding improved during treatment. Studies that have measured responses from patients with anal cancer have generally used colorectal measures, due to a previous lack of anal measures<sup>5,7,11</sup>.

One study evaluated a psychoeducational programme on health-related QoL in patients treated for colorectal and anal cancer<sup>12</sup>. These authors found this programme had a positive effect on the mental health and bodily pain of the intervention group when compared with a control group. Unfortunately, only one patient with anal cancer was included in each group. QoL issues were systematically reviewed with concurrent chemoradiation for anal cancer<sup>2</sup>. This review found relatively few studies of QoL for this patient cohort, and that formal QoL assessment was generally absent from randomised controlled trials. One group of authors measured physician-assessed toxicities and patient-reported outcomes (PRO) during treatment for anal cancer<sup>6</sup>. These authors found high incidence of PRO scores with weak agreement to the Common Toxicity Criteria — Adverse Events (CTCAE) in evaluation of patients' symptoms by clinicians, suggesting that PROs are important tools complementary to the CTCAE.

### Aim of the study

The aim of this retrospective chart audit is to determine the extent of patients' toxicities during treatment for anal cancer as documented by clinical staff in the patients' electronic records. This may assist to establish a standard pathway of care and referral to improve patient comfort and QoL, and reduce admissions to hospital for this relatively small number of patients. The results of this audit also provide information for a larger QoL study from the patients' perspectives, and will provide an indication for sample size over a designated time frame.

## Methodology

### Design, sample and setting

This study used a retrospective chart audit of all patients treated for anal cancer over a two-year period at Radiation Oncology Princess Alexandra Hospital Raymond Terrace Centre in Brisbane, Australia. The author reviewed all the ICD-21.0 codes for anal cancer within a report provided by MOSAIQ<sup>13</sup>, the Radiation Oncology Information System (ROIS), from 1/1/16 until 31/12/17. A total of 16 patients had undergone concurrent chemoradiation for anal cancer in that time frame. Patients' demographic data, such as gender, age and site of cancer, were described and the

use of a spreadsheet for the toxicity data enabled visual data display for ease of toxicity analyses and eventually for ease of grading and reporting. The Self-Assessment Questionnaire (a departmental patient questionnaire) completed by patients on their radiation therapy planning session provided information on baseline weight, pain and distress scores noted on the Distress Thermometer (DT)<sup>14</sup>. The DT is divided into 10 equal parts where "0" = no distress, and "10" = extreme distress. The audit then examined documented toxicities in the MOSAIQ information system, and also in the digital medical record (iEMR) that had been reported by radiation oncologists, nurses and allied health professionals across the course of each patient's treatment. Admission rates and all allied health referrals made by nurses and medical staff were also reported.

The data was arranged into 10 major toxicities and a visual display was created (Table 1). The data were assessed against the Common Toxicity Criteria — Adverse Events (CTCAE) Version 5. However, the 'Oral Chemotherapy Effects' theme included a collection of associated side effects, and was reported as a single criterion.

### Ethical issues

Ethical approval was given for this study by the Metro South Research Ethics Committee, Queensland Health. This approval was based on the author providing complete anonymity for all patient information used for the chart audit. All patients included in the study were each given a separate code against which the documented toxicities were reported. This coding provided confidentiality of the collected data for the patients, and patient anonymity for the reader. All collected data is kept on a password-protected computer on a database in the office of the principal investigator.

### Methodological considerations of chart review/audit

This research strategy requires consideration of several methodological points. This study has clearly defined aims, which is to review toxicities documented by clinical staff on patients during anal cancer treatment. There were no concerns about sampling issues *a priori*, as this was based on a clearly defined time frame and the small numbers of patients within that time frame. The variables that have been reviewed are documented toxicities, which have been considered against experiential knowledge and the literature. All data collection and abstraction was undertaken by the principal investigator, and issues of accuracy, reliability and consistency between data collectors were not required. The burden of accuracy was on the principal investigator alone. All data is available on a database for audit purposes. The only inclusion criterion was that the patient had undergone a course of concurrent radiation therapy and chemotherapy for anal cancer<sup>15</sup>.

## Results

Sixteen patients were identified in the two-year time frame of the audit: 10 females and 6 males, and all were treated for squamous cell carcinoma (SCC) of the anal canal. The ages of the females ranged from 52 years to 81 years, with a median age of 66 years. The ages of the males ranged from 35 years to 71 years, with a median age of 66 years. Patients received concurrent intravenous (IV) Mitomycin C, and IV infusional 5-Fluoracil (5-FU) over 4 days in Week 1 and the IV 5-FU over 4 days again in Week 5 of the radiation therapy. The median dose of radiation therapy was 55.1Gy (Gray = unit of dose) over a median 29 days. The admission rate was reported as 50%: 5 females/3 males, and 47% of patients scored > 5 on the DT at baseline. Three females expressed embarrassment at site of cancer, and three patients had a history of underlying psychological pathology. Seven patients reported pain at baseline in the 4–10 range (mean 5.00): The pain scale is rated on a 10-point Likert-type scale where “0” = ‘no pain’ and “10” = ‘the worst pain imaginable’. Seven (7) patients reported distress scores at baseline in the 7–9 range (mean distress overall = 3.1). The Self-Assessment Questionnaire, incorporating the DT<sup>4</sup>, was the basis for referrals to members of the multidisciplinary team (MDT). All patients referred by clinical staff utilised the services of the MDT: dietitian x 7, social worker

x 6, physiotherapy x 1, and occupational therapist x 12. Vaginal dilators were provided by nurses to 5/10 females (50%). Services offered by allied health staff in the department are outlined in Table 2.

### Oral effects from chemotherapy (single criterion)

Oral side effects of the chemotherapy were reported by 75% of patients and documented toxicities included a facial rash, a sore throat, dry lips, mouth ulcers, the tongue red and cracked, xerostomia, oral mucositis and oral thrush.

### Documented nursing interventions

The documented nursing interventions were regular oral assessment, information on oral hygiene such as salt/sodium bicarbonate mouth washes, maintenance of adequate hydration and nutrition, and lip care. Patients were provided with the eviQ information on mouth care for cancer patients (eviQ)<sup>6</sup>, if not already provided by the medical oncology department. Seven patients were reviewed by the dietitian. Radiation oncologists and registrars were contacted by nurses to prescribe antifungals, topical analgesia and systemic analgesia as needed. Two patients were prescribed topical steroidal cream for rash.

Table 1: Grades of toxicities

Patient	Oral chemo effects	Perianal pain	Nausea	Diarrhoea	Rectal bleeding/mucous	Dysuria/urgency	Fatigue	Erythema perianal/anal cleft	Moist desquamation perianal/natal cleft	Reduced appetite
A1	+++	3		2		1	1	1	3	2
S1	++	1	1	2	2	1	2	2	3	2
J1	+++	2		2		1	1	1	2	
M1	+	3	2	3	2	1	2	2	3	3
E1		3			2	3		1	3	
J2		1	1	2	2	1		2		
L1	+++	1		2		1	2	1	3	2
C1	++	3					2	2	3	
A2	+	2	1				3			3
D1	++	3		2	2	1	2	2	3	2
L2	+	2		2		2	3	2	2	2
C2		3	1		1	2		2	2	2
E2	+++	1	2	2	2			1	3	3
R1		3		1	2			2	3	
S2	+	3	3	1		2		2	2	
A3	+	2	2				2	2	3	
CTCAE Version 5: Grades										

### Perianal pain

All patients undergoing chemoradiation therapy for anal cancer reported perianal pain, with 30% of patients experiencing pain as present before the first treatment. Eight patients (50%) reported Grade 3 severe pain, over the course of treatment, limiting self-care and activities of daily living (ADL), and requiring strong analgesia. Four patients (25%) reported Grade 2 moderate pain, limiting instrumental ADL, and requiring mild analgesia. Four patients (25%) reported Grade 1 mild pain.

### Documented nursing interventions

A pressure cushion provided relief for five patients. However, as documented, all but three patients were reported as requiring analgesia during treatment, with six patients requiring analgesia in the first few days of treatment. Analgesia ranged from paracetamol to opioid analgesics which were prescribed for eight (50%) of the patients. Topical analgesia consisting of lignocaine, hydrogel and paraffin, was prescribed for five patients in the first 11 days of treatment, and for seven patients in days 12–17.

### Nausea, fatigue and reduced appetite

Fifty per cent (50%) of patients reported nausea during the treatment. Four described Grade 1 nausea: loss of appetite without alteration to eating habits. Three patients were assessed at Grade 2 nausea: oral intake decreased without significant weight loss, dehydration or malnutrition. Only one patient had documented Grade 3 nausea: inadequate oral calorific or fluid intake. The majority (81%) of patients were prescribed regular anti-emetics, and all had received anti-emetics during their chemotherapy administration.

Fatigue was reported by 62.5% of patients, with two patients describing Grade 1 fatigue: fatigue relieved by rest. Six patients reported Grade 2 fatigue: fatigue not relieved by rest and limiting instrumental ADL. Two patients reported Grade 3 fatigue: fatigue not relieved by rest, limiting self-care ADL. One patient was

described as being deconditioned after previously being very energetic.

Nine (56%) patients reported a Grade 2 reduction in appetite: oral intake altered without significant weight loss or malnutrition, and oral supplements indicated. A further three patients suffered a Grade 3 reduction in appetite: associated with significant weight loss or malnutrition.

### Nursing interventions for nausea, fatigue and reduced appetite

The nurses documented referrals to a medical officer for anti-emetics if they had not been routinely prescribed, followed by monitoring of antiemetic efficacy. One patient was advised to use ginger as a mild anti-emetic. Fatigue interventions included advice about the need to rest when tired, and maintaining good sleep patterns. Twelve patients (75%) were educated regarding the need to regularly drink water, (especially in hot climate), and referrals (43.5%) were made to the dietitian for ongoing support. Other information included advising small regular meals and supplements.

### Diarrhoea, rectal bleeding/mucous, dysuria

Diarrhoea was reported by 11 (68.75%) patients during the treatment. One patient was assessed as having Grade 3 diarrhoea: >7 stools per day. Eight patients reported Grade 2: 4–6 stools per day. Two patients reported Grade 1 diarrhoea: <4 stools per day.

Eight patients reported rectal bleeding with or without mucous. Three patients were assessed as having Grade 1 rectal bleeding/mucous: rectal discomfort, interventions not indicated. Five patients reported Grade 2 rectal bleeding/mucous: moderate symptoms, intervention indicated. Dysuria and urgency were reported by 11 patients (68%), resulting in pain, discomfort and sleeplessness.

Table 2: Allied health involvement

Dietitian	Social worker	Occupational therapist	Physiotherapist
Gastrointestinal tract issues	Supportive counselling	Lymph nodes removed/in treatment field	Lymph nodes removed/in treatment field
Weight loss	Financial concerns	Altered functional status	Abdomen/pelvis/groin concerns
Decreased appetite affecting oral intake	Practical support	Altered sleep	General mobility concerns
		Relaxation	
		Stress/anxiety	
		Fatigue	
MOSAIQ: Radiation oncology database. Allied health referral/assessments Princess Alexandra Hospital, Brisbane			



### Nursing interventions

When patients reported diarrhoea or rectal bleeding/mucous, the nurses assessed the patient and documented the amount and severity in the notes from the patients' perspectives.

One patient had documented breakthrough of tumour with ulceration. Medical staff were requested to review the patients and prescribe the appropriate medication, if needed. One patient was prescribed antibiotics for continued diarrhoea and intermittent fevers. Those patients reporting dysuria/urgency had their urine tested for possible infection. One patient was confirmed with pseudomonas urinary tract infection and was prescribed IV antibiotics. Another patient was prescribed an alpha blocker for urinary obstruction, and two other patients were prescribed antibiotics for urinary infection. Two patients were prescribed urinary alkalisers.

### Radiation-induced skin reaction

All patients reported painful erythematous reactions to skin, perianal area, and/or natal cleft. Moist desquamation was documented in all but two patients in these areas. Four patients showed Grade 2 moist desquamation: moderate erythema or oedema, patchy moist desquamation, and 10 patients were assessed with Grade 3 moist desquamation: moist desquamation, bleeding induced by minor trauma.

### Nursing interventions

The documentation reported visual assessment of the treated area by nursing staff, and general prophylactic management of skin reactions such as advice using moisturising cream in the treatment area, and reducing trauma to the area. This same advice continued once erythema had been identified. All patients with moist desquamation were prescribed 'Triple Treat' cream, which is equal quantities of hydrogel, topical anaesthetic, and soft white paraffin. The management of moist desquamation included dressings such as hydrogels, topical analgesia mixture, sitz baths (tepid water with a small amount of salt for cleansing purposes), cold compresses, and the use of a cushion (31.5%). The nurses referred to medical staff as needed for review of the treatment area.

### Psychological outcomes

In this current cohort of patients three patients had a history of previous psychological pathology, and seven patients reported psychological distress during treatment. This distress included patient-reported anxiety, depression, nervousness, worry, and sadness. Three female patients expressed embarrassment at the site of the cancer.

One patient required an anti-anxiety drug daily before treatment, then eventually a benzodiazepine. This was followed

by admission during treatment, and eventually transfer to a mental health unit for some months following the completion of treatment. This patient had a previous history of depression.

### Nursing interventions

There was regular assessment of the patients by the nurses, as well as the weekly evaluation by the radiation oncologist. Six patients were referred to the social worker for therapeutic counselling, and 12 patients were referred to the occupational therapist, who assisted with relaxation and functional interventions.

### Implications for nursing

Nurses need to be mindful of the extent of distress caused by treatment for anal cancer. This is important when chemotherapy side effects are superimposed over the radiation side effects, especially when radiation oncology departments do not see patients with anal cancer regularly. The patients in this review generally showed early pain and discomfort at baseline. This requires awareness and early, proactive interventions to reduce this distress, whether physical or emotional. An important outcome of this chart audit is the need for the nurses to be more vigilant about recording patients' weight across the course of treatment. In light of the often debilitating side effects of the chemotherapy and radiation therapy, it is important to have a baseline weight with regular weight review. This may indicate an earlier referral to the dietitian, and to manage emergent nutritional and hydration issues. Vaginal dilators were documented as provided by nurses to 5/10 females (50%). There may have been reasons why the remaining five females did not receive dilators, or that the intervention was not documented. Nurses may need to be reminded that this is an important component of long-term care and well-being for this patient group, where the vagina has received a significant dose of radiation therapy<sup>17</sup>.

Nurses need to be proactive in advising about the extent of specific skin reactions, how to manage these reactions, and measures to reduce further pain and discomfort. It may be worrying for patients when skin starts peeling off in the groin and perianal areas, and sitting down comfortably is problematic. Other proactive interventions include managing oral and bowel regimens, analgesia efficacy, and addressing fatigue issues.

Toxicities from anal cancer may differ from those experienced by colorectal patients. Therefore, in a person-centred approach, nurses must be aware of the needs of patients with anal cancer undergoing combined modality treatment as a distinct cohort from colorectal patients, and ensure that appropriate and timely focused information and support is provided throughout the treatment.

## Conclusion

Common toxicities resulting from these protocols affected all patients audited, with differences only in type, severity and timing. Proactive interventions as part of a formal clinical pathway may result in less toxicity during and after the course of treatment, and reduce admissions, especially as this a generally rare form of cancer. This audit has shown that partnership with radiation oncology professionals and allied health professionals is the cornerstone of holistic care for these patients.

Chart audits may identify gaps in practice; however, a lack of documentation may give incomplete results. There may be gaps in this current audit, and this is a potential limitation of all chart audits of documentation. All staff need to be reminded that documentation is of utmost importance, and all assessments and interventions must be documented. Despite this, the retrospective chart audit is an applicable research methodology that can be used by health care disciplines to elicit important information, and to inform the conduct of subsequent prospective investigations<sup>15</sup>.

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# Moving towards optimal care pathways for colorectal cancer in South West Victoria

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## Abstract

Optimal care pathways have been introduced by Cancer Council Victoria. Our study performed an analysis of treatment and care for colorectal cancer patients in regional/rural South West Victoria and any deviations from optimal recommendations are discussed.

There were 298 newly diagnosed patients (71.8yrs SD 12.6yrs) in 2015. Private health insurance (PHI) was held by 142 (48%) and not by 144 (49%) (11 Veterans' Affairs excluded). A higher proportion with PHI had a colonoscopy within 4 weeks of referral (79% versus 52%) and their first surgical consultation within 2 weeks (76% versus 47%). More with PHI had surgery performed (88% versus 77%), fewer were presented to a multidisciplinary meeting to discuss treatment options (47% versus 77%) and had a higher survival rate for the first 12 months (92% versus 79%) (all  $p < 0.02$ ).

More patients who held PHI were receiving treatment and care within required time frames and had better short-term survival.

## Introduction

The Department of Health and Human Services in Victoria commissioned the Cancer Council Victoria to review optimal care pathways (OCP) for cancer treatment<sup>1</sup>. OCP have been developed as the first step to consistent treatment and care statewide. The Barwon South Western Regional Integrated Cancer Services (BSWRICS) is one of nine integrated cancer services across Victoria that partner with health services to improve patient experiences and outcomes by connecting cancer care and driving best practice. The OCP initiative was

established to support health services and clinical stakeholders in the delivery of health care with the goal of reducing any variation in access or delivery. Integrated cancer services are leading the implementation of OCP at a regional level.

High on the agenda are time frames: time to presentation, time to initial diagnostic investigation and time to first surgical consultation. Care coordination with fast, effective communication and information speeds up this process. Communication is conducted within a complex web of multidirectional interactions between the patient, carer and

family, medical specialist, general practitioner (GP), nursing clinicians and all supportive care clinicians. Prior studies have reported time from diagnosis to first treatment to be related to: tumour site<sup>2,3</sup>, tumour stage at diagnosis<sup>4</sup>, health insurance<sup>5</sup>, age, co-morbidities and distance from Health Service<sup>6</sup>.

The OCP outline recommendations for early detection, initial investigation, referral, diagnosis, staging, treatment planning, treatment and end-of-life care<sup>1</sup>. A detailed analysis of treatment pathways for colorectal cancer patients in a regional/rural region was undertaken and any deviations from optimal treatment or care are discussed in this study.

## Methods

Treatment and care for patients in the Barwon South West Region, in South West Victoria, Australia, is provided by nine major health services: Barwon Health, Geelong Private, St John of God Geelong and Warrnambool, South West Healthcare Warrnambool and Camperdown, Western District Health Service, Colac Area Health and Portland District Health.

Regional gaps and opportunities for enhancing treatment and care for people diagnosed with colorectal cancer were identified from analysis of treatment pathways included in the dataset of the Evaluation of Cancer Outcomes Clinical Registry<sup>7</sup>. The regional data includes all residents newly diagnosed with colorectal cancer presenting to a Health Service within the Barwon South West region. The area consists of the main regional city of Geelong and south-west regional and rural towns with large distances to the closest health service (up to 100 km). Medical records of the health services provided much of the data for the Evaluation of Cancer Outcomes Clinical Registry, while data held at private practices or referral records kept only at GPs were not always available. Percentages were extrapolated from the known data. This study presents the most recent

complete year of data collection, 2015. The registry provides data on demographics, referral pathway, initial investigations, multidisciplinary meetings, treatment pathways and survival. All patients whose residential address is from outside the region are not included.

## Statistical analysis

Averages are quoted as mean and standard deviation (SD) or median and interquartile range (IQR) and frequency data was assessed using a Chi-square statistic.

## Ethics approval

The ECOBSW Registry was approved by the Research and Ethics Committees of Barwon Health (14/24), St John of God Hospital (709), Epworth Hospital Geelong (2016-142) and Cancer Council Victoria (1508).

## Results

### Demographics

There were 311 colorectal tumours in 298 patients (Table 1). Seven patients had 2 tumours and three patients had 3 tumours. Patients were aged 24 to 98 years, with an average age of 71.8 (SD 12.6) years and 54% were male. PHI in Australia is not compulsory and was held by 142 (48%) patients. Those without private insurance often present to the public health system (n=145, 49%) and 11 (4%) were recipients of Department of Veteran Affairs' resources.

### Early detection

Referral pathway was recorded in the hospital records for 229 (77%) of patients, of whom 174 (76%) were referred from a GP, 38 (17%) were diagnosed after presentation to an emergency department and the remaining 17 (7%) from either another consultant or a screening program (Table 2).

Table 1: Number of newly diagnosed tumours in the Barwon South West region by primary site

Primary site of tumours	Number (% of all tumours)
C180 — Malignant neoplasm of caecum	45 (14%)
C181 — Malignant neoplasm of appendix	6 (2%)
C182 — Malignant neoplasm of ascending colon	43 (14%)
C183 — Malignant neoplasm of hepatic flexure	15 (5%)
C184 — Malignant neoplasm of transverse colon	36 (11%)
C185 — Malignant neoplasm of splenic flexure	10 (3%)
C186 — Malignant neoplasm of descending colon	18 (6%)
C187 — Malignant neoplasm of sigmoid colon	47 (15%)
C188 — Overlapping malignant lesion of colon	3 (1%)
C189 — Malignant neoplasm of colon, unspecified	9 (3%)
C19 — Malignant neoplasm rectosigmoid junction	24 (8%)
C20 — Malignant neoplasm of rectum	55 (17%)
<b>Grand total</b>	<b>311</b>

Table 2: Colorectal cancer pathways of newly diagnosed cancer patients in the Barwon South Western Region by age, public/private cover, residential area, stage of tumour at diagnosis and site.

	Age		Public or private health insurance		Region		Stage at diagnosis				Tumour stream		
	All patients	<60yrs	>60yrs	Public	Private	South West Region	Geelong	I	II	III	IV	Colon	Rectal
311 tumours	n=298	n=53	n=245	n=145	n=142	n=125	n=173	n=44	n=88	n=76	n=40	n=219	n=55
<b>Early detection</b>													
Referral pathway:													
GP	174 (76%)	36 (77%)	138 (76%)	108 (77%)	60 (74%)	92 (83%)	82 (69%)	25 (81%)	55 (81%)	46 (78%)	23 (66%)	117 (72%)	41 (87%)
Consultant/screening program	17 (7%)	4 (9%)	13 (7%)	9 (6%)	8 (10%)	7 (6%)	10 (8%)	4 (13%)	6 (9%)	4 (7%)	1 (3%)	15 (9%)	2 (4%)
Emergency department	38 (17%)	7 (15%)	31 (17%)	24 (17%)	13 (16%)	12 (11%)	26 (22%)	2 (6%)	7 (10%)	9 (15%)	11 (31%)	31 (19%)	4 (9%)
			p = 0.90		p = 0.64		p = 0.05				p = 0.06		p = 0.10
<b>Initial investigation</b>													
Colonoscopy < 4 weeks	79 (62%)	13 (48%)	66 (66%)	44 (52%)	31 (79%)	46 (75%)	33 (50%)	9 (43%)	31 (67%)	20 (67%)	9 (64%)	54 (61%)	19 (63%)
Colonoscopy > 4 weeks	48 (38%)	14 (52%)	34 (34%)	40 (48%)	8 (21%)	15 (25%)	33 (50%)	12 (57%)	15 (33%)	10 (33%)	5 (36%)	35 (39%)	11 (37%)
			p = 0.09		p < 0.01		p < 0.01				p = 0.25		p = 0.80
<b>Diagnosis and staging</b>													
Tumour stage recorded at diagnosis													
Stage I	44 (18%)	10 (21%)	34 (17%)	18 (15%)	24 (20%)	15 (15%)	29 (20%)					32 (18%)	8 (17%)
Stage II	88 (35%)	13 (28%)	75 (37%)	44 (37%)	41 (35%)	37 (36%)	51 (35%)					69 (39%)	15 (31%)
Stage III	76 (31%)	15 (32%)	61 (30%)	32 (27%)	40 (34%)	32 (31%)	44 (30%)					52 (29%)	15 (31%)
Stage IV	40 (16%)	9 (19%)	31 (15%)	26 (22%)	13 (11%)	19 (18%)	21 (14%)					24 (14%)	10 (21%)
			p = 0.62		p = 0.10		p = 0.66						p = 0.57
<b>Treatment planning</b>													
Multidisciplinary meeting to discuss treatment plan	182 (61%)	35 (66%)	147 (60%)	111 (77%)	67 (47%)	75 (60%)	107 (62%)	29 (66%)	62 (70%)	53 (70%)	28 (70%)	125 (57%)	41 (75%)
			p = 0.41		p < 0.01		p = 0.75				p = 0.96		p = 0.02
<b>Treatment</b>													
Surgical consult < 2 wks	53 (53%)	9 (43%)	44 (56%)	37 (47%)	16 (76%)	22 (52%)	31 (53%)	4 (25%)	18 (51%)	12 (55%)	11 (73%)	41 (55%)	9 (47%)
Surgical consult > 2 wks	47 (47%)	12 (57%)	35 (44%)	41 (53%)	5 (24%)	20 (48%)	27 (47%)	12 (75%)	17 (49%)	10 (45%)	4 (27%)	34 (45%)	10 (53%)
			p = 0.29		p = 0.02		p = 0.92				p = 0.06		p = 0.57
Surgery	247 (83%)	45 (85%)	202 (82%)	112 (77%)	125 (88%)	98 (78%)	149 (86%)	41 (93%)	83 (94%)	71 (93%)	26 (65%)	188 (86%)	42 (76%)
			p = 0.67		p = 0.02		p = 0.08				p < 0.01		p = 0.09
Radiation therapy	30 (10%)	10 (19%)	20 (8%)	24 (17%)	5 (4%)	20 (16%)	10 (6%)	0	10 (11%)	12 (16%)	7 (18%)	2 (1%)	25 (45%)
			p = 0.02		p < 0.01		p < 0.01				p = 0.10		p < 0.01
Systemic agent	80 (27%)	22 (42%)	58 (24%)	41 (28%)	38 (27%)	40 (32%)	40 (23%)	2 (5%)	9 (10%)	39 (51%)	26 (65%)	42 (19%)	27 (49%)
			p < 0.01		p = 0.77		p = 0.09				p < 0.01		p < 0.01
<b>End-of-life care</b>													
Survived 12 months	252 (85%)	48 (91%)	204 (83%)	114 (79%)	131 (92%)	102 (82%)	150 (87%)	43 (98%)	85 (97%)	69 (91%)	22 (55%)	183 (84%)	51 (93%)
			p = 0.18		p < 0.01		p = 0.23				p < 0.01		p = 0.09

• Maximum sample sizes are reduced throughout the table where patients have not followed a specific treatment pathway and/or dates are not recorded in the medical record at the health service.

### Initial investigation

The OCP recommend a colonoscopy within 4 weeks. In the region, 244 (82%) patients had a colonoscopy. Of these patients, 127 had referral and colonoscopy dates recorded in the hospital medical record and 79 (62%) had their colonoscopy within 4 weeks of the referral. Median time from referral to colonoscopy was 16 (IQR 5–60) days. Colonoscopy within the optimal time frame occurred more commonly for those with PHI (79% versus 52%,  $p < 0.01$ ) and those residing outside of Greater Geelong (75% versus 50%,  $p < 0.01$ ) (Table 2).

### Specialist consultation: Diagnosis and staging

The OCP recommend staging with a CT scan for colorectal patients and the addition of an MRI for rectal patients. CT scan details were recorded in the hospital records for 206 (69%) patients with 75% (130/173) residing in the Greater Geelong region, compared to 61% (76/125) in the regional/rural areas ( $p < 0.01$ ) and more public patients (81%, 118/145) compared to private patients (58%, 83/142) ( $p < 0.01$ ). Of patients with rectal cancer, 65% (36/55) had an MRI. Tumour stage was recorded in hospital records for 248 patients (83%). Tumour stage was recorded as 44 (18%) Stage I, 88 (35%) Stage II, 76 (31%) Stage III and 40 (16%) Stage IV. There was no association between tumour stage at diagnosis and whether a patient had PHI.

### Treatment planning

The OCP recommend all newly diagnosed patient cases to be presented at a multidisciplinary meeting (MDM) to discuss treatment and devise a care plan. Within the region, 182 (61%) patients had their treatment plans discussed. More with PHI (77% versus 47%,  $p < 0.01$ ) and patients with rectal cancer (75% versus 57%,  $p = 0.02$ ) were presented to an MDM (Table 2).

### Treatment

Surgery is often recommended. Systemic agents and radiotherapy may be recommended for those at high risk with radiotherapy treatment usually restricted to rectal carcinoma. In summary, 247 (83%) patients had surgery, 30 (10%) radiotherapy, 80 (27%) systemic agents and 30 (10%) had no treatment. Time from diagnosis to first consultation with the surgeon was 9 (IQR 1–41) days. Of 100 patients, whose dates were duplicated in the hospital records, 53 had their consultation within 2 weeks of diagnosis and a higher proportion were private patients (76% versus 47%,  $p = 0.02$ ) (Table 2). Time from diagnosis to surgery was an average of 15 (IQR 2–28) days. There was a higher proportion of patients with PHI (88% versus 77%,  $p = 0.02$ ) and patients with Stage I–III tumours that had surgery (93% versus 65%,  $p < 0.01$ ). Average time from diagnosis to neoadjuvant radiotherapy was 50 (IQR 44–55) days. Time from diagnosis to neoadjuvant systemic agent was 53 (IQR 48–62) days and to adjuvant systemic agent was 56 (IQR 41–90) days. Radiotherapy and systemic agents were significantly associated with those younger than 60 years, later stage tumours and rectal cancer (Table 2). Eleven patients

(4%) received treatment outside the region; 25 (8%) underwent supportive care screening and 20 (7%) completed an advance care plan.

### End-of-life care

Forty-three (14%) patients were referred to palliative care. Two-hundred and fifty-two (85%) survived the first 12 months after diagnosis with a significant association with patients with PHI and earlier stage of tumour at diagnosis (Table 2). Tumour stage and patients with PHI remained independent significant predictors of short-term survival in a multivariate model including both variables.

### Discussion

Patients with PHI have been reported to have a greater survival rate in a metropolitan study of colorectal cancer in Victoria<sup>8</sup> and in a large study of all patients diagnosed in Western Australia over 10 years<sup>9</sup>. Field *et al.*<sup>8</sup> reported that those with PHI were more likely to receive chemotherapy and be treated with curative intent. Morris *et al.*<sup>9</sup> reported higher five-year survival rates for private patients. Our study reported a higher proportion with PHI survived the first 12 months post-diagnosis, had a colonoscopy within 4 weeks and their first surgical consultation within 2 weeks. In addition, more with PHI had surgery performed and fewer were presented to an MDM.

We acknowledge that within our report we have compared persons with and without PHI and not simply those that were treated at the private health service. However, those with PHI and treated at the public health service are more likely to have access to their own surgeon, specialist and a private room. This occurred for nine patients living in Hamilton, where no private health service exists and 31 patients across the region.

Patients initially presenting to the emergency department and subsequently diagnosed with cancer often have more advanced disease at diagnosis. More work is needed to understand why some patients present late in their disease progression. The region outside Greater Geelong stretches to the South Australian border. Patients not residing within Greater Geelong were more likely to have their colonoscopy within the required time frame, suggestive of longer waiting lists for services in the Geelong region and the public health system. This is another area of interest for the integrated cancer services to address.

We acknowledge that due to missing dates within the medical record that sample sizes were reduced and we might have experienced a Type I error; however, our findings are consistent with other studies and therefore are suggestive of no sample bias.

Using large datasets to help drive change in health services is advantageous. Knowing what is currently occurring without anecdotal bias is important and is the first step in our opportunity to change the model of care. Health equity is something we



aspire to but we need to make it real. More health promotion, resources and support is needed to provide equitable access to a public system that facilitates timeliness to care.

### Declarations

All authors have no conflict of interest or competing interests. No external funding was received for this study.

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# Pulmonary rehabilitation and eHealth practices for patients undergoing surgical treatment for lung cancer — a survey of multidisciplinary team sites in Australia

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## Abstract

**Objective:** 1) To determine the pre- and post-operative rehabilitation services available for patients with lung cancer undergoing surgery. 2) To determine the availability and use of eHealth technologies within this population.

**Design, setting and participants:** A purpose-designed survey was sent to sites around Australia with a lung cancer multidisciplinary team (MDT) to manage lung cancer surgical patients. There were 49 eligible MDTs.

**Results:** The response rate was 51%. Most respondents (79%) reported that the pulmonary rehabilitation needs of lung cancer surgical patients are currently not being met. Around half (52%) of sites offer referral to pulmonary rehabilitation programs. Around half (52%) of sites use eHealth technologies for practitioner-to-practitioner communication, with 22% using it for direct patient interactions.

**Conclusion:** The findings highlight a need to integrate pulmonary rehabilitation into service delivery pathways. Cancer nurses could have a significant role in optimising such pathways. The use of eHealth technologies in this setting is not widespread.

## Introduction

Lung cancer is the leading cause of cancer-related deaths in Australia, with an estimated 12,741 new cases being diagnosed in 2018<sup>12</sup>. Between 1983–1987 and 2008–2012, five-year relative survival from all lung cancers combined improved from 8% to 15%<sup>2</sup>. In those patients who are candidates for lung cancer surgery, typically classified as disease stages I, II and IIIA, with preserved exercise capacity, there is a wide variance in current five-year survival rates for non-small cell lung cancer up to 92%<sup>3</sup>.

The most common surgical procedures for patients with lung cancer are pneumonectomy, lobectomy, segmentectomy and wedge resections<sup>3</sup>. There is currently a need to improve clinical care practices to optimally enhance physical health and health-related quality of life (HRQoL) in these patient populations. Optimal care for patients receiving such surgical treatment for

lung cancer includes access to coordinated multidisciplinary care<sup>4</sup>. Current clinical practice guidelines indicate that an important component of this care involves improving and/or maintaining exercise capacity through pulmonary rehabilitation (PR) programs both prior to surgery (prehabilitation) and post-surgery (rehabilitation)<sup>4</sup>. It is currently unknown which specific surgical cohort would benefit most from PR.

PR is a multidisciplinary therapeutic intervention that includes a focus on exercise training, education and behavioural change components<sup>5</sup>. There is Level 1 evidence supporting its use in the management of patients with chronic lung disease<sup>5,6</sup>. The evidence-based benefits of PR include improved dyspnoea, fatigue and emotional function<sup>6</sup>. This is particularly relevant to the lung cancer patient population, given their high incidence of co-morbid lung disease<sup>7</sup>.

For patients with a diagnosis of lung cancer, a recent Cochrane review concluded that exercise-based prehabilitation reduced the risk of post-operative pulmonary complications and decreased length of hospital stay<sup>8</sup>. In addition, a 2014 Cochrane review of post-operative training for NSCLC showed improvement in exercise capacity compared to no intervention<sup>9</sup>. While the sample sizes included in these reviews were relatively small, they demonstrate the potential benefits of prehabilitation and rehabilitation in this patient group.

Studies focusing on structured exercise programs, a significant component of PR, post-surgery for lung cancer suggest benefits such as improved exercise capacity, increased muscular strength and reduced levels of fatigue<sup>10-12</sup>.

Despite the many benefits of PR, barriers exist that may restrict patients with lung cancer, including surgical populations, from participating in such programs<sup>13,14</sup>. One of the major barriers identified in the Australian population is geographical distance<sup>14</sup>. For this reason, there is increasing interest in eHealth technologies to improve availability and delivery of rehabilitation services for individuals who are unable to access PR services due to distance<sup>15</sup>. eHealth can have varied definitions but can be seen as one, or a combination of three domains: "(1) health in our hands (using eHealth technologies to monitor, track, and inform health); (2) interacting for health (using digital technologies to enable health communication among practitioners and between health professionals and clients or patients); and (3) data enabling health (collecting, managing, and using health data)"<sup>16</sup>.

The availability of PR services for patients with lung cancer within Australia is largely unknown. Multidisciplinary teams (MDTs) have been established in sites across Australia to improve the coordination of care in lung cancer. Lung cancer MDTs typically include various members of a patient's care team such as lung cancer nurses, cardiothoracic surgeons, medical oncologists, respiratory physicians and allied health professionals<sup>17</sup>.

The aims of the study were: 1) To determine the range of pre- and post-operative rehabilitation services available for patients with lung cancer undergoing surgery; and 2) To determine the availability and use of eHealth technologies within this population.

## Methods

The study was a cross-sectional design using a survey. A representative of the lung cancer MDT, typically a cancer nursing care coordinator, was identified via the Lung Foundation Australia registry<sup>18</sup>. MDTs were considered the most appropriate because they provided a practical way of accessing health professionals at major surgical sites across Australia. If direct email details were not available, then a phone call was placed to the cardiorespiratory department (or equivalent) to gather this information. The identified MDT contact was sent an email with a description of the study and a link to the survey and invited

to complete the survey online anonymously. If a survey was not submitted, then three automatic email reminders were sent at 7, 14 and 21 days. As the survey was anonymous, no further follow-up contact such as emails or phone calls could be completed.

The purpose-designed survey consisted of 28 closed and open-ended questions. Questions included information about service demographics, staffing, prehabilitation services, inpatient services, rehabilitation services, referral pathways and eHealth practices and barriers. The Qualtrics™ online survey system was used to administer the survey. Descriptive statistics were used to analyse responses.

Since no validated survey tool was available that addressed the area of interest, a survey was developed specifically for this study. The survey was developed in consultation with an experienced research team and reviewed by members of a local lung cancer MDT before wider distribution.

Study approval was obtained from the Concord Repatriation Hospital Ethical Review Board (LNR/15/CRGH/211). Informed consent was implicit if surveys were completed.

## Results

Fifty-six (n=56) sites with lung MDTs were identified and emailed a link to the survey. Of these, 87.5% (49/56) provided lung cancer-specific MDTs, while the remainder (n=7) provided general oncology MDTs and were, therefore, not included. Twenty-five (n=25) surveys were completed, yielding a response rate of 51% (25/49). The majority of respondents were oncology nursing care coordinators (n=20; 80%), while comparatively fewer surveys were completed by medical oncologists (n=2), respiratory physicians (n=2) and thoracic surgeons (n=1). The majority of completed surveys were from NSW (40%; n=10), Queensland (20%; n=5) and Victoria (16%; n=4), reflective of the higher number of services operating in these states. Australian Capital Territory, Western Australia and Tasmania had two respondents each (8%). No responses were provided from sites in South Australia or the Northern Territory.

### Surgery

Over 70% of the MDTs surveyed reported providing services for more than 50 new lung cancer cases each year. The vast majority of respondents (n=19) indicated surgery for lung cancer was completed in a public hospital (79%), with one site a private hospital (4%) and a variable distribution accounting for 4 sites (17%). A mean of 32% of patients seen by these services had some form of lung surgery (Table 1).

### Allied health services

Allied health service availability varied across the centres surveyed, with physiotherapy available in most sites (95%), while fewer offered social work (58%), dietitian (54%), psycho-oncology (46%), and exercise physiology (25%) services (Table 1).

Post-operative inpatient physiotherapy assessment and treatment was offered as part of the service in 73% of sites. Inpatient education post-operatively was also offered in 73% of sites, dietetics/nutrition services in 50% and psych-oncology services in 27% of sites (Table 2).

#### Pre-surgical services (prehabilitation)

Allied health services were offered pre-operatively to a low proportion of patients. These included physiotherapy (42%), dietetics (16.7%) and psych-oncology (12.5%) services.

A third of sites (33%) indicated that they were referring surgical patients to prehabilitation programs prior to surgery (Table 2).

#### Post-operative PR services

On patient discharge, the majority of respondents (83%) reported the *availability* of PR for lung cancer surgical patients, either at their institution (58%), another institution (13%), or a community-based program (33%). Eight per cent of respondents did not know whether patients had access to these services. 52% of all sites offered *referral* to PR programs at this time.

Table 1: Overview of service

New patients with a lung cancer diagnosis (12-month period)	Number of sites (%)
0–5	1 (4%)
5–20	3 (12%)
20–50	1 (4%)
50–100	4 (16%)
100–200	7 (28%)
200–300	3 (12%)
>300	4 (16%)
Unknown	2 (8%)
<b>Health professional staff focused on PR</b>	
Cardiopulmonary CNC (or equivalent)	15 (63%)
Exercise physiologist	6 (25%)
Dietitian	13 (54%)
Physiotherapist	24 (100%)
Psychologist	11 (46%)
Social worker	14 (58%)
Occupation therapist	1 (4%)

Table 2: Preoperative and inpatient services

Preoperative services	Number of sites (%)
General education/Information	22 (92%)
Pre-operative exercise program (prehabilitation)	8 (33%)
Physiotherapy assessment	10 (42%)
Dietitian/nutrition assessment	4 (17%)
Psychology/counselling assessment	3 (13%)
<b>Inpatient services</b>	
General education/information	16 (73%)
Physiotherapy assessment	17 (77%)
Walking program	7 (32%)
Dietitian/nutrition	11 (50%)
Psych-oncology	6 (27%)
Occupational therapy	2 (9%)
NA (surgery elsewhere)	2 (9%)
None	1 (5%)

### Unmet needs

Seventy-eight per cent of respondents thought the PR needs of lung cancer surgical patients were not being met. This was reported as being due to access/location of the PR programs (56%), complex or no referral process (56%), lack of availability of PR programs (50%), and limitation of PR programs to chronic

obstructive pulmonary disease (COPD) patients only (44%). No standardised process of referral to PR was reported by 30% of respondents.

The majority of referrals were by letter (52%) with only 4% of respondents providing referrals via an electronic medical record (Table 3).

Table 3: Access to PR services

Outpatient services	
Referral to PR	12 (52%)
Referral to dietitian	13 (57%)
Referral to psychologist	7 (30%)
Referral to exercise physiologist	4 (17%)
Occupational therapy	2 (9%)
Social work	1 (4%)
Recommend for GP referral to allied health	13 (57%)
Unsure	4 (17%)
Barriers to access	
Access/location	10 (56%)
Patient uptake and interest	6 (33%)
Cost	0 (0%)
Complex or no referral processes	10 (56%)
Health professional time	4 (22%)
Overwhelming to patient	2 (11%)
Availability of service	9 (50%)
Limitation of program to COPD or other patient groups	8 (44%)
Referral process for PR	
Electronic medical record	1 (4%)
Letter/referral form	12 (52%)
Phone	1 (4%)
Give the patient information for self-enrolment	0 (0%)
No standardised process	7 (30%)
Unknown	2 (9%)
Management of patients from different health district	
Referred to local PR program	10 (42%)
Referred to GP	14 (58%)
Referred to local physiotherapist or exercise physiologist	4 (17%)
Referred to community health service	13 (17%)
Relies on medical oncology	1 (4%)
Unsure	7 (29%)

Forty-two per cent of sites reported referral to PR for patients living in a different health district from the hospital. A large proportion (74%) of respondents indicated there was no (26%) or unknown (48%) follow-up of these patients.

Existing PR programs focussed primarily on COPD (83%) and other chronic lung conditions (4%), rather than lung cancer post-surgical rehabilitation, which was the target population for only three sites (13%).

Private hospital patients had access to PR 33% of the time, with over half (54%) of respondents unsure of the referral pathway for these patients and responded as 'unknown', with 13% of sites responding as 'no' access.

### eHealth technology

Almost half of respondents (48%) reported that they did not currently use or support telehealth or eHealth technology. Specifically, 52% of sites used videoconferencing to communicate with other health professionals within the MDT and 22% of sites had provided video consultations for patients. One site reported the use of accelerometers to encourage physical activity. Mobile applications (apps) and remote data monitoring were not reported as being used by any sites.

Challenges to eHealth implementation included perceptions of respondents regarding patients' abilities to access technology. Fifty-two percent of respondents believed that patients had limited access to internet and 34% believed that patients had low technical ability, poor phone connections (35%) and slow internet (26%).

Respondents identified time and administrative burden (86%) and lack of staffing resources (76%) as major limiting factors to providing eHealth technology to support patient care. The lack of centralisation of medical records and local computer infrastructure (such as firewalls) were also reported as barriers to effectively using eHealth (Table 4).

### Discussion

There is a significant gap in the provision and delivery of rehabilitative care both pre-and post-operatively for people undergoing surgery for lung cancer. There is also little use of eHealth technology to support lung cancer patients in the period after diagnosis or surgery.

### Prehabilitation

In addition to post-operative rehabilitation, mounting evidence supports optimising the health of newly diagnosed cancer patients before surgery (that is, prehabilitation). Such programs have been shown to improve physical and psychological health and have the potential to improve post-operative recovery, increase functional status, and reduce length of admission<sup>19-21</sup>.

This study has indicated that although prehabilitation programs and services exist across Australia, referrals pathways are unstructured and inconsistent. However, the result of 33% of

Table 4: eHealth use, attitudes and barriers

Current clinical use of eHealth technologies	Number of sites (%)
Not used and not supported	11 (48%)
Videoconferencing with other health professionals (e.g. MDTs)	12 (52%)
Video consultations with patients	5 (22%)
Mobile applications	0 (0%)
Remote monitoring of patient data	0 (0%)
Physical activity monitors (e.g. Fitbits™)	1 (4%)
<b>Perceived patient technical ability</b>	
Low technical ability (i.e. rarely use computer or mobile phone)	0 (0%)
Medium technical ability (i.e. consistently use email and mobile phone to communicate)	8 (35%)
High technical ability (i.e. regularly use email, video call, apps)	1 (4%)
Don't know	4 (17%)
Highly variable	10 (44%)
<b>Perceived patient barriers to eHealth</b>	
Low technical ability	8 (35%)
Limited access to internet	12 (52%)
Slow internet connection	6 (26%)
Poor mobile phone reception	8 (35%)
Cost	2 (9%)
No challenges	4 (17%)
<b>Service barriers to eHealth</b>	
Time/administration burden	18 (86%)
Technical ability	7 (33%)
No need — face to face is sufficient	5 (24%)
No centralised medical record (e.g. Australia wide)	9 (43%)
Information/education	6 (29%)
Staffing/resources	16 (76%)
Limited or no equipment	9 (43%)
Hospital computer infrastructure (e.g. firewalls)	11 (52%)



sites referring patients to prehabilitation programs compares favourably with a 2012 Australian survey of physiotherapists where only 9% of patients with lung cancer were referred<sup>22</sup>. It should be noted that our question was framed around ‘offering’ such a service to a patient, rather than the actual percentage of patients referred, which may have inflated this result.

Future research could consider the questions of whether some types of surgery or other treatments should be delayed in order for a prehabilitation program to take place, and what subgroups of participants would benefit the most from such services.

### Rehabilitation

This study reaffirms previous research which indicated PR referral for patients who have had surgical treatment for lung cancer is inconsistent across Australia<sup>22</sup>.

The majority of surveyed sites had PR services ‘available’ to these patients either on site or community-based; however, referrals were not part of standard care pathways.

PR services exist within many health services across Australia, totalling nearly 300 programs nationally<sup>23</sup>. Most of these PR programs provide rehabilitation for people with chronic lung diseases, particularly COPD. These programs could provide an ideal venue for post-surgical lung cancer patients, though further research is needed in this area.

Patients with a history of lung cancer may often present with significant co-morbidities, such as a history of myocardial infarction or congestive heart failure<sup>24</sup>. PR, or structured cardiac rehabilitation, may be particularly useful in these sub-populations. PR should also be offered to patients with bronchiectasis, interstitial lung disease and pulmonary hypertension, all of which have higher incidences in patients with lung cancer<sup>25</sup>.

### eHealth technology

Survey results showed that there is minimal use of eHealth interventions for lung cancer surgical patients. eHealth service delivery was found to be infrequent across the MDT sites and may offer opportunities for improved service delivery. The use of eHealth resources could provide an opportunity to ensure that dedicated and tailored rehabilitation services are available to all lung cancer patients receiving surgical treatment. This may include the use of telehealth to reach physically as well as geographically isolated patients. A barrier reported by some sites was patient access to internet and technology. While this may be the case for some patients, many regional and remote patients do have access to technology, and this access is expected to grow in the future. Currently 86% of Australians reported accessing household internet in 2014–15<sup>26</sup>.

Research has indicated positive findings using eHealth methods for patient self-monitoring, education, and support during cancer treatment<sup>27,28</sup>. Several studies have reported positive findings including high levels of satisfaction with eHealth models, particularly telehealth, among patients and rural

health professionals and significant cost savings, mainly due to avoidance of travel costs<sup>29</sup>. eHealth service delivery may also be an effective option for patients in urban settings who are housebound or unable to use personal or public transport.

Emerging eHealth research that is generalised to patients with lung cancer highlights that tools such as remote monitoring, which includes symptom tracking, may improve patient outcomes<sup>30</sup>. Another study on patients with a history of lung cancer, with a small sample of 17 participants, which included ambulant monitoring and web-accessible home-based exercise prescription, was found to be clinically feasible<sup>28</sup>.

There is a lack of high-quality research specific to the use of eHealth technologies in either the lung cancer surgical cohort, or those with early-stage cancer amenable to surgery in the future. Further research is needed.

### Study limitations

The response rate of 51% may increase the risk of a biased sample, though compares well with similar studies<sup>31</sup>. There were no respondents from sites in South Australia or the Northern Territory, with five lung MDT sites identified across those states.

As discussed, the survey tool was purpose-designed for the study and therefore has not been formally validated in this setting; however, it was peer reviewed prior to distribution.

The survey respondents were recruited from MDTs and therefore the information only reflects the services known to the MDTs. It is also acknowledged that some patients with lung cancer are not managed within MDTs.

Of note, the survey tool sent to respondents referenced three types of surgery (resection, lobectomy or pneumonectomy), and did not specifically include segmentectomy and wedge resections.

As this study was specifically designed to target health care professionals, survey feedback from a patient cohort or consumer group was not included. Such insights would have provided valuable feedback to researchers and may be included in future studies.

### Clinical implications

Although there are approximately 260 PR services available in Australia<sup>32</sup>, the survey demonstrated referral to these services for lung cancer patients who are preparing for, or who have had, surgery is limited. As PR programs have qualified and experienced health professionals able to provide exercise training and education for people post-lung cancer surgery increased referrals to utilise these services is warranted. There is a need to provide a coordinated and effective lung cancer surgical prehabilitation and rehabilitation program across service centres.

Clinicians are often unaware of how and where to refer patients. Development of a standard of care patient referral pathway is

needed. Cancer nurses are in an optimal position to identify and optimise referral pathways for these patients and should be utilised.

Opportunity exists for an innovative model of care utilising eHealth technologies to improve access to pulmonary prehabilitation and rehabilitation services for lung cancer patients pre- and post-surgery. Implementing a consistent model of care that links and draws on existing staffing and resources will maximise capacity for the delivery of such programs.

### Conclusion

The findings of this study indicate that there is a wide variation in the provision of PR services for patients with lung cancer. Results have highlighted a lack of integration of PR into service delivery pathways, for which oncology nurses are well positioned to improve. Further research is needed to determine the specific sub-groups of this population that may benefit from prehabilitation or rehabilitation. The use of eHealth technologies is not widespread, but may offer opportunity for improved access to PR services for patients who are limited in accessing services locally.

### Conflicts of interest

The authors declare no conflicts of interest.

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## The ISNCC Announces a New Global Citizen Program

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ISNCC has recently launched the Global Citizen program at the International Conference on Cancer Nursing (ICCN) 2018 in Auckland, New Zealand. The program recognizes nurses or other professionals, whether or not they are members of their national society, who wish to support the ethos, objectives, strategy and philanthropic goals of the ISNCC. The program provides various contribution options and benefits to the global community.

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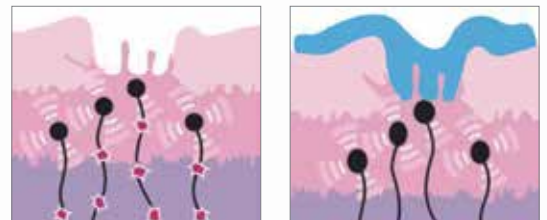


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